The right to supported decision-making for people rarely heard

By

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Submitted in fulfilment of the requirements for the degree of

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I am the author of the thesis entitled:

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submitted for the degree of Doctor of Philosophy

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Dedication

This thesis is dedicated to two men who participated in this research. These men died during the writing of this thesis, both of aspiration pneumonia. Aspiration pneumonia is a leading, and largely preventable cause of death for people with severe and profound intellectual disability.

Neil (pseudonym), you taught me about the essence of human connection. You taught me how to “listen”, not simply to words, but to sensory expression, sounds, cries, laughter, smiles, breath, movement, and even silences. Your wonderful Mum and Dad taught me what true advocacy means. There is nothing those two would not do for you. Their love for you and your sister is eternal.

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Publications/presentations relating to this study

Journal publications

Watson, J. (In Press). The relevance of Article 12 of the UNCRPD for people with severe or profound intellectual disability: Is supported decision-making for everyone? Laws (Special Issue "Disability Human Rights Law").


Book chapters

(Eds.), *Clinical and fieldwork placement in the Health Professions* (2nd ed.). Melbourne, Australia: Oxford University Press.


**Conference proceedings**

Watson, J. (2012). Supported Decision Making for People with severe or profound intellectual disability: We’re all in this together, aren’t we? In C. Bigby & C. Fyffe (Eds.), *Services and families working together to support adults with intellectual disability: Proceedings of the sixth roundtable on intellectual disability policy* (pp.33-48). Bundoora, Australia: LaTrobe University.

**Published practice resources**


**Non peer reviewed articles**

Watson, J. (2013, August). Listening to those rarely heard: Supporting people with severe to profound intellectual disability to participate in decisions about their lives. *Belonging Matters, 16,* 16-22.


**Government Submissions regarding legislative reform**


Conference presentations

*Invited presentations*


Watson, J. (2014). *UNCRPD Article 12 'Equal recognition before the law': Are we ready to uphold it for all Australians, including those rarely heard, those with severe or profound intellectual disability’?* Paper presented at the Melbourne Social Equity Unit: Inaugural Conference. Imagining Social Equity, Melbourne Cricket Ground, Melbourne, Australia.


Watson, J. (2011). *Supported Decision-making for People with severe or profound intellectual disability: We’re all in this together, aren’t we?* Paper presented at the 6th Roundtable on Intellectual disability Policy 'Services and families working together', LaTrobe University, Australia.


**Peer reviewed abstract presentations**


Watson, J. (2012). *Decision-making support for people with severe or profound intellectual disabilities “Listening to those rarely heard”.* Paper presented at the Second World Congress on Adult Guardianship, Melbourne, Australia. [http://www.youtube.com/watch?v=JVWhPGCx9yI](http://www.youtube.com/watch?v=JVWhPGCx9yI)

Abstract

The adoption of and entry into force of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) represents an important step towards promoting, protecting and ensuring human rights for people with disability (United Nations., 2006). Article 12 of the Convention, requires that legal capacity should not be defined based on cognitive disability. It mandates that all people with disability be recognized before the law on an equal basis with others and importantly be supported to exercise that legal capacity. In so doing, it challenges the use of substitute decision-making. Substitute decision-making allows others to make decisions for someone else. In response to the UNCRPD, supported decision-making is emerging as an alternative paradigm to be employed in lieu of substitute decision-making, consistent with signatory nations’ obligations under Article 12 of the UNCRPD.

Australia ratified the Convention in 2008. Since this time, tension has existed around the relevance and application of Article 12 for those who communicate informally, and sometimes unintentionally: people with severe or profound intellectual disability. Due to the interdependent nature of their lives, autonomous decision-making is obviously challenging for this group. However, if signatory nations to the UNCRPD are to live up to their obligations under Article 12 attention needs to be paid to how best to support this population to have their preferences heard and reflected in the decisions that are made about their lives. This is the central focus of this thesis.
This study used an interpretative, multiple case study design. Five people with severe or profound intellectual disability and their circle of support participated in a supported decision-making approach, targeting a range of life decisions. Interview, focus group, questionnaire and observation data were collected and analysed.

A primary aim of this study was to characterize supported decision-making for people with severe or profound intellectual disabilities. Addressing this aim, supported decision-making was characterized for this group in terms of the existence of two distinct but interdependent roles. Drawing from the study’s data, the thesis describes the roles played by (a) the person with a disability (supported), and (b) the circle of support (supporters) in the supported decision-making process. The role of the person with a disability in this dynamic is their expression of preference, and the role of supporter is to respond to this expression of preference by acknowledging, interpreting and acting on this expression in some way. Within this decision-making dynamic, supporter responsiveness, as opposed to focus people’s expression of preference, is the component that is amenable to change through structured practice guidance, making the enablement of responsiveness a crucial strategy for supporting decision-making. This focus is consistent with the social model of disability, where the onus of enhancing decision-making capability should not rest with the person with a disability, but with the environment of which they are a part.
A secondary aim of the study was to identify and discuss factors that underlie supporter responsiveness and therefore supported decision-making for people with severe or profound intellectual disability.

Five themes and ten sub themes, characterizing supporter responsiveness within the context of supported decision-making for people with severe or profound intellectual disability were identified. These themes are explored in this thesis.

The thesis furthers understanding of what supported decision-making looks like specifically for people with severe or profound intellectual disability. These findings give a focus for practice and policy efforts for ensuring people with severe and profound disability receive appropriate support in decision-making, a clear obligation of Australia under the UNCRPD.

Keywords: supported decision-making, severe and profound intellectual disability, UNCRPD, complex communication needs.
Easy English Abstract

The United Nations Convention on the Rights of Persons with Disabilities is an important document. It is about human rights for people with disability. Sometimes people call this document the UNCRPD or CRPD. The UNCRPD is an agreement by countries around the world that they will make sure that people with disability are treated the same as people without disability. Australia has signed the UNCRPD. This means the Australian government has promised to treat people with disability and people without disability equally.

This thesis is about the human right of people with severe or profound intellectual disability to drive their own decisions. These people usually have others make decisions for them. This is called substitute decision-making. The UNCRPD says substitute decision-making should not exist. Supported decision-making is an approach that many people think is better.

Supported decision-making is a way of helping someone to make decisions. People with severe or profound intellectual disability rely on people who know and love them for support to do most things. This is particularly true for decision-making.

This thesis is about a research study that looked at how people with severe or profound intellectual disability are supported to make decisions. Five people with severe or profound intellectual disability and their...
supporters participated in the study. The researcher spent time with each of these five people and their supporters over six months.

The study found that people with severe or profound intellectual disability express their likes and dislikes in many ways. They usually do not use words. Instead, they may use facial expression, body language, breath, vocalisations and even behaviours some people think are challenging. The study also found that these expressions of preference are sometimes hard to understand. Therefore, people with severe or profound intellectual disability often have decisions made for them that are not about what they want. It is hard for supporters to make sure the preferences of someone with severe or profound intellectual disability are part of the decisions made about them. However, this study found that some things help supporters respond to expressions of preference. This thesis is about these things.

At the end of the thesis, some suggestions are made about how people, organizations and governments can do better when supporting people with severe or profound intellectual disability to participate in decisions.
Foreword

“We all declare for liberty; but in using the same word we do not all mean the same thing”

(Lincoln, 1864 para.4)

At the heart of this thesis are notions of choice, decision-making, self-determination, personhood and human rights. I reflect on these concepts watching a sulphur-crested cockatoo dive into the escarpment below me. I am sitting on an ancient rock, over one billion years old, in the Australian Blue Mountains. I have hiked a couple of kilometres to be rewarded with this glorious view.

Figure 1: View from Australian Blue Mountains (my study for the day)
I feel a sense of autonomy, self-determination and freedom, I suspect exceeded only by the cockatoo gliding into the valley below. How is it though that I am present in this location with such a view?

I have made an autonomous decision to be here. Few barriers have been placed in my way. I am well prepared physically, materially and intellectually for the potential risks. In my backpack, I am carrying extra supplies of insulin, jellybeans and my mobile phone, should one of those pesky hypoglycaemic attacks take a grip. I have chosen sensible footwear, allowing my able body to climb to this slice of paradise. I have arrived here with the help of a map that I have requested, using my voice, from the ranger at the visitor’s information centre. She gave me verbal and written information (in a format I understand) about my options, the terrains, distances and highlights of each of the trails. I was able to make sense of both this written and spoken information. My life experiences of hiking in the Australian bush have taught me to stick to the track and, if need be, read the map. Hence, I am not yet lost.

My mind wanders to those who are the focus of this research, people with severe or profound intellectual disabilities. Is there a place on this ancient rock for them? Do they have the option of travelling such a trail? Do they have access to such a view? If so, do they want it, or are they content with their current view, perhaps through a van window, on their way to being included in the community?
As I sit, I think about Neil, a participant in this study, who died over the course of the research. Neil had a profound intellectual and physical disability. As is typical of someone with such a disability, he did not use or appear to understand formal communication like speech, sign, pictures or photos. Instead, he communicated using idiosyncratic facial expression, sounds and body language, interpreted by those in his life who knew and loved him. Neil was reliant on those who knew him well, his parents and some paid support workers, to have his expressions of preference acknowledged, interpreted and acted upon.

Considering his interdependent life, was self-determination a relevant concept for Neil? If so, what did self-determination look like for him? What barriers existed to him achieving a self-determined life, and what attempts were made to overcome them? What enablers existed and how were they utilised?

I reflect on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), particularly Article 12, and its requirement that signatory nations “recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” (UN General Assembly., 2006 Article 12). What does this promise mean for people with disability, and in particular, those with severe or profound intellectual disability, like Neil? Can signatory nations of the UNCRPD such as Australia, live up to this promise? This study had its genesis in these questions.
CHAPTER ONE

Introduction

1.1 Who is this study about?

This thesis focuses on adults with “such profound intellectual disabilities that no existing standardised tests are applicable for a valid estimation of their level of intellectual capacity” (Nakken & Vlaskamp, 2007 p.85).

Multiple terms are used to describe the people Nakken and Vlaskamp (2007) are referring to. These terms include, people with high support needs (De Waele & Van Hove, 2005), profound multiple learning disability (Emerson, 2009), profound intellectual and multiple disability (Hogg, 2007; Hostyn & Maes, 2009), profound and multiple learning disability (Carnaby, 2004; Ware, 2004) and severe or profound intellectual disability (Amado, Stancliffe, McCarron, & McCallion, 2013; McVilly, 2009). These terms differ from each other subtly; however, no differentiation between them will be made in this thesis. The term severe or profound intellectual disability will be used in the interests of consistency.

People with severe or profound intellectual disability are dependent on others for support in most life areas, including communication. They generally communicate informally using nonverbal behaviours such as gesticulation, vocalisations, eye gaze, facial expression, respiration shifts and touch, much of which can be very subtle. Understanding formal communication such as written text, sign, speech, photos or pictures is
challenging for them. In addition to communicating informally, many people with severe or profound intellectual disability communicate unintentionally. This means, they communicate without the intention of conveying a message to another person. They appear unaware that their actions can have an impact on their environment. This means that for effective information transfer communication partners infer meaning from the person’s behaviours, an activity acknowledged in the literature as an ambiguous and subjective task (Bradshaw, 2001; Bunning, 2009a; Grove, Bunning, Porter, & Olsson, 1999a).

People with severe or profound intellectual disability have been referred to as the “excluded amongst the excluded” (European Disability Forum., 2000 p.1). This exclusion may be related in part to the views of some who argue that without intentionality, rationality and self-consciousness, these people lack personhood (McMahan, 2002; Singer, 1993). Consequently, these scholars infer that people with severe or profound intellectual disability are non-persons and therefore do not share the moral status of those with lesser degrees of disability. This conclusion is emphatically rejected within the contemporary disability community. This community refutes the idea that personhood, or humanness should depend on an individual’s ability to engage in purposive behaviour (Hogg, 2007; Hughes, Redley, & Ring, 2011; Kittay, 2005).

In addition to those with severe or profound intellectual disability, this study is about supporters of these people, individually and within the context of circles of support. A ‘circle of support’ or ‘support circle’ is
defined inconsistently in the literature. This will be explored in the proceeding chapter.

**1.2 Setting the scene**

Today in Australia, and in most of the western world, concepts related to self-determination such as freedom, choice, individualism and autonomy are embraced and celebrated. Within neoliberal cultures, the making of decisions seems ubiquitous throughout everyday life. Most Australians lead lives that bring with them an expanding smorgasbord of options.

What clothes to wear? Where to live? Who to spend time with? Whether to pray, and if so, to whom? Australians are enamoured with freedom, variety and choice. There is little argument within the literature that concepts relating to self-determination are highly valued within western societies (Loewy, 2005; Schwartz, 2000; Schwartz, 2004). Opportunities for self-determination have long been regarded as a sign of individual and societal wellbeing (Fan, 2002; Swanson, 1994).

Driven by the disability rights movement, the 1970s saw notions of self-determination increasingly reflected in the lives of people with disability. This movement championed a philosophical shift within which notions of autonomy, choice, and therefore self-determination, became more explicit to the disability community.

However, despite gains for those with physical and milder intellectual disability, not all people with disability have the opportunity to lead self-determined lives (Agran, Storey, & Krupp, 2010; Burton-Smith, Morgan, &
The literature suggests that this lack of opportunity is related to the highly dependent nature of the lives of people with severe or profound intellectual disability, with such dependency defying notions of self-determination (Dodds, 2007; Harding, 2012).

When it comes to decision-making, people with severe or profound intellectual disability have traditionally been viewed as requiring the appointment of formal (state appointed), or informal substitute decision-makers. Substitute decision-making involves the legal appointment of a person to make decisions on behalf of a person with disability where they are assessed as unable to do so themselves. Decisions made under a substitute decision-making model are based on an objective assessment of the ‘best interests’ of the person concerned. The United Nations’ Convention on the Rights of Persons with Disabilities (UNCRPD), herewith called ‘the Convention’ or the UNCRPD, challenges the use of substitute decision-making as well as the notion of best interest.

The UNCRPD was adopted in December 2006 by the United Nations’ General Assembly. It was entered into force in May 2008. The Convention marks a paradigm shift from the perception of disability as a medical condition to one that views disability as the result of the interaction between a person’s condition and the disabling society to which they belong. The Convention’s signatory nations are obligated to bring local laws, policy and practices in line with the Convention’s core concepts of
self-determination, equality, non-discrimination, participation, inclusion and accessibility.

Article 12 (Equal recognition before the law) of the Convention is of particular relevance to this thesis. It emphasizes the full and equal legal capacity of all citizens to participate in decisions. It requires signatory nations to “recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” (United Nations., 2006 Article 12). This means that everyone has a right to be recognised as a person before the law. From this premise, Article 12 stipulates the universal right of all humans to receive appropriate support to make decisions. The United Nations monitoring body for the Convention (the UNCRPD Committee) interpreted Article 12, adopting a general comment in 2014. In doing so, the Committee called for the recognition of ‘universal legal capacity’. Locally, Australia responded to the UNCRPD by ratifying it in 2008. This, coupled with the roll out of Australia’s National Disability Insurance Scheme (NDIS) in 2016, underscores the Australian government’s commitment to ensuring a national focus on genuine choice and control for Australians with disability.

The UNCRPD Committee’s interpretation of Article 12 presents a challenge to existing systems of substitute decision-making. Australia has responded to this challenge by retaining an interpretative declaration, in relation to Article 12. An interpretative declaration is, “a statement made by a State, in which that State purports to specify or clarify the meaning or scope of a treaty or of certain of its provisions” (Commonwealth of Australia., 2014
Australia’s declaration allows for the use of substitute decision-making in situations where a person is assessed as having no or limited decision-making capability, an assessment outcome typically the case for people with severe or profound intellectual disability. Australia’s retention of this declaration is arguably in direct conflict with the spirit of the Convention, particularly Article 12.

1.3 Legal capacity and decision-making capability

Acknowledging that under Article 12, the human right to legal capacity, is a given, this thesis’ focus is not on legal capacity, but the notion of decision-making capability. Within the context of this thesis, decision-making capability is conceptualised as a person’s ability to participate in decisions. This capability may be realized independently or through a collaborative process of support from a group of people in the concerned person’s life who know them well, from here on referred to as supported decision-making. This definition embraces the collaborative and interdependent nature of decision-making particularly for people with severe or profound intellectual disability, rejecting the notion of independent decision-making. Rather than focusing on the legal concept of ‘capacity’, this thesis’ focus is on the process and mechanics of decision-making support for people with severe or profound intellectual disability within their everyday lives. It is important to note, that while the term ‘decision-making capability’ is not considered synonymous with the notion of legal capacity, it is acknowledged that where a person is perceived to have decision-making capability, they are more likely to have
their right to legal capacity, under Article 12 upheld. Acknowledging, its practical importance, this thesis focuses on the notion of decision-making capability.

1.4 Contextualising supported decision-making within this thesis

Supported decision-making is characterized inconsistently within legislation, policy and practice. Highlighting the elasticity of these characterizations, Carney and Beaupert (2013) describe supported decision-making as being “conceptually ill-defined” (Carney & Beaupert, 2013 p.178). Carney (2014) highlights the uncertainty that currently exists around the concept, due to its wide spectrum of interpretations, frameworks and models. He claims that these varying interpretations range from:

The purely informal supports we all enjoy as citizens when making decisions in our daily lives, through organizational assistance associated with service provision (or other civil society schemes), up to the variety of different forms of legally structured schemes of supported decision-making (Carney, 2014 p.1).

Further illustrating the broad characterisation of supported decision-making, Dinerstein (2012) describes the concept as,

A series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to
assist an individual with a disability to make and communicate to others decisions about the individual’s life (Dinerstein, 2012 p.4).


Supported Decision-Making can take many forms. Those assisting a person may communicate the individual’s intentions to others or help him/her understand the choices at hand. They may help others to realise that a person with significant disabilities is also a person with a history, interests and aims in life, and is someone capable of exercising his/her legal capacity (Byrnes et al., 2007 p.90)

Supported decision-making is used as an umbrella term that encompasses a range of processes that support an individual to exercise their decision-making capacity. A range of terminology is used to describe this support paradigm, including ‘supported decision-making’, ‘decision-making support’ and ‘support with decision-making’. Supported decision-making is used within this thesis to describe the process of decision-making support used within this study.

Within this thesis, supported decision-making is characterised as a process of enhancing the decision-making capability of people with severe or profound intellectual disability through a collaboration of support from
a group of people in the relevant person’s life who know them well. An important component of this approach is the use of a circle of support, a group of key members of the concerned person’s life, who have a good understanding, or are prepared to develop this understanding, of the person’s life history, personal characteristics, and their preferences. Unlike substitute decision-making, this approach emphasizes the primacy of a person’s will and preference rather than considering what is in their perceived best interests.

1.5 Statement of the problem

Article 12 of the UNCRPD has contributed to a paradigm shift in the way decision-making is conceptualized for those with intellectual disability. Highlighting its importance, Quinn describes the rights embodied within Article 12 as “cut[ting] to the heart of what it means to be human” (Quinn, 2010 p.3). Despite the strength of this paradigm shift, there remains a lack of focus on the practice of decision-making and supported decision-making. As argued by Bigby et al., “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” (Bigby, Whiteside, & Douglas, 2015 p.9). Although, Bigby et al.’s study did not include people with severe or profound intellectual disability, this lack of focus is particularly evident for this group who, due to their profound difficulties with communication, present specific challenges to those identifying and responding to their expressions of preference.

Despite these challenges, for signatory nations to uphold their obligations
under Article 12 of the UNCRPD, there is a clear need for research focused on this neglected area of practice. Specifically, there is a need for research that: 1) describes decision-making and decision-making support for people with severe or profound intellectual disability, 2) outlines factors that impact on this support, and 3) suggests mechanisms to enhance this support.

1.6 Research aims

This study had two aims. They were to:

1. Characterise supported decision-making for people with severe or profound intellectual disability in terms of the roles played by, a) the supported, and b) the supporters.

2. Focusing on the role of supporters, identify the processes, enablers and barriers, to supported decision-making for people with severe or profound intellectual disability, in order to understand how it can be fostered in practice.

1.7 Thesis overview

This thesis has five chapters.

Chapter one has introduced the thesis. It has described whom this thesis is about, namely people with severe or profound intellectual disability and their supporters. It has set the stage in terms of the overarching legislative and policy environments, predominantly focusing on the UNCRPD, specifically Article 12. Supported decision-making, as it is conceptualised
within the thesis, is introduced. The chapter concludes with a statement of the research problem and the study’s aim.

Chapter two provides an examination of the academic, policy and legislative literature, with the intention of illuminating current research, practice, philosophy, and legislation around decision-making and decision-making support for people with severe or profound intellectual disability. Ten broad questions were brought to the literature, and these form the chapter’s structure. This review strives to identify gaps in knowledge, which this research will seek to fill.

Chapter three describes the study’s methodology. It provides a detailed description and justification of the epistemological framework underpinning the study, social constructivism. It outlines the study’s research design and includes a detailed description of the supported decision-making intervention and framework that lies at the centre of this research project (Watson, 2013). It provides justification for the methods employed, and a discussion of their limitations. It outlines how rigor and trustworthiness were achieved.

Chapter four presents and discusses the findings of the study. In this chapter, data is presented in various ways including illustrative extracts from interviews, vignettes or stories and, in some cases, as descriptive statistical data. This chapter not only describes the data but also makes connections between the data, literature and emerging themes. This
Chapter is arranged in subsections each of which represents a particular theme emerging from the study.

Chapter five draws conclusions and, based on these, presents some new insights for support networks, service providers, and governments, in providing decision-making support for people with severe or profound intellectual disability.
CHAPTER TWO

A focus on literature, legislation, and current practice

"None who have always been free can understand the terrible fascinating power of the hope of freedom to those who are not free"

(Buck, 1943 p.43)

2.1 Introduction

In order to provide background and rationale for the research described in this thesis, this chapter examines the academic, policy and legislative literature, relating to research, practice, philosophy, and legislation around supported decision-making for people with severe or profound intellectual disability.

The review encompasses material from peer-reviewed journals, books, practice literature and policy, and was performed primarily by searching electronic bibliographic databases. The psychological, sociological, communication, intellectual disability and legal literature were canvassed. No exclusion criteria were imposed on the literature reviewed, because a wide review incorporating multiple theoretical and disciplinary perspectives was deemed necessary due to the broad range of topics incorporated into this thesis. Additionally, the reviewed materials were not limited in terms of when they were published. Ten questions were asked of the literature.
1. How are people with severe or profound intellectual disability described in the literature?

2. How is communication for people with severe or profound intellectual disability described in the literature?

3. What is self-determination?

4. How is self-determination for people with severe or profound intellectual disability described in the literature?

5. How are people with severe or profound intellectual disability perceived in terms of their decision-making capability?

6. What kinds of decisions do people with severe or profound intellectual disability typically face?

7. How does relational closeness affect decision-making for people with severe or profound intellectual disability?

8. What legislation exists designed to enhance signatory nations obligations under Article 12?

9. What is the evidence base behind supported decision-making?

10. What systemic factors are discussed in the literature as undermining supported decision-making approaches for people with severe or profound intellectual disability?

Six sets of search terms were initially taken to the literature, as illustrated in Figure 2 below. These terms were derived from the above ten questions.
These words were combined with each other in their singular and plural forms. A snowballing technique was then used, where the reference lists of key articles were examined to identify other relevant literature for examination. Across this sizeable literature set, the researcher selected material based on their compatibility with the research questions outlined in section 2.1.
It is important to highlight that this review is biased towards the discussion of literature from the English-speaking world, and as such, cannot be classified as representative of the global situation.

The chapter concludes with four research questions that will be answered in this thesis.

2.2 People with severe or profound intellectual disability

How are people with severe or profound intellectual disability described in the literature?

2.2.1 Labeling: A contentious issue

As described in Chapter one, several terms are used to describe those who are the focus of this thesis, including severe or profound intellectual disability, profound and multiple learning disability and profound mental retardation. Not only does the terminology differ, there is debate as to whether labels should be used at all. Over the last two decades, philosophies that have emerged within disability culture generally have discouraged the use of labels to describe people with intellectual disability (Gillman, Heyman, & Swain, 2000; Rivers, Henderson, Jones, Ladner, & Williams, 1975; Seymour, 2009). Movements such as ‘People First’ (People First., 1993) along with paradigms such as Person Centred Practice (McIntosh & Sanderson, 2005; O’Brien & Lyle-O’Brien, 1998) argue against the categorisation of people into specific disability groups for fear of their individuality being buried within stereotypes. There is a view within these movements that imposed categories serve to confine people to their label. Those opposed to labelling claim that a label can lead to social
disadvantage and exclusion (Gillman et al., 2000). Opponents of labels relating to disability emphasize the diversity of all people as an argument against the use of labels. In discussing the dilemma of disability labels, Seymour (2009) states,

The term intellectual disability brings into being a cultural intelligibility, a knowledge, image and/or idea about a person so labelled. Yet, each person is different and diverse and has a vast range of skills and limitations, as do we all. No two people are the same; no matter how seductive it is to believe the label creates a homogeneous grouping, this is not a reality (Seymour, 2009 p.7).

Despite the move away from using labels, there is a compelling argument for using specific language to describe people with severe or profound intellectual disability to signal the degree of support a person requires. Luckasson and Reeve (2001) advocate for the importance of “applying a specific term to something or someone”, while at the same time being aware that a label should not have precedence over seeing the person first (Luckasson & Reeve, 2001 p.47).

Moreover, there is a growing call amongst researchers and practitioners for an international agreement on an accepted taxonomy for this group (Leonard & Wen, 2002; Luckasson & Reeve, 2001; Nakken & Vlaskamp, 2007). Leonard and Wen (2002) state:

The implications for epidemiological research of having a stable definition or classification system that will allow comparison over
time and place are critical. Taxonomy in this field is particularly
difficult because professionals and consumers come from a range of
backgrounds and have different purposes such as advocacy,
education, medical care and service provision (Leonard & Wen,
2002 p.120).

Hall and Du Gay (1996) suggest that the function of words is to take on
meaning, so that they can be shared within a culture to describe concepts
and entities. They suggest that by doing this, words become the
foundation for shared knowledge (Hall & Du Gay, 1996). Drawing from
Hall and Du Guy’s work, Seymour suggests it is difficult to progress the
cause of any group without “using the words that have this shared cultural
meaning” (Seymour, 2009 p.9). Those supportive of a consistent
taxonomy for people with severe or profound intellectual disability
(Forster, 2010b; Nakken & Vlaskamp, 2007; Watson, 2011a) infer that
without it, those with severe or profound intellectual disability are at
particular risk of exclusion. They believe that to achieve true inclusion
individual difference needs to be named as the means by which this group
of people can obtain the supports and the resources they require.
Supporters suggest that it will improve the reliability of communication
and collaboration (Nakken & Vlaskamp, 2007), reduce misunderstandings
(Nakken & Vlaskamp, 2007), simplify the process of comparative research
(Forster, 2010), and increase the visibility of this group of people to
governments, service providers and funders (Forster, 2010b; Hogg, 2007).
Forster (2010), arguing the need for a consistent taxonomy for people
with profound intellectual and multiple disability (PIMD), wrote “people with PIMD deserve the dignity of being named, counted and recognised for who they are, what they need, and how they might be a unique part of our community” (Forster, 2010b p.33). Collectively, the pros and cons of labelling should be balanced carefully with the use of culturally sensitive labels and the utmost respect for the innate humanity of any group being labelled.

2.2.2 Definitions: People with severe or profound intellectual disability

Despite, the existing debates regarding the use of labels, definitions and descriptions for people with intellectual disability exist. Intellectual disability has historically been described as ‘mental retardation’ in the United States (US), although this is changing with increasing use of the term ‘intellectual disability’ (Schalock et al., 2007). In the United Kingdom, ‘learning disability’ is most commonly used. Section three of the Victorian Disability Act (The Parliament of Victoria, 2006) defines a person with an intellectual disability (ID) as having “significant sub-average general intellectual functioning and significant deficits in adaptive behaviour each of which became manifest before the age of eighteen years” (The Parliament of Victoria, 2006 Section 3). Notably, this Act (2006) makes no mention of people with severe or profound intellectual disability.

In the revised edition of the Diagnostic and Statistical Manual Disorders (DSM-5) the diagnosis of mental retardation has been revised to intellectual disability (American Psychiatric Association, 2013). In addition, DSM-5 no longer categorizes people strictly on intelligence
quotient (IQ) but asks those diagnosing to consider a person’s level of adaptive functioning. A diagnosis of intellectual disability requires a score that falls approximately two standard deviations from the mean (i.e. 70 or less). According to DSM-5, a severe intellectual disability is diagnosed when a person has an IQ between twenty and thirty-five. A profound intellectual disability is defined as an IQ below 20 (American Psychiatric Association, 2013). However, it should be noted that this is not consistently applied in research or service delivery.

Research foci and conceptual views of intellectual disability have varied throughout history. Up until the early 1970s the concept of human defect was the primary emphasis of research and practice in the area (Grossman, 1973). More recently, an emphasis on the role environmental and contextual factors play in the construct of intellectual disability became more prominent (Amos, 2004; Mirenda, Iacono, & Williams, 1990). Bronfenbrenner’s (1979), seminal work regarding the ecology of human development strongly influenced this paradigm shift (Bronfenbrenner, 1979). An ecological focus is consistent with other contemporary disability paradigms. These paradigms challenge historical conceptions of what it means to have a disability (Fujiura, 2004). For example, the World Health Organization’s (WHO) International Classification of Functioning, Disability, and Health (ICF) framework (World Health Organisation (WHO). 2001) emphasises an ecological approach. The WHO categorises disability in terms of its focus on limitations to activities and barriers to participation, rather than a person’s Intellectual Quotient (IQ) score.
2.2.3 Prevalence: People with severe or profound intellectual disability

Existing prevalence data in relation to disability generally is rare, inconsistent and fragmented. This is the case not only in Australia but globally. Reported disability prevalence rates from around the world vary dramatically. Mont (2007) identifies a number of reasons for inconsistencies in reported prevalence rates, citing the differences in definitions of disability, methodologies of data collection and quality of study design as contributing factors (Mont, 2007).

Specific prevalence rates for people with severe or profound intellectual disability are less established than those for people with intellectual disability generally. An Australian epidemiological study, carried out in 2002, estimated the prevalence of people with severe or profound intellectual disability (defined in this study as an IQ under thirty five) in Western Australia to be 0.14% of the general population (Leonard & Wen, 2002). The Australian Bureau of Statistics’ (ABS) most recent published data regarding people with severe or profound intellectual disability reported that in 2009, 5.8% of the disability population had a severe or profound limitation in core activity, equating to 0.06% of the general Australian population (Australian Bureau of Statistics (ABS). 2009). It should be noted that this data is not restricted to intellectual disability. A Finnish study estimated 0.13% of Finns had a severe or profound intellectual disability (Arvio & Sillanpaa, 2003). Emerson (2009) in his predictive report, *Estimating Future Numbers of Adults with Profound Multiple Learning Disabilities in England* estimated a prevalence rate of children with severe or profound intellectual disabilities to be 0.1% to
0.14% of the general population in England. Drawing on a range of mortality and birth related data, Emerson has suggested “sustained and accelerating” growth in the numbers of adults with Profound intellectual disability in England over the coming two decades (Emerson, 2009 p.3).

There is a view within the literature that the lack of consistent terminology, already described, has led to a dearth of consistent prevalence data for people with severe or profound intellectual disability (Forster, 2010b; Luckasson & Reeve, 2001; Nakken & Vlaskamp, 2007).

### 2.3 Communication and people with severe or profound intellectual disability

*How is communication for people with severe or profound intellectual disability described in the literature?*

Although people with severe or profound intellectual disability are dependent on others for support in many areas of life, it is the complexities of their communication that are one of the most cited areas of concern for those providing them with support (Bunning, 2009b; Carnaby & Pawlyn, 2009; Ogletree & Pierce, 2010; Thurman, Jones, & Tarleton, 2005). People with little or no speech are described in the literature and practice as having complex communication needs, an umbrella term characterizing communication, across a continuum of intellectual functioning (Beukelman & Mirenda, 2005; Iacono, West, Bloomberg, & Johnson, 2009).
2.3.1 The human communication continuum

Communication is described as progressing through a series of stages that reflect a continuum from unintentional to symbolic communication (Iacono et al., 2009; Ogletree & Pierce, 2010). At one end of the continuum, typical adult communication is characterised by the use of words, whether spoken or written, which are supplemented with nonverbal communication forms such as gesture, facial expression and body language. In contrast, at the other end of the continuum, the typical communication of people with severe or profound intellectual disability is characterized by nonverbal communication and formal symbols such as words and signs are rarely used. This communication is sometimes described as ‘preverbal’ (Adamson, Romski, Bakeman, & Sevcik, 2010; DeRuyter, 1988), ‘pre-symbolic’ (Granlund & Olsson, 1999), ‘pre-linguistic’ (Tait, Sigafoos, Woodyatts, O’Reilly, & Lancioni, 2004) or ‘informal’ (Bloomberg, West, Johnson, & Iacono, 2009). The term ‘informal’ has been adopted throughout this thesis. The literature further categorizes informal communication into two stages. Bates and her colleagues (Bates, Camaioni, & Voltera, 1975) described the earliest stage of communication as ‘perlocutionary’, suggesting that the onus is on communication partners to infer meaning from a person’s behaviours. For the purpose of this research, the term ‘unintentional communication’ will be used to describe this early communicative phase. This is the term predominantly used within Australia. The second phase is described as ‘illocutionary communication’, referred to as ‘intentional informal’ in this research (McLean, McLean, Brady, & Etter, 1991). This phase involves a shift from
“unintentional (i.e., perlocutionary) communication that relies on assignment of ‘intent’ by a partner to intentional (illocutionary) communication that is generated with the intent of affecting a listener” (Carter & Iacono, 2002 p.177). This communication continues to be considered informal, meaning that it is not characterised by the use of symbols such as speech and words. At the far end of the continuum is intentional and formal communication, which for the purposes of this thesis will be described as ‘symbolic’. This form of communication is not the focus of this research. The people who are the focus of this research all communicate within the first two thirds of the continuum depicted in figure 3.

Figure 3: Human Communication Continuum (Watson & Joseph, 2011)

Few assessment protocols exist specifically designed to assess informal communication behaviours, whether they are intentional or unintentional. The *Triple C: Checklist of Communicative Competencies (CCC)* is an exception (Bloomberg et al., 2009). The *Triple C* has been found to be a reliable tool to gather data regarding the communication skills of adults with severe or profound intellectual disabilities (Iacono et al., 2009).
According to the *Triple C*, ‘unintentional passive’ communicative behaviours are “produced in response to internal and external stimuli and are assigned intent or meaning by a communication partner” (Iacono et al., 2009 p.53). The *Triple C* describes ‘unintentional active’ communicative behaviours as “beginning attempts to act purposefully on objects” (Iacono et al., 2009 p.53). Like unintentional passive communication, these behaviours are assigned intention or meaning by a communication partner. The *Triple C*’s authors describe ‘Intentional informal’ communicative behaviours as action “on the environment to create a specific effect, resulting in communication attempts through informal rather than symbolic means” (Iacono et al., 2009 p.53).

To summarise this section, people with severe or profound intellectual disability are likely to function at the earliest phases of communication development. This means they generally communicate informally using subtle nonverbal behaviours such as facial expression, gesture, vocalisations, eye gaze, muscle tensions and touch. They have difficulty understanding formal communication such as sign language, speech, pictures, photos or written text. In addition to communicating informally, some people with severe or profound intellectual disability communicate unintentionally. For these people, when compared to intentional communicators, there is a disproportionate responsibility on communication partners to surmise meaning from their behaviours. This ambiguous and subjective task will be explored below.
2.3.2 Perceptions of communication capability

There is a lack of acceptance that people with severe or profound intellectual disability can communicate and therefore participate in decisions. Brown and Gothelf (1996) note that the tools needed to achieve self-determination are dependent on individual communicative competence that they claim are not generally seen in people with severe or profound intellectual disability (Brown & Gothelf, 1996). Additionally, Felce (2002) and Cummins (2002) raise serious doubts about the communicative competence of people with this level of intellectual disability specifically within the context of consenting to research (Cummins, 2002; Felce, 2002). Purcell, Morris and McConkey (1999), investigating how staff perceived the communication of their clients with severe or profound intellectual disability, found that they generally had negative perceptions of the communication capability of those they supported (Purcell, Morris, & McConkey, 1999). In their 1993 and 1995 studies, Granlund and his colleagues examined the impact of group training interventions on the communication of Swedes with a profound intellectual disability (Granlund, Bjorck-Akesson, Brodin, & Olsson., 1995; Granlund, 1993). Both studies reported that at pre-intervention, supporters had a low perception of the communicative abilities of those they supported; however, this increased over the course of the study. A study carried out over twenty-five years ago by Evans and Ware (1987) found that teachers of people with severe or profound intellectual disability judged eighty one per cent of their students as having no communication skills (Evans & Ware, 1987). Goldbart (1994) stressed
concern about these findings not in terms of the accuracy of teachers’ judgments, but the treatment of students as non-communicators, and therefore their ability to communicate preference, and consequently to participate in decisions (Goldbart, 1994).

It is suggested in contemporary literature that these historically negative perceptions regarding the communicative capability of people with severe or profound intellectual disability are attributable to a disregard for informal and unintentional communication (Grove, Bunning, Porter, & Morgan, 2000; Johnson, Watson, Iacono, Bloomberg, & West, 2012b). The candidacy approach, prominent in Speech Pathology policy and practice in the 1980s, directed practitioners to reserve communication related intervention only for those who had reached a prerequisite level of cognitive functioning, one that indicates an ability to communicate intentionally (Johnson et al., 2012b). As highlighted by Johnson et al., (2012), such a use of candidacy criteria has now been rejected by the American Speech Language Association (2005) and the National Joint Committee for the Communication needs of Persons with Severe Disabilities (1992). The candidacy approach has been replaced with an understanding that communication reflects a continuum of behaviours, ranging from simple unintentional communicative attempts to highly symbolic and sophisticated communication, as illustrated in Figure 3. Describing this paradigm shift, Johnson et al (2012) state:

Although it took a long time for policy to catch up, intervention became directed at supporting a person’s communication
regardless of his/her base level skills. Hence, the communication potential of all individuals, irrespective of their level of intellectual ability, was acknowledged (Johnson et al., 2012b p.65).

Responding to this historical exclusion of people with severe or profound intellectual disability from the definition of communicative competence, Clegg (2009) and Johnson et al. (2012) call for a reconceptualization of the concept (Clegg, 2009; Johnson et al., 2012b). This reconceptualization has drawn from an inclusive and interdependent view of communication, both of which are discussed in proceeding sections.

2.3.3 An inclusive view of communication

Central to an inclusive view of communication is the acceptance that “all people, no matter how severe their level of disability, can and do attempt to communicate” (Mirenda et al., 1990 p.3), and although this communication may be developmentally primitive it has inherent value.

Supporting an inclusive view of communication, Hostyn and her colleagues claim there is considerable value in the use of knowledge gleaned from literature and practice around mother child interaction (Hostyn, Petry, Lambrechts, & Maes, 2011). During the 1970s and 1980s, researchers and practitioners explored developments in communication theory, particularly in relation to mother-infant interaction, an area that had been under the microscope for many years (Bruner, 1978; Haft & Slade, 1989; Stern, 1977). Bruner highlighted the value of informal and unintentional infant communication with their mothers, claiming it was a vital part of their development and wellbeing (Bruner, 1978). Drawing
from Bruner’s work, Dunst (1978) proposed a new definition of communication to encompass:

Any overt conventional or nonconventional behaviour, whether used intentionally or not, that has the effect of arousing in an onlooker a belief that the signal producing organism is attempting to convey a message, make a demand, request etc. to an onlooker (Dunst, 1997 p.111).

Hostyn and her colleagues are not alone in their view that descriptions of interactions between caregivers and children with typical development are particularly relevant to the interaction between adults with severe or profound intellectual disability and their supporters (Forster, 2010a; Hodapp, Burack, & Zigler, 1990; Nind, 1996; Saunders, Saunders, Struve, & Munce, 2007). Saunders et al. (2007) found that interaction, typical of parent-infant interaction, in the form of singing, funny noises and tickling were effective reinforcement for people with severe or profound intellectual disability (Saunders et al., 2007). Similarly, staff participants in interviews conducted by Forster and Iacono (2008) highlighted the importance of being playful and responsive to the specific needs of those they were supporting (Forster & Iacono, 2008).

The acknowledgment of the similarities between mother-child interactions and adults with severe or profound intellectual disability and their supporters highlights an important paradigm shift in the way people with severe or profound intellectual disability are viewed in terms of their
ability to communicate. The seminal work of researchers and practitioners such as Donnellan, Mirenda and colleagues in the 1980s and 90s helped fuel this shift. This body of work contributed to a characterisation of people with severe or profound intellectual disability as people who did not communicate to people who could communicate, albeit through unintentional, infant-like means (Calculator, 1988; Donnellan, Mirenda, Masseros, & Fassbender, 1986; Mirenda et al., 1990; Ogletree, Fischer, & Turowski, 1996).

Cannella, O’Reilly, and Lancioni (2005) further articulated the paradigm shift in how people with intellectual disability are perceived in their ability to express preference. They reviewed thirty studies published from 1996 to 2002 relating to the assessment and intervention of choice and preferences of people with severe or profound intellectual disability (Cannella, O’Reilly, & Lancioni, 2005). They highlighted that current views and practice have moved from a narrow interpretation of communication to one that acknowledges the communicative function of a broad range of human behaviour, regardless of its formality and intentionality (Donnellan et al., 1986; Durand & Merges, 2001). This contemporary view has provided motivation to further develop strategies and supports for people who communicate informally and unintentionally, to express preference.

2.3.4 An interdependent view of communication

Another factor influencing the reconceptualization of communicative competence is the acceptance that communication is an interdependent and collaborative process. This view places less emphasis on individual
communicative capability, and more emphasis on the didactic and collaborative nature of successful communication. It acknowledges that communication is transactional and usually co-constructed (Johnson et al., 2012b). Bunning (2009) describes the co-construction of communication as “two or more people working together and coordinating their actions in ongoing response to each other and the context” (Bunning, 2009b p.48).

2.4 Self-determination

What is self-determination?

2.4.1 Self-determination theory (SDT)

Self-determination is a concept of particular relevance to the disability field. It is articulated in current policy and legislation and has significance in discussions of decision-making. Self-determination for people with disability is now understood as a goal and the past decade has seen increasing research to test the efficacy of practices to support it. During the current century, research regarding self-determination has expanded to include studies focused on the efficacy of interventions to promote self-determination across a variety of disability groups and life contexts. This is exemplified in the literature’s focus on self-determination regarding a range of disability including psychiatric (Moran, Russinova, Yim, & Sprague, 2014), physical (Saebu, Sorensen, & Halvari, 2013) and sensory (Luckner & Sebald, 2013) disability. A focus on self-determination is also evident in research literature relating to acquired brain injury (Knox, Douglas, & Bigby, 2012; Knox, Douglas, & Bigby, 2013), age related cognitive disability (Miller, Whitlatch, & Lyons, 2014; Moye, Marson, &
Edelstein, 2013; Samsi & Manthorpe, 2013; Srinivas Rao & Blake, 2002) and autism (Chou, 2014). This focus is within educational (Hong, Haefner, & Slekar, 2011; Wehmeyer, 2015; Wehmeyer et al., 2012; Wehmeyer, Palmer, Shogren, Williams-Diehm, & Soukup, 2013), early childhood (Palmer et al., 2013), employment (Agran & Krupp, 2011; Timmons, Hall, Bose, Wolfe, & Winsor, 2011), family planning (Conder, Mirfin-Veitch, Sanders, & Munford, 2011), and health care settings, including end of life decision-making (Ferguson, Jarrett, & Terras, 2011; Schroeder, 2013).

Although its principles have been part of the fabric of human civilization and thinking for centuries (Stern-Gillet, 1994), self-determination as a theory was not defined and developed until the 1980s. Self Determination Theory (SDT) is a psychological need theory developed by psychologists (Deci & Ryan, 1985; Deci & Ryan, 2000). A central tenet of SDT is that human beings have three basic interrelated psychological needs. The first is for autonomy, the second for competence, and the third for relatedness. Ryan (1995) likens the human need for these three elements to the need that plants have for key nutrients (i.e., soil, sun, water) in order to thrive (Ryan, 1995). Ryan and Deci propose that, “the basic needs for competence, autonomy, and relatedness must be satisfied across the life span for an individual to experience an ongoing sense of integrity and well-being” (Ryan & Deci, 2000 p.75). They characterize these needs as universal to all people and all societies (Deci & Ryan, 2000). Ryan, Huta, and Deci (2008) define these three psychological needs, stating:

The need for autonomy refers to a sense of choice and volition in
the regulation of behaviour. The need for competence concerns the sense of efficacy one has with respect to both internal and external environments. The need for relatedness refers to feeling connected to and cared about by others (Ryan, Huta, & Deci, 2008 p.153).

2.4.2 Autonomy and relatedness: Interrelated?

Among the three needs postulated by Deci and Ryan within self-determination theory, autonomy is the most controversial. Some of the controversy appears to stem from disagreement within the literature regarding the compatibility of the constructs of ‘autonomy’ and ‘relatedness’.

On one side of the argument is the view that the psychological needs of autonomy and relatedness are antagonistic to one another. This view is based on specific definitions of autonomy embedded within neoliberal societies. Within these cultures, autonomy is associated with “being able to do things for oneself, to be self-supporting and self-reliant” thereby excluding the role of others (Reindal, 1999 p.353). Markus and Kitayama (2003) describe this view as a disjoint model of agency. Within a disjoint model, the self is constructed as “an independent essence that is bounded within the individual and disconnected from others” (Markus & Kitayama, 2003, p.5).

Chirkov and her colleagues oppose this view. They suggest that a disjoint model of agency does not concur with the SDT definition intended by Deci and Ryan (Chirkov, Ryan, Kim, & Kaplan, 2003). They are of the view that this portrayal is based on a false assumption that SDT’s constructs of
autonomy and self-determination are realized independently from one’s social network. Agreeing with Chirkov (2003) and exploring these ideas in a disability context, Reindal (1999) suggests that an individualistic view limits characterizations of personal autonomy to those that imply independence. She supports a reconceptualization of the human condition as ultimately one of interdependence between people, stating:

> When the human condition is viewed as one of interdependency and vulnerability, this leads to an understanding of independence as ‘partnership’. Departing from a relational view of the subject, independence becomes a two-way responsibility and not solely an individual ability (Reindal, 1999 p.354).

Supporting Reindal’s view, Dekker explores these concepts in relation to chronic illness and argues that autonomy and dependence should not be considered as two mutually exclusive human states (Dekkers, 2001). Further support for this notion is provided by feminist theorists who suggest that a liberal focus on the individual rather than the community of which a person is a part, leads to further marginalization of the less powerful (Lacey, 1998). A particular focus of the feminist critique, outlined by Clough (2014), advocates for a “move away from ‘masculine’ accounts of the self and towards a relational approach” (Clough, 2014 p.130).

The above views promote a conjoint, as opposed to disjoint, model of agency, whereby “the self is understood as the presence of interdependent
selves in relation to others” (Markus & Kitayama, 2003 p.5). Research into adolescent autonomy, supports this conjoint model of agency, showing positive, rather than negative links between relatedness to parents and autonomy in teenagers (Lynch, Plant, & Ryan, 2005; Ryan & Lynch, 1989; Vansteenkiste, Lens, Soenens, & Luyckx, 2006).

The value of conjoint as opposed to disjoint models of agency is also reflected in recent commentary around Article 12 of the UNCRPD. Arstein-Kerslake (2014) proposes that the revolutionary element of Article 12 lies in its marriage of autonomy and interdependence (2014). She proposes that Article 12 calls for the recognition that autonomy is not an individually occurring phenomenon, but can be exercised through social interaction. This recognition is characterised by Arstein-Kerslake as the re-positioning of a person “as an individual who exercises liberty within a web of social supports” (Arstein-Kerslake, 2014 p.1).

2.4.3 Cross-cultural views of autonomy

A collective and relational view of autonomy is also highlighted in cross-cultural studies of self-determination, positing the family, community, or village as central to decision-making (Blackhall, 1995; Chan, 2004; Fan & Tao, 2004; Iyengar & Lepper, 1999a; Shogren, 2012). Iyengar and Lepper (1999) suggest that individualized (as opposed to collective) autonomy is a western postmodern construct and is not generally desired in more “socially interdependent cultures”, such as parts of Asia and South America (Iyengar & Lepper, 1999, pp. 349-366). They found that while Anglo American children were most likely to be motivated when they
personally chose aspects of a puzzle activity, Chinese and Japanese children were motivated the most when they were told that their mothers’ had chosen for them (Iyengar & Lepper, 1999a). Through this research, Iyengar and Lepper (1999) conclude that, for an Asian American group, implementing choices made by trusted social supports enhanced intrinsic motivation for self-determination.

Shogren (2012) in her exploration of the perceptions of self-determination held by Hispanic mothers of youth with severe disability, supports this view of collectivism within self-determination (Shogren, 2012). Shogren (2012) highlights a Hispanic mother’s characterisation of self-determination for her son, particularly within the context of his schooling. “This mother valued interdependence, and she felt that the school viewed her negatively because of this” (Shogren, 2012 p.179). Additionally, racial and ethnic differences have been found in relation to the health related decisions made by patients, with particular ethnic groups tending to favour a more shared, non-patient centred approach to making decisions (Blackhall, 1995). Blackhall (1995) surveyed a diverse cultural group of elderly people. He found that Mexican-Americans and Korean-Americans were more likely to view optimal medical decision-making as a collaborative process, rather than one that is individualised or patient-centered, as preferred by most of the African-American and European-Americans surveyed (Blackhall, 1995).

Shogren, Blackman, and Iyengar and Lepper all found that within the non-western cultures they studied, optimal decision-making occurred within
the context of families and communities. They each describe a collaborative view of autonomy in these cultures, whereby it is best realized collectively rather than individually. They contrast the uniqueness and independence at the center of individualistic societies, such as Australia, with the prized values of relatedness and interdependence in collectivistic societies, such as those found in many non-western cultures (Blackhall, 1995; Iyengar & Lepper, 1999a; Shogren, 2012).

The above section has characterised self-determination, how it is viewed in different cultures, and its application to people with disability generally. The following sections are focused on how self-determination is applied specifically to people with disability focusing on those with severe or profound intellectual disability.

2.5 Self-determination and people with severe or profound intellectual disability

How is self-determination for people with severe or profound intellectual disability described in the literature?

As discussed, in contemporary society, people with disability are encouraged and supported to take control over their lives. Self-determination is increasingly being recognised as a useful construct with which to understand and implement this control. Specifically, research provides evidence of the benefits of being self-determined in relation to achieving positive outcomes for people with mild to moderate intellectual disability. These benefits are evident within the context of independent
living (Wehmeyer & Palmer, 2003), community inclusion (Wehmeyer & Schwartz, 1997), and behaviours of concern (Perry, Felce, Allen, & Meek, 2011; Shogren, Faggella-Luby, Bae, & Wehmeyer, 2004). These benefits are also evident in relation to psychological wellbeing (Neely-Barnes, Graff, Marcenko, & Weber, 2008) and quality of life (Brown & Brown, 2003, 2009; Brown, Hatton, & Emerson, 2013; Lachapelle et al., 2005; Nota, Ferrari, Soresi, & Wehmeyer, 2007; Wehmeyer, 2007; Wehmeyer & Bolding, 2001).

Although contemporary literature focused on self-determination intervention is primarily related to people with mild to moderate intellectual disability, there is a body of earlier research focused on self-determination intervention for people with severe or profound intellectual disability. Shevin and Klein’s seminal research began a body of research highlighting the importance of choice availability in the lives of people with severe or profound intellectual disability (Dattilio & Rusch, 1985; Nietupski et al., 1986; Shevin & Klein, 1984).

Despite this focus, opportunities for self-determination remain restricted for people with severe or profound intellectual disability (Burton-Smith et al., 2005; Felce et al., 1998; Heller, Miller, & Factor, 1999; Stalker & Harris, 1998). The literature points to a number of reasons for this restriction, including, a lack of opportunities for choice, a general perception of self-determination as an independent as opposed to an interdependent construct, and a factor central to this thesis, a lack of supporter responsiveness to the communication of preference of those they support.
The first two of these factors are discussed in this section, while, considering its role within this thesis, supporter responsiveness to the will and preference of those they support is explored in depth in section 2.6.

2.5.1 Opportunities for choice

Wehmeyer and Garner (2003) conducted a series of regression analyses that evidenced opportunity for choice as the strongest predictor of self-determination for people with intellectual disability (Wehmeyer & Garner, 2003). Despite its importance, it is evident that overall people with intellectual disability have fewer opportunities for choice and preference expression than the remainder of the population (Stancliffe, Abery, & Smith, 2000; Stancliffe, 2001). This lack of opportunity is particularly evident in the lives of people with severe or profound intellectual disability when compared to those who are less cognitively impaired.

Exploring daily choice availability for fifty nine people with intellectual disability living in Tasmanian group homes, Burton-Smith et.al (2005) found that choice availability was significantly lower for adults with more severe intellectual disability, than their less disabled peers (Burton-Smith et al., 2005). This finding was consistent with those of Felce et.al (1998) who found that within a residential setting, residents’ access to choice was significantly associated with their level of intellectual disability. As was the case in the study conducted by Burton-Smith and her colleagues, they found that more choice was afforded to those with milder disability, as measured by scores on the adaptive behavior scale, than their more disabled co-residents (Felce et al., 1998). This correlation between intellectual ability and opportunity for choice is not surprising considering
the complex nuances in communicative behavior of people with severe or profound intellectual disability, previously discussed.

2.5.2 Independent/interdependent perceptions of self-determination

There is growing acknowledgment in the literature that the exclusion of people with severe or profound intellectual disability from the self-determination movement may be related to the conceptualization of self-determination within western culture. This conceptualization is incompatible with the interdependent needs of people with severe or profound intellectual disability (Bach & Kerzner, 2010; Pepin, Watson, Hagiliassis, & Larkin, 2013; Wehmeyer, 1998, 2005). These commentators suggest that for self-determination to be relevant to people with severe or profound intellectual disability, the concept of autonomy should be re-conceptualised to better reflect the realities of these people's lives. These authors reject the neoliberal constructions of individualised self-determination, previously discussed, which emphasize individual intellectual 'capacity' and explicitly exclude the role which social and environmental factors make to a person's decision-making (Bach & Rock, 1996). Like Reinder (1999), Bach and Kerzner (2010) make the point that human beings do not exercise their "self-determination as isolated, individual selves, but relationally, interdependently and intersubjectively with others” (Bach & Kerzner, 2010 p.40). Wehmeyer (1998) further highlights this point, stating “when self-determination is interpreted strictly to mean “doing it yourself”, there is an obvious problem for people with significant disability, many of whom may have limits to the number
and types of activities they can perform independently” (Wehmeyer, 1998 p.65).

2.6 Supporter responsiveness to the expression of preference of those they support

The literature discussed so far, in relation to both communication and self-determination highlights the important role of interaction with others in the realisation of both. In the context of supporting people with severe or profound intellectual disability, this focuses attention on the nature of this interaction, and in particular on the area of supporter responsiveness.

Bunning (2009) states that “a person’s communication is only as effective as the responses of others” (Bunning, 2009b p.51). Over the past four decades, researchers have stressed the important role of supporter responsiveness within the process of self-determination for people with severe or profound intellectual disability (Bunning, 2009a; Finlay, Walton, & Antaki, 2008; Guess, Benson, & Siegal-Causey, 1985; Johnson, Bigby, Iacono, Douglas, & Katthagen, 2014a; McConkey, Morris, & Purcell, 1999; Ware, 1996, 2004). The complexities of responding to the communicative behaviours and expressions of preferences of people with severe or profound intellectual disability are well documented (Belfiore, Browder, & Mace, 1994; Cannella et al., 2005; Finlay, Walton, et al., 2008; Houghton, Bronicki, & Guess, 1987; Hughes, Pitkin, & Lorden, 1998). For example, Finlay and his colleagues acknowledged the complexities of supporter responsiveness particularly within the context of determining preference found poor levels of supporter responsiveness to expressions of
preference by students with profound intellectual disability, especially in
the context of no direct instruction. They suggest that this poor
responsiveness is due to difficulties acknowledging or noticing the
expressions of preference of those they support (Houghton et al., 1987).

Supporter responsiveness to the expressions of preference of people with
severe or profound intellectual disability is ill defined in the literature. A
review of the literature has revealed that responsiveness is primarily
discussed in terms of three factors. Firstly, supporters’
acknowledgement/noticing (as opposed to the ignoring) of the
expressions of preference of those they support (Finlay, Walton, et al.,
2008; Grove, Bunning, Porter, & Olsson, 1999b; Schepis & Reid, 1995).
Secondly, their interpretation of those expressions of preference (Carr &
Durand, 1985; Kern et al., 1998; Petty, Allen, & Oliver, 2009; Romaniuk &
Miltenberger, 2001), and finally the ultimate action supporters take in
response to the expression of preference of those they support (Bach &
Kerzner, 2010). These three factors are given unequal attention in the
research literature. Each will be explored below.

2.6.1 Acknowledging expressions of preference

A pre-requisite to a person’s expression of preference being interpreted
and then acted upon, is that it is noticed and acknowledged by a
communication partner (Grove et al., 1999b; Schepis & Reid, 1995).
However, for this population, who are often extremely passive
communicators, the acknowledgment or noticing of communication
attempts by those providing them with support is challenging resulting in
their expressions of preference being ignored (Findlay, Williams, de, Baum, & Scior, 2015; Lima et al., 2012; Vlaskamp, Hiemstra, Wiersma, & Zijlstra, 2007).

The literature provides strong support for the value of high quality and close interactions between people with severe or profound intellectual disability and their supporters, in increasing the likelihood that expressions of preference will be noticed and acknowledged. Beadle-Brown and her colleagues (2012) found that expressions of preference were more likely to be acknowledged within the context of active support, an intervention designed to enhance interaction (Beadle-Brown, Hutchinson, & Whelton, 2012). Mansell and Beadle-Brown’s (2012) review of the literature relating to active support, found that a consistent use by staff of person-centred active support increases the likelihood that the expressions of preference of those being supported were acknowledged (Mansell & Beadle-Brown, 2012). Finlay and his colleagues observed and videotaped interaction in residential settings of five people with intellectual disability and those who supported them. Their study highlighted the role of close interactions between support workers and residents in acknowledging expressions of preference, specifically via nonverbal means (Finlay, Walton, et al., 2008).

In summary, there is evidence of the value of high quality and close interactions between people with severe or profound intellectual disability and those who support them, in increasing the likelihood that their expressions of preference will be noticed and acknowledged. The
value of high quality relationships and interactions between people with severe or profound intellectual disability and their supporters is discussed later in this chapter.

2.6.2 Interpreting expressions of preference

Multiple methodologies have been designed to interpret the preferences of those with severe or profound intellectual disability. Largely explored in the field of speech pathology, augmentative communication, and severe or profound intellectual disability, these methodologies are described in the literature as preference assessment, storytelling (including multi-sensory methods), and communication profiles.

Direct preference assessment

A handful of empirical studies and literature reviews have identified direct preference assessment as a valid way of identifying preferred items, environments, people and other stimuli for people with severe or profound intellectual disability (Cannella-Malone, Sabielny, Jimenez, & Miller, 2013; Cannella et al., 2005; Green et al., 1988; Kang et al., 2013; Parsons & Reid, 1990; Tullis et al., 2011). Direct preference assessment involves observations and documentation of responses to the systematic presentation of different items, stimuli, or situations. A variety of direct preference assessments are examined in the literature. Single stimulus assesses an individual’s approach or non-approach to a single stimulus (Pace, Ivancic, Edwards, Iwata, & Page, 1985). Paired stimulus offers the focus person two items allowing them to choose one (Piazza, Fisher, Hagopian, Bowman, & Toole, 1996). Multiple stimuli presentations give
the focus person an array of stimuli to choose from, allowing them to choose one (DeLeon & Iwata, 1996; Singh, Lancioni, O’Reilly, & Molina, 2003). For example, Singh et al.’s study demonstrated that a fourteen year old girl with multiple and profound physical and intellectual disability could choose from multiple stimuli using micro switch technology (Singh et al., 2003).

Drawing from their systematic review of the area, Cannella et al. (2005) concluded that direct preference assessments can lead to greater self-determination, particularly in the lives of people with severe or profound intellectual disability (Cannella et al., 2005). Kang’s et al (2013) more recent review compared fourteen studies. Each of these studies examined the efficacy of particular direct preference assessment procedures. They found that the majority of procedures used across the fourteen studies were accurate in their identification of preference for a reinforcer (Kang et al., 2013). Virués-Ortega and colleagues (2014) also conducted a review of the preference assessment literature confirming Kang et al.’s results (Virués-Ortega et al., 2014). They found that people with severe or profound intellectual disability were reliably able to express likes and dislikes within the context of preference assessments. They used this literature to guide them in the development of a decision-making framework designed to increase the use of preference assessment methodologies within this population (Virués-Ortega et al., 2014).

Despite support for the use of direct preference assessments, there is also opposition. Cote, Thompson, Hanley, and McKerchar (2007) observed
extremely poor correlation between teacher reports of preference and
direct preference assessment of young children. Specifically, a correlation
between rankings generated through the two assessments existed only
one out of nine times (Cote, Thompson, Hanley, & McKerchar, 2007).
Adding further to the questions surrounding the use of direct preference
assessment, Reid and Green (2002) found that proxy ratings of
preferences of people with severe or profound intellectual disability
differed from preferences identified through direct preference assessment
in response to different stimuli (Reid & Green, 2002). Direct preference
assessments have come under further scrutiny with Ten Brug, Van Der
Putten and Vlaskamp (2013) highlighting the fleeting nature of such
assessments, claiming that they rely on observational snapshots that are
difficult to generalize across a person's life, making reliable
interpretations of preference difficult (Ten Brug, Van Der Putten, &
Vlaskamp, 2013).

*Interpreting preference through storytelling*

Narration, life stories and personal storytelling are increasingly proving to
be a powerful vehicle for people with intellectual disability to have their
voices and preferences heard (Atkinson, Jackson, & Walmsley, 1997;
Hamilton & Atkinson, 2009). However, for people with severe or profound
intellectual disability opportunities for story telling are rare (Grove, 2012;
Grove, Harwood, & Ross, 2010). Grove (2012) highlights the complex
reasons for this, pointing out that the difficulties people with severe or
profound intellectual disability have with initiating communication is only
part of the issue (Grove, 2012). Grove (2007) attributes her finding of a
relative absence of storytelling in the lives of people with severe or profound intellectual to the dominance of uninteresting, repetitive and negative events in their lives, none of which are the ideal basis for telling a story (Grove, 2007a). Additionally, Grove (2012) cites Peterson and McCabe (1983) who assert that typical structural approaches to expressing narrative are unsuitable for people with a cognitive age less than four years, such as those who are the focus of this thesis (Peterson & McCabe, 1983). Grove (2012) suggests that a more applicable narrative approach for these people should recognise the unique nature of their communication. This recognition should include the non-symbolic nature of their communication, predominantly made up of body language and vocalizations, making them “highly dependent on others for the interpretation of their communication signals” (Grove, 2012 p.342). She advocates for a move away from the Anglo-Western approach to narration emphasising coherence and resolution, to the story telling approaches used by non-Western indigenous people. Within these cultures, stories are often “open-ended, elliptical, and concealed” (Grove, 2012 p.343). Grove makes particular reference to the Mi’kmaw stories of the first peoples of Nova Scotia and the indigenous peoples of Australia. Referring to the Mi’kmaw stories she states that they “do not conform to Western logic for sequencing time” (Grove, 2012 p.343). She quotes Sable and Francis (2012) who describe these stories as “an open system, filled with possibility, mutability and ongoing interpretation based on personal and shared experience” (Sable & Francis, 2012 p.57). Grove (2012) draws parallels between these indigenous perspectives and the process of
interpreting preferences of people with severe or profound intellectual
disability, whose communication lacks coherence and formality, but in
reality can be “highly complex and multilayered” (Grove, 2012 p.344). She
also highlights the interdependent nature of indigenous narrative
tradition, which reflects a collectivist perspective that values relationships,
family and community. Once again she quotes Sable and Francis (2012)
who state that within the Mi’kmaw language of Nova Scotia, “everything,
every person is spoken of in relation with something or someone else ...
Everything existed within a network of relationships” (Sable & Francis,
2012 p.32). This recognition of mutual dependence is of clear relevance to
people with severe or profound intellectual disability and this thesis.

Multisensory story telling (MSST) is a technique that is increasingly being
used to explore preferences of people with severe or profound intellectual
disability in the United Kingdom, the Netherlands and Belgium (Ten Brug,
Van der Putten, Penne, Maes, & Vlaskamp, 2012; Ten Brug et al., 2013).
The technique involves developing a personalised story for someone using
different means of sensory stimulation. Multi-sensory stories are generally
shaped according to a recognised set of guidelines articulated in the
literature (Lambe & Hogg, 2011; Ten Brug et al., 2012). A multi-sensory
story is typically organised into short sentences spread over a number of
pages. Each of these pages has a sensory stimulus (tactile/sound/smell)
associated with it to add meaning to the content. An MSST book is typically
used repetitively and consistently with the same person over time,
allowing a supporter to systematically assess patterns in reactions and
therefore preferences. As described by Ten Brug and her colleagues “it allows the teacher to notice recurring, subtle communicative behaviours, which otherwise might be overlooked” (Ten Brug et al., 2013 p.340).

Despite its frequent use, to date the technique of multi-sensory storytelling has a shallow empirical base guiding its practice. In an attempt to deepen this evidence base Ten Brug et al. (2013) aimed to ascertain whether the use of multi-sensory story telling changed teachers’ knowledge of the sensory, motor and contextual preferences of the children with severe or profound intellectual disability they taught. In this study, three dyads of teachers and their students were read an MSST book twenty times over a ten-week period. The teachers completed a questionnaire to ascertain their knowledge of students' preferences before, during and after the intervention. The authors found that teachers increased their knowledge of the person’s preferences, and this was particularly the case for motor and contextual preferences (Ten Brug et al., 2013). Young and her colleagues used multi-sensory storytelling to deal with sensitive topics with seven young people with severe or profound intellectual disability. Amongst several outcomes, they found that supporters reported an increased ability to ascertain preference within the context of the multi-sensory storytelling session (Young, Fenwick, Lambe, & Hogg, 2011).

Although not using multi-sensory storytelling, Lyng’s study examining how to ‘get under the skin’ of people with severe or profound intellectual disability, uses a particular narrative technique to ascertain preference.
Lyng’s technique aims to see a person ‘beyond their disability’ (Lyng, 2007 Slide 16). He points out that there are very few narratives about people with disability that do not focus on their disability. Casey and Houghton (2010) agree with Lyng, stating, “there are few or no narratives available for the disabled without a focus on the disability” (Casey & Houghton, 2010 p.31). Lyng’s technique allows supporters to hone in on the focus person around a diverse range of life contexts. For example, by producing a simple narrative around what clothes a focus person may wear if they had complete control over their life, supporters’ are able to develop a picture of the focus person’s preferences around their appearance. Asking supporters to consider what music they would listen to if they had complete control over their life, provided supporters in Lyng’s study with a vehicle anticipate or hypothesise focus people’s preferences around sound and rhythm. Lyng (2007) found that this technique allowed supporters to view focus people as having preferences beyond those typically associated with their support needs (Lyng, 2007).

**Individualised communication profiles**

An important activity in interpreting the preferences of people with severe or profound intellectual disability is documentation of idiosyncratic communicative behaviours. The use of individualised communicative behaviour profiles is common practice within services for people with severe or profound intellectual disability and complex communication needs. Such profiles are used to support the quick and thorough exchange
of information and understanding of a person’s affective expressions of wants, likes and preferences. Examples of this practice include Personal Communication Dictionaries (Beukelman & Mirenda, 2005) and ‘Books about me’ (Bloomberg, West, & Johnson, 2004), Communication Passports (Millar & Aitken, 2003), Health Passports (Brodrick, Lewis, Worth, & Marland, 2011), Sensory profiles (Dunn, 2008), and Multimedia Profiling (Acting Up, 2003). These tools provide a way of collecting information about a person, by consulting with people who know them best, observing, analyzing, discussing and then organizing that information into a format such as a book or multimedia/digital profile. Compiling detailed profiles of someone’s communication in this way is considered to be an important component of a person-centered planning process (Sanderson, 1998).

Multimedia profiling uses a combination of “digital video, still photography, sound, graphics and text” to capture a person’s communication profile (Bunning, 2009a p.57). This approach is a practical way of sharing important information about someone. It is a way for service users’ preferences to be recognized and collaboratively interpreted and therefore their needs met more accurately. Bunning, Heath, and Minnion (2010) describe it as a way to “convey the personal agenda of a person with severe/profound intellectual disabilities and complex needs” (Bunning, Heath, & Minnion, 2010 p.62). In 2012, a pilot study implementing multimedia profiles with eight informal communicators and their circle of support was carried out (Rezzani, 2012). The pilot demonstrated that, overall, the technique was a useful
tool to develop a clear profile of a person’s unique communication system. In particular, it appeared that the use of video increased supporters’ awareness of the idiosyncratic communication of those they supported. When compared to written forms of profiling and sharing information, supporters reported that a multimedia method was more effective.

Rezzani (2012) also reported a perception that the development of a multimedia profile helped build their capacity to provide detailed verbal and written descriptions of how the person they support communicates. Additionally, supporters reported that the technique encouraged staff to review and reflect upon their own behaviour, with the view to improving the quality of the interactions they have with those they support. The greatest barrier reported was that of having enough time, not only to produce and watch the profile, but also to develop the necessary technological skills to produce it (Rezzani, 2012).

*Dependence on the interpretation of others*

Grove et al (1999) describe people with severe or profound intellectual disability, as having a high level of “dependence on the interpretations of others to make themselves understood which often leads to ambiguity of meaning” (Grove et al., 1999a p.190). They highlight difficulties of interpretation stating that people with severe or profound intellectual disability have “an inability to contradict an interpretation and tell you ‘No, that’s not what I meant’” (Grove et al., 1999a p.190). In reference to supported decision-making mechanisms, Kohn and Blumenthal (2013) express concern around the “potential for coercion or other inappropriate
influence by a representative or supporter”. They claim that “there is the potential for the supporter to lead the principal to particular or pre-determined outcomes by issue-framing, inaccurate assessment of the principal’s preferences, or simple conversational style” (Kohn & Blumenthal, 2014a p.2).

Concern is also expressed around the validity of proxy reporting with regard to quality of life indicators (McVilly, Burton-Smith, & Davidson, 2000; Stancliffe, 2000), support needs (Guscia, Harries, Kirby, & Nettelbeck, 2006) and the domain most relevant to this study, the expression of personal preferences (Cannella et al., 2005; Petry, Maes, & Vlaskamp, 2007a). Moreover, although recognising that the use of a proxy is sometimes inevitable, researchers express concern as to the methodological limitations such an approach places on a research study (Petry, Maes, & Vlaskamp, 2007b). Agreeing with Cummins (2002), McVilly et al. (2000) stated, “overall research findings to date indicate a need for caution when interpreting proxy-based data” (Cummins, 2002; McVilly et al., 2000 p.60).

To date, the literature has yielded conflicting results concerning the value of using proxies in determining the views of people with intellectual disability. Much of the research investigating the reliability of proxy informants has been within the context of ascertaining views regarding quality of life, particularly with regard to people with mild to moderate intellectual disability that have the ability to self-report. Researchers examining the accuracy of staff members’ predictions of the views of
people with intellectual disability have reported both satisfactory (McVilly et al., 2000; Schalock & Keith, 1993; Schmidt et al., 2010; Stancliffe, 1999), and questionable reliability (Hogg, Reeves, Roberts, & Mudford, 2001; Janssen, Schuengel, & Stolk, 2005; Parsons & Reid., 1990; Stancliffe, 1995).

Schalock and Keith (1996) as well as Stancliffe (1999) both found satisfactory staff/client correlation between reports of verbal adults with intellectual disability and their support staff on the empowerment factor of the Quality of Life Questionnaire (QoL-Q) (Schalock & Keith, 1993; Stancliffe, 1999). More recently, Schmidt and her colleagues (2010) found a positive correlation between the views of participants with intellectual disability and proxy reports on the World Health Organization’s Quality of Life measure (Schmidt et al., 2010).

In contrast, Hogg et al. (2001) found that paid supporters were relatively skilled in distinguishing between varying communication expressions of people with severe or profound intellectual disability, but they showed significant variation in judging the level of affect expressed by the focus person. That is, their relative judgments differed in terms of strength (e.g., she appears to like a stimulus a great deal versus very little) (Hogg et al., 2001). Parsons and Reid (1990), investigating food preferences of people with severe or profound intellectual disability, reported that supporter opinion was not predictive of preferences as ascertained through the use of preference assessments (Parsons & Reid, 1990). Concurring with Parsons and Reid (1990), Stancliffe (1995) concluded his review of studies relating to staff versus self-reports, suggesting that proxy and self-reports
on the expression of preference through choice making activities could not be assumed to be equivalent (Stancliffe, 1995). This conclusion was also made in Hogg et al.’s study (2001). Janssen, Schuengel and Stolk (2005) agreed with this conclusion finding only a mild to moderate agreement between supporters’ and clients’ perspectives on their quality of life (Janssen et al., 2005).

Despite this body of research supporting poor concurrence between direct preference assessment and proxy views, those wanting to enhance choice and control for people with severe or profound intellectual disability are faced with a dilemma. As described by Grove et al. (1999) this dilemma is intensified because, unlike people with milder cognitive impairment, people with severe or profound intellectual disability have “an inability to contradict an interpretation and therefore the dilemma is difficult to resolve” (Grove et al., 1999a p.190). Petry and colleagues claim supporters have a choice, “Either ignore these individuals because they cannot self-report, or obtain data from proxies that may be biased or invalid” (Petry, Maes, & Vlaskamp, 2009 p.1404). Perhaps rather than questioning the value of proxy reports, there should be an increased acceptance that in many cases, “their use is inevitable and therefore the question that should be asked is how and by whom are the person’s preferences obtained, interpreted and shared” (Watson, 2012 p.41). Supportive approaches to decision-making may go some way towards answering this question.
2.6.3 Acting on expressions of preference

An important role of any communication partner is the action they engage in following their acknowledgment and interpretation of a person’s expression. Within legislation, policy and practice there is a strong focus on the right of people with disability to have support in exercising choice and control in their lives (Commonwealth of Australia., 2013; United Nations., 2006). To date, this focus has largely been on the availability of choice as well as the role of supporters in assisting people with disability to enact their choice, while the acts of acknowledging and interpreting preference expression (described above) are largely viewed as “unproblematic” (Finlay, Walton, et al., 2008 p.354). For example, policy guidance around Australia’s National Disability Insurance Scheme (NDIS) tends to ignore the complex processes of preference acknowledgment and identification and instead directs most attention to the translation of these preferences into action (Commonwealth of Australia., 2013; Watson, 2010c). Moreover, to date, pilot studies in Australia focused on supported decision-making, are predominantly centered on the enactment of choice and preference for people with mild cognitive disability, not addressing the complexities of how a person with severe or profound intellectual disability’s preferences are acknowledged and interpreted (e.g. Bigby et al., 2015; Wallace, 2012). This trend is also evident in the empirical related literature focused on choice and self-determination. Wehmeyer and Abery’s 2013 review of the research literature focused on self-determination and choice highlighted that little attention had been paid to the complexities of supporting choice and self-determination for people
with severe or profound intellectual disability (Wehmeyer & Abery, 2013). For these people, attention needs to be given to the mechanics of supporter responsiveness beyond merely providing opportunities for choice and assisting in the enactment of these choices. Finlay et al. (2008) observed interactions in multiple group homes for people with severe communication needs, and found a notable absence of staff acknowledging and interpreting the preferences of those they support. Rather they found service structures geared toward the enactment of choice and preference, with little attention being paid to the prerequisites of this enactment, the acknowledgment and then interpretation of preference (Finlay, Walton, et al., 2008).

This narrow focus on the support provided to people with intellectual disability in realising their choices/preferences is evident in a variety of training intervention studies focused on enhancing direct support staff’s responsiveness. For example, Wong and Wong (2008) developed a training model designed to enhance staff competence in responding to the expression of preference of those they support. Although a pre-post comparison indicated an increase in staff attitudes and knowledge regarding the importance of people with intellectual disability exercising their right to self-determination, it paid little attention to the mechanics of acknowledging and interpreting preference. Similarly, Cooper and Browder (1998) demonstrated the ability of people with intellectual disability to exercise their right to self-determination by making independent purchases in fast-food restaurants. Once again, the mechanics
of acknowledging and interpreting preference were absent from the study (Cooper & Browder, 1998). This disproportional focus on the enactment of choice, is also seen in the law oriented literature, which tends to focus on the right of a person with a disability enacting their will and preference, with little attention paid to how this will and preference can be acknowledged and interpreted (Carney, 2015; Ciccarello & Henry, 2014; Dawson, 2015; Devi, 2013; Taylor, 2014).

Although the translation of a person’s preferences into action is a fundamental part of the role supporters play in responding to the will and preference of those they support, so to is the role they play in acknowledging and interpreting preference. An analysis of the literature relating to supporter responsiveness has revealed that all three components discussed in this section, acknowledging, interpreting, and acting on focus people’s expressions of preference are important aspects of responsiveness.

### 2.7 Perception of decision-making capability

*How are people with severe or profound intellectual disability perceived in terms of their decision-making capability?*

The literature discussed above suggests that the concept of supporter responsiveness offers a mechanism to achieve self-determination for people with severe or profound intellectual disability. However, the complexity of this practice is not the only barrier to its use identified in the literature. This section turns to supporters’ perception of decision-making
The literature highlights a widely held assumption that concepts relating to self-determination and autonomy are irrelevant to people with intellectual disability, because they have limited decision-making capability (Jenkinson, 1993; Jenkinson, Copeland, Drivas, Scoon, & Yap, 1992; Ward & Stewart, 2008; Wehmeyer, 1998, 2005). “Historically, people with an intellectual disability have been assumed to be incapable of exercising the sort of control over their own lives which others take for granted” (Jenkinson, 1993 p.362). In a later publication, Jenkinson and Nelms (1994) made the point: “since by definition intellectual disability is characterized by significant impairments in adaptive behaviour, discretion, social competence, and comprehension of own self-interest, the temptation has been to presume total incompetence in decision-making” (Jenkinson & Nelms, 1994 p.199). More recently Ward and Stewart (2008), referring to people with intellectual disability, stated “it is often assumed that they are eternal children, unable to speak on their own behalf and therefore not competent to make their own decisions” (Ward & Stewart, 2008 p.305).

This negative perception of decision-making capability is particularly apparent for people with the most severe intellectual disability.

Wehmeyer, Agran and Hughes (2000) surveyed over a thousand teachers regarding their understanding of self-determination and decision-making capability of their students. They reported that the severity of a student’s
disability influenced these teachers’ perceptions of the decision-making capability of their students. Specifically, teachers working with students with severe or profound intellectual disability rated the capacity of their students to make decisions significantly lower than their colleagues working with students with milder intellectual disability (Wehmeyer, Agran, & Hughes, 2000).

Research within the intellectual disability and complex communication needs arenas may go some way to explain the doubts that exist around the decision-making capability of people with severe or profound intellectual disability. This research suggests that such perception exists predominantly due to profound difficulties with communication (Evans & Ware, 1987; Kearney, Bergan, & McKnight, 1998; Ware, 2004). These perceptions of communicative incompetence have been discussed previously.

The value of supporters having a positive perception of people with intellectual disability’s decision-making capability is reflected within the research literature. This literature provides evidence that people are more likely to lead self-determined lives, when those who support them have a positive view of their capability to participate in decisions (Harchik, Sherman, Sheldon, & Bannerman, 1993; Rawlings, Dowse, & Shaddock, 1995). Reviewing over one hundred articles, Harchik et al (1993) concluded that people who are expected and encouraged to express choice and preference are more likely to behave autonomously, be happy, and exhibit positive as opposed to negative behaviour (Harchik et al., 1993).
Rawlings et al (1995) conducted a participant observation study of four women with intellectual disability. They concluded that supporters who presume those they support can participate in decision-making are likely to be willing and able to “encourage, recognise and respond to expressions of choice” (Rawlings et al., 1995 p.143). Conversely, Antaki et al. (2009) drawing from their analysis of interactions between staff and fifteen people with intellectual disability, across 2 houses, suggest that the negative perceptions of the capacity of a person to participate in decisions, is one factor responsible for reducing the opportunities people with intellectual disability have for decision-making (Antaki, Finlay, & Walton, 2009).

The impact of supporters’ assumptions regarding a person’s decision-making capability is not only reflected in the research literature relating to people with intellectual disability, but also that related to acquired brain injury (ABI). Drawing from two case studies and the research literature, Knox et al. (2013) discuss the impact of clinicians holding negative assumptions regarding decision-making for people with ABI. They suggest that negative assumptions held by rehabilitation professionals that people with ABI cannot participate in decisions is a factor that influences the self-determination of their patients (Knox et al., 2013).

Negative perceptions of the capability of people with severe or profound intellectual disability to make decisions are further fueled by the legal system’s emphasis on cognition and routine provision of cognitive based assessments to guardianship tribunals/boards (Darzins, 2010; Fitten,
These tools, provided to assist board members in determinations of legal capacity, are structured around the premise that decision-making capability is characterised by a set of individual cognitive abilities serving as prerequisites for decision-making capability. The use of such tools are thought to be on the increase, particularly within jurisdictions that maintain guardianship law (Bach, 2015). For example, within the current Victorian Guardianship system, various types of specialist psychology reports (usually neuropsychology) submitted to the Victorian Civil Administration Tribunal (VCAT) continue to form a central component of the evidence the tribunal considers when deciding whether someone is capable of making a decision. Such reports are written to assess and report on a person’s capability at a particular time, predominantly taking into consideration cognitive factors such as problem solving, memory function, rationality and language (Shiraishi, 2007). These skills are predominantly assessed independent of environmental factors such as support from family, friends and support staff. Due to the arguably narrow nature of these assessments, people with severe or profound intellectual disability, who come before the tribunal, are usually assessed as having no or very limited mental or decision-making capability (Dearn, 2010). In most jurisdictions, the legal response to this assessment is to deny legal capacity, and permit a third party, in Victoria known as a legal guardian, to make decisions on behalf of the concerned person. Donnelly (2010), discussing approaches to guardianship in current western society,
suggests that one of the reasons for such a black and white view of legal
capacity within the guardianship arena is “the ease with which this
particular ethical concept can be converted into legal doctrine” (Donnelly,
2010 p.47). However, as argued by Clough (2014) “this ease comes at the
cost of nuance, and that the individualistic conception of the person fails to
accord with the reality of human interdependence” (Clough, 2014 p.131).

Human rights scholars are increasingly highlighting the profound impact of such
formal assessments of incapacity. Bach (2006) claims that a formal assessment of
decision-making incapacity results in “state-sanctioned removal of personhood from
an individual with respect to one or more or all areas of personal decision-making”
(Bach, 2006 Slide 9). Perlin and the European based Mental Disability Advocacy
Centre, characterize it as a form of “civil death” (Mental Disability Advocacy Center.,
2013; Perlin, 2012). A system of law is increasingly being promoted that moves away
from the focus on cognition in denying personhood, to one that recognises that a
person’s ability to make decisions (and therefore be recognised as a person) does not
rest on their individual cognitive capability but on the quality of support available to
help them to make decisions (Alford, 2015; Bach, 2015; Brayley, 2009; Pepin, Watson,
Hagiliassis, & Larkin, 2010; Pepin et al., 2013). Beamer and Brooks (2001) articulate
this view stating that:

The starting point is not a test of capacity, but the presumption that
every human being is communicating all the time and that this
communication will include preferences. Preferences can be built
up into expressions of choice and these into formal decisions. From
this perspective, where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices (Beamer & Brookes, 2001 p.4).

While assessment of individual cognitive capability is currently central to existing legal frameworks, it is likely to become less so in new regimes of support for decision-making (Browning, Bigby, & Douglas, 2014). There is a growing acknowledgment that instruments designed to test an individual’s capability are found wanting because they are weighted toward individual cognitive capacity and generally fail to evaluate the substantial role of environmental support in human decision-making.

2.8 Decisions faced by people with severe or profound intellectual disability

What kinds of decisions do people with severe or profound intellectual disability typically face?

Human beings make and participate in decisions every day. “Our decisions make us who we are” (Redish, 2013 p.9). Despite this, and not surprising given the above discussion, there is a dearth of literature focused on the nature of decisions faced by people with intellectual disability, compared to the general population.

2.8.1 Life transition points

It may be useful to think about the variation in decisions faced by people with severe or profound intellectual disability in terms of a life course paradigm such as that articulated by Elder and colleagues (Elder, Kirkpatrick, & Crosnoe, 2003). A life course perspective proposes that
each person experiences a range of life transitions, or changes in roles and statuses. It offers a framework around transition points and trajectories, highlighting the various decisions associated with each of these. Elder et al. (2003) suggest that these decisions are the vehicle by which a person exercises human agency and is able to construct his/her life course. The trajectories or transition points include but are obviously not limited to such life activities as, starting school, entering puberty, leaving school, gaining employment, leaving home, becoming a parent, retiring and so on.

Despite this framework being applied to other diverse groups, to date there is little research applying it to the lives of people with severe or profound intellectual disability.

The traditional view of the process of transition to adulthood focuses on the attainment of traditional milestones such as leaving school, getting a full time job, going onto further education, leaving the parental home to establish an independent residence, entering a romantic relationship and having children (Settersten & Ray, 2010). Priestley (2003) claims that people with intellectual disability are unlikely to achieve some or any of these milestones. He wrote: "Many people (often with learning difficulties or complex impairments) are consigned to a nether world of repeated, unresolved transitions in which true adult status is neither envisaged or attained" (Priestley, 2003 p.113).

In particular, due to the severity of disability, achieving such transition milestones is likely to be rare for people who are the focus of this research.
Viewing decision-making for people with severe or profound intellectual disability through a life course paradigm illuminates critical differences in decision-making between them and the general population. The remainder of this section explores several decision-making points within the life course paradigm focusing on people with severe or profound intellectual disability.

2.8.2 Planning for the future

Transition into adulthood is identified as one of the most stressful and pivotal decision-making areas for people with intellectual disability and their families (Freedman, Krauss, & Seltzer, 1997a; Heller & Factor, 1993). This anxiety is particularly related to future caring and living arrangements (Bigby, 2000; Bigby, Bowers, & Webber, 2011; Heller, Factor, Sterns, & Sutton, 1996).

A significantly growing life expectancy and the rapidly aging 'baby boomer' generation means the number of aging people with intellectual disability is increasing (Yang, Rasmussen, & Friedman, 2002). However, research suggests that in comparison to the general population, there is very little planning regarding the future of those with intellectual disability. This is the case for those living in supported accommodation as well as within the family home (Freedman, Krauss, & Seltzer, 1997b; Heller & Factor, 1993).

Freedman et al. (1997), drawing from a sample of 461 United States based families with a member with intellectual disability, reported that fewer than half of the families in their study had made plans for future living
arrangements for their loved ones (Freedman et al., 1997a). The reasons for this lack of planning are scantily covered in the literature. Although not specifically focused on people with intellectual disability, Dew (2010) discusses the frustrations her Australian participants had in navigating the system, suggesting that services may be ill equipped to provide the support needed in terms of planning and providing clear options for the future (Dew, 2010). In the United States, Heller (2000) proposed that a gap in transition services may be one reason why families of people with intellectual disability, might be reluctant to support their loved one to participate in decisions about their long term future (Heller, 2000). In addition, the literature suggests that families of people with intellectual disability are anxious due to a fear that they will not outlive their family member with an intellectual disability (Freedman et al., 1997a; Heller & Caldwell, 2006). Despite this fear, Bowey and McGlaughlin (2005) as well as Prosser (1997) suggest that families of people with intellectual disability often ignore the need for future planning (Bowey & McGlaughlin, 2005; Prosser, 1997). Exemplifying this issue, one of the participants in Bowey and McGlaughlin’s (2005) study said: “Mum and Dad don’t say anything about the future; they don’t talk about it” (Bowey & McGlaughlin, 2005 p.1386).

Despite a historical lack of planning, in more recent years there has been a greater focus on planning for the future, particularly around accommodation, financial and guardianship issues, for people with intellectual disability (Bigby et al., 2011). Supported approaches to
decision-making are increasingly being used within the context of such planning (Finlay, Walton, et al., 2008; Ramcharan et al., 2013). Bigby’s body of work in the area of aging and intellectual disability suggests that a key ingredient in this planning process is the presence of:

Someone committed to the adult with ID ... to oversee their well-being, act as an advocate especially in respect of formal services, and respond flexibly to the contingencies likely to arise in the post parental care phase of the life course (Bigby et al., 2011 p.778).

2.8.3 Individualised planning and supports

Roulstone and Morgan (2009) describe a rapid shift toward self-direction within disability support services in neo-liberal societies such as Australia (Roulstone & Morgan, 2009). This shift has seen a number of key self-determination and personalized mechanisms such as person centered planning (O’Brien & Lyle-O’Brien, 1998), direct payments (Glasby & Littlechild, 2002; Stainton & Boyce, 2004) and individualized budgets (Glendinning et al., 2008).

A self-directed approach to service delivery underpins Australia’s National Disability Insurance Scheme (NDIS) (Commonwealth of Australia., 2013). The Australian Productivity Commission’s inquiry report on the feasibility of an NDIS clearly articulated the need for a system that shifts the focus in decision-making to people with a disability and those who support them (Productivity Commission., 2011):

People should be given much greater power and choice in a new
system, with the objective of giving people greater flexibility and control over their lives — with the ultimate goal being greater wellbeing. Consumer choice is one aspect of power (Productivity Commission, 2011 p.2).

At the heart of Australia’s new disability support scheme and individualized funding generally, is the notion that system users have the opportunity to express preference and have these preferences realized regarding the disability related services and supports they receive. Much of the policy documentation and guidance around the NDIS celebrate these notions of choice and control within the new system (Bonyhady, 2015; Commonwealth of Australia, 2014; Productivity Commission, 2011; Walsh & Johnson, 2013). However, the expression of preference, choice and therefore self-determination for people with severe or profound intellectual disability is rarely straightforward demanding dedicated time and attention (Finlay, Walton, et al., 2008; Grove et al., 1999a; Hogg et al., 2001). As pointed out by Fyffe et al. (2010), the design and delivery of an individualized service, such as the NDIS, is significantly more complex for people with severe or profound intellectual disability than for people without such disability, who can independently choose and direct their own services (Fyffe, Pierce, Ilsley, & Paul, 2010). Finlay and colleagues highlighted that individualized approaches to service delivery can present the act of preference assessment as unproblematic, ignoring the realities for people with severe or profound intellectual disability (Finlay, Walton, et al., 2008). An analysis of available policy and practice guidance around
the NDIS supports Finlay et al.'s observation, revealing that these materials largely ignore the complex process of preference identification and interpretation, instead, directing most attention to later phases of the decision-making process, focusing largely on the translation of these preferences into action (National Disability Insurance Agency., 2014).

Bigby et al. (2008) suggest that this focus may stem from the fact that historically individualized approaches to funding have been monopolized by people with physical disabilities, for whom the act of communication is less challenging, utilizing symbolic means such as speech or aided augmentative communication systems. They suggest that the successful implementation of individualized funding is dependent on the acknowledgment of the diversity of system users. They highlight the need for the development of mechanisms that acknowledge this diversity, and are not only tailored to those who communicate intentionally and formally (Bigby, Fyffe, & Mansell, 2008).

### 2.8.4 Health care related decisions

Healthcare is an area of particular relevance to people with severe or profound intellectual disability due to their complex health needs. Despite an increasing focus on health related decision-making for people with intellectual disability, inequalities remain in terms of inclusion and participation (NHS Health Scotland., 2004; Shogren, Wehmeyer, Reese, & O'Hara, 2006). Melville et al. (2006) have identified a number of barriers to this inclusion and participation, suggesting that these can be addressed through better training of medical professionals, particularly nurses (Melville, Cooper, Morrison, Finlayson, & Allan, 2006). Melville et al.
(2006) and others have identified communication as a major barrier to the inclusion of people with intellectual disability in decisions that affect their health. Racine et al. (2013) studied the experiences of people with cerebral palsy within a healthcare context, observing that although autonomy was valued, there were “multiple tension points in respecting autonomy” (Racine, Larivière-Bastien, Bell, Majnemer, & Shevell, 2013 p.877). These included a lack of respect for patients’ ability to participate in decisions due to complex communication needs, and a “lack of fallback solutions to support patient autonomy in absence of relatives” (Racine et al., 2013 p.877). Similarly, Sowney and Barr (2007) and Forbat and McCann (2010) highlighted examples of health professionals not involving patients with intellectual disability in decisions about their healthcare due to negative perceptions of their communication and decision-making capacity (Forbat & McCann, 2010; Sowney & Barr, 2007).

2.9 The role of relationships and human interaction in self-determination for people with severe or profound intellectual disability

How does relational closeness impact decision-making for people with severe or profound intellectual disability?

2.9.1 The importance of relationships and the role of interdependence

The importance of interdependency within the context of self-determination has been discussed in this chapter. Reindal (1999) and Gordon’s (2000) categorisations of self-determination as ultimately one of interdependence, are particularly relevant to people with severe or profound intellectual disability and their supporters (Gordon, 2000a;
Reindal, 1999). They promote a conjoint as opposed to a disjoint model of self-determination, particularly for people with severe or profound intellectual disability. As discussed, this view is highlighted in cross-cultural studies (Blackhall, 1995; Iyengar & Lepper, 1999; Shogren, 2012).

Drawing from this work, the importance of positive relationships for people with severe or profound intellectual disability is increasingly recognised in the literature (Clegg, 2009; Johnson et al., 2014a; Petry, Maes, & Vlaskamp, 2005; Petry et al., 2007b; Pierce, Ilsley, Paul, & Fyffe, 2010; Seltzer & Krauss, 2001). The value of relationships, such as family and friends, in the lives of people with severe or profound intellectual disability is far reaching and includes strengthened interconnectedness, community participation, life opportunity, and quality of life (Pierce et al., 2010). Literature focused on workforce related skills of disability support workers refers to interpersonal and interactional skills as the “most undervalued skill sets” of disability support workers (Fattore, Evesson, Moensted, & Jakubauskas, 2010 p.82). Specifically, such skills have been found to be beneficial to people with severe or profound intellectual disability in terms of happiness and wellbeing (Davis, Young, Cherry, Dahman, & Rehfeldt, 2004; Johnson et al., 2014a; Maes, Lambrechts, Hostyn, & Petry, 2007), alertness, engagement (Arthur, 2004), and inclusion (Finlay, Antaki, Walton, & Stribling, 2008; Johnson et al., 2014a). Petry and her colleagues found that social well-being, particularly personal relationships, was the only domain that was spontaneously named by all participating supporters as vital for the quality of life of people with severe or profound intellectual disability (Petry et al., 2005).
Reinforcing this importance, Seltzer and Krauss (2001) examined the nature of the relationships between adults with intellectual disability and their family members. They found that on the Positive Affect Index (Bengtson & Black, 1973), a measure of social closeness, those with the most severe intellectual disability measured higher on closeness with their family members, particularly their mothers, than those with milder intellectual disability or mental illness (Seltzer & Krauss, 2001). This is not surprising considering the interdependent nature of their lives.

Considering the importance of interdependent relationships, especially for people with severe or profound intellectual disability, the questioning, which took place earlier in this chapter, of society’s focus on individuality as opposed to interdependency is relevant at this point. Parmenter (2011) makes the point that an emphasis on individualism presents a threat to people with intellectual disability.

In our goal to encourage their independence, we have overlooked the essential fact that the vast majority of this population [people with intellectual disability] will, in many aspects of their daily lives, remain dependent on supports (Parmenter, 2013 p.23).

2.9.2 The importance of relational closeness in responding to preference

Relational closeness is associated with intuitive knowing and tacit knowledge of another person, concepts first used by Polanyi (Polanyi, 1967). Smith et al. (2004) operationally define intuitive knowing in their work with student nurses as a “non-linear process of knowing, perceived through emotional and physical awareness or through the making of
connections at the physical and/or spiritual level” (Smith, Thurkettle, & dela Cruz, 2004 p.615). Phelvin (2012), discussing professional relationships with people with profound intellectual disability, describes the concept of tacit knowledge as having “action orientated and personal quality that makes it difficult to formalize or communicate and is acquired through practical experience” (Phelvin, 2012 p.34). These terms are increasingly being discussed in severe or profound intellectual disability related literature as vehicles by which supporters develop a picture of the preferences of those they support (Forster & Iacono, 2008; Lam, 2000; Reinders, 2010; Schuengel et al., 2010; Smith, Thurkettle, & dela Cruz, 2004).

These intuitive modes of knowing are considered problematic in some parts of the literature. This is because they based on subjective interpretations of informal and sometimes unintentional reactions, and therefore can be considered biased and consequently unreliable. Warning of the pitfalls associated with relying on intuitive knowing’ and tacit knowledge, Phelvin (2012) describes such interpretations as “service users acting as screens for the inadvertent projection of staff tastes, desires and agendas” (Phelvin, 2012 p.34). Thus, although the personal intuitive skills employed by supporters in the interpretation of focus people’s communication may be valid sources of evidence, their use has limitations that should be acknowledged. Heeding this warning, Clegg (2003), suggests that supporters should be ‘given space’ to express and record any values and potential biases they bring to a relationship with
those they support. In her work, she encourages supporters to intentionally engage in a process of reflection by keeping diaries of potential biases and checking in with these periodically when interpreting someone’s expressions of preference (Clegg, 2003).

2.9.3 Social networks and interaction

Despite the established value of relationships and positive interaction, the literature highlights that people with severe or profound intellectual disability have small social networks (Clement & Bigby, 2009; Kamstra, van der Putten, & Vlaskamp, 2014a; Lippold & Burns, 2009). In addition, they have limited opportunities for quality interaction (Bayley, 1997; Johnson, 2012; Johnson et al., 2014a; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006; Tipton, Christensen, & Blacher, 2013; Ware, 1990). Ware (1990) found that even when interaction occurred, it was brief, lasting less than one minute, and was rarely lead by focus people (Ware, 1990). In a study with one hundred and three adolescents with and without intellectual disability in the United States, Tipton and her colleagues found that the friendships of young people with intellectual disability are generally less warm and close than their peers without disability (Tipton et al., 2013). Clement and Bigby (2009), exploring the social inclusion of residents with severe intellectual disability who had moved into the community from Kew Residential Services, an institution in inner city Melbourne, Australia, found limited changes to residents’ social networks after leaving the institution. They found that participants tended to live in a “distinct social space” made up of family, other people with disabilities and paid support staff (Clement & Bigby, 2009 p.264).
Specifically, they found that sixty-two per cent of service users had no 
unpaid relationships with people who could be characterised as knowing 
them well. Kamstra and her colleagues collected data regarding the 
number, type and frequency of social contacts of two hundred and five 
people with severe or profound intellectual disability. They found that 
people with severe and profound intellectual disability have relationships 
generally limited to three genres, “staff, family members and other 
persons with an intellectual disability” (Kamstra, van der Putten, & 
Vlaskamp, 2014b p.249). This speaks to the paradox of people with severe 
or profound intellectual disability having limited relationships yet a 
greater need for such relationships (Schuengel, Kef, Damen, & Worm, 
2010; Schuengel, Schipper, Sterkenburg, & Kef, 2013).

The literature suggests a variety of reasons why people with severe or 
profound intellectual disability have small social networks. An obvious 
reason is the consequence of institutionalization of people from a young 
age, meaning they are likely to have limited, if any, community supports 
(Emerson & Hatton, 1996; Young, Sigafoos, Suttie, Ashman, & Grevell, 
1998). Waldon and colleagues argue that institutionalised living is 
incompatible with the making and maintenance of close emotional 
relationships (Walden, Pistrang, & Joyce, 2000). Although those living in 
the community with support of family are likely to have greater number of 
reported friendships (Emerson & McVilly, 2004), social isolation continues 
to be documented as a reality for this group (Emerson & Hatton, 1996; 
McConkey, 2007). This social isolation is likely to become most acute as
they age and their family supports diminish. The fact that these people rarely marry or have offspring means they lack the typical support hierarchy and structure that most people enjoy as they age (Cantor, 1979). Cantor developed a hierarchical compensatory model, with a descending order of formal and informal support based on the primary relationship of the caregiver to the care recipient. According to this model, a spouse and children are at the top of the hierarchy, followed by siblings and other family members. In the absence of a spouse or children, people with severe or profound intellectual disability often rely on their parents to provide care and support (Balandin & Morgan, 2001). With improvements in health care for people with severe physical disability many now outlive their parents (Strauss, Brooks, Rosembloom, & Shavelle, 2012), and so they may turn to their non-disabled siblings to provide ongoing support. If their siblings do not exist, are not available, or are unwilling to provide support, they are left to rely on service providers and the general community.

Therefore, the question is increasingly asked, is the community truly ready to build relationships with people with severe or profound intellectual disability. Clement and Bigby (2009) are concerned that the answer may be no. They found that the blame for this situation can not solely rest on the general community itself, but the attitudes and practices of service providers (Clement & Bigby, 2009). They reported that disability support workers often view people with severe or profound intellectual disability as “too different” for community participation to be a realistic goal.
Such attitudes from service providers have a clear impact on the development of positive trusting relationships with those in the community not paid to provide support. Hillman et al. (2012) in their ethnographic study of nine personal support networks support Clement and Bigby's finding. They found that supporters believed that the community perceptions of the socially inappropriate behaviours of people with severe or profound intellectual disability “added to their exclusion from participating in valued community activities” (Hillman et al., 2012 p.1070).

Behaviours of concern are also reported to have a role to play in further socially isolating people. The use of restrictive interventions has been reported to affect relationships by cultivating feelings of distrust toward those doing the restraining (Amos, 2004; Wynn, 2004). O’Brien (1991), in his early work, focused on the importance of relationships for people with intellectual disability. He makes the point that trusting, positive, supportive human relationships cannot coexist with the use of aversives, restraint, and seclusion, which either destroy them or preclude their formation (O’Brien, 1991).

2.9.4 **Interventions designed to enhance interaction**

Despite the importance of relational closeness for people with severe or profound intellectual disability, to date, there is little literature around the factors that impact on such relationships. As reported by Johnson (2012):

> Although there is anecdotal evidence of positive and mutually rewarding relationships between people with
severe intellectual disability and paid supporters, the factors involved in developing these relationships are not apparent (Johnson, 2012 p.3).

However, a review of the research and practice literature relating to enhancing interaction between people with severe or profound intellectual disability and those who support them, reveals some interventions found to be useful in achieving this goal of enhancing interaction.

**Intensive Interaction**

Intensive Interaction is a practical approach based on play-based activities (e.g. games, songs, mimicry) that have been documented in infant/mother interaction literature. When using intensive interaction, these play-based activities are used to promote social engagement. “It is based on how communication ordinarily develops – on ways we know are effective – and in ways we know can be enjoyable for all involved” (Nind & Hewett, 2001 p.4). An adaption of the Intensive Interaction approach is the Hanging Out Program (HOP), a framework designed for supporters to spend time ‘hanging out’ with people who are traditionally difficult to engage (Forster, 2008; Forster & McDonald, 2013). HOP’s emphasis is not to directly evaluate preference, but rather to simply ‘be with’ the focus person engaging in positive interaction. Such positive engagement provides an ideal context in which people with severe or profound intellectual disability can express preference and importantly have this preference acknowledged.
Individualised Sensory Environment

Individualised Sensory Environment (ISE) is another interactive approach established for use with adults with severe or profound intellectual disability (Bunning, 1998). Describing the development of ISE, Bunning stated:

The aim was to affect positively the interactive behaviours displayed by clients in the natural environment: specifically, to reduce the level of non-purposeful engagement, characterised by stereotypic actions, self-injury and neutral behaviour and to increase the levels of purposeful interaction with people and objects (Bunning, 1998 p.387).

ISE focuses on recognizing and developing sensory-based communicative behaviours, and therefore is an ideal platform for supporters to identify sensory preference. Bunning (1996) reported a positive impact of ISE on the purposeful interactions of people with severe or profound intellectual disability (Bunning, 1996). These purposeful interactions include expressions of preference.

Video Feedback

Approaches using video feedback are gradually emerging as effective techniques to expose communication partners to an objective record of their interaction with those they support, with a view to encouraging self-reflection and improving the quality of interactions. These interventions aim to improve effective communication, attunement and interaction between communication partners using shared video feedback. In essence,
they aim to support communication partners to increase their sensitivity
to those they are interacting with, encouraging them to “reflect on their
interactions, drawing attention to elements that are successful and
supporting them to make changes that will enhance their sensitivity”
(Kennedy, Landor, & Todd, 2010 p.61-62).

Video feedback mechanisms have been used for several decades within
the context of communication research, intervention and training, in the
areas of communicative interaction with people with severe or profound
intellectual disability and child language. For example, the Hanen©
approach developed in Canada some thirty-five years ago, uses video-
feedback techniques with parents and other communication partners of
children and adults with language delay and autism spectrum disorder
(Pennington & Thomson, 2007). The suite of Hanen© programs has
provided evidence that such feedback is an important factor in the
promotion of communication partners’ positive interaction skills with
those they support (Baxendale & Hesketh, 2003; Pepper & Weitzman,
2004). Fukkink’s (2008) meta-analysis suggests that interventions using
video-feedback are effective in increasing the sensitivity of communication
partners, as well as positive behaviour and attitudes toward adults with
severe or profound intellectual disability (Fukkink, 2008). Finlay et al.
(2008) promote this approach stating,

If a staff member is to change their practice, then a good way to
encourage the self-reflection that must be the first step to that
change is to talk them through a video record of their day-to-day experience with residents (Finlay, Antaki, & Walton, 2008 p.228).

An analysis of interventions designed to promote attachment found that interventions using video-feedback were more effective than those that did not, particularly in relation to communication sensitivity (Bakermans-Kranenburg, Van IJzendoorn, & Juffer, 2003).

Another video-feedback technique is Video Interaction Guidance (VIG) (Kennedy & Sked, 2008). VIG is a technique widely used in the United Kingdom predominantly in the area of child and adult interaction. It is based on a framework developed in the Netherlands originally called Video Home Training (VHT) (Biemans, 1990). Over time the technique has evolved, with different styles and emphases developing across a range of areas including most recently the interactions between people with severe or profound intellectual disability and their supporters (Kennedy et al., 2010).

2.9.5 Natural and unnatural relationships

The literature on the effects of natural relationships in the general population is extensive, suggesting the vital importance of friends and family for the maintenance of health, social functioning, and psychological well-being (Dean & Lin, 1977; House, Landis, & Umberson, 1988). There is a parallel emphasis in the literature on the importance of such relationships for people with intellectual disability (Schalock, 2005; Wightman, 2009).
This focus is particularly apparent in the literature and practice relating to citizen advocacy. A citizen advocacy approach can be described as deliberate or intentional network building. This approach acknowledges that for people with intellectual disability trusting functional relationships are critical, and that unfortunately such relationships do not exist for everyone. These models have done much to expand the unpaid social networks for people with intellectual disability generally (Brookes & Harris, 2000; Rouget, 2010; Walker, 2014), however to date, there is little empirical evidence of their efficacy for people with more severe or profound intellectual disability.

There is a particular focus in the literature on the importance of unpaid support within circles of support. A circle of support is defined inconsistently in the literature. Rouget (2010) describes it as “a group of unpaid citizens who come together to support and share a relationship with a person who is vulnerable because of having a disability” (Rouget, 2010 p.68). Rouget is not alone in her assertion that a circle of support should be confined to unpaid or natural supports. This assertion is emphasised within practice and policy based literature, focused on person-centered approaches (Craig & Cocks, 2009; O’Brien & O’Brien, 2002; Sanderson, 2000; Wightman, 2009). Wightman (2009) highlights the value of unpaid/natural relationships, stating,

A freely given relationship is the most valuable experience we can have... If our relationships are artificially restricted to people and
places we have not chosen, and over which we have little control, we cannot expect to grow as a person (Wightman, 2009 p.4).

In parallel with this focus on the importance of natural supports within intellectual disability services and supports is the presence of restrictive and highly regulatory practices around paid and unpaid support relationships. Dalley’s (1996) distinction between paid and unpaid support in the lives of people who receive community care provides a helpful description of these roles. She makes the distinction between two caring roles in the lives of service users, those who ‘care for’ and those who ‘care about’ those they support (Dalley, 1996). The ‘care for’ role involves the provision of hands on day-to-day care, while the ‘care about’ role involves the provision of emotionally oriented support, such as affection, love and friendship.

There is a sense within literature and practice that the roles Dalley (1996) describes can and should be mutually exclusive, and that they should be assigned according to whether the person doing the supporting is paid or unpaid for the time they devote to the person with a disability (Lutfiyya, 1993; Nisbet & Hagner, 1988; Spagnolo et al., 2011). Todd & Shearn (2000) described the relationships paid supporters had with service users as rewarding, however this aspect of their work was frequently discouraged because it was seen as unprofessional (Todd & Shearn, 2000). Forster and Iacono (2008) described the presence and importance of emotional closeness between paid supporters and people with severe or profound intellectual disability. They noted however that despite their
value, existence of such emotionally close relationships were often contrary to expectations from management (Forster & Iacono, 2008).

Smull's (1996) doughnut framework, adapted from Handy's (1994) doughnut principle, is a person centered tool used to assist paid support workers in making this distinction, by providing guidance as to the level of personal involvement they should have with someone they support. Pepin et al. (2013) provide a representation of this framework, duplicated in Figure 4 (Pepin et al., 2013).

Handy’s (1994) doughnut principle was developed within the context of philosophical management (Handy, 1994). Smull (1996) adapted it as a person-centered thinking tool. Smull's doughnut (Figure 4) has a third concentric circle, in addition to the two proposed by Handy (1994). The first, inner, circle is identified as core responsibilities of supporters whether paid or not paid. The second, outer circle refers to situations that Smull (1996) suggests may require creativity and sound judgment and can be the responsibility of paid or unpaid supporters. Finally, Smull (1996) suggests that the outer ring contains those aspects of a person’s life that are not the role of paid supporters, such as loving the focus person.
The work of Finlay and her colleagues (2008), although not directly referring to the doughnut principle, reflects its use in practice. They found that in their day-to-day work, paid disability support workers report pressure from service providers to prioritise activities relating to their duty of care over social relationships with service users (Finlay, Antaki, Walton, et al., 2008). Finlay et al. (2008) highlight this in their study, quoting one of their research participants, “being a competent team member seemed to involve making sure the residents had all eaten and gone to the toilet before the next shift came on and making sure the house was clean and the laundry done” (Finlay, Walton, et al., 2008 p.351). They suggest:

These priorities are not difficult to understand if we recognize that an unannounced visit by a relative or manager is more likely to lead
to a complaint about lack of cleanliness than to a challenge over whether residents’ preferences had been respected earlier in the day. The former is immediately visible, the latter is not (Finlay, Walton, et al., 2008 p.351).

The implication that close paid relationships are inappropriate is problematic for people who have limited unpaid support. People with severe or profound intellectual disability have relatively small social networks. Many of these networks are comprised only of paid supporters (Bigby & Clement, 2009; Clement & Bigby, 2009; Jackson, 1997). Additionally, there is a growing body of literature reporting, where unpaid supports do exist, that those providing this support feel unsupported, under resourced, and disrespected (Arksey & Glendinning, 2007; Berger, DeRenzo, & Schwartz, 2008).

In the absence of unpaid support in the lives of these people, the importance of paid relationships is increasingly being examined in the research literature. This literature suggests that close paid relationships are positively related to the wellbeing of people with severe or profound intellectual disability (Dunn, Clare, & Holland, 2010; Forster & Iacono, 2014). Dunn et al. (2010) examined how support workers in care homes for adults with intellectual disability engaged in substitute and supported decision-making (Dunn et al., 2010). A conclusion they drew from their study was that “relationships between paid support staff and people with intellectual disability are inherently meaningful in their own right and that
these relationships have the ability to enhance residents’ quality of life” (Dunn et al., 2010 p.158).

Forster and Iacono (2014) highlight the existence of positive and close relationships between paid support workers and people with severe or profound intellectual disability (Forster & Iacono, 2014). Their study examined the use of affect attunement in interactions between paid support workers and people with severe or profound intellectual disability. Acknowledging the importance of positive and close relationships, they suggest that affect attunement, that is “the recasting of one person’s affect by another with emphasis” (Forster & Iacono, 2014 p.1105) should be viewed as an indicator of the quality of interaction between supporters and those being supported.

Despite acknowledgment of the value of paid relationships, Wilson et al. (2008) found that the enduring and intimate relationships of disability support workers with those they support are generally not acknowledged as central influences on ethical judgments, including those made within the context of substitute, supported, or co-decision-making (Wilson, Clegg, & Hardy, 2008). They found that disability support workers are more likely to rely on external and rigid guidelines provided by service providers, than information gleaned from the personal relationships they have with those they support. They conclude by suggesting that paid support workers “need to draw on ethical frameworks that can accommodate relational aspects of their practice, rather than relying on external and abstract guidelines” (Wilson et al., 2008 p.608).
2.10 Supported decision-making legislation globally

What legislation exists designed to enhance signatory nations obligations under Article 12?

There is little argument that the UNCRPD has been responsible for a profound paradigm shift in the way the world’s citizens with disability are viewed. This shift has seen a move from disability viewed as a medical or social welfare concern, to it being recognized as a human rights issue. At the center of this paradigm shift is an acknowledgment that all people have a right to lead self-determined lives. Article 12.3 of the Convention (2006) promotes an assumption of capacity and mandates signatory nations to develop “appropriate measures to provide access by persons with disability to the support they may require in exercising their legal capacity” (United Nations., 2006). Article 12.3 mandates signatory nations to move from an approach of decision-making support driven by supporters’ perceived best interest of the person at the centre, to one where their will and preference is at the heart of the decision.

This is reflected in a global shift toward enhancing decision-making capability for people who have traditionally been subjected to guardianship. Signatory nations to the UNCRPD have interpreted their obligations under Article 12 in varying forms, implementing a range of supported decision-making mechanisms. This section outlines some of these mechanisms, all of which fall under the umbrella of supported decision-making. The literature is lacking in detailed descriptions of how these legislative mechanisms are implemented, and therefore this section
predominantly focuses on supported decision-making initiatives at a legislative level.

2.10.1 Canada

The Canadian Association for Community Living Taskforce is thought to have articulated the first principles of supported decision-making in 1992. This taskforce emerged in the early 1990s from a loud call from People First of Canada, a national self-advocacy group, for the abolition of guardianship law. The taskforce held the view that people needing support to exercise legal agency, didn’t mean that they should have to give up their rights (i.e. be subjected to guardianship) (Bach, 2015). From this view, they developed a legal and practical supported decision-making framework. The taskforce proposed “supported decision-making as an alternative conceptual framework for decision-making that challenged the belief that personal autonomy could only be expressed independently” (Browning et al., 2014 p.2). Further articulating this perspective, Bach and Kerzner (2010), promote “a positive liberty view of autonomy [whereby] we do not exercise our self-determination as isolated, individual selves, but rather relationally, interdependently and intersubjectively with others” (Bach & Kerzner, 2010 p.40).

These principles were progressively reflected in supported decision-making legislation introduced over time in several Canadian provinces and became internationally recognised within the UNCRPD in 2006.

The British Columbia’s Representation Agreement Act (RAA) provides a mechanism for adults to enter into a contractual agreement or
‘representation agreement’ with one or more trusted people, to formalize a support relationship. This contract empowers supporter(s) to assist someone to make and communicate decisions. Importantly, the person does not forego legal capacity by entering into the representation agreement. However, it can be questioned whether this type of agreement is in line with Article 12 of the UNCRPD, as the Act allows for decisions to be made on the person’s behalf, and therefore arguably may be no different to substitute decision-making.

Representation agreements have been used previously within the context of Microboards. David and Faye Wetherow developed the Microboard concept in 1984 in Manitoba, Canada, to provide a decision-making support network for their adopted daughter. In the late 1980s, the concept was adopted by other jurisdictions throughout Canada and North America (Bach, 1991; Bach & Kerzner, 2010; Browning, 2010; Etmanski, 2000; Gordon, 2000a; Verma & Silberfeld, 1997). Today in British Columbia, there are approximately 900 microboards, supported by the Vela Microboards Association. A Microboard resembles a typical circle of support, being comprised of a group of people who come together to assist a person to have their preferences heard and realized. It differs from a typical circle of support in that it is a formalized and legally recognized organization. Shea (2001) describes it as “a non-profit society of family and friends, committed to knowing a person, supporting that person, and having a volunteer (unpaid), reciprocal relationship with that person” (Shea, 2001 p.1). Microboards are said to exemplify supported decision-making, increasing “the participation of people with disability who are
unable to be supported to make their own decisions, to be central to
decision-making in their own lives” (Browning et al., 2014 p.4).

Much can be learned from the supported decision-making practices
initiated and developed in Canada and more specifically, British Columbia,
however to date, they are supported by little empirical evidence
(Browning, 2010; Carney, 2014; Kohn, Blumenthal, & Campbell, 2013).

2.10.2 The United Kingdom

The English and Welsh Mental Capacity Act 2005 (MCA) aims to provide a
legal framework in which to regulate substitute decision-making. The Act
came into full effect in October 2007. Since its conception, there has been
positive and negative commentary around the Mental Capacity Act in a
range of contexts, particularly in relation to its continued endorsement of
substitute decision-making and the best interest framework (Clough,
2014; Dunn, 2013b; Dunn et al., 2010; Shah, 2011; Speker Obe & Scully,
2009).

Dunn et al. (2010) claim that the 'best interests checklist', embedded in the
MCA legislation, sets it apart from substitute decision-making
arrangements in other countries. They describe the checklist as a tool that
"requires substitute decision-makers to weigh up a range of objective and
subjective information about the wishes, feelings, beliefs and values of a
person lacking capacity in order to identify a single best outcome" (Dunn
et al., 2010 p.145).

However, drawing from twenty one interviews with support workers
working in residential care homes for adults with intellectual disability and observations of care practices, Dunn et al. (2010) concluded that the best interest checklist is too procedural and they advocate for a re-engagement with the concept of ‘best interests’ more broadly (Dunn et al., 2010). Furthering this view, Clough’s examination of the best interest framework, along with case law relating to best interest decisions, demonstrates little recognition of the contextual and relational aspects of service provision. Clough believes that there are “shades of individualism underlying the best interests sections of the legislation” (Clough, 2014 p.134). Clough acknowledges that Section 4 of the Mental Capacity Act appears to value the importance of considering the interests of significant others when making best interest decisions. However, she points out that Section 5 “goes on to emphasize that such views are only of importance in relation to finding out what is in the best interests of the person lacking capacity” and the effect of the decision on the “overall caring relationship” is not considered relevant (Clough, 2014 p.134). Herring (2007) and Clough (2014) argue that this view is problematic, because the best interests of the supported and supporter are intertwined. Herring (2007) suggests that it is not possible to consider the supported person’s best interests without considering those of the supporter. He writes: “In truth there is often give and take in the ‘carer’ and ‘cared-for’ relationship” (Herring, 2007 p.68).

Recently the MCA has come under particular scrutiny, regarding its compliance with the UNCRPD, in particular, the place of its ‘best interest
checklist’ in relation to the UK’s obligations under Article 12. Although, in recent years, the UK’s MCA (2005) has been lauded as a leading mechanism in progressive legal capacity legislation, the adoption of the UNCRPD has raised questions as to its compliance with the international treaty. The Centre for Disability Law and Policy in Galway articulates these questions in its Submission to the House of Lords Select Committee on the MCA (2013):

The MCA falls short in several aspects when compared with the standards established in Article 12 CRPD. The key problems with the legislation from the perspective of the CRPD are: the conflation of mental capacity and legal capacity in a functional test; the ‘best interests’ standard for substitute decision-making; and the legislative sanctioning of informal capacity assessments by third parties (Centre for Disability Law and Policy, 2013 p.7).

The Essex Autonomy Project is a research and knowledge-exchange initiative based at the University of Essex. The project’s work is centered on the history, theory and practice of self-determination. Within the context of this project, Martin et al., (2014) have examined the question of whether the Mental Capacity Act of England and Wales (MCA) complies with the UNCRPD (Martin, Michalowski, Jutten, & Burch, 2014). They found that the MCA is not fully compliant with the UNCRPD, to which the United Kingdom is a signatory. Specifically, they found the definition of incapacity in Section 2 of the MCA violated the antidiscrimination provisions of Article 5 of the UNCRPD. Additionally, the best-interests
decision-making framework of Section 4 was found to be non-compliant with the requirements of Article 12 (4) of the UNCRPD, which requires the will and preferences of people with disability to be paramount over perceived best interests. However, although Martin and his colleagues raised these concerns, they unequivocally found that “the United Nations Committee on the Rights of Persons with Disabilities is not correct in its claim that compliance with the CRPD requires the abolition of substitute decision making and the best-interests decision-making framework” (Martin et al., 2014 p.2).

2.10.3 Sweden

Sweden is considered one of the most progressive nations in terms of guardianship law reform under the UNCRPD (Devi, Bickenbach, & Stucki, 2011). In 1976, it replaced formal guardianship with two alternatives, the ‘god man’ and the ‘Forvaltare’. The primary form of decision-making assistance is called ‘the god man’, ‘good man’ or ‘mentor’ (Herr, 2003; Sparring Björkstén, 2008). Within this system the appointment of a god man does not automatically imply the adult’s loss of legal capacity (Blankman, 1997). According to Blankman (1997), such an appointment “reinforces rather than disregards the capacity for self-determination” (Morrissey, 2012 p.434). Morrissey (2012) describes the Swedish ‘god man’ system as one where a person’s preferences are “accommodated through the development of a relationship which finds ways to make it possible for the person to express and communicate what they want” (Morrissey, 2012 p.435).
In contrast to the appointment of a ‘god man’, the appointment of a ‘Forvaltare’, particularly aimed at financial interests, implies loss of legal capacity. Therefore, while the Swedish framework is considered progressive, it maintains a mechanism to remove legal capacity, arguably placing Sweden in breach of its obligations under UNCRPD, specifically Article 12. However, despite maintaining a guardianship mechanism, the Swedish model has attracted international attention and praise for emphasising a supported rather than substitute model of decision-making. Clinical Professor of Law at the Cardozo School of Law, in New York, Salzman (2010) illustrates this view.

While the Swedish program is not without its limitations, it does appear that even when the court appoints an administrator, rather than a god-man, Sweden’s national effort to focus on supported (rather than substitute) decision-making has helped to limit the scope of the administrator’s control over the incapacitated person’s affairs. This altered focus enables the individual to be more directly involved in his or her own life’s activities than he or she would under a system in which surrogate decision-making is the norm (Salzman, 2010 p.237).

 Despite anecdotal evidence of the Swedish system’s value, little empirical attention has been paid to its operation (Bigby et al., 2015).

2.10.4 Australia

Australia responded legislatively to the UNCRPD by ratifying it in 2008. As a result, the nation is now focused on law reform designed to meet its
obligations particularly within the area of supported decision-making. Highlighting this focus, Carter and Chestman (2009), from Victoria’s Office of the Public Advocate, place supported decision-making within a local context, stating:

Guardianship in Australia has, under the Guardianship and Administration Act 1986, been conceptualised as a last resort with a guardian appointed only when less restrictive options have failed or are not available. For guardianship to properly be a last resort there must be an adequate first resort. The United Nations Convention establishes supported decision-making as the first resort: the preferred alternative and, where necessary, precursor to guardianship (Carter & Chestman, 2009 p.3).

Pilot studies into supported decision-making have been implemented in the Australian jurisdictions of South Australia (SA), Victoria and the Australian Capital Territory (ACT). These pilots have largely excluded informal communicators as participants. Although the reasons for this exclusion is not documented, it may imply that such mechanisms are not considered appropriate for people with severe or profound intellectual disability by those carrying out the pilots. Such a view is consistent with Australia’s retention of the Interpretative Declaration in relation to Article 12 discussed below.

The South Australian pilot was carried out by the state’s Office of the Public Advocate (OPA). It involved the creation of non-statutory supported
decision-making arrangements for a total of twenty-six people whose decision-making capacity was questioned, but were able to give independent consent to participate. Specifically, it provided supported decision-making in the absence of a statutory mechanism to do so. An independent evaluation reported that “the project has demonstrated that supported decision-making can be a powerful mechanism to affirm the right of people with disability to make decisions and therefore exercise their legal capacity” (Wallace, 2012 p.57). The pilot succeeded in diverting people from the path of guardianship and administration orders. An unexpected outcome of the pilot was a notable increase in service providers’ perception of the decision-making capability of the person supported. In addition, the pilot expanded the decision maker’s network of service providers, family and friends (Wallace, 2012).

ACT Disability, Aged and Carer Advocacy Service (ADACAS), a disability advocacy organization servicing the Australian Capital Territory (ACT), reported on their supported decision-making trial (ADACAS., 2013). The project aimed to explore the local application of the supported decision-making model, developed in the South Australian trial, previously described. The overarching purpose was “to understand how people with a decision-making impairment or whose decision-making capacity is undervalued, might be supported to make more decisions” (ADACAS., 2013 p.9). Despite ADACAS’s attempt to include those with varied levels of intellectual ability, the decision-making model implemented required participants to intentionally indicate a desire to participate. As is the case
in the South Australian trial, this meant those with severe or profound intellectual disability were excluded. As was the case in the South Australian trial, the ACADAS trial demonstrated an increase in supporters’ perception of the decision-making capability of the person supported (ADACAS., 2013).

The Victorian Law Reform Commission (VLRC) in their report on guardianship reform in Victoria (2012), proposed “a new continuum of decision-making assistance” (Victorian Law Reform Commission., 2012 p.10). This continuum is similar to the stepped approach to supported and substitute decision-making used by the South Australian Office of the Public Advocate in its pilot study of supported decision-making (Brayley, 2009; Wallace, 2012). This spectrum would see, at one end, autonomous decision-making and non-intervention by the state, and at the other end, substitute decision-making and extreme state intervention. In between these extremities would be the options of informal, supported and co-decision-making arrangements as discrete mechanisms. This proposed decision-making continuum has been adapted and reproduced (with permission) from the VLRC’s final report in figure 5 below.
The statutory mechanism for “co-decision-making” sees the appointment of a “co-decision maker” who makes decisions jointly with the person requiring support. Unlike a guardian, a co-decision-maker is explicitly required to maximize the participation of the person they assist in decisions.

More recently, Victoria’s Office of the Public Advocate (OPA) has designed and is currently implementing a Supported Decision-Making Pilot Project. Through this project, OPA is aiming to train and connect volunteers with isolated people who have cognitive disability and require decision-making support. At the time of writing, this project has not been evaluated.

The United Nations’ Committee on the Rights of Persons with Disabilities met in late 2013 to evaluate Australia’s performance regarding its commitment as a signatory nation to the UNCRPD. The Committee
commended Australia’s adoption of the National Disability Strategy 2010-2020, an instrument designed to implement the Convention across all jurisdictions (Commonwealth of Australia., 2011). It also commended Australia for introducing the NDIS, the national scheme of self-directed disability support (Commonwealth of Australia., 2013). Additionally, the Committee welcomed Australia’s commissioning of the Australian Law Reform Commission (ALRC) to inquire into barriers to equal recognition before the law and legal capacity for people with disability (Commonwealth of Australia., 2014).

In addition to the positive responses provided, the Committee articulated some specific concerns regarding Australia’s performance in relation to the UNCRPD. The Committee highlighted a need for Australia to further broaden its definition of supported decision-making to include its application to all people with disability, including those with severe or profound intellectual disability (United Nations Committee on the Rights of Persons with Disabilities., 2013). At the core of the Committee’s criticisms is the existence of Australia’s interpretative declaration, in relation to Article 12. In relation to Article 12 of the Convention, Australia has the following interpretative declaration in place:

Australia recognizes that persons with disability enjoy legal capacity on an equal basis with others in all aspects of life. Australia declares its understanding that the Convention allows for fully supported or substitute decision-making arrangements, which provide for decisions to be made on behalf of a person, only where
such arrangements are necessary, as a last resort and subject to safeguards ("Convention on the Rights of Persons with Disabilities: Declarations and Reservations (Australia)," 2008).

This Australian declaration allows for the use of substitute decision-making in situations where a person is assessed as having no or limited decision-making capability. While Australia continues to have this interpretative declaration in place, the UN Committee on the Rights of Persons with Disabilities are of the view that the universality of supported decision-making is not being recognised, and therefore Australia is not acting within the spirit of the Convention (Committee on the Rights of Persons with Disabilities., 2-13 September 2013).

Responding to the UN Committee’s criticisms, the Australian Law Reform Commission (ALRC) mirrored these concerns regarding Australia’s interpretative declaration to allow for substitute decision-making. The Commission’s 2014 Inquiry and Report, *Equality, Capacity and Disability in Commonwealth Laws* provide a blueprint for reform. It claims that the interpretative declaration “may act as a handbrake on reform” (Commonwealth of Australia., 2014 p.46). Within its discussion paper, the ALRC proposes that, “the Australian Government should review the Interpretative Declaration in relation to Art 12 of the United Nations Convention on the Rights of Persons with Disabilities with a view to withdrawing it” (Commonwealth of Australia., 2014 p.9).
In its report, the ALRC has formulated four decision-making principles to guide reform of Commonwealth, state and territory laws concerning supported decision-making. These principles, as articulated by the ALRC are outlined in Table 1, further defining the concept of supported decision-making in this study (Australian Law Reform Commission., 2014b p.64).

<table>
<thead>
<tr>
<th>Principle</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>Principle 1: The equal right to make decisions</td>
<td>All adults have an equal right to make decisions that affect their lives and to have those decisions respected.</td>
</tr>
<tr>
<td>Principle 2: Support</td>
<td>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.</td>
</tr>
<tr>
<td>Principle 3: Will, preferences and rights</td>
<td>The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.</td>
</tr>
<tr>
<td>Principle 4: Safeguards</td>
<td>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.</td>
</tr>
</tbody>
</table>

Principle three, “will, preferences and rights” proposes that regardless of what decision-making mechanism is used, the will and preferences of those at the center, rather than the perceived best interests of that person, should drive the process. The report states that "the emphasis is on the autonomy and independence of persons with disability who may require support in making decisions—their will and preferences must drive
decisions that they make, and that others make on their behalf (Australian Law Reform Commission., 2014b p.24).

The ALRC’s report explicitly acknowledges the complexities of providing decision-making support to Australians with cognitive disability such as severe or profound intellectual disability. Despite these challenges, the Commission advocates for the abolishing of substitute decision-making in Australia.

The most difficult policy challenges in this area concern those who require the most support. Where a person's will and preferences are difficult, or impossible to determine, they may need someone else to make decisions on their behalf. These hard cases should not, however, be treated as a barrier to building law and legal frameworks that move towards supported decision-making in practice, as well as in form (Australian Law Reform Commission., 2014a p.17).

Despite this commentary, no legislative reform has as yet occurred in Australia.

2.10.5 Supported decision-making: An overview of the evidence

Despite a focus on supported decision-making mechanisms within international and local legislation, there is a dearth of empirically based research validating this approach specifically. The outcomes of self-determination and empowerment espoused by proponents of supported decision-making approaches are clearly desirable. However, as expressed
by Kohn et al. (2013, 2014) they are yet to be evidenced by research, meaning that policy and legislative changes may be made without the benefit that insight into empirical research can provide (Kohn & Blumenthal, 2014b; Kohn et al., 2013). Kohn and colleagues (2013, 2014) in recent reviews of the evidence base around supported decision-making, highlight the limited number of studies available in this area. They suggest an urgent need for additional research on supportive approaches to decision-making. Specifically, they highlight the need for a clear theoretical framework, claiming that there is no common language to communicate about supported decision-making. Additionally they claim there is a need for the development of measurement tools and interventions to assess, evaluate and implement supported decision-making (Kohn & Blumenthal, 2014a; Kohn et al., 2013).

Despite these concerns having merit, it should be noted that although not called supported decision-making, there is an evidence base supporting the use of self-determination interventions and communication interventions, previously described in 2.2. Much can be inferred from this evidence base and applied to supported decision-making practice. Therefore, claims that supported decision-making practice is largely lacking an evidence base are not entirely accurate. The process of adequately supporting someone with severe or profound intellectual disability to participate in decisions is likely to draw heavily on this evidence base, specifically that focused on communication and self-determination interventions previously described.
Dunn et al.’s (2010) grounded theory analysis of supported decision-making mechanisms in the United Kingdom, suggests that while there is an increased focus on interdependence in evolving frameworks of supported decision-making, the translation of these into practice, particularly for those with severe or profound intellectual disability remains challenging. Dunn et al. (2010) examined how paid supporters of people with intellectual disability provided decision-making support in England where the previously discussed MCA (2005) is in force. Despite the existence of the Act, they found that so called ‘best interest’ decisions could not be characterised as interdependent, as they did not always take the perspective of the focus person, but rather paid supporters tended to “draw on the personal decisions they make in their own lives as a starting point” (Dunn et al., 2010 p.154).

In their “state of the art review” of empirical literature on supported decision-making, Kohn et al. (2013) questioned the demographics of those who use supported decision-making arrangements. There is little research on the demographic composition of those who enter into supported decision-making arrangements as focus people or supporters (Kohn et al., 2013). Most of the demographic data available comes from British Columbian jurisdictions, specifically relating to the formal application of supported decision-making within the context of Representation Agreements, previously discussed. In terms of the focus person, or as Kohn calls them, ‘the principal’, data suggests that women are most likely to enter into such agreements, as are adults in their twenties, with people
who are aging following close behind (Harrison, 2008; Kohn et al., 2013; NIDUS., 2009). According to Kohn et al. (2013) it is unclear as to how representative this research is of people with intellectual disability, therefore its generalizability to this population is questioned (Kohn et al., 2013). In terms of who is providing the support, relatives appear most likely to be selected as supporters, with ninety per cent of Representative Agreements in British Columbia naming a family member as a representative (NIDUS., 2009). Therefore, the small amount of existing information suggests that supported decision-making is likely to occur within the context of family relationships. However, Kohn et al. (2013) highlight that “more information on the identities of supporters and their relationships to principals is critical if we are to understand how supporters are selected and the relational context in which decision-making is likely to occur” (Kohn et al., 2013 p.1135).

Responding to the lack of focus on how supported decision-making is delivered in practice, Douglas, Bigby, Knox and Browning (2015) describe four propositions characterising effective decision-making support (Douglas, Bigby, Knox, & Browning, 2015). These include, “orchestration by the primary supporter; commitment to person; support principles; and a repertoire of strategies that can be used flexibly depending on the type and context of particular decisions” (Douglas et al., 2015). These propositions have been developed from a range of qualitative studies conducted by Douglas and her colleagues (Bigby et al., 2015; Browning et al., 2014; Knox, Douglas, & Bigby, 2014, 2015). Although these studies
provide important insights into factors that may underpin supported
decision-making for people with mild to moderate cognitive disability,
their generalizability to people with severe or profound cognitive
disability is not established.

2.11 System factors that undermine self-determination

What systemic factors are discussed in the literature as undermining
supported decision-making for people with severe or profound intellectual
disability?

The promotion of choice, self-determination, and supported decision-
making are at the center of disability support services, policy and
legislation throughout the western world (Bonyhady, 2015;
Commonwealth of Australia., 2011, 2013; Dunn, 2013a; Emerson &
Hatton, 1996; Schalock, 2004; Victorian Government., 2006). Despite this
clear policy and legislative direction, obstacles and tensions remain in
translating policy into practice, particularly for people with intellectual
disability. Consistent with a social model of disability, these obstacles and
tensions are increasingly characterised beyond the service user as
environmental, constructed by the service system and the society in which
a person with a disability lives. Beamer and Brookes (2001) highlight this.
“Services are important in the lives of many people with high support
needs and yet how they are structured and provided is often also part of
the problem” (Beamer & Brookes, 2001 p.77).

The literature is increasingly pointing to tensions that exist for disability
support workers, who are asked to choose between the interests and expectations of multiple stakeholders (e.g. themselves, management, service users, other workers, families, and the law). These interests are often at odds with one another (Ferguson et al., 2011; Finlay, Walton, et al., 2008; Hawkins, Redley, & Holland, 2011; Hollomotz, 2012; Pilnick, Clegg, Murphy, & Almack, 2010; Stancliffe et al., 2000).

Finlay et al. (2008) highlight the complexities of achieving true choice for people with intellectual disability within service systems which are highly regulated and suggest that these complexities are often underestimated (Finlay, Walton, et al., 2008). This is in accordance with the findings of Stancliffe et al. (2000), who claim that the skills and attitudes of disability support workers have little impact on the opportunities for self-determination afforded to service users, when compared to the negative impact of agency policies and procedures (Stancliffe et al., 2000).

Hollomotz (2010) analyzed the impact of the United Kingdom’s White paper, *Valuing People* (UK Government, 2001) on the availability of mundane choices, by interviewing service users. She found that, despite the rhetoric, not all of the choices afforded to the people in her study were based on an infinite set of options. Highlighting the manipulation of decisions and options, she stated,

Under the guise of choice-based policy rhetoric, some people with learning difficulties are at times presented with a pre-arranged ‘menu of choices’. For instance, a person may be free to choose activities at their day center, but they may have limited control
when deciding whether to attend the service in the first place (Hollomotz, 2012 p.12).

Supporting Hollomotz, Ferguson et al. (2011) and Pilnick et al. (2010) found that in the interest of reducing risk and ensuring outcomes perceived to be in the best interest of service users, some supporters actively shape the decisions offered and options available to those they support (Ferguson, et al. 2011; Pilnick, et al., 2010). Such an approach is believed to be related to a range of policy and legislative based restrictions, such as out-dated notions of duty of care, occupational health and safety regulations, and a culture adverse to risk taking, particularly for this population (Hollomotz, 2012).

2.11.1 Duty of care

An obvious aspect of policy and legislation that disability support workers are expected to conform to is ‘duty of care’. “A duty of care is the obligation to exercise a level of care towards an individual, as is reasonable in all circumstances to avoid injury to that individual or his/her property” (Baxter & Carr, 2007 p.6-7).

As Pepin et al. (2013) highlight, understanding the complexities surrounding notions of duty of care is “one of the most difficult but critical and underestimated skills for anyone working in health and human services” (Pepin et al., 2013 p.162). Considering their duty of care, it is easy to understand why some supporters and service providers express concern in relation to relinquishing control and fostering the autonomy of those they support.
Juxtaposed with duty of care is an obligation on supporters to promote the autonomy and self-determination of those they support. As discussed, this obligation is reflected in legislation such as the UNCRPD and is central to rhetoric around Australia’s NDIS (Commonwealth of Australia., 2013). The promotion of this autonomy and control inevitably involves a degree of risk, often placing supporters in a dilemma around which policy/legislative messages should be regarded as priority. There is tension between rights to risk taking on one hand, and service providers’ perspectives of duty of care on the other. These tensions are not new and have been reported in policy and practice literature in relation to intellectual disability and mental health service provision, increasingly over the past four decades (Alaszewski & Manthorpe, 1998; Brown & Brown, 2003; Hawkins et al., 2011; Manthorpe, Walsh, Alaszewski, & Harrison, 1997; Parton, 1996; Perske, 1972; Rose, 1998; Sawyer & Green, 2011).

There is concern that the choice agenda is losing out to supporters’ perceptions of the duty of care they owe to service users. Julian Gardner, previous Public Guardian in Victoria, Australia, emphasized this concern when he asked the question at a Victorian discussion forum in 2004, “Is the way in which we rightfully or wrongfully apply duty of care the new form of manacled straight jacket?” (Gardner, 2004 Slide 1). Finlay and his colleagues, also articulated this concern, providing evidence through their video analysis of observed interactions in residential services, that notions of duty of care regularly take precedence over the preferences of service
users (Finlay, Walton, et al., 2008). Supporting Finlay et al.’s (2008) view, Kilbane and Thompson (2004) identified conflicts in achieving person centered goals and service providers’ management of duty of care (Kilbane & Thompson, 2004). Their research highlighted the difficulties that professionals experience in balancing their perceived duty of care with the choices of people with disability and their supporters. Kilbane and Thompson (2004) highlight the practices of some professionals, who they claim are guilty of allowing their perceptions of duty of care to take precedence over the self-determination of those they support, concluding that:

Ultimately it has to be acknowledged that people who have a learning difficulty have the same life choices as the rest of the population, and the professionals’ duty of care, while being a serious responsibility, does not give them the right to take control over the lives of others (Kilbane & Thompson, 2004 p.30).

Discussing balancing risk and social work practice, Parton claims that society is disproportionately concerned with risk avoidance and defensive practice than with enhancing opportunities for self-determination for service users (Parton, 1996). Drawing from one hundred and sixty six interviews with disability support staff and management, Sawyer and Green (2011) concluded that “the practice of individualised community care demands a positive view of risk and risk-taking, balanced with safety, rather than a predominantly negative framing” (Sawyer & Green, 2011 p.34). Moreover, Hawkins et al. (2011) highlight the challenges that exist
for supporters of people with Prader-Willi Syndrome (PWS) in balancing the autonomy of those they support with the risks associated with allowing the to over eat (Hawkins et al., 2011).

Opposing this view that the choice agenda is losing out to notions of duty of care and risk avoidance, Jackson and Irvine (2013) argue that although ideological policies have positively influenced practice, they may also have “tied the hands of those working in the field of intellectual disability” (Jackson & Irvine, 2013 p.20). They claim that respect for the self-determination of people with an intellectual disability has taken precedence over the obligations of service providers in terms of their duty of care. They state:

When there is an excessive promotion of the normalization agenda, which is in part defined by the aim to respect the client’s choice in all things, there is a risk that duty of care is neglected when healthcare professionals are expected to witness unhealthy choices and behaviour and let it go (Jackson & Irvine, 2013 p.25).

This tension is reflected in Smyth and Bell’s (2006) paper which proposes that there is an element of “political correctness” emerging that “at times has taken precedence over duty of care” (Smyth & Bell, 2006 p.8). They make this claim within the context of their research around dietary decision-making in the lives of people with intellectual disability. They conclude that choice about food can have significant implications for a person’s health, and therefore the implications of such decisions should
not be taken lightly.

Additionally, Fyson and Cromby (2013) critically examine the assumptions and theoretical positions associated with human rights in relation to people with intellectual disability. In doing so, they call for “policy-makers and practitioners to develop a more nuanced and realistic understanding of the very real dangers which an unfettered neoliberal approach to welfare poses to making real the rights of people with ID” (Fyson & Cromby, 2013 p.1171). They exemplify their point highlighting Steven Hoskin’s case reviewed by Flynn (Flynn, 2007). Steven was murdered following his choice to discontinue support services, a consequence that was defended by service providers as “simply the price Steven paid for his autonomy” (Fyson & Cromby, 2013 p.1169).

Fyson and Cromby’s paper (2013) analyzes an application of human rights shaped by neoliberal views that promote the notion that all people are rational autonomous individuals, capable of effective decision-making without support. They claim that such models of service de-emphasize service users’ human rights of protection, health, wellbeing, and safety, which are at risk of being denied when a person is assumed able to make rational informed choices without support. They promote the interdependent and relational view of decision-making, already discussed (Bach, 2006; Gordon, 2000b; Markus & Kitayama, 2003; Reindal, 1999), suggesting that supporters have a duty of care to facilitate support with decision-making when a service user lacks capability to make decisions on their own. Acknowledging the resource intensive nature of decision-
making support, Fyson and Cromby (2013) cynically suggest a denial of such support may be less to do with the individualised choice agenda per se, and more to do with “a cost-cutting agenda presented precisely as increasing opportunities for choice, self-direction and empowerment” (Fyson & Cromby, 2013 p.1170).

2.11.2 Occupational health and safety

Service providers’ focus on occupational health and safety (OH&S) is increasingly being discussed in the literature and in conversations around how best to support service users to lead lives that reflect their preferences (Pepin et al., 2013). At the core of these conversations are perceived dilemmas and contradictions around risk to service providers, organisations and governments. A forum held by the Victorian Office of the Public Advocate (OPA) (2004) titled Risks and rights: redressing the imbalance reflected this national conversation (Office of the Public Advocate., 2004). This forum highlighted a “clear tension between balancing risk and rights of clients, workers and other key groups” and that the way risk is defined is often perceived to “be at odds with the mission statement of the organisation” (Office of the Public Advocate., 2004 p.1).

In addition, it highlighted an increasing concern in the sector that OH&S appears to be “taking priority over clients rights reinforced by work cover legislation” and that generally there was a “fear of litigation and Occupational Health and Safety (OH&S) breaches, [that] promotes an inflexible negative and narrow approach to risk” (Office of the Public
Advocate., 2004 p.3). Forum participants reported that “risk is primarily interpreted and managed in relation to the possible risk to the organisation, with the effect on the client being generally a secondary consideration” (Office of the Public Advocate., 2004 p.5). Participants also reported that there was “a lack of effective engagement and support of clients and workers in confronting the dilemmas associated with assessing and responding to risk” and this “significantly impaired the response to risk and the quality of life of the person with a disability” (Office of the Public Advocate., 2004 p.4).

2.12 Summary of Chapter two

This chapter has presented a review of the research, practice and legislative literature relating to decision making for people with severe or profound intellectual disability. The evidence base has been examined by asking ten questions of the literature.

Four research questions (listed below) were developed from this review of the literature, legislation and practice.

The research questions are:

1. What is the role of people with severe or profound intellectual disability within a supported decision-making context?
2. What is the role of a supporter of someone with severe or profound intellectual disability within a supported decision-making context?
3. What factors underlie supporters’ role in supported decision-making for people with severe or profound intellectual disability?
4. What are the implications of this study’s findings on policy and practice relating to decision-making support for people with severe or profound intellectual disability?
CHAPTER THREE

Method and methodology

3.1 Overview of Chapter

This chapter describes the study’s method and methodology. Firstly, it defines the study in terms of its aim and the research questions it is guided by. This is followed by a description of social constructivism, the theoretical perspective underlying this research. The study’s exploratory qualitative design is then described. The main focus of this design is an exploration of the experiences of five people with severe or profound intellectual disabilities and their supporters were explored in the context of a supported decision-making intervention. This intervention, a training package titled: Listening to those rarely heard, developed by the author, is then described and contextualised within the research study. The chapter then discusses the study’s population, participant-selection criteria, and recruitment procedure. Methods of data collection are described. The chapter then details the data analysis procedure, and presents examples of research findings in order to concretise for the reader how analysis occurred. The chapter concludes with a discussion of the methods used to ensure rigour and trustworthiness.

3.2 Defining the current study

3.2.1 Research aim

As discussed in Chapter one, this study had two aims. They were to:
1. Characterise supported decision-making for people with severe or profound intellectual disability in terms of the roles played by, a) the supported, and b) the supporters.

2. Focusing on the role of supporters, identify the processes, enablers and barriers, to supported decision-making for people with severe or profound intellectual disability, in order to understand how it can be fostered in practice.

Drawing from the literature in regard to what is known about supported decision-making for people with severe or profound intellectual disability, and the lack of research focus on their participation in supported decision-making, the following research questions were adapted for this study.

3.2.2 Research questions

1. What is the role of people with severe or profound intellectual disability within a supported decision-making context?

2. What is the role of a supporter of someone with severe or profound intellectual disability within a supported decision-making context?

3. What factors underlie supporters’ role in supported decision-making for people with severe or profound intellectual disability?

4. What are the implications of this study’s findings on policy and practice relating to supported decision-making for people with severe or profound intellectual disability?
3.3 Epistemological framework: Social Constructivism

In order to address the aims of this thesis, an epistemological framework was used. Epistemology, the branch of philosophy that studies knowledge, attempts to answer the basic question: what distinguishes truth from untruth (Pietersma, 2000; Vandevenle & Hermberg, 2011)? From a historical perspective, there is a clear trend in the evolution of epistemology as described by Heylighen (1993). Heylighen describes this historical trend as a continuum moving from a “static, passive view of knowledge towards a more and more adaptive and active one” (Heylighen, 1993 p.1). At one end of the continuum is objectivism, sometimes referred to as positivism, and at the other is social constructivism, an interpretative paradigm. Ernest (1998) argues that all learning rests on this epistemological continuum (Ernest, 1998).

Heylighen (1993) describes objectivist/positivist theories of knowledge as characterized by "absolute" and "permanent" understandings of truth (Heylighen, 1993 p.1). Objectivists or positivists emphasise knowledge as being the awareness of objects existing independently of a subject (Heylighen, 1993). The hallmark of objectivist/positivist science is that it views the world as having a single reality that can be independently observed and measured by objective scientists, preferably under laboratory conditions, where all variables can be controlled and manipulated to determine causal connections.

At the other end of the epistemological continuum is social constructivism, the framework underpinning this study. Social constructivism is believed
to have developed as an alternative epistemological viewpoint to objectivism/positivism (Cupchik, 2001). Social constructivists claim that a positivist or objectivist concept of causality is misleading, too simplistic and that the process of assembling meanings does not generally happen in a linear fashion (Lincoln, 2001). Instead, a social constructivist paradigm proposes that there is no one absolute reality, but multiple realities. It proposes that “meaning is not discovered but constructed” (Crotty, 1998 p.8). As articulated by von Glasersfeld, this construction of knowledge is thought to be highly contextual and to happen via human interaction within a specific research environment. “To the constructivist, concepts, models, theories, and so on are viable if they prove adequate in the contexts in which they were created” (von Glasersfeld, 1995 p.7). Under this paradigm, data is constructed by researchers from their perceptions and experiences in interacting with the phenomena studied (Sandelowski, Voils, & Knafl, 2009). Therefore, within this paradigm, the researcher does not propose that an absolute reality exists. Rather, it is acknowledged that reality can be interpreted in various ways, and understanding is dependent on not only theirs, but the participants’ subjective interpretation of the research context. Guba and Lincoln (1989) claim that all those involved in a research study bring their own values, preconceived ideas, knowledge, life experience and assumptions to the research context, and these are acknowledged as influencing the inquiry design and processes (Guba & Lincoln 1989).
Social constructivism not only considers knowledge construction as contextual, but collaborative. Heylighen (1993) explains that social constructivism, “sees consensus between different subjects as the ultimate criterion to judge knowledge. ‘Truth’ or ‘reality’ will be accorded only to those constructions on which most people of a social group agree” (Heylighen, 1993 p.2). Ernest (1995) agrees, suggesting that social constructivism places an emphasis on collaboration, negotiation, iterative methodologies (e.g. action research), reflexivity and the construction of shared meanings (Ernest, 1995).

3.4 Social constructivism within the disability context

It is suggested that the medical approach to disability that has dominated disability research and practice for much of last century has its roots in objectivism, while social-ecological models, such as that promoted by the International Classification of Functioning (World Health Organisation (WHO). 2001) are derived from social constructionism (Anastasiou & Kauffman, 2011; Barnes, 1991; Oliver, 1996).

Social constructivism is reflected in Shogren and Wehmeyer’s (2015) description of social-ecological models of disability, which explain disability as a constructed and contested concept. They claim that these models “hold that people with disabilities experience a mismatch between their personal capacities or abilities and environmental or contextual demands, which creates a need for supports” (Shogren & Wehmeyer, 2015 p.6). Oliver promotes a social constructivism approach toward disability, particularly within the context of research (Oliver, 1992, 1996). He writes:
“Disability cannot be abstracted from the social world which produces it; it does not exist outside the social structures in which it is located and independent of the meanings given to it. In other words, disability is socially produced” (Oliver, 1992 p.101). Further highlighting its links to contemporary approaches to disability, social constructivism is characterised by Mallory and New (1994) as a “theoretical framework for inclusion” (Mallory & New, 1994 p.325). Mallory and New (1994) emphasize the influence of social context and activity on the notion of inclusion, specifically for students with disabilities within an educational context. They suggest that inclusion is most optimal when social constructivist principles are in place. They draw particular attention to the importance of social interaction and collaboration, key elements of a social constructivist approach, in the promotion of inclusion, specifically within educational settings.

3.5 A personal perspective

Social constructivists propose that the values, preconceived ideas, knowledge, life experience and assumptions a researcher brings to a study influence the inquiry design and processes (Guba & Lincoln 1989). In keeping with this transparent approach advocated by social constructivism, a description of my background and the assumptions I hold, particularly in relation to the research are outlined. These assumptions have been formed through my engagement with the literature, my clinical and personal experiences, and the experiences, values and practices of participants in the present study.
Over my forty-five years, I have supported and come to know and love people with a range of disabilities, as a support worker, sister, daughter, friend, and speech pathologist. Drawing a line between my personal and professional involvement with people with disability has been challenging. Quarantining these two aspects of my life has, at times, felt disingenuous. The blurring of personal and professional roles is considered problematic in some social services literature and practice that suggests that relationships between professionals and people with disabilities should be clearly delineated (Lutfiyya, 1993; Queensland Health., 2011; Spagnolo et al., 2011). However, the artificial constraining of relationships is not compatible with a social constructivist philosophy, which calls for transparency, and therefore honesty, regarding the realities of such relationships, which in truth are often blurred.

3.6 Research design

Using an action research approach this study explores the experiences of supported decision-making in the lives of five people with severe or profound intellectual disability and their supporters. Each case is studied through the lens of a supported decision-making intervention, designed specifically for this population.

3.6.1 Action research

Action research was chosen as the primary research framework for this project. One of the most widely cited definitions of action research is that of Rapoport’s (1970), who described it as “contribut[ing] both to the practical concerns of people in an immediate problematic situation and to
the goals of social science by joint collaboration within a mutually acceptable ethical framework” (Rapaport, 1970 p.499). Eden and Huxham (1996) contributed to this picture by insisting, that action research, within their field of human relations, should be related to “a matter which is of genuine concern’ to those participating” (Eden & Huxham, 1996 p.75).

McNiff, Lomax and Whitehead (1996) describe a basic action research as an iterative process of firstly reviewing current practice, then identifying an aspect of this practice for improvement. A way forward is then imagined, trialled and evaluated. This evaluation leads to the original plan being modified and then implemented. This process of planning, action, review and reflection continues until the practice is considered satisfactory (McNiff, Lomax, & Whitehead, 1996).

Action research is a paradigm that subsumes a variety of established research approaches. These include, Patton’s (1990) approach to evaluation, Checkland’s (1991) soft systems’ analysis, Argyris’ (1985) action science and Kemmis’ critical action research, which incorporates Participatory Action Research, sometimes, referred to in the literature as the Deakin model (Argyris, Putman, & Smith, 1985; Carr & Kemmis, 1986; Checkland, 1991).

There is now a plethora of literature promoting action research as a legitimate social science methodology (Boog, 2003; Bradbury & Reason, 2003a; Burgess, 2006; Coghlan & Shani, 2005; Davis, 2007; Frideres, 1992; Vickers, 2007). This literature not only describes action research, and participatory action research, as legitimate but also attempts to address
the criticisms around its use.

The addition of the word “participatory” to action research emphasizes the collaborative focus of participatory action research. Like all action research, participatory action research emphasizes the use of a defined cycle of research consisting of four steps: plan, act, observe and reflect as described in the Deakin participatory action research model popularized by Kemmis and McTaggart (Kemmis & McTaggart, 1988). Reason and Bradbury (2001) in their definition, state that action research, participatory action research in particular “seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people and more generally the flourishing of individual persons and their communities” (Reason & Bradbury, 2001a p.1). According to Reason and Bradbury (2001), participatory action research is both a methodology and an ideology. As a methodology, it prescribes ways to collect and interpret data. As an ideology, it is rooted in the belief that research with human beings should be democratic and participatory. An additional characteristic described by participatory action researchers is the emancipatory component highlighted in Boog’s (2003) definition which states that “action research is designed to improve the researched subjects’ capacities to solve problems . . . increase their chances for self-determination and to have more influence on the functioning and decision making processes of organizations” (Boog, 2003 p.426). Schwandt's (2001) definition of participatory action research is in sync with most
contemporary definitions, however expands on them by suggesting that participatory action research has an added asset of empowering people who belong to groups traditionally oppressed to have their voices heard (Schwandt, 2001). There is little argument that those who are the focus of this research, people with severe or profound intellectual disability fall into such an oppressed group (Johnson, Watson, Iacono, Bloomberg, & West, 2012a).

Despite this project attempting to be as participatory as possible, considering the definitions of participatory action research, described above, it would be disingenuous to characterise this study as participatory action research. The emancipatory nature of participatory action research described in the literature is certainly reflected within the role played by circles of support in this project, however not by the focus people, who, because of the dependent nature of their disability were unable to take on a strong leadership and planning role. Although attempts were made to reduce it, a power imbalance clearly existed between the researcher and those participants with severe/profound intellectual disability. This power imbalance was not as prominent between the researcher and those participants who were classified as supporters. Therefore, although this project strives to be highly participatory, it is classified as action research as opposed to participatory action research.

Bargal (2008) has identified eight guiding principles drawn from the diverse action research literature (Bargal, 2008). Five of these principles have particular relevance to this study. Firstly, this study strived to be
highly participatory and collaborative. Secondly, throughout the study careful attention was paid to the concept of power relationships. As much power as possible was shared between the researcher and all participants, although as already mentioned this was more challenging for participants with severe or profound intellectual disability. Thirdly, Bargal (2008) emphasizes the importance of recruitment, training, and support of those responsible for change, described by Bargal as change agents. The change agents within this study can be operationally defined as those participants who formed the support circle around the focus person with a severe or profound intellectual disability. The fourth of Bargal’s action research principles forming an important component of this study states that “the small group plays a central role in decision making and in achieving change in people” (Bargal, 2008 p.22). As previously described, small group structures were important components within the study particularly in relation to the construction and maintenance of circles of support. Finally, this study adopted one of the key principles articulated by Bargal (2008) and embraced in most descriptions of action research, that being that the approach is highly iterative and “includes a spiral process of data collection to determine goals, action to implement goals, and assessment of the results of the intervention” (Bargal, 2008 p.22). Each of these principles and how they will be achieved will be further detailed in proceeding sections of this thesis.

3.6.2 Multiple case study design

This study uses a multiple and sequential case study design. Case study research is widely used to study a phenomenon in its natural setting and
social context and is “especially useful when the boundaries between phenomenon and context are not clearly evident” (Yin, 1994 p.13), as is the case for the current study. It investigates a predetermined phenomenon, but does not involve explicit control or manipulation of variables. Rather, it achieves a detailed understanding of a phenomenon in a particular context. A multiple case study design allows cross case analysis and comparison across diverse settings, in contrast to single case study, which is limited in generalizability. It should be noted however, that considering the small number of cases examined in this study, generalizability remains restricted.

3.6.3 The study’s intervention

A supported decision-making intervention, *People with severe or profound intellectual disabilities leading lives they prefer through supported decision-making: Listening to those rarely heard* (Watson & Joseph, 2011) was implemented in this study. This intervention provided a lens through which to observe the phenomenon of supported decision-making for people with severe or profound intellectual disability. This population generally has limited experience of decision-making and therefore it was necessary to provide a context in which it could be observed and explored.

For each case study, the intervention brought together a group of people who care for and about someone with a severe or profound intellectual disability (circle of support). The intervention involved a combination of on-site mentoring, observation, modeling, coaching and provision of feedback. In conjunction with on-site mentoring and support from the
researcher, the group attended a five-hour workshop facilitated and
guided by the researcher. Each case-study engaged with the intervention
process for approximately six months. The five case-studies were
predominately carried out sequentially with some minor overlap.

**Supported decision-making framework**

Embedded within the intervention implemented in this study is a
supported decision-making framework (Pepin et al., 2013; Watson, 2013;
Watson & Joseph, 2011). A representation of the final framework used is
depicted in figure 6. Using an action research/iterative approach, both the
framework and the training package, in which it is embedded, was
implemented, analysed and refined over a period of three years. Such a
cyclic approach is designed to continuously improve the quality and
functionality of a design, system or framework by facilitating evolution
and improvement, as successive versions, or iterations of a design are
implemented. The action and the research evolve as the study progresses
(Bargal, 2008; Burgess, 2006; Reason & Bradbury, 2001b).
The framework is “designed to gather a consensus view on what a person with severe or profound intellectual disabilities may be communicating and/or what may be in their best interests and from there make a decision” (Watson, 2012). At each phase of the framework, the focus person’s expression of preference is central to the process.

**Key elements of the intervention**

The first iteration of the intervention was developed before the study commenced. The content and structure was based on research literature and practice knowledge, related to severe or profound intellectual disability (Goldbart & Caton, 2010; Hogg, 2007), behaviour support, complex communication needs (Bunning, Smith, Kennedy, & Greenham, 2013; Mirenda et al., 1990), choice making (Brown, Raphael, & Renwick,

The intervention was guided by an interactive approach, as described and implemented by a number of researchers and practitioners within the field of intellectual disability services (Bloomberg, West, & Iacono, 2003; Bradshaw & Goldbart, 2013; Bradshaw et al., 2004; Totsika, Toogood, Hastings, & Nash, 2008). An interactive model is highly individualised and customised to a particular person and their support network. It involves service providers (including managers) and the focus person’s informal supporters across the focus person’s life, coming together to collaboratively problem solve and tailor support strategies to the needs of the particular individual. The involvement of managers and supervisors in training has been found to be important in facilitating change in practice, specifically within training relating to behaviours of concern (Bradshaw et al., 2004; Harchik et al., 2001; Smith, Taubman, & Lovaas, 1992). Due to its focus on an individual person, this approach is often referred to in the literature as Person Focused Training (Grey & McClean, 2007; McClean et al., 2005). Within this model a skilled facilitator trains, mentors and guides supporters and their managers through a topic of practice, over an extended period. Training is not confined to a workshop environment. In addition to group workshops, on-site interactive training takes place in the real life environments of the person at the center of the training.

In support of such an approach, Graves highlighted the limitations of didactic approaches to training. Graves (2007) found that hands-on
training, such as described here, was perceived by paid supporters to be "an effective way of sharing knowledge and skills" (Graves, 2007 p.118). Further promoting the value of a ‘hands-on’ approach to training within disability support services, Bradshaw and Goldbart (2013) provide evidence that support workers see professional knowledge as having greater validity if it comes from someone with a demonstrated knowledge of the service user in question (Bradshaw & Goldbart, 2013).

Practitioners who work using a consultative rather than a hands-on approach may well limit the effectiveness of their interventions. The responses from the participants interviewed in these studies would seem to indicate that this type of intervention was likely to have the least influence over their actual practice (Bradshaw & Goldbart, 2013 p.295).

The intervention used in this study involves a combination of on-site mentoring, observation, modeling, coaching and provision of feedback in techniques of service provision. These characteristics are seen commonly in active support (Bradshaw et al., 2004; Stancliffe, Harman, Toogood, & McVilly, 2007; Totsika et al., 2008). Totsika et al. (2008) found that the use of an interactive training approach was effective, particularly when applied to the area of active support. Specifically, they demonstrated that in-house interactive training was positively viewed by paid supporters in residential settings (Totsika et al., 2008). Bradshaw et al. (2004) and Jones et al. (2001) found similar results in the implementation of active support, particularly highlighting the value of managerial and senior staff
involvement in the delivery and ownership of the training process (Bradshaw et al., 2004; Jones et al., 2001).

An aspect of the approach used within this study was the provision of time for reflection and discussion. Merriam and Caffarrella (1999) highlighted the benefits of time to reflect upon personal and group assumptions both individually and within group discussions (Merriam & Caffarrella, 1999).

A significant aspect of the interactive training was a focus on consensus building amongst the support group. Within any consensus building process, there is potential for misinterpretation and conflict of personal agendas. When a decision is to be made about a person's lifestyle there are likely to be many different entities involved. Frequently, these people will have different perspectives regarding what the focus person needs. Moreover, as discussed in the previous chapter, it can be difficult to know the extent to which supporters are projecting their own interests onto an interpretation (Dunn et al., 2010). In an attempt to overcome these challenges, the supported decision-making framework used in this study incorporates a range of collaborative and consensus-building techniques designed to ensure no one supporter's agenda monopolises the process.

**An overview of the intervention's phases**

The four core phases of the decision-making support framework are described below. The process of documentation is important during each of these phases.
Phase 1: Identify decision and options together

This phase launches the supported decision-making process. It involves collaboratively identifying a decision the focus person is currently faced with. This takes place within the context of a gathering with all members of the focus person’s circle of support. The focus person is present at this meeting.

As illustrated in the framework, documentation throughout the process is considered important, and therefore, a note taker is assigned and detailed minutes are taken of the discussion and stored in a dedicated folder set up to document the entire supported decision-making process. This folder is ideally a shared digital folder accessible to the person’s circle of support. A digital folder allows for the inclusion of multimedia information such as video and audio. Where this is not possible, a paper-based folder is used.

The facilitator begins the process by asking the question, “Is there a decision to be made?” Together, the group explores whether the status quo is adequate or not.

If it is agreed that a decision is to be made, the group ascertain for whom the decision is important and why it is important. This allows for an exploration of each person’s hopes, assumptions and agendas, and unpacks any potential conflicts of interest.

The group are asked to open their minds to new possibilities and opportunities for the person at the centre, and therefore are encouraged
to consider and document all options available to the person, regardless of any system barriers.

Supporters are encouraged to suspend or set aside their personal and collective habitual preconceptions or biases. They are asked to explore their own hopes, assumptions and agendas and document these. This process is referred to in the phenomenological tradition as ‘reflexive bracketing’ (Ahern, 1999; Crotty, 1998). Using a technique suggested by Clegg (2003), support circle members are asked to engage in this reflexive process individually, privately documenting and setting aside these thoughts for later reference. Supporters are ‘given space’ to express and diarise any values and potential biases they individually bring to the ‘supported decision-making table’. This process is not only carried out individually, but collectively, where group biases and presumptions are documented and set aside to be referred to throughout the decision-making process.

Phase 2: Listen Together

This phase is centred on the activity of getting to know the focus person’s preferences through a process of listening. It takes place over a period of several months, within the context of the focus person’s and their supporters’ real life environment, and via the use of facilitated discussion in a workshop setting.

Listening is typically characterised as the acquisition of meaning predominantly via formal verbal language, governed by explicit coding
rules. This characterisation tends to treat nonverbal and informal communication as incidental rather than essential to the communication process (Shanmuganathan, 2005). When 'listening' to people with severe or profound intellectual disabilities, this characterisation is particularly unhelpful, as these people communicate informally, using no formal language. As described in the previous chapter, for this group, the task of listening is increasingly being recognised as a deep, multisensory and complex task (Griffiths & Smith, 2015; Hayes, McGuire, O’Neill, Oliver, & Morrison, 2011; Petry et al., 2009; Ten Brug et al., 2013; Young et al., 2011).

Within this phase of the framework the notion of listening is extended to include the acquisition of meaning via non-symbolic communication such as intonation, body language, gesture, facial expression, touch, behaviour or environmental and contextual cues. Therefore, the term 'listening' in this context is used metaphorically, and for the purpose of the implemented supported decision-making framework means acute observation (visual and aural) with the aim of inferring meaning from non-symbolic communication.

During this phase circles of support are asked to collaboratively “listen to the person's sounds, cries, laughter, scratches, smiles, grimaces, tapping, shouts and silences” (Watson & Joseph, 2011 p.8). They are asked to ‘listen’ to the person's behaviour, some of which may be considered challenging. The communicative role of behaviours, including those considered concerning, is well documented within the literature (Carr &
Circles of support are asked to ‘listen’ to what the focus persons’ behaviour may be telling them about their preferences.

This phase of the framework encourages circles of support to listen together to the person’s stories, because as stated in the training manual “their identity exists in their story” (Watson & Joseph, 2011 p.8). As explored in chapter two, there is growing interest in the ways in which narrative practice provides insight into the preferences of people with intellectual disabilities (Grace, 2014; Grove, 2013; Hamilton & Atkinson, 2009; Ten Brug et al., 2013). This research however has predominantly focused on people with mild intellectual disabilities. People with severe or profound intellectual disabilities are unable to tell their stories without significant support in the form of interpretation and scaffolding from people who know them well (Grove, 2007b). Drawing from Grove’s work in this area, this phase asks circles of support to provide this scaffolding by identifying past experiences that the focus person enjoyed, but also by documenting and sharing these experiences and key events so that personal histories and stories are not forgotten.

In addition, circles of support are asked to focus on narratives that describe people with disabilities ‘beyond their disability’. Drawing from Lyng’s work, circles of support are asked: if the person “had control over their life, what clothes do you think they would wear? What music do you think they would enjoy? What food do you think they would eat” (Watson
& Joseph, 2011 p.8)? Examples of the narratives generated collaboratively during workshops using this technique are displayed in Appendix 3.18.

For all phases, documentation is encouraged, however for this phase it is particularly important. This documentation is not limited to a written format and multimedia approaches to documentation are promoted. In this phase supporters are asked to pay particular attention to documenting the person's communication collaboratively, claiming that "a person's voice can become very clear when information about their communication is gathered and documented well" (Watson, 2011b p.9).

Within the workshop setting supporters are asked to collaboratively record detailed information about how the person they are supporting communicates in different situations, with different people and at different times. Within the workshop, supporters are introduced to a range of communication profiling tools, and they are asked to use these over the proceeding months to further document detailed information about how the person they are supporting communicates. These tools include written templates, photography and video. As discussed in the literature review, these tools are commonly used within services for people with intellectual disabilities (Cantor, 1991; Thurman et al., 2005). Examples include Communication passports (Brodrick et al., 2011; Millar & Aitken, 2003), Communication dictionaries (Bloomberg et al., 2004; Scope., 2004b), Sensory profiling (Dunn, 2008) and Multimedia Profiling (Watson & West, 2011). The development of these tools, regardless of the medium used, involves collating information from people who know the
person well, observing, analysing and then distilling and organising this information. Collaboratively compiling such a detailed profile of the communication of someone who does not communicate formally is considered in this intervention to be an essential component of supported decision-making. This is because their expression of preference is at the heart of a supported decision-making approach.

Phase 3: Explore options and build evidence together

This phase of the framework aims to further identify and refine the list of options developed in the first phase. It aims to build evidence and gather information about the specific factors that affect the focus person’s preferences generally, so the best option available is selected. It involves the building of evidence that either supports or rules out each option.

The Preferred Activity Analysis (Watson, 2010b) and the Exploration of Options tool (Watson, 2010), are tools developed as part of the package. They are displayed in Appendix 3.3 and 3.4. These tools were developed in consultation with a group of practitioners who trialled draft versions of each before they were finalized. They provided valuable feedback regarding the tools, both verbally and in written form. The tools are designed to assist circles of support to discover, explore and trial the activities the person they are supporting appears to enjoy and not to enjoy. The Preferred Activity Analysis aims to develop a picture of how a person prefers to spend his/her time and what the common elements are across these preferences.
Specifically, the Preferred Activity Analysis asks supporters to identify ten activities/experiences that occur routinely in the person’s day, and order them on scales from one to ten, according to the focus person’s preference. They are then asked to choose two preferred activities and two non-preferred activities and provide a detailed description for each of them. Circles of support are asked to be extremely detailed in this description. To guide them through this process the facilitator asks questions about the activity/experience in terms of its visual, auditory, olfactory and tactile elements. For example, they may be asked whether the activity involves movement and if so, to describe the pace of that movement. They may be asked questions about the structure and the predictability of the experience, as well as the physical environment in which it takes place (e.g. temperature, noise level, smell). The circle of support is also asked to answer questions about the social environment in which the experience takes place, specifically in terms of the number of people present, the degree of interaction and the social expectations that are present.

Based on the detailed information collated about each of the activities, supporters are asked to identify two lists. The first list is a set of characteristics that are generally present when the person likes an activity (e.g. sunshine, visual stimulation, warmth, water). The second is a set of characteristics that are generally present when the person dislikes an activity. Based on this list of characteristics supporters are asked to make two additional lists. The first list is a set of activities that incorporate
factors the person is likely to enjoy, and the second is a list of activities that incorporate factors the person isn’t likely to enjoy.

As a team, the circle of support is then asked to work through the *Exploration of Options tool*. This process involves the circle of support documenting the decision the person is facing, and using the information gathered in the *Preferred Activity Analysis* and previous phases to agree on some options that are worth exploring with the person. Supporters are asked to consider the practicalities that may impact on the options available. These practicalities may include system-based barriers such as funding constraints, staff duty of care, or lack of transport. Supporters are asked to consider these practicalities in terms of how they may be able to be overcome.

The circle of support is then asked to support the person through an in-depth trial process of each potential choice. Supporters are asked to clearly document the person’s reactions to each of the options, not limiting themselves to written means, but making use of multimedia techniques such as video and photography to share with other supporters during brainstorming sessions.

*Phase 4: Make decision and act on it together*

This phase involves the making and implementation of the decision collaboratively. Participants are asked to ensure that no supporters’ agenda is driving the decision. They are reminded that the focus person’s preference should be at the centre of the decision.
Participants are guided through a process of reflection whereby they are asked to consider the possibility that the decision made may not reflect what is important for the person but what is important to them. This question is considered fundamental within person centred practice (Sanderson, 2000). Participants are asked to separate what is important to someone from what is important for them. The phrase important to is related to what really matters to the person from their perspective. The phrase important for is related to the help or support that they need to stay healthy, safe and well. Once these ideas are separated, participants are asked to collaboratively find a balance between the two. Disability support services are usually very good at describing and delivering what is important for someone (e.g. medication, positioning, diet, hygiene). What is often missing is what matters to the person (O’Brien & Lyle O’Brien, 1998; Sanderson, 1998).

Participants are asked to consider how to balance the person's need to take risks with their safety. Kinsella (2000) has developed The Person Centred Risk Assessment (Kinsella, 2000). Kinsella describes this tool as a “qualitative process designed to fully explore a risk, problem solve around it and come up with strategies which balance safety within the context of the person's happiness” (Kinsella, 2000 p.1). Specifically, Kinsella’s process involves participants collaboratively clarifying the perceived risk and identifying the negative and positive consequences involved for the person themselves, for other people in their life, and for the public. Supporters are asked to plot each identified option on the graph in figure
balancing each scenario against the likely impact it will have on the safety of the person and others, and their happiness. Supporters are then asked to use this graph in deciding which options should be adopted and which should be abandoned.

Once the decision is made, it is reinforced that very few decisions are set in stone. Supporters are reminded that the person will obviously need support to act on the decision and to navigate the many attitudinal and system barriers that may stand in their way. Some of these barriers are discussed in Chapter two.
3.7 Participants

The people who are the focus of this research are adults with severe or profound intellectual disabilities who communicate informally. Severe or profound intellectual disability has been defined in detail in Chapter two of this thesis. However, to reiterate, people with severe or profound intellectual disabilities can be characterised as dependent on others for support in most aspects of their lives, including communication and decision-making. They generally communicate informally using nonverbal behaviours such as facial expression, gesticulation, vocalisations, eye gaze and touch. They have difficulty understanding formal communication such as speech, sign, written text, pictures or photos. In addition to communicating informally, some people with severe or profound intellectual disabilities communicate unintentionally. This means that an additional onus is placed on communication partners to infer meaning from the person’s behaviours, a subjective and ambiguous task (Bradshaw, 2001; Grove et al., 1999a).

The five adults who were the focus of this research lived either with their parents or within group homes in metropolitan Melbourne or regional Victoria, Australia. Pseudonyms have been assigned to each, and in this thesis they are identified as Angela, Neil, Nathan, Yuri and Kevin. They faced a range of decisions both large and small. These varied, ranging from decisions about future living arrangements, service provision, healthcare (including end of life), nutrition and personal finances. Neil’s case study was ceased before the end of data collection due to his death.
Research participants also included people who supported the focus person. For the purpose of this research, this group is called a ‘circle of support’ or ‘support circle’. A circle of support is defined inconsistently in the literature. Rouget (2010) describes it as “a group of unpaid citizens who come together to support and share a relationship with a person who is vulnerable because of having a disability” (Rouget, 2010 p.68). Elsewhere, a circle of support is described as being inclusive of both formal (paid) and informal supporters (Wightman, 2009), which was the case for the current study.

In total, thirty-three supporters participated in the study. Twenty-five of these supporters had a paid relationship with the focus person, while the remaining eight supporters’ relationships were purely unpaid. One other supporter participated in the study as an unpaid volunteer for two focus people, Yuri and Kevin. She was not counted in the sample of supporters as she chose to withdraw her support after a month of her involvement with the men.

Demographic information relating to focus people and supporters is represented in tables 2 and 3.

### 3.7.1 Participant selection criteria

**People with severe or profound intellectual disabilities**

People with disability were invited to be part of this study if they were over the age of eighteen, had a severe or profound intellectual disability, communicated informally, and received disability support services within Victoria, Australia.
Presence of these qualities was determined through a combination of strategies. These comprised a judgment by the person who provided proxy consent, as recorded on the consent form, researcher discussion with families and support staff (including allied health personnel) and researcher observation of the person within their daily environment.

Being an informal communicator was confirmed via the administration of the *Triple C: Checklist of Communicative Competencies* (Bloomberg et al., 2009). The *Triple C Checklist* (2009) is widely used in Victoria, Australia for determining the intentionality and symbolic nature of the communication of people with severe or profound intellectual disabilities. The assessment comprises a checklist of behaviours organized within five communication stages: unintentional passive, unintentional active, intentional informal, intentional formal basic symbolic, and established symbolic. The *Triple C checklist* has been evaluated as demonstrating a high level of internal consistency and construct validity (Bloomberg et al., 2009). Potential participants met the criteria of being an informal communicator if their completed *Triple C checklist* indicated they were communicating at either Stage three (intentional informal) or below (unintentional active or passive). Communication at these stages is considered basic. Appendix 3.5 provides complete descriptions of Stages one, two and three.

**Supporters**

Supporters were initially invited to be part of the study if they had known the focus person for more than twelve months. However, meeting this
criterion was challenging for some of the focus people. As discussed in Chapter two, one of the challenges faced by people with severe or profound intellectual disability is the lack of a durable and sizeable personal social network (Bigby & Clement, 2009). This means that they often have no option but to rely on an atypical support network, which, for Yuri and Kevin, consisted of only paid support staff. Therefore, for Kevin and Yuri’s supporters, this restriction of relationship longevity was loosened allowing people who had known them less than a year to be included in the study. Each circle of support consisted of at least four people. No age restriction was placed on potential participants as Nathan’s circle of support included a child. No data was collected from this child without the presence of one of their parents.

3.7.2 Recruitment

This project had two recruitment phases, the first for the initial two case studies and the second for the remaining three. The recruitment procedure however was generally the same for all case studies, and is described below.

Email expression of interest flyer

An explanatory email was sent throughout Victoria, Australia to managers of disability support services employed by both government and non-government service providers. Attached to this email was an expression of interest flyer (Appendix 3.6).
**Flyer shared with potential participants**

Service managers were asked to post the flyers in prominent places throughout their work place. They were also asked to share the flyer with the ‘person responsible’ for anyone within their service who they believed had a severe or profound intellectual disability and could benefit from the project.

**Phone conversations with interested parties**

Interested parties were invited to call the researcher if they wanted to discuss the project further. In the first phase of research, the procedure described above generated seven phone calls, three from residential service managers, two from day service managers, and one from a mother. In the second phase of research, one phone call from the communication coordinator of a disability service in outer eastern Melbourne was received. These phone calls provided an opportunity for any questions about the project to be answered. In addition, it provided an opportunity to ascertain collaboratively whether the identified person(s) and their support network(s) were appropriate participants. All but one phone call concluded with an agreement that each of the discussed person(s) and their support network(s) appeared appropriate for participation in the study. However, in order to confirm their suitability, a *Triple C* checklist was completed if it had not already been, to ascertain that the potential participant was an informal communicator.

During this phone call, the significant time commitment required for supporter participation in the study was discussed. This conversation
resulted in all managers agreeing to budget (where necessary) for casual staff to backfill paid supporters who participated in the study.

**Plain English statements sent to appropriate circles**

A Plain Language Statement (PLS) (Appendix 3.7) was sent to each of these callers for their further consideration. One of the sent PLSs was translated into Vietnamese on request from a potential participant’s family (Appendix 3.8). Once this information was read and discussed with relevant parties, recipients were invited to re-contact the researcher if they remained interested in participating.

**Face to face meetings**

Before ascertaining consent, a meeting was held with each of these focus people and their circle of support. Supporters chose where these meetings were held. Neil’s first meeting was held in his home, a residential unit, managed by a non-government disability provider in metropolitan Melbourne, Victoria. The remaining participants’ first meetings were held at their day services.

These meetings gave potential supporters an opportunity to make an informed decision regarding participation for both themselves and those they supported. At these meetings those supporters who had not received a PLS were provided with one. All supporters were given consent forms (Appendix 3.9). One proxy consent form (Appendix 3.10) was given to the ‘person responsible’ for each focus person. Supporters were invited to sign the forms during the meeting or take them away for further consideration.
During these meetings, I, as a Speech Pathologist, observed the identified person’s communication in order to build further evidence that either confirmed or refuted the selection criteria of being an informal communicator. Two out of five of the participants had a completed *Triple C* before their participation in the study. For both these participants the *Triple C* indicated they were communicating at an unintentional active level. The remaining three participants did not have a current *Triple C*, and therefore a *Triple C* was administered once consent to participate had been established and prior to data collection. Two participants were assessed as communicating at an intentional informal level; one was assessed as communicating at an unintentional informal level (Bloomberg et al., 2009). In total, three participants with disabilities were assessed as communicating at an unintentional informal level, while two were assessed as communicating at an intentional informal level. Informal communication is generally associated with a diagnosis of severe/profound intellectual disabilities.

### 3.7.3 Human ethics approval process

Ethical approval for this study was granted through Deakin University Human Research Ethics Committee (EC00213) and Scope Human Ethics Committee (EC00428). The process of gaining ethics approval was complex, particularly in relation to the University HREC, who had understandable concerns about involving people who were unable to consent to participate in the study. These concerns were not surprising. There is ample discussion in the literature regarding the vulnerability of people with severe or profound intellectual disabilities, particularly in
relation to their participation in research (Iacono, 2006a, 2006b; Nicholson, Colyer, & Cooper, 2013; Siegal & Ellis, 1985).

The University HREC was predominately concerned about participants’ ability to consent to their participation in the study. However, the HREC agreed with the researcher that although independent consent to participate in research is the ideal, in the absence of legally appointed guardians, the use of proxies was acceptable considering the unique and complex lives of people with severe or profound intellectual disabilities. Together the researcher and the University HREC representative developed a set of criteria as key in establishing whether a person was able to act as a proxy on behalf of the focus person. For each of the five case studies in this research a person providing proxy consent was someone who:

1. Had a positive and stable relationship with the participant, or was willing/able to develop such a relationship;
2. Knew the focus person’s history or was willing to learn about it;
3. Had a commitment to the focus person’s duty of care (within this context duty of care included the concepts of both minimizing harm and facilitating individuals’ rights and choices);
4. Was familiar with the focus person’s communication and therefore their expressions of preference;
5. Was willing to vantage the perspective of the focus person.

As previously discussed in Chapter two, there is concern in the literature around the validity of proxy reporting with regard to the expression of
personal preferences (Cannella et al., 2005; Petry, Maes, & Vlaskamp, 2007a; McVilly et al, 2000). Heeding these concerns, those providing proxy consent were required to adhere to the principle of assent. That meant any consents obtained by proxy were required to be accompanied by nonverbal indications that the person was comfortable participating in the study, and as mandated by the National Human Medical Research Committee (NHMRC) any indication at any time over the course of the study of refusal to participate had to be respected (NHMRC, 1999). The researcher spent time with each proxy explaining this principle, using examples of expressions that the participant may use to indicate discomfort or a desire to withdraw from the study.

Although not raised by the HRECs reviewing this research, confidentiality was identified as an issue by the researcher’s supervisors. The community of adults with severe or profound intellectual disabilities in Victoria, Australia is relatively small. Therefore, there is the potential for oral and written presentations about this research to inadvertently expose the identity of participants. This potential has been explored by Balandin (2013), who questions the promises made regarding confidentiality, particularly in relation to people with severe or profound intellectual disability (Balandin, 2013). In an attempt to minimise the risk of participant confidentiality being breached, a pseudonym was allocated to each participant immediately following recruitment and used in all subsequent references to that person in the research context. Additionally, reporting on personal background information about participants was
kept to a minimum. Background data was only reported on where it added
information to research findings.

A question not put forward by the HREC teams reviewing this research,
but recognized by the researcher, was the way in which potentially
emotionally sensitive material was to be dealt with. Members of support
circles were asked to speak openly and transparently both individually as
well as within the context of workshops. Speaking about close personal
relationships with those who are perceived as vulnerable can be an
emotional experience. In addition, any group decision-making process has
the potential of raising conflict and negative responses from participants.
The researcher’s personal and professional experience makes her aware
of the emotions that this subject matter can bring to the surface.

Strategies used to manage potential emotional responses during data
collection comprised: (1) turning off the digital recording and/or
suspending the interview/group discussion until the participant(s)
recovered and wished to proceed; and (2) having on hand the name and
contact details of suitably qualified counsellors, if needed by participants.
Table 2: Study participants’ (supporter) demographics

<table>
<thead>
<tr>
<th>Name (pseudonym)</th>
<th>Paid/unpaid support?</th>
<th>Number in circle of support</th>
<th>Living environment</th>
<th>Identified decision</th>
<th>Decision enacted?</th>
<th>Communication (according to the Triple C)</th>
<th>Communication coordinator (yes/no)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angela</td>
<td>P&amp;U</td>
<td>II</td>
<td>@HF</td>
<td>Joining a community music group EVOLVED INTO: Playing basketball AND Making a decision about future living arrangement</td>
<td>Partially</td>
<td>II</td>
<td>Y</td>
</tr>
<tr>
<td>Name</td>
<td>Category</td>
<td>Age</td>
<td>Context</td>
<td>Description</td>
<td></td>
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<tr>
<td>Neil</td>
<td>P&amp;U</td>
<td>7</td>
<td>RU</td>
<td>Contents of lunch</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>EVOLVED INTO: Having life saving medical treatment</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>AND CONSEQUENTLY: Funeral proceedings</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Nathan</td>
<td>P&amp;U</td>
<td>8</td>
<td>@HF</td>
<td>Bedroom furnishings in new home</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>EVOLVED INTO: Sensory based activities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yuri</td>
<td>PD</td>
<td>6</td>
<td>RU</td>
<td>Technology to purchase for communication between home and day service</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kevin</td>
<td>PD</td>
<td>4</td>
<td>RU</td>
<td>How he spends his time during the week in terms of who supports him and how.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supporter</td>
<td>Age</td>
<td>Paid/unpaid support</td>
<td>Length of relationship</td>
<td>Frequency of interaction</td>
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<tr>
<td>A1</td>
<td>56</td>
<td>UP</td>
<td>24 years</td>
<td>ED</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>A2</td>
<td>59</td>
<td>UP</td>
<td>24 years</td>
<td>ED</td>
<td></td>
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<tr>
<td>A3</td>
<td>49</td>
<td>P</td>
<td>5 years</td>
<td>5 DPW</td>
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<tr>
<td>A4</td>
<td>21</td>
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<td>3 years</td>
<td>5 DPW</td>
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<tr>
<td>A5</td>
<td>21</td>
<td>UP</td>
<td>21 years</td>
<td>1 DPM</td>
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<tr>
<td>A6</td>
<td>48</td>
<td>P</td>
<td>15 years</td>
<td>2 DPW</td>
<td></td>
<td></td>
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<tr>
<td>A7</td>
<td>45</td>
<td>P</td>
<td>12 years</td>
<td>4 DPW</td>
<td></td>
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<tr>
<td>A8</td>
<td>68</td>
<td>P</td>
<td>15 years</td>
<td>2 DPW</td>
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<tr>
<td>N1</td>
<td>65</td>
<td>UP</td>
<td>42 years</td>
<td>ED</td>
<td></td>
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</tr>
<tr>
<td>N2</td>
<td>61</td>
<td>P</td>
<td>5 years</td>
<td>4-5 DPW</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N3</td>
<td>44</td>
<td>P</td>
<td>5 years</td>
<td>5 DPW</td>
<td></td>
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</tr>
<tr>
<td>N4</td>
<td>45</td>
<td>P</td>
<td>8 years</td>
<td>5 DPW</td>
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<tr>
<td>N5</td>
<td>62</td>
<td>UP</td>
<td>42 years</td>
<td>1 DPM</td>
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<tr>
<td>N6</td>
<td>24</td>
<td>P</td>
<td>4 years</td>
<td>5 DPW</td>
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<tr>
<td>N7</td>
<td>27</td>
<td>P</td>
<td>3 years</td>
<td>5 DPW</td>
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<tr>
<td>Na1</td>
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<td>UP</td>
<td>28 years</td>
<td>ED</td>
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<tr>
<td>Na2</td>
<td>12</td>
<td>UP</td>
<td>3 years</td>
<td>3 DPW</td>
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<tr>
<td>Na3</td>
<td>82</td>
<td>UP</td>
<td>3 years</td>
<td>4-5 DPW</td>
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<tr>
<td>Na4</td>
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<td>P</td>
<td>3 years</td>
<td>4-5 DPW</td>
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<tr>
<td>Na5</td>
<td>28</td>
<td>P</td>
<td>2 years</td>
<td>2 DPW</td>
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<tr>
<td>Na6</td>
<td>18</td>
<td>P</td>
<td>3 years</td>
<td>4 DPW</td>
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<tr>
<td>Na7</td>
<td>70</td>
<td>P</td>
<td>3 years</td>
<td>5 DPW</td>
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<td>Na8</td>
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<tr>
<td><strong>Y1</strong></td>
<td>27</td>
<td>P</td>
<td>1 month</td>
<td>1 DPW</td>
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<tr>
<td><strong>Y2</strong></td>
<td>21</td>
<td>P</td>
<td>1 year</td>
<td>5 DPW</td>
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<tr>
<td><strong>Y3</strong></td>
<td>56</td>
<td>P</td>
<td>15 years</td>
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<td><strong>Y4</strong></td>
<td>48</td>
<td>P</td>
<td>20 years</td>
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<td><strong>Y5</strong></td>
<td>59</td>
<td>P</td>
<td>8 years</td>
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<tr>
<td><strong>Y6</strong></td>
<td>53</td>
<td>P</td>
<td>3 years</td>
<td>5 DPW</td>
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</tr>
<tr>
<td><strong>K1</strong></td>
<td>27</td>
<td>P</td>
<td>1 month</td>
<td>1 DPW</td>
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<tr>
<td><strong>K2</strong></td>
<td>45</td>
<td>P</td>
<td>20 years</td>
<td>5 DPW</td>
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<tr>
<td><strong>K3</strong></td>
<td>71</td>
<td>P</td>
<td>20 years</td>
<td>5 DPW</td>
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<tr>
<td><strong>K4</strong></td>
<td>41</td>
<td>P</td>
<td>6 years</td>
<td>5 DPW</td>
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</tbody>
</table>
3.8 Data collection tools and strategies

The data collected within the context of this study was predominately subjective and constructed, and therefore is qualitative in nature.

However, some descriptive statistical data was collected that focused on levels of change over the course of the study. This data included simple rating scales, enabling participants to register levels of various factors. This data served as an aid to interpreting the qualitative data.

It can be argued that the use of descriptive statistical data makes this study incompatible with a social constructivist stance. This argument is rooted in the perception that quantitative data implies “the existence of a single ‘objective’ reality that can be measured and statistically analysed to reach generalizable conclusions” (Maxwell, 2010 p.475). In response, Maxwell (2010) argues that there are “legitimate and valuable uses of numbers even in purely qualitative research” and there is inherent value in drawing from numerical and narrative data to achieve socially constructed meaning (Maxwell, 2010 p.476). Accepting Maxwell's (2010) view, it can be argued that all meaning, whether it is generated through qualitative or quantitatively orientated data, is socially constructed. Other qualitative researchers (e.g. Erickson, 2007, Hammersley 1992, Sandelowski et al., 2009, and Miles and Huberman, 1984) report the legitimacy and value of integrating descriptive statistics with qualitative data collection, analysis and reporting. Sandelowski et al. (2009) refer to the utilisation of numerical data in qualitative research as “quantizing qualitative data sets”, claiming that its purpose is to “allow analysts to
discern and to show regularities or peculiarities in qualitative data they might not otherwise see” (Sandelowski et al., 2009 p.210).

The study triangulated multiple data sources. Triangulation uses and compares multiple data collection methods in an attempt to determine congruence of the various results (Brewerton & Millward, 2001). The data collection methods comprised interviewing, discussion groups, workshops, observation and document review.

### 3.8.1 Observation

Observation was one of the methods used to describe the processes, characterisations, enablers and barriers relating to supported decision-making for people with severe or profound intellectual disabilities. Although time consuming, this method is described in the literature as a useful for examining the behaviours of people with severe or profound intellectual disabilities (Arthur, 2004; Lyons, 2005; Maes & Petry, 2006; Reinders, 2010). Finlay et al., argue that observation of the mundane details of a person’s life provides more reliable evidence than asking disability support staff (Finlay, Walton, et al., 2008).

For each case study, six hours of observation took place pre-intervention, five hours during workshops, and six hours post-intervention (except in Neil’s case). During this observation, field notes and video footage were taken for later analysis. For each case study, the pre and post observation sessions took place within the same environmental contexts. For example, both Angela’s pre and post general observation sessions took place during
lunch at her day service on a Thursday, after swimming, with the same communication partner. In total, approximately eighty-one hours of observation occurred across the study. This observation can be described as both unstructured and structured.

**Unstructured observation**

Some of the researcher’s time spent observing involved her being immersed in ‘the field’, simply spending time in each of the focus person’s environments, recording unstructured field notes of direct observations along with reflections of these. Two examples of these notes are displayed in Appendix 3.11. Prior professional and personal experiences of support work influenced the decision to adopt a semi-detached strategy of observation to blend in with life in the home or day service. Such an approach is consistent with Shanmuganathan’s (2005) view that a purely non-participatory approach to observation could unsettle the ‘naturalness’ of the environment (Shanmuganathan, 2005). Therefore, while the researcher attempted to become “part of the wallpaper” (Dunn et al., 2010 p. 147), the researcher also welcomed being included in activities and conversations that took place, when appropriate.

**Structured observation**

Some of the researcher’s time spent observing involved her recording structured notes, enabling specific information to be collected. Four templates were developed for this purpose. These included a general observational template (Appendix 3.12), two supporter responsiveness
templates (Appendix 3.13 and 3.14) and a supporter conflict template (Appendix 3.15). These tools are discussed in more detail later in this chapter.

3.8.2 In-depth open ended interviews

Twenty-one interviews took place ranging in duration from forty-three minutes to one hour and forty-nine minutes. These interviews were held at pre and post intervention phases with individual members of circles of support. Interviewees were selected based on the amount of time spent with the focus person. For example, a supporter at Kevin’s day service was invited to be interviewed who was his key worker, which meant she spent several hours a day with him. One additional interview took place in relation to three participants, in an effort to probe for understanding particular areas of interest. Two people from each circle of support were interviewed pre and post intervention. The interviews took place in a variety of locations, which included people’s homes, coffee shops, restaurants and day services. These were audio taped for later transcription and analysis.

As mentioned, one of the participants (Neil) died during the project. An informal meeting took place with his parents, a month after his funeral. Due to the circumstances it was not appropriate to conduct a structured interview with them, however the conversation was audiotaped with consent, and it provided some rich data as to the supported decision making process that took place not only around the decision made to
cease life saving medical treatment but also around the funeral proceedings.

Each interview began with an informal conversation unrelated to the research topic. These conversations were related to topics such as sport (usually Australian rules football, an interest of many living in Victoria, Australia), family, their health and holidays. Although this conversation had the primary purpose of building rapport, sometimes it allowed necessary background data to be gathered (such as age of interviewee and nationality) and therefore this part of the interview was audiotaped (with consent) for later transcription.

Pre and post intervention interview guides are presented in Appendix 3.16. Using an action research, iterative approach, these guides evolved as interview data was analysed during each case study. Initial interviews were framed around the observation sessions, as discussed above, and questions gleaned from the literature and the researcher's professional practice. Blumer (1954) describes these broader questions put to the study as "sensitizing concepts" (Blumer, 1954 p.7). He characterises such concepts as providing "a general sense of reference and guidance in approaching empirical instances" and makes it clear that they are not prescriptive in nature but "merely suggest directions along which to look" (Blumer, 1954 p.7). As the interview data was analysed the interview guide for subsequent pre-intervention interviews focused on questions relating to emergent theoretical categories from the study itself. Questions
were also modified over the course of each interview, depending on the responses given and the direction that the discussion was moving in. The general content of the interviews can be gleaned from the guide displayed in Appendix 3.16.

During each interview, some time was spent engaging in self-disclosure, allowing the person the researcher was interviewing to hear some of her life story, particularly as it related to the experience of disability. The practice of self-disclosure has predominantly appeared in literature relating to psychotherapy (Counselman, 1997; Simon, 1988). This research literature suggests that self-disclosure has an important role to play in promoting a sense of solidarity with the person being interviewed, but also should be managed sensitively ensuring boundaries are appropriate.

The interview continued with questions that were relatively simple and uncontroversial, leading to deeper and possibly more contentious questions. This served the purpose of building confidence and trust with the interviewee. The interview procedure complemented previous data collated within the context of participatory observation. That is, questions were sometimes asked to shed further light on what had been observed. Video was also used for this purpose. For example, one of Yuri’s support workers was asked, while watching a video of him assisting Yuri with his lunch, “I see you put the cake away there, did you think he had had enough? How did you work that out? How did he tell you?” By using video
observational data in this way interview discussions were framed and anchored in reality. It also provided opportunity for interviewees to be gently challenged when what was said in an interview contradicted what had been observed.

Interviewing was open-ended, allowing responses to be given as ‘free narrative’, a method referred to in literature relating to interviewing within a legal context (Brewster, 2004; Fisher, 1995; Powell, Fisher, & Wright, 2005). Free narrative occurs when interviewees are encouraged to answer questions in their own words, in their own time, and without interruption (Fisher, 1995). This approach “assumes that unconscious connections will be revealed through the links that people make if they are free to structure their own narratives” (Hollway & Jefferson, 2008 p.315). The interviews were carried out in such a way that invited the respondents to tell stories in an open-ended and organic fashion. Open-ended interviews are useful for eliciting accurate (Dent & Stephenson, 1979) and long (Sternberg et al., 1996) responses as well as encouraging an active role in the interview process.

The following method, adapted from Powell, Fisher, and Wright (2005), was used for interviews in this study.

1. The process begins with a “broad open-ended question” (Powell et al., 2005 p.19).
2. This open-ended question is followed by the use of:
Minimal, nonverbal encouragers (such as head nods, pauses, silence, ‘mmmm,’ ‘uh-huh’ and additional open-ended statements or questions) to steer the interviewee to provide additional narrative information (for example, ‘Tell me more about that.’ ‘What happened then?’ ‘What else can you remember about that?’) (Powell et al., 2005 p.19);

3. Once the interviewee has finished, they are “usually guided back to parts of the narrative and given an opportunity for further recall (for example, ‘You said this ... can you tell me more about it?’)” (Powell et al., 2005 p.19).

3.8.3 Facilitated group discussions

Data was collected within the context of a workshop at the beginning of the intervention. This workshop is a key aspect of the intervention, already described, *Listening to those rarely heard: People with severe or profound intellectual disabilities leading lives they prefer through supported decision-making* (Watson and Joseph, 2011). This workshop took place after the pre-intervention component of data collection. An outline of the workshop package is displayed in Appendix 3.18.

Although workshops in each case study shared the same training goals, adaptations were made to the general workshop style of delivery to cater to the needs of the focus person and their support network. For example, the unique nature of Nathan’s circle of support, called for an informal gathering in order to make the most of participants’ close relationships.
with one another. The workshop was carried out within a social setting with the sharing of food and wine. This informal setting also catered for Nathan’s need to explore his environment, and he and some of the children present spent time together outside while the workshop took place.

The workshop content and delivery evolved over the course of the study, consistent with the study’s action research paradigm. For example, there was a strengthened role for multimedia within the context of Nathan’s case study. Responding to specific feedback from workshop participants regarding the value of using video material to collaboratively discuss Nathan’s communication and more specifically, his preferences, the remaining workshops incorporated a variety of activities to encourage the use of multimedia. The workshops were audio-recorded for later transcription and analysis.

Three to six months after the initial workshop, each circle of support participated in at least one three-hour discussion facilitated by the researcher. Two circles participated in an additional facilitated group discussion. These additional gatherings were necessary due to conflict existing within the circle of support and the need for facilitation to move the process forward.

Guided by the work of Krueger and Casey on focus groups (Krueger & Casey, 2009), a flexible structure for each facilitated group discussion was developed based on a focus group questioning guide (Appendix 3.17).
Consistent with an action research iterative design, this document was individualised to each case study and to the phase of research in which the questioning took place. One adaptation included the inclusion of prompts, designed to ‘test’ any emerging conclusions or preliminary hypotheses. For example, the question: “You will see from this video of Neil that he is really vocal when he is being hoisted, what are your thoughts about that?” was included in a facilitated group discussion late in the research process. This question was designed to gather information about supporters’ collective ability/confidence in interpreting Neil’s communication attempts. This information was needed to strengthen or weaken an emerging hypothesis that Neil’s supporters’ had confidence interpreting his communication as a group. This is a method of theoretical sampling commonly used in grounded theory methodology (Charmaz, 2003). It involves progressively asking focused questions of participants, designed to strengthen or weaken any developing themes. In this way, the questions became more focused as the research progressed.

A number of planned discussion/activities were incorporated into the workshops and final gathering, several of which were designed to generate data. These activities comprised:

1. Groups collaboratively watching video of the focus person expressing preference. This data was compared to the reaction generated by individual supporters watching the same video during individual interviews;
2. Group discussion about focus person’s preferences. During the initial workshop, participants were asked to collaboratively rate, on a scale from one to five, how confident they were as a group identifying the focus person’s preferences. Participants’ response to this question was compared with their response within the final group discussion.

3. Group discussion regarding their confidence supporting the focus person to implement the decision. Groups collaboratively answered the question. “As a group, what is your level of confidence in supporting focus people to participate in a decision that reflects their preferences (using a scale from 1-5)?” This data was compared to answers to the same question asked during a post intervention discussion.

4. Training activities designed to develop participants’ understanding of the human communication continuum, particularly as it applies to the person they support. Within the workshop a range of training activities were used to achieve this aim. These included facilitated group discussion and an activity colloquially referred to as the ‘line up activity’. This activity, involved asking participants to construct the communication continuum through a process of collaborative brainstorming. Participants’ understanding of the continuum was evaluated during individual interviews at two time points in the study, before and after the workshop.

5. Group discussion comparing decisions made in supporters and focus people’s lives. Supporters were asked during group discussions what
decisions they made in their own lives and what decisions those they supported made. The number of and variation in decisions was compared between the two contexts.

3.8.4 Questionnaires

Workshop evaluations

The workshop evaluation was designed to capture both qualitative and descriptive statistical data about the supporters’ perception of the impact of the workshop as well as any changes in their skills, confidence, and attitudes. This evaluation is displayed in Appendix 3.1. The questionnaire is made up of nine questions that generated descriptive statistical data and three open-ended questions generating qualitatively orientated responses.

A Questionnaire about choice

The ‘Questionnaire about choice’, adapted from the Resident Choice Scale (Hatton, et al., 2004) (Appendix 3.2) was administered during the pre intervention (i.e. the first workshop) and post intervention gatherings to all supporters in the study (n=33). The Resident Choice Scale (Hatton, et al., 2004) is a twenty-six-item scale, designed to assess environmental opportunities for self-determination. It has been found to have acceptable inter-rater reliability (Hatton et al., 2004). Both Hatton’s (2004) tool and the adapted Questionnaire about choice begin the interview with the question “In what ways is X supported in making choices with regard to the following areas of their life?” In this study, the remainder of Hatton et al.’s (2004) scale was adapted to better reflect the living environments and choice opportunities available to people with severe or profound
intellectual disabilities. The number of questions was reduced from twenty-six to eighteen. Appendix 3.20 outlines the adapted scale comparing it to Hatton et al.'s (2004) original version.

Answers to the *Questionnaire about Choice* provided early in the project were compared with those provided at the end. This comparison was an attempt to shed light on the impact of the supported decision making approach on supporters’ perception of the capability of those they support to participate in decisions. In addition, it provided some insight into the impact of a supported decision making approach on environmental opportunities for choice in the focus person’s life.

*Supporter responsiveness*

Once the components of supporter responsiveness were conceptualised through an inductive analysis of the qualitative observational data, an observation template (using this conceptualisation) was configured to record supporter responsiveness and unresponsiveness to focus people’s communication pre and post intervention (Appendix 3.13). As this template was not configured until the end of the study, it was applied to videotaped data already collected. An example of analysis generated using this template is included in Appendices 3.14. Pre-intervention nineteen supporters were observed, however, due to a participant’s death only fifteen of these were observed post-intervention.

An instance of responsiveness was defined as a communication partner acknowledging an expression of preference, interpreting that preference and ultimately acting on that preference. Conversely, an instance of
unresponsiveness was defined as a communication partner failing to acknowledge an expression of preference, interpret that preference or act on it.

Supporters were classified as ‘unresponsive’ if they failed to respond to more than sixty per cent of a focus person’s communication as identified by the researcher, within observation sessions. Supporters were labelled as being ‘responsive’ if they responded to more than sixty per cent of a focus person’s communication as identified by the researcher, within a two-hour observation session.

**Perceptions of decision-making capability**

Descriptive statistical data designed to ascertain supporters’ perception of focus people’s decision-making capability pre (n=33) and post (n=27) intervention was generated via two data collection methods. These methods included the *Questionnaire about Choice* (Appendix 3.2) and a scaled interview question, “on a scale of one to five, how much do you agree with the statement ‘X is able to participate in decisions about his/her life?’” Each of these has been described previously in this chapter. The data from these two sources was triangulated and is summarised in Appendix 3.25. An overall analysis of each supporter’s perception of the capability of those they support based on the dominant result across the two sources. Where the data was contradictory across these two sources, supporters’ perception of decision-making capability was determined to be inconclusive at this stage of analysis. In these cases, a final decision was
made regarding each supporter’s perception of the decision-making capability of focus people based on qualitative data.

**Perceptions of communication capability**

Descriptive statistical data designed to ascertain supporters’ perception of focus people’s communication capability was generated via interview. Pre and post-intervention assessment was made of supporters’ understanding that the person they support was able to communicate. The interviewees, a sample of supporters (ten pre-intervention and 8 post intervention) were asked, “Would you describe the person you support as able to communicate (Yes/No)?”

**Relational closeness**

A fundamental dimension along which all relationships vary is interpersonal closeness. This concept of closeness is increasingly being recognized as an important variable for people with severe or profound intellectual disabilities (Forster & Iacono, 2008; Johnson, Bigby, Iacono, Douglas, & Katthagen, 2014b; Rushbrooke, 2014). Considering its importance, existing measures of relational closeness were reviewed within the personal relationships literature, however, no tool was found appropriate for measuring relational closeness between a supporter and someone with severe or profound intellectual disability, as was the case in the current study. Therefore, a tool was developed specifically for the current study. This tool drew from existing measures, including Berscheid et al.’s (1989) *Relationship closeness inventory* and Dibble, Divine and Hee

Within the context of the workshop, each supporter was asked to rate the level of ‘closeness’ they had with the focus person by choosing from five descriptive categories, ‘distant’, ‘not close’, ‘close’, ‘very close’ and ‘intimate’. Each ‘nature of relationship’ descriptor was operationally defined and embedded within a ‘continuum of relationship closeness’ as illustrated in figure 8 below. These operational definitions were drawn from Berscheid et al.’s (1989) Relationship closeness inventory, which defines closeness using three main properties, frequency of contact, diversity of activities engaged in, and the strength of this engagement. This continuum was offered to supporters as a guide to assist them in choosing the best descriptor for the relationship they shared with the focus person. The points under each descriptive category were not strict criteria in order for supporters’ relationships to meet that particular category. Rather, these points served as a guide for supporters to describe their relationship with focus people relative to other relationships in their lives.
The value supporters place on collaboration

As discussed in Chapter two, Deci and Ryan (1985) support the notion of collaboration within the context of optimal human decision-making (Deci & Ryan, 1985). They are not alone in holding this view. Modern day psychology and sociology positively emphasise a collective view of optimal decision-making, particularly highlighted in cross-cultural studies (Bandura, 1989; Iyengar & DeVoe, 2003; Kagitcibasi, 1996; Ryan & Deci, 2000).

Considering its importance, this study collected and analysed data relating to supporters’ attitudes toward responding to the will and preference of those they support collaboratively as opposed to individually. Data was collected via pre (n=10) and post (n=8) intervention individual interviews. Interviewees’ responses were recorded (see Appendix 4.1) to a question
designed to measure the value they placed on responding to focus people’s expression of will and preference collaboratively as opposed to individually. This question was: “How much do you value a collaborative as opposed to an individual approach to responding to X’s expressions of preference? (Using a scale from 1-5)?” Responding to preference was described to the interviewee as “acknowledging, interpreting and acting on a focus person’s expression of preference”. During analysis, supporters who provided a rating of three or above were considered to positively value a collaborative approach to decision-making support, while those who provided a rating of less than three were considered to have a negative value of such an approach. Average ratings for each focus person’s support circle were calculated for the purpose of comparison across case studies, and are recorded in Appendix 4.1.

*Conflict in circles of support*

Data generated using the conflict template allowed for the calculation of a ‘conflict score’ for each circle of support, calculated by counting instances of conflict pre and post intervention. An ‘incident of conflict’ between circle of support members was defined in the following ways:

- A disagreement that affected the flow of a workshop, focus group or discussion;
- A conflict considered significant enough by supporters to report it to the facilitator/researcher, but not necessarily discussed openly;
- Conflict observed during an observation session;
- Conflict evidenced through an email between circle of support members;
- Conflict identified in focus group or interview transcripts not already reported above.

### 3.8.5 Data collection trajectory

Figure 9 summarises the data collection trajectory for each case study. Embedded in this trajectory are the four phases of the supported decision-making framework.
### 3.9 Data analysis procedure

As described in the previous section, data analysis occurred concurrently with the gathering of data, as is usually the case in research methods.
that are interpretive or exploratory (Ezzy, 2002). During observation, decisions were made about where and when to observe and what to record. In both individual interviews and group discussions decisions were made about what to probe for, what to ask, and what to emphasise. These early decisions are considered by Hatch (2002) as an “informal kind of data analysis” shaping the study based on analytical judgments about what data are desirable” (Hatch, 2002 p.149).

The data analysis process adopted was based on Colaizzi’s (1978) seven stages of data analysis, Morse’s (1994) analytical framework and Hatch’s (2002) typological framework (Colaizzi, 1978; Hatch, 2002; Morse, 1994).

The remainder of this chapter is divided into two sub sections; the first describes the activities undertaken in preparation for analysis (phase 1), the second, reports the procedure involved in generating meaning from the data (phase 2).

3.9.1 Phase one

Data management

As a preliminary step, a system for organising, labelling and storing data in preparation for coding and electronic entry was developed. Each research participant was given an identification number. Audio-recordings, transcription files of interviews/facilitated group discussions, correspondence were labelled with the participants’ unique identification number, type of data (e.g. interview), the date, as well as the phase of research in which the data was generated (e.g.
Workshop feedback forms, questionnaires about choice, and handwritten personal reflections were scanned, saved on the computer and labelled using the same system (e.g. N4.workshopfeedback.01.01.13.postint). Memos and field notes were also scanned, but were labelled according to focus person, rather than supporter participant (e.g. K.fieldnotes.30.10.12.int). All data files were arranged in electronic folders according to the phase of the study in which they were carried out.

For the purpose of this thesis, the term ‘data corpus’ was used to refer to all data collected for this study. The term ‘data set’ was used when referring to data from the ‘data corpus’ used in a particular analysis.

**Data transcription**

Audio and video taped data was transcribed. An interpretative perspective views transcription as a necessary but imprecise science. Transcriptions are highly interpretative and therefore cannot reflect the entire reality of the actual interaction. They are at best, a close approximation of that reality (Lapadat & Lindsay, 1999). “All transcripts take sides, enable certain interpretations, advance particular interests, favour specific speakers, and so on” (Bucholtz, 2000 p.1440) and therefore they are never neutral.

Each interview, meeting, focus group or workshop was digitally recorded and transcribed word for word so it appeared as a representation in written text. Interviewees were reminded of this periodically throughout
the research, to provide them with an opportunity to withdraw their consent. No interviewee expressed any concern regarding the contributions he/she made to the research being audio taped or transcribed.

The transcription of recordings was not a straightforward task. The recordings were sometimes of low quality, with speakers often talking quietly or quickly. Background noises within day and residential services sometimes masked the speakers’ words. Five (one from each case study) of the twenty-one recordings were transcribed professionally. After each transcription was completed, it was read in the presence of the audio recording, field notes and any reflections that were noted at the time of the recording. Corrections and annotations were made at this time.

For all of the individual interviews (10 in total) a process of ‘member-checking’ took place (Merriam, 1998). Member-checking allows participants to read the transcription of their interviews before analysis, “to ensure that these have been accurately recorded and are therefore credible” (Houghton, Casey, Shaw, & Murphy, 2013 p.14). This process is discussed and exemplified later in this chapter.

All the transcriptions, including those done professionally, used standard orthography, as opposed to phonetic transcription. Guided by the Jeffersonian Transcription System (1984), these orthographic transcriptions included some indicators of emotion (e.g., exclamation point, notation of laughter) however omitted extra linguistic factors such
as dysfluencies and false starts. These factors were omitted as the research was primarily concerned with the content of an interviewee’s remarks, and therefore it was not necessary to engage in narrow transcription, inclusive of such factors. In addition, the omission of these extra linguistic factors was an attempt to promote ease of reading during the process of ‘member-checking’ (described above). Additionally, drawing from the researcher’s experience of using phonetic transcription clinically in her professional role as a Speech Pathologist, she chose not to use it. It was decided that for the purposes of this study its use would be unnecessarily burdensome, have the potential to alienate readers and may contribute to a power imbalance by unintentionally stigmatizing participants. Moreover, Kvale (1996) cautions that “the publication of incoherent and repetitive verbatim interview transcripts may involve an unethical stigmatization of specific persons or group of persons” (Kvale, 1996 p.172-173).

The final step in transcription involved stripping it of information that identified participants, such as names and places. Care was taken to include enough information so that the informational content was not lost. These transcripts were saved in iAnnotate (Branchfire, 2013), an application on a tablet computer.

**Data immersion**

Early immersion in the data and examining it as it was collected and transcribed, allowed the researcher to become progressively familiar with its informational content, and identify new topics and themes to
explore. As previously described, conducting analysis immediately after collecting data is consistent with the cyclic process of action based research, allowing the researcher to move easily from data gathering to reflection/analysis and then, with new insights and questions of the data, back into data collection and so on. During this process of data immersion, notes were taken, and ideas in the data corpus were highlighted and revisited in subsequent phases of analysis. These ideas were literally written on the transcripts within iAnnonate (Branchfire, 2013) on a tablet computer. An example of one of these ‘marked up’ transcripts is in Appendix 3.21.

3.9.2 Phase two: Generating meaning from the data

Phase 2 of the analytical process has been divided into six analytical steps. It is important to reiterate that although these steps are recorded here as distinct stages, the activities within them overlapped. This is consistent with an iterative action based research approach.

Some analytical activities, such as pruning and sculpting the coding structure, took place across all of the six stages. That is, throughout the analysis, a process of cleaning, merging, and collapsing codes took place. As the analytical process evolved, the redundancy of some codes became clear and, where this was the case, these codes were either removed or merged with other codes.

Another activity that was important across each of the stages was memo writing (Miles & Huberman, 1984). This involved recording reflective
notes regarding insights from the data. The process of memo writing diminished the potential of losing ideas and thoughts during the complex process of data collection and analysis. It also initiated the process of data analysis by identifying early concepts and themes, as well as the connections between them. These memos provided a vehicle where by striking aspects of data (e.g. unusual or frequent occurrences) could be recorded for later expansion in a reflexive journal. Some examples of these memos are displayed in Appendix 3.22.

A comprehensive coding table/book was generated detailing this six-step process (partially displayed in Appendix 3.23).

**Step one: Identifying focused topic areas**

Focused topic areas were derived from the research questions and entered into Dedoose (2012), forming the first level/column of the codebook (examples of entries are displayed in Appendix 3.23). Dedoose (2012) is a web-based qualitative and mixed-methods research application developed by Lieber and Weisner at SocioCultural Research Consultants LLC (SocioCultural Research Consultants LLC., 2012b).

This task was the first coding activity. Coding or encoding is a way of attaching names or ideas represented by labels to pieces of text as representative of the same phenomenon (Houghton et al., 2013). Coding gathers the material that is behind an analytical or descriptive interpretation of the data and puts a pointer to it. It entails the compilation of a list of defined codes, which correspond to concepts/keywords/topics.
that appear in a piece of text. Data is then combed for representations of these codes. These codes are tagged with one of the code labels, so that they can easily be retrieved for analysis. As Coffey and Atkinson state, “attaching codes to data and generating concepts have important functions in enabling us rigorously to review what our data are saying” (Coffey & Atkinson, 1996 p.27). Richards and Morse (2007) describe coding not simply in terms of labelling but in terms of linking. “It leads you from the data to the idea, and from the idea to all the data pertaining to that idea” (Richards & Morse, 2007 p.137).

Figure 10: A screenshot of the study’s first level of coding (focused topic areas) taken directly from Dedoose (2012) software.

The data corpus, which included one hundred and eighty-three documents, was systematically entered into Dedoose (2012). Extracts from the data (930 in total) were then linked within Dedoose (2012) to one or more of these topic areas.

Each piece of data was then assigned descriptors/attributes within
Dedoose (2012). They allowed the data to be cross-referenced across descriptor variables later in the analysis process. These descriptors included demographic information about the focus person (e.g. communication intentionality) and members of circle of support (e.g. paid or unpaid). In addition, in response to emerging questions regarding patterns and possible correlations within the data corpus, further descriptive information was generated. This additional descriptive statistical data included relational closeness between supporters and focus people, perceptions of decision-making capability, conflict levels amongst circle members and supporter responsiveness to the expressions of preference of those they supported. The generation of each of these statistical data sets is outlined later in this chapter. Using this information and the descriptor function in Dedoose (2012) it was possible to respond to questions about the data, generating reports containing specific information about particular groups. This additional information, along with the demographics, allowed comparisons and patterns to be identified.

Once these descriptors were tagged to each piece of data, the excerpts were read through and linked to one of the topic areas illustrated in figure 10. At this point the level of interpretation was limited to asking, 'does this information relate to any of the four topic areas?'

There is disagreement in the literature, regarding the appropriateness of initially approaching data analysis deductively, with a predetermined set
of topics in mind. This argument is predominantly within the early grounded theory literature, which promotes the notion that data ‘speaks’ for itself and points of interest ‘emerge’ from the data set, rather than deductively from the researcher (Glaser & Strauss, 1967). In contrast to this view, a social constructivist paradigm recognizes that a researcher does not approach data as an empty vessel. A researcher is influenced by their own prior practice, readings, research agendas and life experiences, which cannot be ignored. Therefore, the data was approached with a focused set of topic areas, derived from the research questions, which in turn were derived from the literature and previous life experience.

**Step two: Identifying descriptive (parent) codes**

This stage of the process involved the generation of descriptive codes. For the purpose of this thesis, a descriptive code is operationally defined as one that describes what participants say and do and what may be happening in the environment. It is, as its name suggests, purely descriptive, serving as a means of labelling data for what it is. These codes are referred to as parent codes from here on.

To begin developing these parent codes, a process of “open coding” (Richards & Morse, 2007 p.137) was carried out. This involved reading through the textual content line-by-line and labeling sections of data (excerpts) with parent codes. The establishment of these codes was guided by three questions suggested by Charmaz (2003). She suggests describing the data and coding it in terms of, “What is going on? What are
people doing? What is the person saying” (Charmaz, 2003 p.94-95)?

Influenced by Charmaz’s approach these codes were written as gerunds (Charmaz, 2006). A gerund is defined in the Collins English Dictionary (2000) as “a noun formed from a verb, denoting an action” (Sinclair, 2000). In addition, some of the codes were ‘In Vivo’ codes, that is, they were descriptions used by participants.

Thirty-four parent codes were generated each related to one of the four topic areas. These codes were incorporated into the Dedoose (2012) coding application. Figure 11, taken directly from Dedoose (2012), demonstrates how these codes were incorporated into the coding tree.
Figure 11: Coding tree as displayed in Dedoose (2012) demonstrating how child codes were incorporated into the coding tree

**Step three: Generation of Analytical (child) codes**

This step involved the generation of analytical codes, as opposed to descriptive codes in the previous step. An analytical code is one that focuses deeply, honing in on similarities, differences, correlations and sequences across a data set. These codes, referred to in this thesis as child codes, were developed through a process of purposefully looking for patterns and relationships within the data.

The process began by exporting all data extracts from Dedoose into a
word document, printing them and cutting them into individual excerpts. These data excerpts were arranged on the floor under the focused topic areas and parent codes they were attached to. Manually displaying the extracts and parent codes in this way, allowed the large data set to be viewed holistically so that patterns and relationships within and between the data could be easily identified. Because most excerpts were attached to more than one parent code, several copies of each excerpt were printed, so they could be placed under each parent code they were tagged with. In addition, each excerpt was labelled with abbreviations of the descriptors they were associated with. Each abbreviation was colour coded, to make descriptors common across multiple excerpts more visible. These descriptors included demographic information relating to focus people and their supporters.

Several techniques designed to query the data, suggested by Hatch (2002), were used in the process of developing child codes. Hatch (2002) describes the process of querying as looking for:

Similarity in the data (things happening the same way), difference (things happening in predictably different ways), frequency (things happening often or seldom), sequence (things happening in a certain order), correspondence (things happening in relation to other activities or events) and causation (something happening that appears to cause another) (Hatch, 2002 p.155).

Excerpts that shared the same parent codes were interrogated. As
suggested by Hatch (2002) this interrogation involved finding and describing similarities and differences between the extracts. It also identified elements in the data that appeared frequently or rarely. Any sequences (i.e. things happening in a predictable or unpredictable order) were identified, as well as any aspects of the data that appeared to be related to particular demographic descriptors. For example, the question was asked of the data, ‘how did supporters who were found to be responsive to the expressions of preference of those they supported describe the closeness of their relationship with those they supported?’ Examples of causation were also sought (i.e. the question was asked, ‘did an element of the data appear to be related to another element?’).

Appendix 3.30 provides a simplified description of this process, using one parent code as an example. It should be emphasized that this table is a simplified description of the process involved in developing child (analytical) codes. It does not illustrate the true reality of the complex, time consuming and nonlinear nature of coding, a process made up of continuous abandonment, merging, and collapsing of codes.

Once a list of child codes had been developed, they were incorporated into the coding structure. A process of assigning these codes to the data followed. The data excerpts were once again read through, however, this time, the reading was done within Dedoose (2012), not manually. Each excerpt was coded with the newly developed child codes.

**Step four: Theme generation**
Themes are statements of meaning that run through the majority of the data. In this study, themes were sought by asking Hatch’s (2002) question: “What broad statements can be made that meaningfully bring all of these data together?” (Hatch, 2002 p.156). The process of theme generation involved a deliberate search for relationships or patterns across the child codes previously generated in step three. To do this, specific questions were asked of this body of codes. These questions were derived from the study’s research questions that were outlined at the beginning of this chapter.

**Co-occurrence tables**

A number of co-occurrence tables within Dedoose (2012) were used to assist in the answering of these questions. Code/code and code/descriptor co-occurrence tables provide information about how specific codes and/or descriptors are used across a data set. They present frequencies for which code/code and code/descriptor pairings are applied to the same excerpt (SocioCultural Research Consultants LLC., 2012a). These tables make possible code/code and code/descriptor correlations visible. For example, as will be described in the following chapter, an association between supporters’ perception of the communication capability of those they support and their responsiveness to that person, was sought within the qualitative data set using code and descriptor co-occurrence tables. The theme emerging from this analysis warranting further investigation was ‘Supporters who perceive the person they support as being able to
communicate are likely to be responsive to that person’.

Descriptor reporting

In response to emerging questions regarding patterns and possible correlations within the data corpus, further descriptive information was generated. This additional descriptive statistical data included:

1) Supporters’ responsiveness to the expression of preference of those they supported;
2) Information about supporters’ attitudes, specifically their a) perceptions of the decision-making and b) communication capability of those they supported;
3) The degree of relational closeness between those supported and their supporters;
4) Information about the functioning of circles of support, specifically the extent to which they valued collaboration and the degree of conflict between circle members.

The generation of each of these statistical data sets is outlined below. Using this information and the descriptor function in Dedoose (2012) it was possible to respond to questions about the data and to generate reports containing specific information about particular groups. This additional information, along with the demographics, allowed comparisons and patterns to be identified, generating a set of developing themes, recorded in column four of the codebook (examples of entries in
These themes are discussed in Chapter four.

*Treatment of outlying data*

Over the course of the study, some outliers occurred in the descriptive statistical data. An outlier is an instance in which the outcome for a small number of participants differs considerably from the outcomes for the rest of the population. Within the current study, such deviant instances were further analysed, with a view to establishing under what conditions these ‘exceptions to the rule’ occurred.

*Step five: Data revisitation*

Further questions were asked of the themes generated in step four. These questions were recorded in column 5 of the codebook. Examples of these entries are recorded in Appendix 3.23. These questions were answered by ‘revisiting’ the existing data within Dedoose (2012). Elements of the data that appeared to answer these questions were sought, using the same applications within Dedoose already described. Where the existing data did not provide satisfactory answers to the questions, new data was collected in proceeding case studies, using a process of theoretical sampling that sought specific new data relevant to questions at hand. Theoretical sampling is a method of testing the relevance and significance of codes within the field and modifying them based on additional insights from the field (Bryant & Charmaz, 2007).

In addition to this process of theoretical sampling, a technique called
negative case analysis was used (Whittemore, Chase, & Mandle, 2001). In an effort to maximise objectivity, this involved searching for alternative explanations of the data. This strategy is rooted in the idea that a researcher should be “able to come up with more than one model for explanation, simply by forcing oneself to think alternatively” (Levin, 2012 p.145). Balbach (1999) states,

Like all human beings, [the researcher] enters into a situation with a set of beliefs and preconceived notions... the challenge... is to prove himself, or herself, wrong by finding evidence that disconfirms a pet theory (Balbach, 1999 p.112).

The process of negative case analysis involves searching for and discussing elements of the data that do not support, or appear to contradict, patterns or explanations that have developed from data analysis (Whittemore et al., 2001). Explanations of disagreement were also sought within focus groups. For example, within a workshop there was an inconsistency in opinion between participants regarding the level of choice a focus person had around their evening meal. In an attempt to understand this discrepancy, the group was asked, “can we explore this disagreement some more? Can you describe what the expression of choice around his evening meal looks like for each of you?”

To exemplify these processes of negative case analysis and theoretical sampling further, an example within the project is illustrated. A preliminary hypothesis recorded in column 4 of codebook was that, over
the course of the study, several areas of supporters’ knowledge increased. The data was revisited in an attempt to find evidence that either supported this hypothesis, refuted it or supported an alternative or refined conclusion. The ‘testing’ of the preliminary hypothesis continued within proceeding data collection, using theoretical sampling, seeking specific new data that may contradict the preliminary hypothesis. For example, within a follow-up workshop, the participants were engaged in collective discussions designed to ascertain whether there were any areas where they felt their knowledge had not increased. The discussion was audio taped, providing data that either refuted or supported the preliminary conclusion. Moreover, in post intervention observation, areas of knowledge that appeared not to have improved over the course of the study became a focus.

The point of data saturation occurred at this stage of analysis, whereby any additional data collection activities carried out in the name of negative data analysis or thematic sampling, revealed no new insights.

**Step six: Articulation of evolving conclusions**

The answers to the questions posed in step five were recorded in column six of the codebook, as exemplified in Appendix 3.23. This column forms the structure and content of the proceeding chapters of this thesis.

**3.10 Rigor and trustworthiness**

There is a long-standing debate on what constitutes 'quality' in qualitative research (Coghlan, 2002; McNiff & Whitehead, 2002; Reason &
Bradbury, 2001b; Seale, 1999). Measures of quality developed within positivist paradigms, such as objectivity, validity, reliability, and generalizability, are arguably unhelpful when applied to qualitative research. Therefore, the question was asked within the context of this study, whether such measures of quality should be replaced with alternative criteria, better suited to the qualitative and interpretative nature of the study. Additionally, if alternative criteria were to be set, what types of standards should be adopted? This is explored below.

There is disagreement in the literature not only about the characteristics that define good quality qualitative research, but also on whether criteria for quality in qualitative research should exist at all. Within the context of this “criteriology debate” (Cassell, 2008 p.8) positions are polarised. Some have called for an end to “criteriology”, arguing that it leads to privileging of the method as a “sacred prescription” rooted in positivist philosophical traditions, and “the stifling of the interpretive and creative aspects of qualitative research” (Schwandt, 2001 p.60). On the opposite end of the continuum is an acceptance of common criteria for both qualitative and quantitative research, mainly with regard to reliability and validity (Kirk & Miller, 1986). Smith (1984, 1990) discarded the notion of criteria, accepting a looser concept of guiding principles (Smith, 1984, 1990). He rejected the use of fixed standards to measure quality in qualitative research, however did not oppose “characterizing traits” (Smith, 1984 p.384). Smith bases his objection to criteria on the notion that qualitative research is essentially relativist and anti-foundational and therefore the
existence of standards is problematic.

Like Smith, Lincoln and Guba (1985) believed that qualitative or interpretivist research differs from quantitative research in terms of its underlying epistemological assumptions. However, unlike Smith, they did not reject the notion of criteria. They formulated an alternative set of criteria to assess the trustworthiness of a piece of qualitative research (Lincoln & Guba, 1985). These criteria addressed parallel concerns to the concepts found in quantitative methodologies, of reliability, validity, and objectivity.

Lincoln and Guba (1985) replaced the traditional positivist concept of objectivity with confirmability. Confirmability refers to the neutrality and accuracy of the data (Tobin and Begley 2004), and is closely linked to dependability – the processes for establishing both are similar.


In place of reliability, or the consistency of findings, Lincoln and Guba (1985) used the notion of replicability. Replicability is often referred to as how stable the data is (Graneheim and Lundman 2004, Tobin and Begley 2004, Shah and Corley 2006, Rolfe 2006).

Finally, Lincoln and Guba (1985) replaced external validity, the extent to
which findings are more generally applicable, with transferability. ‘Transferability’ refers to whether or not particular findings can be transferred to another similar context or situation, while still preserving the meanings and inferences of the completed study (Leininger 1994).

The importance of addressing the legitimate criticisms directed at qualitative research, around notions such as objectivity, internal and external validity, and reliability were recognised within the context of this study. The following section attempts to address some of these criticisms, outlining how they were managed within this study during both data collection and analysis. Alternative criteria, arguably more suited to this study, are presented and discussed.

3.10.1 Confirmability: Addressing the question of objectivity

A lack of researcher objectivity in qualitative research is questioned in the literature (Cassell & Johnson, 2006). These questions are rooted in the belief that if research is to be considered truly scientific, it should be objective. It is clear that for this project, like most qualitative research, a value free/objective ideal is not possible. By its very nature this study is socially constructed, meaning that the researcher and participants, bring to the process a set of values and assumptions, that will have an unavoidable role in shaping and defining the research. Recognising this reality, several compensatory techniques were incorporated into the project’s design, with a focus on notions of ‘confirmability’ (Lincoln & Guba, 1985).
Triangulation of data as a mechanism of confirmability

Within the study data was triangulated (Brewerton & Millward, 2001). This involved the use and comparison of multiple qualitative data collection methods (interviewing, discussion groups, participatory observation and document review) in an attempt to determine congruence of the various results found. Referring to case study research, Houghton and Casey (2013) claim that triangulation is a “major strength of the design” (Houghton et al., 2013 p.13). Thorne (2008) claims that the multiple perspectives triangulation provides is likely to result in a more “probable truth” of participants’ experiences (Thorne, 2008 p.78), resulting in greater confirmability.

Reflexive bracketing as a mechanism of confirmability

Additionally, this project strived for confirmability through a process of reflexive bracketing, a methodological approach used in phenomenological research (Ahern, 1999). It involved laying out the values, biases, assumptions and political preferences that guide the researcher’s perception of the world. Honest reporting of potential biases functions as a mechanism by which the researcher and reader can become aware of existing predispositions, allowing the implementation of measures to identify and compensate for these. A specific bracketing technique, suggested by Levin (2012), was employed to explicate the personal biases and assumptions regarding the eventual findings of the study (Levin, 2012). This involved writing a possible conclusion to the research before the study began (Appendix 3.26). This provided an avenue
to explicitly identify and list the preconceptions and biases brought to the research. In the words of Levin (2012), a list of biases “serve(s) as controlling exclamation marks that should signal awareness to the researcher” (Levin, 2012 p.144). The process maximizes the likelihood that an emerging body of knowledge “is faithful to the phenomenon, regardless of the idiosyncrasies of researchers” (Ahern, 1999 p.407). In addition, Ahern’s process of ‘reflexive bracketing’ was continually employed throughout the research, where possible biases were added to the reflexive journal within an application called Noteshelf (Ramki, 2012). Where a bias was identified as having a potential impact on the analysis and developing conclusions, a process of negative analysis previously described was carried out.

**Audit trail as a mechanism of confirmability**

The research process was made visible by keeping an audit or decision trail, documenting the decisions and interpretations made at each stage of the research (See Appendix 3.28 for an entry example). Audit trails, which document how data was collected, analysed and responded to, provide a way of recording the process from data to conclusions. In keeping with the emergent nature of action research, it is particularly important that the inevitable deviations from planned data collection or analytical processes are “described and justified” (Meyrick, 2006 p.803). In addition, the use of the computer aided qualitative data analysis tool, Dedoose (2012), provided an evidentiary quality sometimes found lacking in manually conducted qualitative research (Johnston, 2006; Sin, 2007). The most cited
reason for adopting Computer Assisted Qualitative Data Analysis Technology (CAQDAT) is that it provides material evidence of the data collection and analytical process, facilitating auditability (Wickham & Wood, 2005). Specifically, developers of CAQDATs claim that they enable other researchers to examine/audit data and either come to the same conclusions or see logical evidence of the basis of these conclusions (Wickham & Wood, 2005).

Sharing data as a mechanism of confirmability

The achievement of inter-coder consistency is important amongst positivist orientated scholars to describe the extent to which independent coders evaluate a characteristic of a piece of data and reach the same conclusion. Some qualitative researchers, who follow a positivist philosophy, advocate for it as an important measure of objectivity (Ambert, Adler, Adler, & Detzner, 1995; Armstrong, Gosling, Weinman, & Marteau, 1997; Krippendorff, 2004). Given the interpretative and contextual nature of this research, to embark on a formal process of establishing inter-coder consistency was unlikely to yield any useful results. As is the case in many qualitative studies, analysis in this study, can be described as a “unique process between the researcher and the data” (Houghton et al., 2013 p.14). The researcher brought with her a highly individualised set of values and life experiences and, therefore, interpretations of the data, difficult to replicate in anyone else. This made the establishment of a level playing field between potential coders difficult. In addition, the researcher spent many hours engaged in
participatory observation, which was not the case for other potential coders.

Therefore, a constructivist process of establishing agreement regarding the contents of the coding schema or codebook was undertaken. Harris et al. (2006) advocate such an approach, promoting a process of peer debriefing, rather than a formal process of establishing inter-coder consistency (Harris, 2006). A three-hour meeting was held with the research team (PhD Candidate and supervisors) where coded sections of the dataset along with the codebook were presented and discussed. The codes and their assignments were examined and any discrepancies or disagreements were resolved when they arose. The aim was not for each researcher to arrive at the exact same coding and thematic structure, but to establish some agreement with the data labels and the logical paths taken to arrive at those labels. This content analysis approach is further described by Graneheim and Lundman (Graneheim & Lundman, 2004).

Additionally, small portions of data were shared with colleagues, both individually and in groups, in the form of conference presentations throughout the research process. Sharing data in this way had the benefit of serving as a ‘reality check’ on the researcher’s interpretations, adding awareness of dimensions in the data, prompting fresh ideas and new questions to pursue. Notes were made of each discussion and, in conjunction with records of supervision, these form part of the analysis audit trail.
3.10.2 Credibility: addressing the question of internal validity

Credibility “refers to the confidence in the truth value or believability of the study’s findings” (Jeanfreau, 2010 p.616). It involves two processes: “conducting the research in a believable manner and being able to demonstrate credibility” (Houghton et al., 2013 p.13). To ensure the credibility of this study, certain questions regarding the research design were addressed, via a number of techniques.

Member checking as a mechanism of credibility

To maximize credibility, member checking was conducted in an attempt to partially control for personal biases. Member checking was conducted during and after interviews, discussions and focus groups. Immediately after the interview, discussion or focus group, or at the end of a long section of observation, a verbal summary was provided, which participants were invited to respond to and correct if necessary. In some cases, a written summary was provided via email. An example of one of these written email summaries is in Appendix 3.29. Although it would have been beneficial to send all participants a written summary of these interpretations following every session of data collection, this was not practical due to the busy schedules of most participants. For all individual interviews (10 in total), participants were invited to read the transcript of their interviews before analysis, “to ensure that these have been accurately recorded and are therefore credible” (Houghton et al., 2013 p.14). This was done by sending (emailing) interviewees a copy of the transcript and asking them to call the researcher with any adaptations.
Only one participant called, indicating that they felt the transcript accurately represented what was said during the interview, however that they were uncomfortable with the ‘strong language’ used when the commitment of another circle of support member was being questioned. She requested that the language be ‘toned down a little’, so that it did not appear so ‘judgmental’. We collaboratively rewrote that section of the transcript to her satisfaction.

At the beginning of each follow-up interview, participants were given a verbal account of the evolving analysis and were asked to reflect on whether and if so how much the developing themes related to their experience of supporting someone with a severe or profound intellectual disability to participate in decisions. Additionally, during the concluding focus/training session with circles of support, the preliminary findings were shared giving participants an opportunity to provide feedback.

**Prolonged and persistent engagement as a mechanism of credibility**

The nature of an action research study generally means that researchers have a prolonged and persistent engagement with participants. This was the case for this project. This allowed a deeper understanding of participants and their experiences further adding to the credibility of the study (Hammersley, 1995).

**Direct reporting of raw data as a mechanism of credibility**

A final strategy used to maximize credibility was the direct reporting of raw data, either in the form of participant quotes or field notes. Such direct
reporting allows other researchers to draw their own conclusions from the data, adding to its believability.

3.10.3 Replicability: Addressing the question of reliability

Another criticism often directed at action research relates to the issue of replicability. By its very nature, action research does not lend itself to repeatable experimentation. This is because action research is highly responsive, meaning that the researcher is in a constant process of reviewing and adapting the research procedure. Decisions about this adaptation are based on emerging findings within the current study, making it very difficult to replicate. Positivist research on the other hand tends to sacrifice responsiveness in the interests of achieving replicability. Despite difficulties in replication, there are examples in the research literature of action research forming the basis for understanding of other similar situations for studies. Pope & May (1995) illustrate some of these studies in a series of papers showing the value of a range of qualitative techniques (Pope & Mays, 1995). Informed by this work, a precise procedural explanation to maximize the possibility of future replicability was provided throughout this research. The use of the computer aided qualitative data analysis tool, Dedoose (2012) assisted in this process of procedural explanation and provided an evidentiary trail as described by Johnston (2006) and Sin (2007) (Johnston, 2006; Sin, 2007).

3.10.4 Transferability: Addressing the question of external validity

Another common criticism of action research is its lack of generalizability or transferability, sometimes called external validity. These concepts
refer to how well findings can be transferred to a similar context, while still preserving the meanings and the inferences from the completed study. It is clear that action research is more difficult to generalize than traditional quantitative research, as it is context specific (Bradbury & Reason, 2003b; Cassell & Johnson, 2006; Lincoln, 2001). It is likely that the findings generated in action research are most relevant to the people or systems actually studied. Coghlan (2002) points out that action research “does not attempt to create a universal knowledge” (Coghlan, 2002 p.64). Agreeing with this, Baskerville and Lee (1999) claim that it “aims for an understanding of a complex human process rather than prescribing a universal social law” (Baskerville & Lee, 1999 p.7).

Although the views of Coghlan (2002) and Baskerville & Lee (1999) are accurate, action research outputs can have a broader interest (Dick, 1993), as is the case in this study. In this study, although abstract generalizability is de-emphasized, the generation of usable knowledge for both those participating and others with severe or profound intellectual disability and their supporters is emphasized.

Within this study, the responsibility of the researcher was to provide detailed ‘thick’ descriptions of the research, so that the reader will be able to make informed decisions about the transferability of the findings to their specific contexts (Lincoln & Guba, 1985). These ‘thick’ descriptions included detailed accounts of the context and background to the study, research methods and examples of raw data, including direct quotes and
extracts from field notes, so that readers can interpret some of the data set themselves. Ultimately, then, if this has been done well, the researcher has done her job, and it is up to the reader to decide whether the findings are transferable to another context.

3.11 Chapter summary

This chapter has explained the methods and procedures involved in the study. A social constructivist theoretical perspective underlies the study, and action research is the research framework used. Five people with severe or profound intellectual disability and their support networks were sampled, using a multiple case-study research design. Each of these participants and their support networks participated in a three to six-month intervention. A mixed method of data collection was used. 

Interview, workshop, focus group, questionnaires and participatory observation data were collected and triangulated. The data analysis process adopted was based on Colaizzi’s (1978) seven stages of data analysis, Morse’s (1994) analytical framework and Hatch’s (2002) typological framework (Colaizzi, 1978; Hatch, 2002; Morse, 1994). The chapter has detailed the data analysis procedure, and presented some examples of research findings in order to give the reader a sense of how analysis occurred. The chapter concludes with a discussion of the methods used to ensure rigour and trustworthiness.
CHAPTER FOUR

Findings and discussion

4.1 Overview of chapter

This chapter combines the findings and discussion sections of the thesis.

The chapter addresses the first three research questions listed below. The fourth research question is addressed in chapter five.

1. What role do people with severe or profound intellectual disability play within a supported decision-making process?
2. What role does a supporter of someone with severe or profound intellectual disability play within a supported decision-making process?
3. What factors underlie supporters' role of responsiveness in supported decision-making for people with severe or profound intellectual disability?
4. What are the implications of this study’s findings on policy and practice relating to supported decision-making for people with severe or profound intellectual disability?

Drawing from the results of a review of the literature and an inductive thematic analysis of this study’s data corpus, supported decision-making for people with severe or profound intellectual disability is broadly described in terms of the existence of two distinct but interdependent roles. This description is outlined in section 4.2. These roles include that played by (a) the person with a disability (supported), and (b) the circle of support (supporters) within the supported
decision-making process. Section 4.2.1 focuses on research question one, describing the role of people with severe or profound intellectual disability within a supported decision-making process. Section 4.2.2 focuses on research question two, describing the role that supporters play in the supported decision-making process for this population.

Section 4.3 focuses on research question three, describing the results of a thematic analysis identifying ten main factors and nine sub factors, organised into five overarching domains, as underlying supporters’ role of responsiveness in the supported decision-making process for people with severe or profound intellectual disability. This section explores these clustered factors in depth, describing associations between them and highlighting the impact they appear to have on supporters’ responsiveness as a key element in the supported decision-making process.

4.2 Characterising supported decision-making for people with severe or profound intellectual disability

In order to understand supported decision-making for people with severe or profound intellectual disabilities it was important to investigate what engagement in decision-making may look like for this population. This was examined within an intervention specifically designed to support decision-making for people with severe or profound intellectual disability. The roles played by the supported and supporters in this process were explored.

4.2.1 The role of people with severe or profound intellectual disability

As discussed in chapter two, a person’s expression of preference is presented in the literature as a core component of choice and decision-making. The data
highlights the expression of will and preference informally, and sometimes unintentionally, as the key role people with severe or profound intellectual disability play in supported decision-making. This expression of will and preference for people with severe or profound intellectual disability can take multiple forms, including facial expressions, gesture, head and eye movement, vocalisations, behaviours of concern, cries, laughter, breathing, and other unintentional physiological functions (e.g. changes in skin tone). The five focus people in this study were observed to express preference frequently, examples of which are provided below. A data analysis technique involving underlining and labelling elements of particular interest (Creswell, 2007) was used to explore the role played by people with severe or profound intellectual disability in the supported decision-making process. The evidence of preference expression found in this study is consistent with the literature presented in chapter two that identifies that people with severe or profound intellectual disability are able to communicate preference.

A supporter describes Nathan's expression of his will and preference using body language, vocalisations and behaviour. “He screamed and splashed the shower water [expression of preference using body language and vocalisation]. I came into the shower cubicle thing and asked him if he had finished, he smacked me over the head [expression of preference using behaviour]”. Another of Nathan's supporters described his expression of will and preference using behaviours of concern. “Look, spitting again [expression of preference using behaviour of concern], does it stop? ... The spitting [expression of preference using behaviour of concern] is usually when he is distressed about something”.

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A supporter described Yuri’s expression of will and preference using head/eye movement saying, “Sometimes if he’s interested, his head is down but his eyes are up [expressing preference using head/eye movement] ...”. Another of Yuri’s supporters described Yuri’s expression of will and preference using facial expression saying, “He is hungry. That is an anxious look [expression of preference using facial expression]”. Two supporters described Yuri’s expression of preference using vocalisations and breath. The first described Yuri’s expression of will and preference as “...noises and huffing and puffing and that [expression of preference using vocalisations and breath]”. The second described Yuri’s preference in the following way.

He communicated... that he was hungry and wanted a chest massage...

with the humming and that [expression of preference using vocalization]

...there's something about the pitch of that noise ... the pitch of hum

[expression of preference using vocalization], the speed of his huffing and puffing [expression of preference using breath].

During an observation session, a supporter was asked what Yuri was communicating. She replied:

He's communicating that he doesn't like change through that behaviour, you know the humming [expression of preference using vocalisation] and gouging [expression of preference using behaviour of concern]. Have you seen him put his hand in his mouth, you know the flapping [expression of preference using behaviour of concern]. That happens when we change something.
When asked, “What did Yuri’s participation in decision-making look like today?” at the end of a workshop, a supporter replied, “he was present”. This response, on the surface, may appear facetious, however a follow-up comment established that this was not the case. The supporter who made this remark followed it up with, “I mean, he told us he was ok about staying here with his humming [expression of preference using vocalisation]. He didn’t cry and teeth grind [expression of preference by not engaging in behaviour of concern], until he was hungry, remember. So to me, he made a decision just by being here [expression of preference by behaviour]”.

One of Kevin’s supporters described Kevin’s expression of will and preference using behaviour saying, “If he doesn’t like something he won’t eat it [expression of preference using behaviour]”. The following observation notes reflected Kevin's communication and therefore his contribution to the decision-making process. “Kevin hangs around the kitchen while dinner is being prepared [expression of preference using behaviour]”. His support worker interpreted this behaviour as Kevin wanting dinner. Another supporter described Kevin as sometimes “feeling frantic” and “wanting to calm down”. When asked to describe this further, another supporter contributed to the conversation, describing his expression of preference to “calm down” in the following way.

Frantic! He screams [expression of preference using vocalizations], and he stiffens, his whole body [expression of preference using body language]. It’s the tone and the people who know him well, it’s about the tone and you can hear... and oh yes, he goes all pale, you know his face, he goes so
pale [expression of preference using vocal pitch, facial colour and muscle tone]

Angela contributed to the decision regarding her hysterectomy through her unintentional physiological behaviour during the years preceding the decision. Her participation in the decision was characterised by her informal and unintentional behaviours as described by her mother.

When she was menstruating, just hygiene-wise, it was just horrific. I would shower her twice a day, if not more. You could wake up in the morning and think, we’ll have a really good day, and that’s fine. And I’d go into Angela’s room, it just, um...yeah, it was just horrific. Sometimes we’d have blood everywhere and, you know, she didn’t know any better. Her mood swings were right up and down [expression of preference using behaviours of concern]. They, um...she could be fine one minute and the next, be just uncontrollable, crying and sobbing [expressions of preference using vocalisations and behaviour]. She was just really happy until the age of 12, when she started menstruating [expression of preference by changing mood].

To summarise, the data in section 4.2.1 paints a picture of the role played by people with severe or profound intellectual disability within the supported decision-making process. This role is to express will and preference using a range of modalities, including behaviour, vocalisation, vocal pitch, muscle tone, facial expression, eye movement, self-harm, and breath. This expression of will and preference is related to a range of aspects of life, including mealtimes, health,
leisure, and interaction with others. Sometimes this will and preference is expressed intentionally and other times it is expressed unintentionally.

While expressions of preference are occurring, and focus people are noted as significant contributors to decision-making, not all expressions of preference occurred at the time the decision was made. In many instances above, supporters recalled and noted expressions of preference over a substantial period, and actively drew on these in enacting decisions relating to the focus person. This role of the supporter in acknowledging, interpreting and enacting expressions of preference is discussed below.

4.2.2 The role of supporters

Exploration of the study’s data corpus highlighted the role of supporters in a supported decision-making process. That is, to respond to focus people’s expressions of will and preference. As discussed in Chapter two, supporter responsiveness is characterised as an important factor in ensuring people with severe or profound intellectual disability have their preferences realised (Bloomberg et al., 2003; Bunning, 2009a; Coupe et al., 1985; Finlay, Walton, et al., 2008; Guess et al., 1985; McConkey et al., 1999; Ware, 1996, 2004). The challenge of responding to the expressions of preference of people with severe or profound intellectual disability is well documented (Belfiore et al., 1994; Cannella et al., 2005; Finlay, Walton, et al., 2008; Houghton et al., 1987; Hughes et al., 1998; Virués-Ortega et al., 2014). Despite this large body of literature, little is known about the mechanics of effective responsiveness, particularly to the expressions of preference of people with severe or profound intellectual disability. To date, there has been no deconstruction of the overall act of
supporter responsiveness with a view to developing a better understanding of its related components. Observation and interview data from this study has highlighted that supporter responsiveness is a multi-faceted activity, made up of a number of tasks mentioned in the literature as synonymous with responsiveness, comprising acknowledging, interpreting, and acting upon a person’s will and preference. The study has highlighted, that although each of these tasks are important, none of them in isolation, characterise responsiveness. Rather, supporter responsiveness is reliant on the implementation of these tasks collectively and often sequentially. Typically, supporters first acknowledge/notice (as opposed to ignore) expressions of preference, secondly they interpret these expressions of preference, assigning meaning to them, and thirdly they act on this meaning.

Analysis of the data in this study evidences these elements repeatedly, as described below.

A supporter demonstrated acknowledgment and interpretation of Kevin’s will and preference.

He’s either telling us he’s bored, he doesn’t like it, he wants to move or it’s an onset of the psychosis [Interpreting expression of preference]. Because when the psychosis starts it might start with that and it will get more vigorous, and then there’s other things that come into play like the noises and ‘woo-woo’ and the shaking [Acknowledging expression of preference] but otherwise it’s probably he’s bored, he wants music, wants to move [Interpreting expression of preference].
Another supporter illustrated her responsiveness to Kevin. “See, look at him, when he’s hovering around the kitchen like that [acknowledging expression of preference], he’s usually hungry. He’s saying give me my dinner now [interpreting expression of preference]... so we know we have to get our skates on [acting on expression of preference].”

A supporter described his responsiveness to Nathan.

If he wants food [interpreting expression of preference] he goes to the pantry [acknowledging expression of preference] and it’s as simple as that, and like if he wants to go somewhere [interpreting expression of preference] he’ll go and get any keys, he’ll bring the bag, he’ll grab your hand [interpreting expression of preference]. He lets you know. If he wants to go to sleep [interpreting expression of preference], he’ll just go to his room [acknowledging expression of preference]

While sitting with him in a spa bath at the local swimming pool, Larry illustrated his responsiveness to Nathan. The scenario is recorded as an entry in the study’s field notes.

The bubbles stopped, and Larry, looked at Nathan, waiting for him to communicate. Nathan looked back at him, for a couple of seconds. He stopped smiling and began spitting. Larry said, ‘ah, we’ll turn them back on mate, I know, I know’ [acknowledging expression of preference]. Larry asked me to turn them on [acting on expression of preference].

Another supporter demonstrated her responsiveness to Yuri, acknowledging,
interpreting and acting on his expressions of preference. “He’s helped us come to a decision about whether or not he gets an Ipad [acting on expression of preference]. If we hadn’t seen him staring at that video [interpreting expression of preference], I mean, did you see his face? [acknowledging expression of preference].”

Illustrating her responsiveness, a supporter while observing Yuri, said, “head back like that, that certainly tells us stuff, oh yeah and the chair rocking [acknowledging expression of preference]. It usually means, get me out of here, or do something [interpreting expression of preference]. Come on mate let’s go outside [acting on expression of preference].”

The above qualitative data set paints a picture of the role played by supporters of people with severe or profound intellectual disability within the supported decision-making process. This role is to respond to the expressions of preference of those they support by acknowledging (e.g. “see look at him...hovering around the kitchen”), interpreting (e.g. “he’s saying give me my dinner”) and acting on (e.g. “get our skates on”) focus people’s expressions of will and preference.

Once responsiveness was characterised through the qualitative data, two responsiveness observation templates were configured both exemplified in Appendix 3.13 and 3.14. The first provided a written space for descriptive data to be recorded in terms of supporters’ responsiveness and the second is a tick box chart allowing the collection of pre and post intervention data regarding each of the three components of responsiveness described above,
acknowledgment, interpretation, and action. Within the context of this observational tool, an instance of responsiveness was defined as ‘a communication partner carrying out all three elements, acknowledging an expression of preference, interpreting that preference and ultimately acting on that preference’. Conversely, an instance of unresponsiveness was defined as ‘a communication partner failing to acknowledge expressions of preference, interpret that preference, and/or act on it’. The results of this pre and post intervention observational task are displayed in Appendix 4.1, and are drawn on extensively throughout this chapter.

An analysis of this responsiveness data has highlighted that for supporters who were characterised as unresponsive, the element of responsiveness most likely missing was the noticing or acknowledgment of the person’s expression of preference. Specifically, eighty-four per cent of times a supporter was found not to respond to the expression of preference of those they support, this unresponsiveness was characterised by a lack of acknowledgment/noticing of the person’s expression of preference.

The social model of disability suggests that a person’s decision-making capability should not rest with them as an individual, but with the environment to which they belong. Such an ecological approach to enhancing decision-making is consistent with a supported decision-making approach, and places the onus of change on supporters, rather than those being supported. In acknowledgment of this ecological approach, this thesis focuses on supporter responsiveness to expressions of will and preference of those they support, as key to supported decision-making for this population. Within the decision-making dynamic
described in the previous section, supporter responsiveness, as opposed to focus people's expression of preference, is the component that is amenable to change through structured practice guidance, making the facilitation of responsiveness a crucial strategy for supporting decision-making.

To summarise section 4.2, decision-making support for people with severe or profound intellectual disability is characterised as an interdependent and complex process shared between people with severe or profound intellectual disability and their supporters. Within this process, both parties contribute differently. People with severe or profound intellectual disability contribute by expressing their will and preference. Supporters' contribution to the process is to respond to these expressions of will and preference, by acknowledging, interpreting and acting on them. Consistent with the social model of disability, the onus of enhancing supported decision-making should not rest with the person with a disability, but with the environment of which they are a part. It is for this reason that the factors associated with supporter responsiveness are explored in this chapter as opposed to those relating to focus people's expression of will and preference. Factors found to underpin supporter responsiveness are reported hereon.

### 4.3 Factors underlying supporters’ role of responsiveness in supported decision-making for people with severe or profound intellectual disability

A thematic analysis described in Chapter three and illustrated in Appendix 3.23 has identified a range of factors underlying supporter responsiveness. These have been organised into five overarching domains as illustrated in Figure 12.
Figure 12: A depiction of supported decision-making as a bidirectional process between supporters and supported impacted on by a range of factors.
4.3.1 Focus person’s communication in terms of intentionality

Some circles of support were comprised of a lower number of instances of responsiveness than others (see, in particular the circles of support for Yuri and Neil in Appendix 4.1). By contrast, other circles of support, in particular, that of Kevin were comprised of a relatively high number of instances of responsiveness than the other case studies. A descriptor shared by Neil and Yuri is their unintentional informal level of communication according to the Triple C. In contrast, Angela, Nathan and Kevin were all assessed as intentional informal communicators. This data signals a possible relationship between focus people’s communication intentionality and supporters’ levels of responsiveness. That is, those who support focus people who communicate intentionally appear more likely to respond to their expressions of preference.

A comment made by Brett, who supported both Yuri (an unintentional communicator) and Kevin (an intentional communicator) evidences this link between responsiveness and communication intentionality.

So, like with Kev, he is much clearer, we know what he wants more, so we tend to respond to him you know. He will bang the cup on the table, saying, ‘I want breakfast. I want it now!’ Not like Yuri, he is so quiet, and we don’t know what he wants, it’s so much harder to work it out, you know. So you know, I guess you could say we ignore him a lot of the time.

A supporter classified as unresponsive to Neil’s (unintentional) expressions of preference, further illustrated a possible link between responsiveness and intentionality. Referring to Neil, she said, “I feel bad, he gets ignored a lot, because he can’t tell us stuff. I guess we don’t respond to him, like, as much as the
others. There’s nothing to respond to. Does that make sense?”

The study’s observational data provided examples of supporters being more responsive to intentional than unintentional communication. A field note recorded during an observation session at Yuri (unintentional communicator) and Kevin’s (intentional communicator) day service, exemplifies this contrasting behaviour.

Kevin and Yuri are watching music videos in the main room. Kevin appears to be enjoying the video, smiling and rocking gently in his wheelchair. Sandy (support worker) says, “Kevin, look at you, you love a bit of Delta (singer) don’t you?” She takes his hands and dances with him. He seems to be enjoying this. Yuri is not looking at the TV, gouging his hard palate and the corner of his eye. He is vocalising (not loudly) and appears distressed. No one is responding or interacting with him.

Although supporters’ unresponsiveness to people who communicate unintentionally is deeply concerning, it is not surprising. As discussed in chapter two, in contrast to their more intellectually able peers, people who communicate unintentionally have a history of having their expressions of preference either ignored or misinterpreted, resulting in severe restrictions to their self-determination (Burton-Smith, Morgan, & Davidson, 2005; Felce et al., 1998; Heller et al., 1999; Stalker & Harris, 1998). Overall, this suggests the need for explicit attention on enhancing supporters’ responsiveness to people who communicate unintentionally.
4.3.2 Supporter attitudes and perceptions

A process of inductive coding, described in chapter three, identified two supporter attitudes and perceptions underlying supporter responsiveness and consequently supported decision-making for people with severe or profound intellectual disability. These are illustrated in figure 12 and include perceptions of decision-making capability and beliefs regarding a person’s communication ability. Each of these factors is explored in turn in this section.

1) Perceptions of communication capability: an underlying factor in supporters’ responsiveness

As described in Chapter two, within contemporary intellectual disability related literature and practice, all human behaviour is characterised as communicative, progressing through a series of stages that reflect a continuum from informal unintentional to symbolic communication (Iacono et al., 2009). Drawing from this contemporary research and practice-based literature, an aim of the intervention used in this study was to develop participants’ acceptance that the person they support is able to communicate, and therefore express will and preference, a key component of decision-making. The intervention focused on developing supporters’ understanding that the ability to communicate is universal to all human beings including those who communicate unintentionally.

As described in the previous chapter, pre and post-intervention assessment was made of supporters’ belief that the person they support was able to communicate. The interviewees, a sample of supporters (ten pre-intervention and eight, post intervention) each was asked, “Would you describe the person you support as able to communicate (Yes/No)?”
As is evident in Appendix 4.1, at pre-intervention five out of ten supporters (50%) described the person they support as able to communicate. At post-intervention, (excluding Neil’s data due to his death) all eight (100%) described the focus person as able to communicate. This evidences a positive change in three supporters’ belief that those they support can communicate over the course of the supported decision-making process.

The data collected pre-intervention, displayed in Appendix 4.1, highlights a positive association between the belief supporters have regarding the ability of those they support to communicate, and their responsiveness when interacting with that same person. This association was specifically found between supporters’ belief in the ability of those they support to communicate and their acknowledgment/noticing of their expression of preference (a component of responsiveness).

Pre-intervention, seven of the interviewed supporters were observed with a view to ascertaining whether they were responsive or not. The remaining three interviewed supporters were not observed, and therefore were not labelled according to responsiveness. Of these seven, five were classified as responsive to the expressions of preference of those they support. Of these five, four (80%) held the view that the person they support was able to communicate. The two who were classified as unresponsive both held the view that the focus person was unable to communicate. In addition, they both demonstrated their unresponsiveness by failing to acknowledge/notice the focus person’s expression of preference (see Appendix 3.14). Post-intervention, six of the seven interviewed supporters were classified as responsive. Of these six, all (100%)
held the view that the person they support was able to communicate.

Considering the descriptive statistical data outlined, deeper evidence of an association between supporters’ perception of the communication capability of those they support and their responsiveness to that person, was sought within the qualitative data set using code and descriptor co-occurrence tables. Characteristic/representative examples of this data are presented below.

A supporter classified as responsive to Nathan's expressions of preference demonstrated her belief that Nathan was able to communicate. “Yeah, he's communicating, he communicates all the time, you know, whether it's spitting, crying, you know so many things”. A supporter of Kevin's classified as responsive to Kevin's expressions of preference also demonstrated her belief in Kevin's ability to communicate saying, “well, he is telling us things all the time you know. You know, what he wants to eat or doesn’t want to eat”.

In contrast, one of Kevin's supporters, classified as unresponsive, expressed a disbelief in Kevin's ability to communicate and also expressed a universal view that the people she supported (all informal communicators) were unable to communicate. “They can't, they can't really tell us things, you know. They can't tell us; they haven't got a voice to speak”. A supporter, who was also classified as unresponsive to Yuri’s expressions of preference, illustrated his disbelief that Yuri was able to communicate, saying, “…At the end of the day, people don’t know what we’re dealing with here. They just can’t communicate. It's different for them, they can’t tell us what they want”. Another of Yuri’s supporters classified as unresponsive to Yuri’s expressions of preference demonstrated his
disbelief in Yuri’s ability to communicate, saying, “Because, you know he can’t communicate. He has a lot of brain damage you know”. This same supporter failed to respond to Yuri’s eye gouging behaviour, a scenario previously discussed.

Of the five case studies, all the interviewed supporters of two case studies (Angela’s and Nathan’s) both had a pre-intervention belief that those they supported were able to communicate. Therefore, with a view to understanding possible enabling factors, data was collected regarding the descriptors assigned to each of these case studies. Angela’s and Nathan’s circle of support shared two descriptors/characteristics not present in the other three case studies’ circles of support.

The first characteristic was the existence of a communication coordinator within the circle of support. Both Nathan and Angela’s circles of support had a communication coordinator. The role of a communication coordinator for disability service providers is becoming more common within the state of Victoria, Australia. A communication coordinator is a disability support worker who is “equipped with the skill, knowledge and attitudes to develop and support a culture of communication” within their residential or day service (Torresi & Muscat, 2009 p.4). They often form part of a communication coordinator network, designed to provide peer support to each other. The amount of resource attached to the role varies across service providers, however generally a communication coordinator is engaged in a range of activities which include the coordination of communication related documentation, basic assessment, meeting facilitation, and importantly, communication training and support. The
role of a communication coordinator can involve the provision of communication training as well as the coordination and administration of the *Triple C* Checklist (2009). Both these tasks place emphasis on building the capacity of supporters to understand that all human behaviour is communicative, falling on a communication continuum. Therefore, it could be hypothesised that supporters who had access to a communication coordinator, prior to the intervention, were more likely than those who didn’t to have previously been exposed to the human communication continuum. One of Angela’s disability support workers, within the context of a workshop activity designed to develop supporters’ understanding of the communication continuum, expressed her belief in Angela’s ability to communicate and illustrated pre-existing knowledge of the universality of communication,

I’d be cheating though, if I jumped in, coz I know this stuff.

[Communication coordinator] did it with us years ago. That’s the one isn’t it [communication coordinator]? Where we all line up, with the cards? And then we realise, you know, the light bulb moment. That everyone communicates.

The role played by the communication coordinator in building knowledge and an understanding that human communication is universal to all, may explain the positive perception held by Nathan and Angela’s supporters of Nathan and Angela’s capability to communicate.

The second characteristic shared by Angela and Nathan’s circles of support was the pre-existence of communication assessment information, specifically the
Triple C. Nathan and Angela, as well as having access to a communication coordinator in their circle of support, had a Triple C checklist (2009) completed before the study commenced. A member of Nathan’s circle of support during an initial gathering, highlighted pre-existing assessment material.

We have a whole lot of stuff that [communication coordinator] has put together for us. You know where he is on the Triple C. It’s great she’s here, coz the rest of us don’t have time to pull all that stuff together, you know.

Just as the presence of a communication coordinator may impact positively on supporters’ understanding that those they support can communicate, so may the presence of communication assessment information, specifically the Triple C: Checklist of Communicative Competencies (Bloomberg et al., 2009).

To summarise this section, the data predominantly supports the notion that supporters’ perceptions of communication capability is an underlying factor in supporter responsiveness to the expressions of will and preference of those they support. This perception may also be associated with the presence/absence of a communication coordinator as well as the availability of communication assessment material.

2) Perceptions of decision-making capability: an underlying factor in supporters’ responsiveness

The literature outlined in chapter two suggests that a presumption of decision-making capability is an important feature in the promotion of a person’s autonomy and self-determination. This evidence implies that people with intellectual disability are more likely to participate in decisions when those who
support them have a positive view of their decision-making capability (Harchik et al., 1993; Rawlings et al., 1995).

Appendix 4.1 details supporters’ individual, and circles’ collective perceptions of focus people’s decision-making capability. As described in chapter three, these descriptors were generated through a process of triangulating two data sources, supporters’ responses to the *Questionnaires about Choice* (completed by all thirty-three supporters) and a weighted interview question (completed by supporters). As a result, pre-intervention, sixteen (48%) of the thirty-three supporters were found to have a positive perception of the capability of those they support to participate in decisions, while seventeen (52%) had a negative perception. Post-intervention, twenty-two of the twenty-seven remaining supporters (81%), were found to have a positive perception of the capability of those they support to participate in decisions, while five (19%) retained a negative perception. The post-intervention sample did not include data from Neil’s supporters, due to his death during the course of the study.

Evidence of an association between supporters’ perception of decision-making capability and their responsiveness was explored within the qualitative data set. A supporter described as having a positive perception of Nathan’s decision-making capability, demonstrated responsiveness to his expression of will and preference through a series of behaviours documented in the study’s field notes. Firstly, the field note described Nathan’s expression of preference using body language:

He got up [expression of preference using body language] and was told to
wait. When (supporter) offered him some sushi he stood up to leave [expression of preference using body language]. When she encouraged him to sit down, he spat and banged his hands on the table [expression of preference using body language].

The field note continued, describing this supporters’ responsiveness, acknowledging, interpreting and acting on Nathan’s expression of preference.

The supporter interacted with Nathan, saying:

What you telling us dude [acknowledging expression of preference]? He has finished what he needs to do here, and he can’t wait so he just wants to leave [interpreting expression of preference]. So, I guess we’re moving, hey mate [acting on expression of preference].

This series of behaviours played out between Nathan and his supporter highlight the interwoven nature of supporter responsiveness and perceptions of decision-making capability. Not only does the supporter demonstrate her positive perception of Nathan’s agency over the decision made (to leave), but also an understanding that in order for Nathan to enact this agency, she is required to respond. She acknowledges and interprets his preference, then acts on his preference, by supporting him to leave. “So, I guess we’re moving, hey mate”.

This supporter's description of Nathan is of a person who is actively contributing to the decision-making process.

Further evidencing an association between supporters’ positive perception of decision-making capability and their positive responsiveness, an interaction between Angela and her father (described as having a positive perception of his
daughter’s decision-making capability) is documented in the study’s field notes. Prior to the situation described, Angela’s father had acknowledged, interpreted and acted upon his daughter’s expression of preference to go outside on the swing by escorting her outside. The field note says:

Angela is out on the swing with [father]. It is cold and wet, freezing in fact! [Father] says: “I know you wanted to come out here Angela, so here we are” [acknowledging expression of preference] [interpreting expression of preference] [acting on expression of preference]. [Father] continues “but it’s a bit cold don’t you think” (touches Angela’s hand). “Come on love, you’re bloody freezing [interpreting expression of preference]. Let’s go inside [acting on expression of preference]”. We all went inside. Angela appeared happy to go inside and [father] acknowledged this, saying:

See [acknowledging expression of preference] now you’re happy hey [interpreting expression of preference]. Good girl, I think that’s what you wanted, hey [interpreting expression of preference]. We’ll see what the weather does later, and we might go out again then, what do you think? [acting on expression of preference].

Angela’s father responded to (i.e. acknowledged, interpreted and acted on) his daughter’s physiological reaction to the cold weather (i.e. her cold hands), as well as her apparent happiness when they went inside. Although, both unintentional expressions of preference, they were at the core of the decision made to move indoors. In this example, Angela’s father, previously assessed as having a positive perception of his daughter’s decision-making capability, clearly
demonstrated responsiveness to his daughter’s intentional and unintentional expressions of preference.

In contrast, the qualitative data set evidenced an association between supporters’ negative perceptions of the decision-making capability of those they support, and their unresponsiveness to expressions of that same person's will and preference. A quote provided by a supporter pre-intervention, classified as having a negative perception of Yuri’s decision-making capability, illustrated his unresponsiveness to Yuri’s expressions of preference. In this incident, the supporter is talking to the researcher about Yuri, while failing to acknowledge, and therefore respond to, his eye gouging behaviour. Yuri is watching television, vigorously (according to field note) gouging his eyes. The field note describes this scenario.

“I said, “what’s going on here then, what’s he telling us with the eye gouging?” [Supporter] responded “I don’t know, he’s always here when I start my shift, watching the box, seems to relax him you know, when he gets off the bus. Doesn’t care what’s on. Seems happy enough... He doesn’t give us much grief” He followed this up with an upbeat “D’ya want a cuppa? I’m having one”.

As is the case for the series of behaviours played out between Nathan and his supporter this interaction between Yuri, the supporter and researcher, highlights the interwoven nature of supporter responsiveness and perceptions of decision-making capability. The supporter, who was identified as having a negative perception of Yuri’s decision-making capability, doesn’t acknowledge, and
therefore doesn’t respond to Yuri’s vigorous eye gouging, saying, “[he] seems happy enough”, while focusing on his own needs and the needs of the researcher “D’ya wanna cuppa? I’m having one”. In addition, he paints a picture of Yuri as someone who is passive and does not contribute to the decision-making process, reflected in his comments, “He’s always here”, “Doesn’t care what’s on”, and “He doesn’t give us much grief”.

To summarise this section, the data predominantly supports the notion that supporters’ perceptions of decision-making capability is an underlying factor in supporter responsiveness to the expressions of will and preference of those they support.

4.3.3 Relationships

Relational closeness: an underlying factor in supporters’ responsiveness

As discussed in Chapter two, within literature relating to severe and profound intellectual disability, relational closeness is increasingly being recognized as an important factor by which supporters develop a picture of the preferences of those they support (Forster & Iacono, 2008; Johnson et al., 2014b; Rushbrooke, 2014). Considering the literature’s view on the importance of relational closeness, this study collected and analysed qualitative and descriptive statistical data to: determine supporters’ levels of relational closeness with those they support; establish if an association existed between relational closeness and supporter responsiveness; and finally, characterise relational closeness for this population.

As discussed in chapter three, determinations of relational closeness were
generated via supporters’ ratings of the level of ‘closeness’ they had with the person they supported, by choosing from five descriptive categories, ‘distant’, ‘not close’, ‘close’, ‘very close’ and ‘intimate’. Operational definitions of these categories are outlined in figure 8 in the previous chapter. Using these definitions as a guide, two supporters (6%) described their relationship as distant, two (6%) as not close, eight (24%) as close, seven (21%) as very close, and fourteen (43%) as intimate.

A comparative analysis of supporters’ reported levels of relational closeness and their levels of responsiveness highlighted an association between these two variables. At post-intervention, fifteen supporters were observed to be either responsive (n=12) or unresponsive (n=3) to the expressions of preference of those they supported. 100% of supporters who were observed to be responsive described their relationship as intimate, very close or close. Specifically, six (50%) reported a relationship with those they support as intimate; two (17%) reported a very close relationship and four (33%) reported a close relationship. No supporter observed to be responsive reported a ‘not close’ or ‘distant’ relationship with those they supported at the post-intervention phase. Of those observed to be unresponsive to the expressions of preference of those they supported at the post-intervention phase, none reported an ‘intimate’ relationship, none reported a ‘very close’ relationship, one reported a ‘close’ relationship (33%), none a ‘not close’ relationship, and 2 (66%) a distant relationship. This data is illustrated in figure 13.

It is important to note that this strong association between relational closeness and responsiveness was not reflected in Angela and Neil’s pre-intervention data
(see Appendix 4.1). In both these case studies, supporters demonstrated less responsiveness prior to the intervention then after it, and unlike post intervention, this responsiveness did not appear to be associated with relational closeness. An explanation of this outlying data is beyond the scope of this thesis, however it is highlighted here to spark inspiration for future research. A possible explanation of this outlying data may be related to Neil and Angela’s supporters’ largely negative perceptions of the decision-making and communication capability of those they support at pre-intervention. Although, relational closeness may be important to supporters’ responsiveness post intervention, at the pre-intervention phase, their perception of decision-making and communication capability appeared to be more important.

![Figure 13: A comparative analysis of supporters’ reported relational closeness and their levels of responsiveness (post-intervention)](image-url)
Paid versus unpaid support in terms of relational closeness

The data relating to relational closeness was further categorized in terms of paid/unpaid status, revealing an unsurprising finding that unpaid supporters (n=8) reported the highest number of intimate relationships with those they supported. Specifically, five (63%) unpaid supporters reported an intimate relationship, and three (37%) reported a very close relationship with those they support. In contrast, paid supporters (n=25) reported a smaller percentage of intimate and very close relationships than those who were unpaid. Specifically, nine (36%) paid supporters reported an intimate relationship, five (20%) reported a very close relationship, seven (28%) reported a close relationship, two (8%) reported a not close relationship, and two (8%) reported a distant relationship with those they support. This data is summarised in Table 4 below, and did not change over the course of the study.

<table>
<thead>
<tr>
<th>Reported level of relational closeness</th>
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<tbody>
<tr>
<td>Intimate</td>
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<tr>
<td>----------</td>
</tr>
<tr>
<td>Entire data set (n=33)</td>
</tr>
<tr>
<td>Unpaid Supporters (n=8)</td>
</tr>
<tr>
<td>Paid supporters (n=25)</td>
</tr>
</tbody>
</table>

Table 4: Supporters’ reported levels of relational closeness

Of particular interest is the finding that a supporter’s paid/unpaid status had no impact on supporter responsiveness. This finding is evidenced in Appendix 4.1 and illustrated in Figure 14 below.
The illustrated data in figure 14 suggests that although supporter responsiveness is associated with relational closeness it is not impacted on by supporters’ paid or unpaid relationship status with those they support. This finding suggests that regardless of supporters’ paid/unpaid role in a person’s life, supporter responsiveness is likely to be enhanced if relational closeness is increased.

An interrogation of the qualitative data set evidenced a strong correlation between qualitative descriptions of relationship characteristics and those chosen by supporters from the *Continuum of Relational Closeness*, developed for the purposes of this study, and described in chapter three. For example, Neil’s mother, who described her relationship with Neil as intimate, recounted the decisions made around her son’s funeral, saying, “It was everything that we all
know he wanted, coz you know, we know him love, we have known him all his life. We’re the closest people to him. We loved him more than anyone”. Neil’s mother’s comments reflect the points used to describe an intimate relationship outlined in the *Continuum of Relational Closeness*. This correlation is particularly evident in Neil’s mother’s words “we love him” and “we’re the closest people to him”.

Describing the opposite end of the relational closeness continuum, a casual support worker employed in Yuri’s house commented on Yuri’s behaviour. This supporter, who categorised his relationship with Yuri as distant using the *Continuum of Relational Closeness*, said, “I don’t know him, really, from a bar of soap. I don’t think I’ve looked after him before”.

An interrogation of data extracts took place in order to describe the characteristics of the categories beyond the *Continuum of Relational Closeness* developed for the purpose of this study. These descriptions were developed with a view to better informing practice in the enablement of relational closeness between people with severe or profound intellectual disability and their supporters. This interrogation found intimate or very close relationships between focus people and their supporters were characterised by each of the elements described in the *Continuum of Relational Closeness*. However, the data evidenced additional characteristics of intimate and very close categories. These were, 1) a knowledge of a focus person’s history and life story, 2) knowledge of the focus person “beyond their disability”, and 3) reciprocal enjoyment of activities together.
1) Knowledge of a focus person’s history and life story

Participants who reported intimate or very close relationships with those they supported described their relationships in terms of having knowledge of a focus person’s history and life story. Such information was not evident in the descriptions provided by the supporters who reported a distant or not close relationship.

A supporter who described her relationship with Kevin as intimate and had known him for more than twenty years recalled Kevin’s childhood, saying: “remember, no you didn’t work at [institution], he used to sit in the creek... loved that water, [he] used to sit there for hours”.

Neil’s mother, who described her relationship with her son as intimate, demonstrated her and her family’s deep historical knowledge of Neil’s preferences when talking about decisions that were made around his funeral.

   It was everything that we all know he wanted, coz you know, we know him love. We have known him all his life...... And Dave reminded me, you know his cousin... he reminded me about the jelly slice that he loved before the peg when he was teeny tiny. So we had to have that after didn’t we, with a cuppa you know. He would have loved it.

Neil’s mother continued talking about the decision for Neil not to have a tracheotomy, demonstrating the use of historical knowledge in responding to Neil’s expressions of preference and ultimately making the decision. “We knew he didn’t want that breathing tube again. He hated it last time. Do you
remember? I have some photos at home I’ll show you, he hated it, didn’t he Mike? He was ready to go”.

Neil’s father, who identified himself as having an intimate relationship with Neil, recalled his son’s love of speed and water, saying,

We used to take him up to Echuca. He liked to go for a ride in the speedboat. We used to sit him in the speedboat and he used to get excited with the water splashing and that sort of thing. He might be like me. I’m a bit of a speed freak!

One of Kevin’s supporters, who described his relationship with Kevin as intimate, demonstrated a similar knowledge of Kevin when asked to describe the communicative function of some of his wheelchair rocking and vocalizations.

For all of those seven years that I knew him, constantly walk, walk, walk! The whole day long he would hum a song and now that he’s in a wheelchair, I think he still sometimes likes that motion, so we will walk with him around the place.

One of Yuri’s supporters, who described her relationship with him as intimate, illustrated her historical knowledge of him, despite knowing him for less than a year. “I feel like I know him, you know really know him, even though I haven’t been here for years, like for instance Ann... it’s the photos and the old diaries and stuff, people’s stories about him as a kid”. Another supporter, who described her relationship with Angela as very close, similarly described the importance of listening to stories of Angela’s past in defining their relationship.
It’s just great to hear all the stories of what she got up to from her folks. You know she’s already had such an amazing life. Thanks to them, I really feel like I know her. Just looking at the family photos, and talking to them, I feel really close to her you know, like I have known her all my life. Really though, I’ve only really worked with her this year.

In contrast, Kevin’s supporter (a casual worker) who described her relationship with Kevin as ‘distant’ characterised her knowledge of his history and life story as limited. “Kevin, nope, I don’t know him, not like the others know him, I’ve only met him once or twice you know”. A supporter who described his relationship with Yuri as ‘not close’ said:

Yuri, well, I’ve worked with him for years. But I don’t know him. I don’t know his story you know. His family, never visited, so we don’t know who he is, you know, there’s nothing you know, no stories passed down. Not even a photo album or you know, there’s nothing for us to work with, you know.

In summary, the study found that supporters, who report ‘intimate’ or ‘very close’ relationships with those they support, are likely to be knowledgeable about their history and life story. In contrast, those who reported a ‘distant’ or ‘not close’ relationship with those they supported articulated little knowledge of the person’s history and life story. Supporters who reported a good historical knowledge did not necessarily acquire this knowledge through relationship longevity, but through stories and visual images shared about the person. That is, for supporters to have an intimate or very close relationship with a focus person,
they did not necessarily need to have known them for a long time, but have access to information from those who had.

2) **Knowledge of the focus person “beyond their disability”**

Participants who reported intimate or very close relationships with those they support described a ‘knowing’ of the person they supported beyond their disability. This notion of seeing a person beyond their disability has been described by Lyng (2007). Lyng suggests that a factor important in relationship closeness is knowledge or appreciation of a person’s life beyond their disability (Lyng, 2007). For example, he asked questions such as, “if a person had complete control over their life, what music might they listen to, what car would they drive or what clothes would they wear?”

A supporter, who described his relationship with Kevin as intimate, was asked “If Kevin had control over the stereo in the bus, what would he listen to?” He replied, “oh yeah... he likes some like rock type music, like ACDC. Yeah something with a bit of guts!” This comment was followed by a response from another supporter who described her relationship with Kevin as very close. “Yeah, you’re right, something with guts, loud loud loud! Yeah louder the better hey Kev. A deep heavy base line doesn’t ya reckon, Nirvana or may be even Primus”.

One of Yuri’s supporters who described her relationship with Yuri as intimate responded to the question, “If Yuri had complete control over what he ate, what would he choose?” with: “He’d be a foodie I reckon. You know creamy yummy cheese, flash wine, chocolate, the works”.
A support worker of Nathan’s, who described her relationship with him as intimate, answered the question, “if Nate had complete control over his life, what would his life be like?”, saying:

He would be comfortable, but stylish. He wouldn’t wear these trackie dacks. I think he would be quite social. He has that Scottish sense of humour. He would have to have a very fast car. I always thought he would be a courier or something like that.

Another of Nathan’s supporters, who described her relationship with him as very close, replied: “I can imagine him being a scientist or something, a focused kind of job. I think he would be a typical science teacher, sort of nerdy”.

Angela’s mother, who described her relationship with her daughter as intimate, when asked what Angela’s life would be like if she didn’t have her disability, replied, “she just really loves interacting with other people, singing, dancing, you know. She would have made a great cheerleader”.

In contrast, a supporter who described his relationship with Neil as “not close” demonstrated an unwillingness to see him beyond his disability. He replied to the question, “If Neil had complete control over his life, what food would he eat, what music would he listen to, what clothes would he wear, and what car would he drive?” “Hmmm, not sure what you mean there, he can’t do any of those things though... He’s not like you and I”. Additionally, the same supporter, who described Yuri as having “a lot of brain damage”, and reported a distant relationship with him, answered Lyng’s series of questions with,
...Really, I can’t really think of him like that, you know like being able to do normal things, like the rest of us. Sorry but that kind of life doesn’t apply to guys like him. I know what you’re trying to do, but I think we have to be realistic. It’s not fair to think about him in that way, do you know what I mean?

In summary, the study found that supporters, who reported an intimate or very close relationship with those they support, demonstrated a willingness to see the person they support “beyond their disability”. In contrast, those who described their relationship as not close or distant did not demonstrate this willingness.

This data taps into the notion of perceptions of personhood, discussed in chapter two. Lyng’s technique of encouraging supporters to see focus people “beyond their disability” illuminates the value of seeing someone as a person, rather than their disability. As discussed in chapter two, negative perceptions of personhood such as those illustrated by supporters in this study, may contribute to the perception that people with severe or profound intellectual disability lack personhood, and therefore do not meet the criteria of being human, a fundamental prerequisite to the granting of human rights. This view held by prominent scholars, such as Singer, promotes the notion that the promises of Article 12 have no relevance to people like Yuri and Neil, who are perceived by some as lacking personhood.

3. **Reciprocal enjoyment of activities together**

Participants who reported intimate or very close relationships with those they support described their relationship with focus people, and the activities they
did together, as enjoyable and humorous. In contrast, supporters who described their relationship as not close or distant described the interactions they had with focus people as lacking in these qualities.

Rochelle, a volunteer, who described her relationship with both Yuri and Kevin as not close, indicated her discomfort and displeasure when interacting with both men. She candidly said:

I know this sounds awful, but I kind of was shocked when I met them. Is it awful that I dry retched! Yuri had a smell! Oh, I'm sorry I sound awful. It wasn't only me though; he didn't seem to care that I was there either...

With Kevin and Yuri, I kind of get the feeling that they don't want me in their life. They give me very little back. D'ya know what I mean?

In contrast, a supporter, who described his relationship with Yuri as very close, illustrated a genuine enjoyment of his company during an afternoon tea at a café, close to Yuri’s home. “Hey Yuri, we love it here, don’t we mate? [He placed his arm around Yuri and squeezed]. We love people-watching together. There's all sorts come here, we have a bit of a laugh, don't we mate?”

One of Angela's paid supporters, Brenda, who reported a very close relationship with Angela, described their weekly “hang out”. “So, we love it. We really look forward to our Thursdays. You know we just hangout. Ang hassles me all week long, you know 'in the car car'. It's so much fun, we spend the whole day laughing!”

Describing the impact of unpleasant interactions on developing friendships and
therefore relational closeness, a supporter commented on Nathan's use of behaviours of concern in his local community and the impact they have on him developing close relationships.

His challenging behaviour don’t help, behaviours of concern, whatever we are calling it these days. The spitting, it’s so not attractive. It’s ok for us because we’re used to it, but all that spitting and then playing in it. We were in Spotlight the other day, people were staring and moving away, it’s just disgusting and I tell him that! I make him clean it up. Who’s going to want to be his friend?

In summary, the study found that supporters, who report an intimate or very close relationship with those they support, often demonstrated an enjoyment of activities together, and that this enjoyment appears reciprocal. In contrast, relationships reported as not close or distant, are characterised as lacking pleasure and, particularly in relation to the use of behaviours of concern, stressful.

The study has found that intimate or very close relationships between focus people and their supporters are characterised not only by the elements described in the Continuum of Relationship Closeness, but three additional elements. These elements are, 1) a knowledge of a focus person’s history and life story, 2) knowledge of the focus person “beyond their disability”, and 3) reciprocal enjoyment of activities together.
4.3.4 The functioning and make up of circles of support

A process of inductive coding, described in chapter three, identified two factors relating to circle of support functioning associated with supporter responsiveness. These are illustrated in figure 12 and include 1) collaboration and 2) conflict. These factors are explored in this section.

1) Collaboration: An underlying factor in supporter responsiveness

As discussed in Chapter two, literature is beginning to reject the concept of individualization within decision-making processes, drawing on the psychological need for interpersonal-relatedness or belongingness (Bach & Kerzner, 2010; Deci & Ryan, 1985; Wehmeyer, 1998). This body of literature is supportive of a collectivist and interdependent view of decision-making, particularly highlighted in cross-cultural studies (Bandura, 1989; Iyengar & DeVoe, 2003; Kagitcibasi, 1996; Ryan & Deci, 2000). Such a view has clear relevance to those with severe or profound intellectual disability, who, by the very nature of their disability, are required to live interdependent, as opposed to individualistic, lives.

In this study, qualitative and descriptive statistical data was collected and analysed relating to supporters’ attitudes toward responding to the will and preference of those they support collaboratively as opposed to individually. Interviewees’ responses were recorded to the question: “How much do you value a collaborative as opposed to an individual approach to responding to X’s expressions of preference? (Using a scale from 1-5)” Supporters who provided a rating of three or above were considered to positively value a collaborative approach to decision-making support, while those who provided a rating of less
than three were considered to have a negative value of such an approach.

Average ratings for each focus person’s support circle were calculated for the purpose of comparison across case studies. Predominantly supporters valued a collaborative approach to responding to the expressions of preference over an individual one, and this increased over the course of the study.

Data was analysed to determine if supporters’ valuing of a collaborative as opposed to an individualized approach to responding to the expressions of preference of focus people was associated with their actual levels of responsiveness.

As illustrated in Appendix 4.1, pre-intervention, six out of ten (60%) interviewed supporters, positively valued collaboration. Of these six, one supporter provided no responsiveness data, taking the comparative sample down to five. Of these five, three (60%) supporters classified as positively valuing collaboration were also classified as responsive.

Also presented in Appendix 4.1, when examined post-intervention, 100% of supporters, for whom data was provided, positively valued collaboration. Of these eight supporters, two provided no responsiveness data, taking the comparative sample down to six. Of these six, five supporters (83%) classified as positively valuing collaboration were also classified as responsive. This data suggests a positive association between supporters’ valuing of a collaborative approach to responding to the expressions of preference of those they support and their responsiveness to that same person’s expression of preference.
Examples of supporters who were classified as responsive and positively valuing collaborative approaches to responding to the expressions of preference of those they support were illustrated within the qualitative data set. Diane, a supporter of Kevin, illustrated the value she placed on a collaborative approach as opposed to an individual approach post-intervention, saying,

You can’t make life-altering decisions if you’re separated, if you have day service and home. You can’t make life-altering decisions if you are only looking at one perspective. So that’s why the collaborative approach, because holistically to make up one person we have to take into account what happens during the day as well as what happens at home.

During a facilitated group discussion, one of Nathan’s supporters, who was classified as responsive, demonstrated the value she places on collaboration in the supported decision-making process. “It’s not just about being his voice. It’s about working out what the hell he is saying. Um, the only way we can do that is to be collaborative”.

Data collected and analysed relating to collaboration was not only related to supporters’ views but also their behaviours. A short video snippet of each focus person was used at two phases of the research. Firstly, it was viewed by one individual supporter from each case study within the context of individual interviews. Secondly, it was viewed within the context of the workshop, by the circle of support collectively. In both contexts, supporters were asked to answer the questions: “Is X communicating here? If so what is s/he communicating? What do we know about his/her preferences?” The compared data provides a
description of what collaborative as opposed to individual interpretation of preference looks like for people with severe or profound intellectual disability.
Table 5: Comparing the value of an individual as opposed to a collaborative approach to supported decision-making using video. It suggests a collaborative as opposed to an individualised approach is most effective.

<table>
<thead>
<tr>
<th>Video snippet watched individually</th>
<th>Video snippet watched collaboratively</th>
</tr>
</thead>
</table>

**Video description:**

Yuri’s participation in an initial group meeting was video taped with a view to making a decision as to whether or not he should be a regular part of group meetings. This had come up because some people felt his presence at the meeting was ‘tokenistic’. Not everyone agreed with this view.

**NOTE:**

Kim provided both an individual and a collaborative response.

**Support worker:**

“Well he didn’t make any decisions. You can’t really say that he did. Really, I don’t know. All I can tell looking at this is that he wants to be out of there. He

**Support worker:**

“He communicated to us all that he was hungry and wanted a chest massage, you know with the humming and that, and we responded you know. I guess that’s a decision... We wouldn’t have made the decision to stop for lunch unless he let us
is certainly telling us that he is hungry”.

Support worker:

“We bounced things off each other until we came up with what we thought he was saying with the humming and rocking and that”.

Support worker:

“Yeah, we hardly ever get to do that you know, all work together on trying to work out what you are trying to tell us, hey Yuri?”

Support worker:

“Yeah, and you know he loved that video of himself, didn’t he ay?”

Support worker:

“That has led us to that first bit of the circle up there. He’s helped us come to a decision that we should help him make a decision about whether or not he gets an Ipad. Lucky bugger, wish I could have one. If we hadn’t seen him staring at that video, I mean, did you see his face?”

**Video description:**

Neil was being hoisted out of his wheelchair to stretch out on the floor. This happened most days at his day service, due to his life long
difficulties with contractures and spasticity, and therefore a physical need to stretch. Some days Neil appeared uncomfortable with the process of being hoisted and other days he appeared relaxed and comfortable. It was agreed that a decision as to whether or not he should be hoisted should be made according to Neil’s communication at the time of the hoisting. Therefore, if it were agreed that Neil was unhappy during a particular hoist, the process would stop and be retried later. A video of Neil being hoisted was made so supporters could practice responding to these expressions of preference.

<table>
<thead>
<tr>
<th>Support worker</th>
<th>Supporter 1</th>
<th>Supporter 2</th>
<th>Supporter 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>He’s not saying anything [No acknowledgment of preference expression]. He’s comfortable I guess. I know I should see something in this, it’s a trick question may be [No acknowledgment of preference expression]. I can’t see anything [No acknowledgment of preference expression]. I don’t know what he is saying, with that noise [No interpretation of preference expression], I don’t get what you’re wanting me to do, may be I’m missing something? Na, I’d just keep him in the sling, I don’t know [No action in response to preference expression]</td>
<td>“Wow look at that. Look at his face? Can you stop the video? I want to show you” [acknowledgment of preference expression].</td>
<td>“Ah, yeah, he looks a little stressed I reckon” [interpretation of preference expression]. “When you pause it like that, you see his little mouth change” [acknowledgment of preference expression].</td>
<td>“Looking at that, he isn’t happy. Not at all” [interpretation of preference expression]. “Listen, listen to that noise, that’s a pissed off noise [interpretation of expression preference]. “Bloody hell, looking at this he wants to stay in his chair” [interpretation of expression preference]. “Why didn’t she just leave him there?” [Identified action in response to preference expression]</td>
</tr>
</tbody>
</table>
The data displayed in Table 5 provides some evidence that supporters are likely to effectively acknowledge, identify, and act on focus people’s expressions of preference, when they embark on this process in collaboration with others, rather than on their own.

It should be noted that other factors may have impacted on these results, and therefore these findings should be considered with caution. The individual data was collected several weeks before the collaborative data. Therefore, supporters’ appreciation of collaborative approaches may have developed between the two data collection points, as a result of the supported decision-making process they were taking part in. Therefore, the change evidenced in Table 5, may have come about due to the education, training and mentorship provided by the researcher (Speech Pathologist), rather than the collaborative nature of the process. Additionally, the presence of other supporters within the collaborative scenario may have created a sense of peer group pressure, impacting positively on supporters’ attitudes when responding to focus people’s expression of preference. However, despite peer group pressure frequently having negative connotations, its value in changing attitudes and skill in terms of supporter responsiveness, within this context should be acknowledged.

*Enabling effective collaboration between circle of support members*

Considering the value of collaboration, the data was further interrogated to provide insight into enablers for collaboration. A thematic analysis revealed that collaboration within the context of the supported decision-making process used in this study, had three enablers. These were supporters, 1) having adequate
1) Supporters having adequate face-to-face time

Throughout the supported decision-making process, supporters from different agencies and environments were asked to spend more time together, face-to-face, than usual. Yuri’s supporter commented on the value of this, saying, “by far the most valuable part of this whole process has been us sitting together”. Another of Yuri’s supporters in his workshop evaluation, responding to the question as to what parts of the process he/she found most useful wrote, “Face-to-face meetings together. We haven’t done that so much in the past. After this I think people will prioritize getting together more”. Other supporters also reported a desire to increase the time they spent collaboratively brainstorming and problem solving. One of Kevin’s supporters answered the written evaluation question, “what part of the workshop helped you the most?”, writing, “Spending time face-to-face that got us talking across [day service] and [residential service]. Without that face-to-face time together, we would not have come to a consensus”.

Discussing the previous system, a support worker from Yuri’s house, highlighted the value of face-to-face time in developing a picture of a person’s preferences. Within the previous system, a bus driven by a support worker from the day service, rather than a taxi, drove service users to and from their day service.

Remember when we had the bus run, before they brought in taxis, and the wonderful Ida [bus driver] as our little carrier pigeon! She used to come
in the morning and every night and just hang out a bit, you know pass on information face to face, organically, you know. It really helped us, I guess with working as a team you know... across services”

Ida replied to this with,

Carrier pigeon, that’s cute! Yes, you know, just that little bit sort of like you come and you say, ‘yeah I know I wrote that, but you should have seen him today doing such and such’. You know those little stories to add to what is written in the diary.

One of the residential staff said:

I used to see Ida every morning. So we were always talking and you wouldn’t need to worry about writing in the diary in the morning, because I don’t have time to do that in the morning. I mean, if there’s something that they need to know I could just say to Ida, I think you need to know this.

These comments highlight support workers’ preference for face-to-face time in which to communicate with each other about those they support.

2) Supporters ‘getting along’

Throughout the supported decision-making process, supporters were required to spend more time together than usual, necessitating a general desire to “get along”. This desire was reflected in a comment from one of Kevin’s day service support workers at the beginning of the process. “Well I guess; we’re going to
have to put all this shit behind us you know. We’re going to have to spend more
time together, so we will try, we really will. Otherwise it will be a nightmare”. 
Reflecting on the supported decision-making process at the end of the study, this 
same supporter said, “Like, look at us ... not wanting to kill each other”. She 
continued, “And really we’re all here for one reason, we can’t do all this stuff for 
Kev, this stuff that Jo [researcher] wants us to do, if we don’t get along”. Angela’s 
father in a workshop demonstrated the value he placed on ‘getting along’. “You 
know, we’re all in this together, aren’t we? That’s what we think anyway. That’s 
why we try so hard to get along with all you lot”. This theme of ‘supporters 
needing to get along for effective collaboration’, is an important one, and points 
to the need for attention to be given to the development of skills relating to 
teamwork, particularly amongst support workers.

3) Supporters using video to collaboratively respond to preference

A comment made by one of Kevin’s supporters highlights the perceived value of 
using video collaboratively to identify preference. “...One thing that we have now 
that we didn't have access so much to back then is video. To me, it is such a gift, 
in terms of allowing us to document. Particularly for people who are 
unintentional communicators.” Another of Kevin’s supporters highlighted the 
value of using video to collaboratively document his communication, specifically 
his behaviours of concern.

So, he took some video of Kevin on his iPhone because [the psychologist] 
said it would be a good idea you know. He did this and it was great 
because we could all get together and have a look at it, and see what was
making him so upset, but rewinding and looking back at what happened beforehand and all that you know. We could really see that he was telling us things, that he really was saying shit with his behaviour, you know.

Further demonstrating the value of collaboratively watching video to acknowledge, interpret and act on expressions of preference, one of Neil’s supporters made the comment:

Wow, [researcher], that’s amazing that we can watch this together and really try to work out what he means. I mean I was there with him on that day, I was the one talking to him, and I didn’t pick up that he was getting upset. We should do this all the time you know, quickly get a snap and watch it back together.

To summarise this section, the study found that supporters are likely to value a collaborative as opposed to an individual approach to responding to the will and preference of those they support. Comparing supporters’ individual with their collaborative responses to video footage of those they support expressing will and preference evidenced this. Finally, the qualitative data set was interrogated with a view to ascertain supporters’ views regarding enablers of effective collaboration between supporters. Three enablers were identified: 1) supporters having adequate face-to-face time, 2) supporters ‘getting along’, and 3) supporters using video to collaboratively respond to preference.

2) Conflict: An underlying factor in supporter responsiveness

Despite multiple examples of collaborative behaviours, supporters also demonstrated non-collaborative behaviour in the form of conflict, particularly at
the beginning of the supported decision-making process. This conflict had an
obviously negative impact on supporters’ collaboration. Additionally, an
association was found between circles of support characterised by conflict and
individual members’ responsiveness.

As described in Chapter three, ‘Conflict scores’ were calculated using a template
to record ‘incidents of conflict’, displayed in Appendix 3.15. Conflict scores for
each circle were calculated at the initial gathering and then again at the final
gathering. For Neil however, there was no final gathering, as he died over the
course of the study.

Pre-intervention, Nathan’s circle of support was observed to have the lowest
conflict score of zero. This circle of support was noted to have the highest level of
group responsiveness, with seventy-five percent of supporters classified as
responsive. Conversely, Yuri’s circle was observed to have the highest levels of
conflict, with a conflict score of 4, and the lowest level of group responsiveness,
with thirty-three percent of supporters classified as responsive. This data might
suggest an association between supporter conflict and responsiveness,
warranting further investigation within the qualitative data set. The qualitative
data set was analysed to explore this association. Data extracts tagged with the
parent codes ‘non-collaborative behaviour’ or ‘circle of support conflict’ and the
descriptor ‘unresponsive’ were interrogated.

One of Yuri's day service supporters, tagged with the descriptor ‘unresponsive’
said to Yuri's house supervisor, “I know you all think they come to [day service]
and sit around all day, that really shits me, that you say that. We work really
hard... and you wonder why we don’t talk to you lot”. Another supporter, tagged as unresponsive, replied, “Ahhh here we go. It’s always our fault”. Similarly, during an observation session at Yuri’s day service, a supporter, tagged as ‘unresponsive’, looking at Yuri’s chair said, “you’d reckon they [residential service] could clean his bloody chair. No, that’s right it’s our job, we just sit around on our bums all day”.

In an initial interview, one of Kevin’s day service supporters highlighted the conflict that existed between day and residential service. Two of the disability support workers named in this quote were tagged as unresponsive to the will and preference of those they support. The third one was not formally observed, and therefore was not classified as responsive or unresponsive.

Yeah, it’s pretty tense! I’m not sure why, but we just don’t get along. I guess though, there’s only a few of them, no there’s quite a few, that prefer to bitch all day, rather than attend to the guys. You know like [day service worker], [day service worker], and you know at the house too, like that, what’s her name, [residential services worker].

This quote not only highlights conflict existing within the circle of support, generally, but also the impact of conflict (“bitch[ing] all day”) on supporters’ responsiveness to those they support. The scenario describes a situation where supporters appear more focused on “bitch[ing]” than “attend[ing] to the guys”, suggesting that conflict is interfering with supporters’ role of responding to the expressions of preference of those they support. Another scenario described in the field notes further highlights this. The field note describes the scenario as:
Yuri is sitting, eye gouging (see photo). [Support worker] is talking (yelling) to [house supervisor] about the ‘state’ [another resident] came home from [day service] in. She said, ‘she was covered in shit, from top to bottom. Surely, they knew she needed to go to the toilet before the bus left. Bloody hell, I’m over this’… Yuri is now rocking in his chair and eye gouging more. He is yelling, beginning to whimper. The staff ignored him.

Three themes frequently appeared describing the root cause of the conflict. These themes were predominantly related to conflict between agencies, namely day and residential services. These included communication breakdown, disrespect between agencies, and competitiveness.

1) Communication breakdown between agencies

A day service worker described the communication breakdown (manifesting in conflict) between day and residential staff. “What makes one group of people not understand what the other group is doing”? Another supporter described the communication breakdown that regularly occurred between day, and residential, services support staff, and the impact this was likely to have on the support provided to service users. “We just don’t connect you know. We’re not on the same page for the guys. They do their thing. We do ours. Imagine the confusion for Kevin and Yuri”. The researcher asked one of Neil’s supporters her opinion on the impact of existing conflict between supporters on Neil’s ability to participate in decisions about his life? She replied with,

Hmmm I guess it means we don’t communicate much, so we don’t know what each other are doing you know. Makes it pretty hard to get a clear
picture of poor old Neil. I guess he’s the one that is affected by it all, all our rubbish you know.

2) Disrespect between agencies

Disharmony between supporters was characterised by feelings of being disrespected. A day support worker described her feeling of being “judged” by other residential support workers. “I don’t know, I think we feel really judged by them. They’re always telling us we’re wrong”. She goes on to highlight the impact this has on focus people. “I don’t know it makes supporting the guys so hard”.

Early in the project, Kevin’s day service support team described tension existing between day and residential service supporters, specifically in relation to them feeling disempowered in the decision-making process, with one of the team making the claim:

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The decision they tried to make without us was about his whole package, it would go over to them, and it would happen on such and such a date, you know, on the Friday, and starting on the Monday with no connection between the two.
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A day service supporter described her feelings of being undervalued.

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You feel like, oh well I feel like, oh so day service doesn’t count. People just think they come here to sleep out the day... Everything we do is really valuable, but that’s not recognized. Makes us just give up talking to them.
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And you know as Sue [pseudonym] said, who does that affect you know?

3) Competitiveness

Competitiveness was evident in supporters’ perceptions of who had the closest
relationship with the focus person. One of Kevin's supporters said:

I mean Barb has known him since he was a tot, like way back in [the institution], when he was dropped off there. But you know that isn’t acknowledged. They think they own him, you know, that they are the only ones who give a shit. I mean we love him too.

Themes of competitiveness were not only evident regarding relational closeness between supporters and supported, but in relation to resource allocation. This is highlighted in a residential supporter’s comments within the context of a conversation with her colleague, a support worker from Kevin’s day service.

Whose got the time for this? I’m sorry, but we can listen till the cows come home, but the reality is they all have needs. You don’t have the workload we have. You should be in the house at dinnertime, baths, meds, food, pegs, bloody hell it’s crazy. Have you ever worked in a house? Kevin is not the only one. The others have needs too. And then you know, just because he says he needs dinner now, doesn’t mean we can physically do it. It’s way more complex than you think. Of course we listen to him and we take into account what he wants, but at the end of the day, it’s not all about him. It might be at work because there is one on one support but we are not that lucky. I think there needs some kind of understanding of that, you know.

Competitiveness between support groups was also illustrated in discussions around individualised support packages. Kevin and Nathan both have individualised support packages. Unlike Nathan however, Kevin has two service
providers supporting him, with one service provider (his day service) receiving and handling his package and the other (residential) receiving block funding to provide him with support. This difference in funding structure between the two services caused tension between the agencies. This tension is exemplified in a residential support worker’s comment,

Ok on the weekend Kev can go for a swim. But there is a lot of work to be done to make it happen, fairly [emphasis on the word], because we are talking about six other people. We need to fairly allocate staff and rotate it around. It’s not like during the week because you guys have the package. You can have one on one with him. We just don’t have that luxury.

Analytical codes relating to conflict were analysed to ascertain how they were distributed across extracts tagged with particular descriptors. This analysis revealed several patterns within the data corpus suggesting associations between particular descriptors and the presence or absence of conflict. Two of these patterns in the data are explored below. Firstly, the role played by unpaid supporters in reducing conflict and enhancing collaboration within a circle of support is discussed. This is followed by a discussion of the role of a communication coordinator within this same process.

*The absence of unpaid support: a factor associated with conflict*

Conflict amongst circles of support was particularly evident for Yuri and Kevin, neither of whom, had any unpaid support in their life. The three circles that were inclusive of unpaid supports, such as family or friends, were found to engage in less conflict than was the case for Yuri and Kevin. This phenomenon is reflected
in the descriptive statistical data. The average conflict score was calculated for circles that had paid supporters and those who did not. Figure 15 displays this data suggesting that the presence of unpaid supports may have a positive impact on reducing conflict within circles of support. The root causes of conflict within the two circles consisting of only paid support, were predominantly competitiveness and disrespect between service providers.

Figure 15: Average conflict scores according to whether or not the circle included unpaid supporters or not.

The study’s qualitative data highlighted the role played by unpaid supporters in reducing conflict. During an initial workshop for Nathan’s circle of support, supporters were asked to describe their roles. Frank, an unpaid friend, described his role as “me, I don’t know, I’m just his buddy. You know, I take him on drives
and that”. A paid supporter in the group, replied, “[Frank] you do more than that. Doesn’t he hey? You cut through the bullshit. You know, you don’t let us carry on with all the politics. Like, the house did that, day service did that. You’re like our referee [group laughter]”. In a workshop, one of Neil’s paid supporters, praised his mother, saying:

Well I have to say, if it wasn’t for [Neil’s mother], you know, we would still be arguing about what poor old Neil has in his lunch each day. She helps us realise what’s really important, and it’s not bloody fighting with each other. You help us kind of get along, I reckon.

**The absence of leadership: a factor associated with conflict**

As previously described, for both Angela and Nathan’s case studies, a pre-existing group leader in the form of a communication coordinator played a significant role in the supported decision-making process carried out during the study, specifically around increasing their perception that the person they support was capable of communicating. Another interesting correlation in the descriptive statistical data was the possible link between reduced levels of conflict and the existence of a communication coordinator.

The average conflict score was calculated for circles that had a pre-existing communication coordinator and those who did not. Figure 16 displays this data suggesting that the presence of a communication coordinator may have a positive impact on reducing conflict within circles of support.
An interrogation of the qualitative data set evidenced a correlation between the presence of a communication coordinator and reductions in conflict between supporters. Specifically, data was interrogated tagged with the analytical codes ‘value of coordination role’ and ‘conflict between supporters’.

A supporter at Kevin’s residential service highlighted the importance of a coordination role in Kevin’s life, specifically in helping reduce conflict. “Yes, there is a clear lack of one person to coordinate things, and help us sort through all this shit. You know to cut through all our bullshit and infighting. You know, to be that country, Switzerland”. The perceived benefit of a person taking on a coordination role, in reducing conflict, was further exemplified in a comment from one of Yuri’s supporters made to a communication coordinator.

We were just talking about key ingredients to collaboration you know.
What does it take to, you know, pull it all together? You know, stop this fighting across here [day service] and [residential service]. We think you’re it darling. Like, you just have this way with people, you know, building a bridge. Weaving the ties that bind.

To summarize, this section identified two factors relating to the function of circles of support, which contributed to supporter responsiveness, and consequently to decision-making support for people with severe or profound intellectual disability. These were identified as collaboration and conflict among circles of support. Both of these factors were explored in this section.

4.3.5 Characteristics of the service system

The disability service system has an undeniable impact on people with disability and their supporters. People with severe or profound intellectual disabilities, in particular, have a high degree of dependency on the system to have their will and preference responded to (i.e. acknowledged, interpreted and acted on). This system, through its structure, allocation of resources, policies, procedures and culture has the power to determine whether these people have their right to self-determination realized. Within the context of this study, the service system brought several challenges and enablers to the supporters’ role of responding to the will and preferences of those they support.

At the end of each case study, during a final gathering, supporters were asked to collectively identify three factors that they believed made the process of responding to the will and preferences of those they supported challenging. These were presented in no particular order and revealed thirteen answers, across the five case studies. The barriers identified were all related to the service
system. These perceived barriers were arranged into four overarching topics: allocation of resources, balancing duty of care with focus people’s right to choice, balancing occupational health and safety with focus people’s right to choice, and system opposition to relational closeness between paid supporters and focus people. This activity provided a list of potential barriers, each of which were explored within the study’s qualitative data set in order to ascertain its relationship to supporter responsiveness.

1) Resource allocation: an underlying factor in supporters’ responsiveness

A strong theme emerging from participants’ answers to the question relating to barriers to supporter responsiveness, and a thematic analysis of the larger data set was resource allocation. Data tagged with the descriptive code ‘resource allocation’ was interrogated, and found to be associated with three main resource categories, time, staff, and finances.

A lack of time:

Time was clearly a concern for supporters, particularly those within a paid role. Concerns around the lack of time were expressed in relation to supporters having time to engage in quality interactions with those they support. Such interactions, as discussed in chapter two, are fundamental to decision-making support for someone with severe or profound intellectual disabilities as they provide the context within which preferences are acknowledged, interpreted and acted upon (i.e. responded to). Within a workshop a supporter said,
Some of the organizational issues that would need to be resolved are around time. Connecting with guys like Nathan, takes time. Because of the personal care needs of some people, a lot of their one to one time is used for their basic needs, you know, stuff that is not negotiable. But we need time just to be with the guys so we can get to know them. Do all this stuff you are talking about, you know really listen to them, explore options, document bla bla...

Kevin’s supporter Jane, highlighted the barriers a lack of time places on supporters’ ability to respond to the will and preferences of those they supported,

I don’t think he was ever given the opportunity to participate in these kind of decisions, because it just wasn’t possible for him to have that choice around where he lives and that. There’s no time, there just isn’t. We can’t implement those things.

Here Jane is implying that time is an underlying factor not in supporters’ acknowledgment or interpretation of Kevin and his peers’ will and preference, but in supporters’ ability to act on these expressions, one of the three key components of responsiveness. One of Yuri’s support workers expressed similar concerns. She blamed a lack of “time, people and money” for supporters’ difficulties acting on the expressions of will and preference of those they support.

I’m just like, it’s not going to work unless things change, you know [raises hands in the air]. It’s all about time, people and money. We can listen all
we like to what he wants but being able to actually give him what he wants. That’s what it comes down to.

Additional concerns around time were evidenced regarding supporters having time to complete the communication diary on a daily basis. This diary serves as the main day-to-day communication between home and day services. It is an important vehicle through which focus people’s experiences and activities are documented and therefore communicated between supporters working in residential and day settings. This documentation is a valuable information source, commonly used by supporters to infer the will and preferences of those they support. Without this communication source, supporters can be further challenged in their ability to respond to those they support. This challenge is illustrated in a comment from one of Neil’s day support staff.

The diary, you know if it’s not in his bag, it’s so frustrating. I rely on it to know what’s up with him. You know what he might need that day. What happened overnight? Is he tired? You know, does he want to plonk in the beanbag all day?

Despite the communication diary’s value in supporters’ ability to respond to focus people, Yuri’s supporter articulated her difficulties in having time to complete the communication diary in the mornings. “Like so we’re trying to get people up and ready in the morning. There just isn’t time to write in the diary”. One of her colleagues replied with, “and they might not even read the diary until lunchtime, because they just don’t have time. That’s a real problem you know, ‘cause there’s important information in there, you know like what he is going to
need that day”. A third supporter from the day service replied with, “that’s right and we end up with people pretending that they are communicating with the house because people are too scared to admit they don’t have time”. Yuri’s supporter from the residential service replied.

I think it is actually getting worse. I have loved coming together, and Yuri has really benefitted from us coming together through this process, you know I reckon we are all on the same page with responding to him and that, but where would we get the time in the real world to do this, it just won’t happen.

The second residential support worker responded to this with, “Yeah, if I was to have this many meetings for all six clients that live here, man, could you imagine?”

A lack of staff:

Supporters blamed a lack of staff on their unresponsiveness to focus people’s expressions of will and preference, not in relation to these expressions being acknowledged or interpreted but acted upon. A descriptive comment on a Questionnaire about Choice exemplifies this. “Staff and time restraints just makes it impossible to let him soak in the bath for as long as he wants”.

One of Yuri’s supporters further highlighted a lack of staff as a resource barrier to her ability to act on Yuri’s preferences regarding the timing of his evening meal. “In relation to the timing of his evening meal, Yuri doesn’t have complete choice. It depends on what works for staff, you know what they already have on
their plate”. A comment within the context of a group discussion further demonstrated similar barriers, specifically regarding choice around support personnel. “Yuri has no choice as to who supports him. I can’t see how that would be possible. We just haven’t got the staff, you know so they can pick and choose. That’s just the way it is”.

As described, supporters highlighted the value of assigning one staff member to the role of coordinator, whose role was focused on communication. Within the context of this study, this value was specifically found to reduce conflict between supporters and increase supporters’ understanding of the universal nature of communication. Despite the value of such a role, supporters articulated that dedicated resources needed to be allocated to the coordination role. At the beginning of the research, Kevin’s circle of support was asked to nominate a group coordinator, the response highlighting feelings of being overburdened. Specifically, the response provided evidence of supporters’ view that there was a lack of staff to carry out a coordination role.

Look, it depends on what you are asking us to do. We haven’t got a minute to scratch ourselves now. We need extra staff to do something like that. Look, we need to dedicate someone with time to it, that’s what I reckon anyway, otherwise its just not going to happen. It will be like so many other programs and shit in the past, they sound great, but we just don’t have the staff to really make them happen.

When a coordinator did not pre-exist within a circle of support, the researcher tended to adopt this role. This role predominantly included the coordination and
facilitation of meetings as well as group communication. Of interest are field notes highlighting the researcher’s challenge in discontinuing her relationship with the focus person and his supporters. The complexities of “exiting the field”, a term used by Kirk and Miller (1986) in their description of the ethnographic process of removing one’s self from the research field (Kirk & Miller, 1986), are not uncommon, particularly within the context of research studies that involve the development of relationships as was the case in this one. An entry in the researcher’s reflective diary highlights the complexities of field exiting, particularly in relation to ensuring the supported decision-making process would continue to be coordinated and facilitated.

I am finding it hard to remove myself from each of the support circles. When I think about where this anxiety stems from, I think it is about a few things: 1. Feeling like the job isn’t finished, not in terms of the research, but in terms of making life better for the focus person; 2. Not trusting that the circle will follow up; 3. I feel the need to constantly be giving them direction. 4. There is no one else to lead the process.

A supporter reflecting on the importance of the researcher’s coordination role, made the following comment in a final gathering. Referring to the researcher, she said,

The only reason why this project is working is because you are here running the show. So how do we make it happen again for the others? They [management] just don’t understand and respect that to develop something like this takes time and to do it well there needs to be someone leading it.
Another supporter continued,

Yes, we need someone to pull it all together. Who’s got the time for that? You know, someone to make sure we meet, send emails, make phone calls, keep notes. All that stuff. That’s just not possible with the staffing we have. You know, it’s about someone leading the process, like I said pulling it all together.

The initial speaker in the dialogue replied, “yes... we’ve had someone, you, here to run the show. We could focus on our job of responding to the guys, not running around coordinating shit”.

The researcher’s hesitation in ‘exiting the field’ further highlighted the lack of leadership and coordination within some of the support circles in the study. The data suggests that this may be caused by the increasing demands placed on disability support workers’ time and energy, as discussed in Chapter two (Bigby & Atkinson, 2010; Bigby, Frederico, & Cooper, 2004; Iacono, 2010). One of Kevin’s supporters expressed her feelings of being over burdened by the job, saying,

You know what, we need to work something out with the powers that be. I can’t do it all. I’ve just got too much. I can’t run this place and do all this stuff and work on the floor. I’m supposed to be on the floor too today. I just can’t. This stuff is all terrific, but at the end of the day, the issue is staffing.
A lack of finance:

Financial constraints were identified by Kevin's support circle as a barrier to him being able to have his identified preference to spend more time outdoors acted upon. A residential support worker said,

Kev’s home is not set up for him to be outside independently. He can’t go out there; the backyard is sloped like this [gestures with hands]. So the one thing that he really enjoys doing, we can't provide it. We have heard his preference, but we’re not allowing him to building these preferences into a decision about what his home looks like.

Outlining the financial tensions, another support worker added, “I know, but it is not just about Kevin. It's just trying to work with what we’ve got. The quotes we got back to do that backyard were horrendous. You find me the money!”

2) Balancing supporters’ duty of care with focus people’s right to choose: an underlying factor to supporter responsiveness

Considering their duty of care, it is easy to understand why some supporters and service providers express concern about relinquishing control, and fostering the autonomy of focus people. However, sitting alongside this duty of care is an obligation on supporters to respond to the expressions of will and preference of those they support. This obligation is reflected in conventions such as the UNCRPD and is central to rhetoric around Australia’s National Disability Insurance Scheme. Responding genuinely to the will and preference of focus people may inevitably involve a degree of risk, placing supporters in a “tricky” position as expressed by, Rachel, one of Angela’s supporters.
We really do try to listen to Ang and what she wants, don’t we guys? But we just can’t let her chase the work experience boys down the street. You know we have a duty of care to her and to others. Poor lads! It’s tricky. It’s like walking a tightrope some days juggling all this stuff. And yeah, how much do we get paid again?

As discussed earlier in this chapter, the study found that supporters were more responsive to focus people’s expression of will and preference if that person communicated intentionally as opposed to unintentionally. This was particularly evident when decisions were perceived as risky. Neil’s supporter, reminisced about the decision that was made for Neil (an unintentional communicator) to have a permanent gastrostomy as his primary nutrition source, saying:

Well he was aspirating all the time. It was just too risky. We had no choice. He was always in hospital with pneumonia. Na, even if he could participate in the decision he would have had no say, it had to go in, you know, it was a matter of life and death. Ask Tina the speechie. That’s just the way it had to be.

The decision made about Neil as to whether or not to have a gastrostomy was contrasted with the same decision made about Kevin, an intentional communicator, some years before. Jill, one of Kevin’s support workers was asked how this decision was made. Her reply highlighted her acknowledgement of Kevin’s will and preference.

Well it was hard. Kev loves his food. I mean he really loves his food, hey guys. So, we knew what he would prefer. But he had so many bouts of
pneumonia, and he gets so sick. Remember that Christmas he was in hospital, poor love. But we weighed things up and it was clear that he wanted to eat orally, so even though he now has the peg, we let him take risks and eat most days. It’s just really important to him, so it’s worth the risk. That’s what we reckon anyway.

A comparison of the way the same decision was approached for Kevin and Neil, highlights the different attitudes toward risk that are overlayed on unintentional versus intentional communicators. That is, those whose expressions of preference are believed to be intentional and less ambiguous may be more likely to be supported to take risks, than those who are unintentional communicators.

3) Balancing occupational health and safety with focus people’s right to choice: an underlying factor to supporter responsiveness

Supporters in this study were overwhelmingly of the view that the system’s focus on occupational health and safety was “over the top”, a descriptor used twice within the context of different case studies. One of Neil’s day service based supporters expressed her concerns around the system she was a part of, saying, “you know, I reckon in our panic to make sure everyone is safe, mostly ourselves, the pendulum has swung too far. It’s not really about the guys anymore”.

The data set highlighted the role of strict occupational health and safety procedures and culture on supporters’ ability to acknowledge, interpret, and act on (respond to) focus people’s expression of will and preference. A supporter of Yuri’s described the decision to purchase him a bed.
Well, as far as the bed goes, he likes a soft mattress, but other than that, I don’t think he needs anything too pricey. I’m sure he would rather spend his money on other stuff, like a fishing rod. But you know, the powers that be, say he has to have a super expensive wiz bang bed that’s like low to the ground and that, so we don’t hurt our backs. I mean the message is that our needs are more important... Our needs are more important. They just don’t give a shit about what he wants, if staff safety is on the table. They’re worried about getting sued.

Another one of Yuri’s supporters in an individual interview said, “we can’t always explore options from his perspective because like with the bed, from management’s point of view, it has to be high low, because our backs are their main concern. They are afraid of getting sued, you know”.

4) System opposition to relational closeness between paid supporters and focus people: an underlying factor to supporter responsiveness

Despite the positive impact relational closeness, and its associated elements, appear to have on supporter responsiveness; supporters expressed reluctance to report having a relationship with the focus person independent of their paid role. For example, two paid supporters who had personal relationships with the focus person beyond their paid role, indicated, in an individual interview that they “loved” them, but they were unlikely to admit this to their employer due to management’s view on “inappropriate relationships”. The qualitative data was combed for further evidence of this phenomenon. This analysis supported these concerns, revealing ethical opposition instigated by service providers to paid supporters blurring boundaries between their professional and personal
relationships with focus people. A service manager during an observation session said:

I’ve told her [paid support worker] that she shouldn’t be dropping in there for a cuppa! She knows too much about Neil and his family. It’s ok that she shares superficial things with them, you know, tell them about what movies she has seen and what she got up to on the weekend, stuff like that. But that should be it. She’s way too open with them. I think she wants to be their friend.

Similarly identifying an organizational discourse which seeks to prevent relationship closeness, a paid support worker, referring to a friendship between an ex colleague and a service user, said, “[It was] decided [that] the pair’s relationship was wrong, that such a friendship was ‘unprofessional’ and crossed the boundaries of what was acceptable. So it stopped. No more meals with the family. No more days out or festive fun”.

Moreover, paid supporters who reported being open to extending their relationship beyond their paid roles expressed concern and confusion regarding service providers’ views of relationships. A paid supporter expressed this confusion. “I don’t know. We get all these mixed messages. You can’t step over the line in terms of professional and personal stuff. I don’t get it. It’s impossible. I’m meant to care, but I’m not meant to care”.

A support worker within a group email, towards the end of the supported decision making process, eloquently articulated this dilemma, stating:
Unfortunately, I think the concept of ‘professional boundaries’ is often misinterpreted as social and emotional distance. Surely, what lies at the heart of what we do is compassion and empathy. Social and emotional support needs to be in our job descriptions... I wholeheartedly hope that one day [service provider] will look for evidence of quality in the relationships between the people supported and their carers and that they provide training in empathy, listening skills, compassion etc., etc.

To summarise this section, four characteristics of the service system were found to impact on supporter’s responsiveness to the expressions of will and preference of those they support and therefore to their role in the decision making support process. These characteristics were each presented and discussed in this section and include, allocation of resources, balancing duty of care with focus people’s right to choice, balancing occupational health and safety with focus people’s right to choice, and system opposition to relational closeness between paid supporters and focus people.

4.4 Impact of the intervention used in this study

This chapter has presented the importance of supporter responsiveness to the expressions of preference of those they support as a central aspect of supported decision-making for people with severe or profound intellectual disability. In addition, it has presented and discussed a range of factors evidenced to have an impact on this responsiveness. Considering the fundamental role of supporter responsiveness, it was pleasing that a pre and post intervention analysis revealed not only a positive change in supporter responsiveness but change in several of the factors found to impact on this responsiveness over the course of
the study.

Statistical descriptive analysis illustrating this change is presented in this section. Although this data is useful in pointing to positive change, the focus of this section is on the qualitative data set describing these changes. In addition to supporter responsiveness, the factors that changed over the course of the study were, a) supporters’ perceptions of focus people’s decision-making capability; b) supporters’ perceptions of focus people’s communication capability; c) collaboration between supporters; and d) conflict between supporters. This data supports the conclusion that these factors have a strong bearing on supporter responsiveness to the expressions of preference of those they support.

4.4.1 Change in supporters’ responsiveness

Pre and post comparative data indicates an increase in the number of times a supporter was responded to during a one-hour observation session across the study. This increase is illustrated in Figure 17. The post intervention data relating to Neil’s supporters was not recorded because he died before this data could be collected.
Despite the absence of statistical testing, it appears that there is an increase in instances of responsiveness over the course of the study within each case study, but an increase in the number of supporters found to be 'responsive' overall.
Of the nineteen supporters observed pre-intervention, eleven (58%) were classified as responsive and eight (42%) were classified as unresponsive. Post-intervention, of the fifteen supporters observed, twelve (80%) were classified as responsive and three (20%) were classified as unresponsive. This data is illustrated in figure 18 below. Only three out of seven supporters, for whom data was available both pre and post intervention, labeled unresponsive at pre-intervention appeared to remain unresponsive post intervention.

![Supporter responsiveness over the course of the study](image)

Figure 18: Supporter responsiveness over the course of the study

The increase in responsiveness by supporters to the expressions of preference of those they support is evidenced through quotes provided at the end of the supported decision-making process. One supporter’s response typified the comments, describing this increase as follows: “I mean I reckon we’ve always been good at working out what she wants, but now I reckon we listen to her better, you know really listen and respond”. Another supporter during a final
gathering said, “Look, the biggest thing for me is how I really focus on him. I didn’t do this before all this. You know what I mean. I really listen, well not listen, you know, focus on what he’s saying. I don’t think I did that before”.

4.4.2 Change in supporters’ perceptions of focus people’s decision-making capability

As illustrated in Figure 19 below, pre-intervention forty-eight per cent of supporters held a positive perception of the decision-making capability of those they supported. Post-intervention, eighty-one per cent held this perception. This positive change of perception over the course of the intervention is most evident via the study’s qualitative data.

![Figure 19: Changes in positive perceptions of focus people’s decision-making capability over the course of the study](image)
Angela’s mother, in a pre-intervention interview illustrated her negative perception of Angela’s decision-making capability, saying, "when it comes to the big stuff, you know, where she goes on holiday, people like Ang can’t make decisions”. In contrast, Angela’s mother demonstrated a possible reconceptualization of her daughter’s decision-making capability in a post-intervention interview. She said, “yep, I can see now, she can make decisions, well not make decisions, you know, but I kind of see what you’re talking about you know. She can participate in the process, mmm”.

This quote does not illustrate a change in Angela’s decision-making behaviour, but in her mother’s conceptualization of what constitutes her daughter’s decision-making capability. This was also illustrated in another supporter’s comments pre and post intervention. While completing the Questionnaire about Choice before the study’s initial workshop, this supporter said, “Jeeze, this questionnaire is hard. She’s just not doing these things, it’s us that makes decisions for her”. In a final gathering this same supporter said, “I mean now it’s clear she’s not always deliberately, intentionally whatever saying something, but she is telling us something, hey don’t you reckon guys? I never really got that before?” As was the case for Angela’s mother, this supporter’s quotes do not demonstrate a change in Angela’s behaviour, but a reconceptualization of supporters’ perceptions of what decision-making capability means for Angela.

For Angela, decision-making capability is illustrated in her expression of will and preference. The success of the overall decision-making process is reliant on her supporters’ responsiveness to her will and preference, as previously described.

The one supporter found to hold a negative perception of Nathan's decision-
making capability pre intervention demonstrated not only a change in his perception of decision-making capability, but an opinion about the nature of this change. Early in Nathan’s initial workshop, this supporter said in a hostile tone, “man, I don’t think people know them. What’s all this about? He can’t make decisions. He just can’t. That’s just the nature of who he is”. In contrast, during a final gathering, post intervention, this same supporter said:

I’ve learnt a lot with you coming in... I see what you mean. Like, he can’t make decisions like you and I, you know like whether he should have a Panadol, but he certainly like you say, contributes, you know helps us, by letting us know he’s in pain, smacking his head and screaming. We just have to listen don’t we?

This supporter appeared to demonstrate a change in the way he conceptualised decision-making capability for Nathan over the course of the study, along with an appreciation of what this reconceptualization might look like. A comparison of his pre and post intervention comments evidences this supporter’s newly found understanding of decision-making capability, particularly for Nathan. In contrast to his earlier articulated belief that Nathan “can’t make decisions”, this supporter articulated a new understanding, stating that he “contributes [to the process], you know helps us, by letting us know”. In addition, he articulated the important role of supporters, that being “to listen”. In this way, this supporter highlighted a move from an understanding of decision-making capability where by Nathan played no part in the process, to a bidirectional process where Nathan’s role is to “contribute” and his role as supporter is to “listen”.

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At the beginning of the supported decision-making process, supporters were asked to suspend or set aside their personal and collective preconceptions or biases regarding the person they supported. They were asked to write these down, to be revisited at the end of the process. Although the effect of this technique is difficult to measure, it appeared to increase supporters’ awareness of their personal biases and their potential impact on their interpretation of preference, as illustrated in Jill’s comment regarding Nathan.

Well yes, it is a bit of a guessing game sometimes. But you have to step back a bit you know. That’s why having this list of our values and things, is important, I reckon. I wouldn’t have thought of doing that. It kind of keeps me honest you know. Coz I know that I would rather not go to Maccas for lunch, so if I had my way, well, we’d be going somewhere else. But I have to check myself you know, it isn’t about me. Just because I hate everything about bloody McDonalds, you know, that’s my values.

One of Yuri’s supporters, reflecting on the use of this technique, demonstrated a change in her perception of Yuri’s decision-making capability. Of particular interest is this supporters’ reconceptualization of decision-making capability from an individualized concept to a collaborative one. While reading her written reflections during a final gathering with Yuri’s circle of support she said:

Looking at this... I’ve absolutely changed the way I think about Yuri. Look what I said here: ‘Yuri doesn’t communicate, so we make decisions for him’. I see now he really does, just needs us to focus on him together you know... If we listen really closely we get to know what he’s telling us, so
from there, you know if we incorporate that into the decision, he’s absolutely making, well not making the decision, but you know. It’s up to us to make sure the decision is about what he wants.

4.4.3 Change in supporters’ perception of focus people’s communication capability

As illustrated in figure 20 below, pre-intervention fifty per cent of supporters held a positive perception of the communication capability of those they supported. Post-intervention, one hundred per cent held this perception. This positive change in terms of perception over the course of the intervention is best illustrated throughout the study’s qualitative data.

![Percentage of supporters who hold positive perceptions of focus people's communication capability pre and post intervention](image)

Figure 20: Changes in positive perceptions of focus people’s communication capability over the course of the study
One supporter’s workshop evaluation highlighted her change of view regarding Angela’s ability to communicate. She was asked whether she found the time spent with Angela’s circle of support useful. She replied “yes”, and qualified this answer with “It got me to listen differently to Angela. I now understand that she is able to make decisions, she just communicates differently, with behaviour, gesture and just a few words”. When asked what things she would change in relation to her practice, she wrote, “I will listen differently”. When asked what parts of the workshop helped her the most she answered: “Discussing the importance of listening, not just to words, but Angela’s behaviours, and gestures, and things. There is so much she is able to tell us about what she wants with her non-verbals”.

In a final interview, one of Nathan’s supporters answered the question “What factors have helped the process?” in this way:

> Look for me, the biggest thing with all this is you getting us to change the way, I guess we listen, not listen, but pay attention, you know, to what Nathan is telling us. The workshop was terrific for that, really got us to think about how he expresses his preferences in decision-making, you know. I guess secretly I didn’t see him as a real communicator before.

This comment demonstrates that not only did Nathan’s supporter change her view regarding Nathan’s ability to communicate but also that she was reluctant to admit previously that she didn’t believe he was able to communicate. It is important to note that this may have been the case for other supporters who reported a positive view of focus people’s ability to communicate at the beginning of the study. When asked why she used the word “secretly” she
replied:

    I don’t know, I guess I knew what you wanted me to say when you asked me, so I just said yes, he can communicate. I’ve been to enough workshops and things. I know you want me to say he can communicate. But I guess deep down I didn’t believe it. I do now though.

As was evident in the quotes that illustrated changes in supporters’ perceptions of decision-making capability, these quotes about communication capability do not illustrate a change in Angela’s, Nathan’s, or Yuri’s communication ability, but in supporters’ conceptualization of what constitutes communication, including a strong focus on listening and ‘paying attention’ on the part of supporters.

4.4.4 Change in the value supporters place on collaboration with one another

As illustrated in figures 21 and 22 below, the value supporters placed on collaborative as opposed to individual approaches to responding to the preference of those they support increased over the course of the study. Pre-intervention sixty per cent of interviewed supporters reported that they positively valued collaboration between members of the circle of support. Post-intervention, one hundred per cent reported this. Moreover, there was an increase in average ratings supporters gave to how much they valued a collaborative as opposed to an individual approach to responding to focus people’s expressions of preference over the course of the study. The qualitative data set paints an even stronger picture of this positive change over the course of the study in supporters’ attitudes to collaboration.
Nathan’s supporter, who post intervention was classified as responsive,
described his decline in confidence when responding to Nathan individually as opposed to collaboratively.

I can see now he is a complex dude. His communication isn’t easy to interpret and I am not sure I am very good at doing it on my own now. I see now that there are real consequences for [Nate] when I don’t get it right. Yep I think the way to go is to try to work out what he is telling us together, like we did with the video today.
Further highlighting this change in attitudes toward a collaborative approach, one of Angela’s supporters, who was classified post intervention as responsive, wrote on her evaluation, “I have found our time together today working through the framework, brainstorming and problem solving together really useful. I would like to see us work together more”. Additionally, one of Yuri’s day service support workers, found to be responsive to Yuri post intervention, highlighted an increase in collaboration between her and Olga, a worker at Yuri’s residence. This day service worker, and Olga (a residential service worker) had established a monthly meeting to discuss the people they support in common.

Like with Olga I am calling it coffee catch up. It’s with the whole house. Olga and I have key clients in common. So anything we develop we’re
developing for everywhere, house, day, respite, anywhere. It’s all for the
good of everybody.

Workshop evaluations provided specific evidence that the workshop’s focus on
the collaboration was perceived to be useful. For example, in a workshop
evaluation one of Angela’s supporters (classified post intervention as
responsive) made the following comment when asked what part of the workshop
she found most useful. “I liked the focus on interdependency with decision-
making and that decision-making is a team effort, particularly for people like
Angela”. One of Nathan’s supporters (classified as responsive post-intervention)
said in a final gathering, in response to the question, “What parts of our time
together over the past five months did you find most useful?”

I don’t know it was the whole thing. I think though for me it was the
sitting down together watching the video, working out that he can’t
express his preferences on his own. He needs us to help him. It was
watching the video over and over again that helped me understand that
he really needs us. It’s a team effort isn’t it?

4.4.5 Change in conflict between supporters

A reduction in conflict between supporters was found over the course of the
study as is illustrated in figure 23.
As illustrated in Figure 23, three out of four case studies showed reductions in conflict over the course of the study. Nathan’s circle of support’s conflict scores increased from no observed incidents of conflict to one incident. This incident however, was relatively minor, compared to conflict observed in other case studies, and was resolved quickly. Despite the descriptive statistical data illustrated in Figure 23, the qualitative data set provided the richest source of evidence of a decrease in conflict over the course of the study.

In a final gathering, a supporter of Kevin’s described the reduction in conflict between circles of support members. “I tell you it is so much nicer; I would never want to go back to where we were a year ago. You know. Just got us nowhere. Always bitching”. In the same final gathering another of Kevin’s supporters
reflecting on the supported decision-making process said, “We have to admit, guys that it is so much better now, don’t you think? Like look at us, we are sitting in the same room”. One of Nathan’s supporters further illustrated this positive change at the end of the research process. “We have to get along if we’re going to help Nathan. No point us bitching at each other. Spending time together over a cuppa has helped us with that, don’t you think?” Another supporter replied to this comment, saying, “yeah it has really helped reduce the conflict between us”. In a final interview, one of Nathan’s supporters answered the question “What factors have helped the process?” with, “it’s all about time... it’s clear. That is what we have been given over the last few months. Time to come together and not only work on our relationship with Nathan, but the relationship we have with each other”.

4.5 Chapter summary

This chapter has combined the findings and discussion sections of the thesis. The first three research questions have been addressed: 1) What role do people with severe or profound intellectual disability play within a supported decision-making process?; 2) What role does a supporter of someone with severe or profound intellectual disability play within a supported decision-making process?; and 3) What factors underlie supporters’ role of responsiveness in supported decision-making for people with severe or profound intellectual disability?

The chapter began with a characterisation of supported decision-making for people with severe or profound intellectual disability, as an interdependent and complex process shared between people with severe or profound intellectual
disability and their supporters. Within this process, both parties contribute differently.

To begin, a picture was painted of the role played by people with severe or profound intellectual disability within the supported decision-making process. This role is to express will and preference using a range of modalities, including behaviour, vocalisation, vocal pitch, muscle tone, facial expression, eye movement, self-harm, and breath. This expression of will and preference is related to a range of aspects of life, including mealtimes, health, leisure, and interaction with others. Sometimes this will and preference is expressed intentionally and other times unintentionally.

The chapter's focus then moved to the role of supporters in this process of supported decision-making for people with severe or profound intellectual disability. This focus is consistent with the social model of disability, where the onus of change, is not on a person with a disability, but rather, the environment of which they are a part. A crucial element of this environment is the role played by supporters, that is, to respond to this will and preference. As discussed in chapter two, the challenge of responding to the expressions of preference of people with severe or profound intellectual disabilities is well documented, however, to date, little is known about the mechanics of effective responsiveness, particularly to the expressions of preference of people with severe or profound intellectual disability. Drawing on the study's data, this chapter has deconstructed the overall act of supporter responsiveness with a view to developing a better understanding of its related components. Drawing on the literature and the study's data, supporter responsiveness is characterised as
multi-faceted, made up of a number of tasks, including acknowledging, interpreting, and acting upon a person's will and preference. Although each of these tasks is important, none of them in isolation characterise responsiveness. Rather, supporter responsiveness is reliant on the implementation of these tasks collectively. Supporters acknowledge/notice (as opposed to ignore) expressions of preference, they interpret these expressions of preference, assigning meaning to them, and they act on this meaning.

The chapter then addresses the third research question, via the identification and examination of factors underlying supporter responsiveness. The results of an inductive thematic analysis of the data corpus were presented. Factors were identified and clustered into five overarching domains as illustrated in figure 12. These domains were 1) focus person’s attributes, 2) supporter attitudes and perceptions, 3) relationships 4) functioning and make up of circles of support, and 5) characteristics of the service system. The chapter explored these clustered factors in depth, describing associations between them and highlighting the impact they appear to have on supporter responsiveness. The articulation of these factors has assisted in concretizing some of the important mechanisms behind supported decision-making for people with severe or profound cognitive disabilities. Finally, the chapter also provided analysis of the impact of supported decision-making intervention on some of these factors associated with responsiveness.

The final research question, what are the implications of this study's findings on policy and practice relating to supported decision-making for people with severe
Conclusion

The UNCRPD, particularly Article 12, has marked a paradigm shift in the way humanity is expected to view concepts of self-determination, autonomy, and choice for people with disability. Australia’s ratification of this Convention, in 2008, signalled the Australian government’s commitment to ensuring the right of all Australians to lead self-determined lives. Australia’s subsequent adoption of the National Disability Strategy 2010-2020, an instrument designed to implement the Convention, across all jurisdictions, has acted as an additional driver of the self-determination agenda for Australians with disability and their supporters (Commonwealth of Australia., 2011). More recently, the NDIS Act (2013), was introduced to drive a new system of services and supports promising to give Australians with disability power, control and choice over the supports and services they receive (Commonwealth of Australia., 2013). Each of these legislative drivers has instigated a shift in the way people with disability are viewed in terms of their right to lead lives of their choice.

Supported decision-making has emerged as a mechanism by which these rights to self-determination, choice and control can be realised. Recently, the Australian Law Reform Commission (ALRC) formulated four decision-making principles to guide reform of Commonwealth, state and territory laws concerning supported decision-making. These principles, as articulated by the ALRC, are outlined in
Table 1, in Chapter two, and assist in defining the concept of supported decision-making in this study (Australian Law Reform Commission, 2014b p.64).

As outlined in chapter two, multiple supported decision-making trials have been implemented across Australia, however, to date, all have excluded people with severe or profound intellectual disability. As has been the case with self-determination movements of the past, such as self-advocacy and person centred practice, opportunities for supported decision-making appear to be dominated by people with mild, as opposed to more severe intellectual disability, whose decision-making capability are less likely to be questioned. This exclusion of people with more severe intellectual disability may in part stem from the fact there is an extremely shallow evidence base around how best to provide supported decision-making to people with severe and profound intellectual disability. Additionally, an argument exists inferring that the promises embedded in the UNCRPD and Australia’s NDIS, have little relevance to these people (McMahan, 2002; Singer, 1993). This argument is centered on the inability of people with severe or profound intellectual disability to understand and process information rationally, engage in purposive behaviour, or communicate preference intentionally. Due to the highly dependent nature of their lives, for them, autonomous decision-making is obviously challenging. However, if Australia and other signatory nations to the UNCRPD are to live up to their obligations under Article 12, and the promises made within the context of the NDIS, significant questions need to be asked. Perhaps the most important of these questions is, how best to support people with severe or profound
intellectual disability to have their will and preference, rather than what is perceived to be in their best interest, drive decisions made about their lives.

The initial aim of this study was to characterize supported decision-making for people with severe or profound intellectual disability. An analysis of this study’s observation data, revealed that supported decision-making can be characterized for people with severe or profound intellectual disability in terms of the existence of two roles, firstly, the role of the person with a disability to express their will and preference, and secondly, the role of a supporter to respond to this expression. Although both roles are crucial to the supported decision-making process, the supporters’ role is most amenable to change. Therefore, the secondary aim of the study was to identify and explore factors that underlie supporter responsiveness and therefore supported decision-making for people with severe or profound intellectual disability. Four research questions were developed providing focus for these research aims:

1. What is the role of people with severe or profound intellectual disability within a supported decision-making process?
2. What is the role of a supporter of someone with severe or profound intellectual disability within a supported decision-making process?
3. What factors underlie supporters’ role in supported decision-making for people with severe or profound intellectual disability?
4. What are the implications of this study’s findings on policy and practice relating to supported decision-making for people with severe or profound intellectual disability?
5.1 Characterising supported decision-making for people with severe or profound intellectual disability

Addressing research question one and two, supported decision-making was characterized for people with severe or profound intellectual disabilities in terms of the existence of two distinct but interdependent roles. The data describes the roles played by (a) the person with a disability (supported), and (b) the circle of support (supporters) in the supported decision-making process. These roles were found to be interdependent, shared between supporters, and supported. This characterisation is depicted in Figure 24 below.

![Figure 24: Characterisation of supported decision-making for people with severe or profound intellectual disability in relation to two distinct but interrelated roles.](image)

The role of the person with a disability in this dynamic is to express their will and preference, either intentionally or unintentionally. The five people with severe or profound intellectual disability, participating in this study, were observed and reported to use a range of communication modalities, including behaviour, vocalisation, vocal pitch, muscle tone, facial expression, eye
movement, self-harm, and breath. This expression of will and preference was found to be related to multiple aspects of life, including mealtimes, health, leisure, and interaction with others.

The role of supporters within this dynamic is to respond to the expression of will and preference of those they support. As outlined in chapter two, prior to this study, this act of supporter responsiveness had not previously been applied to a supported decision-making process for this population. This study's data has evidenced that supporter responsiveness to the expression of will and preference of those they support is a multi-faceted activity, made up of a number of tasks. These tasks include acknowledging, interpreting and acting on the expression of will and preference of those they support. The study has highlighted, that although each of these tasks are important, none of them in isolation, characterise responsiveness. Rather, supporter responsiveness was observed and described in this study as reliant on the implementation of these tasks collectively. Supporters acknowledge/notice, as opposed to ignore, expressions of preference, they interpret these expressions of preference, assigning meaning to them, and they act on this meaning.

This thesis has explicitly centred on the role of supporters within the supported decision-making dynamic as opposed to the role of focus people. This focus is consistent with a social model of disability, where the onus of change is not on the person with a disability, but rather, the environment of which they are a part.
5.2 Key factors underlying supporter responsiveness to the expressions of will and preference of focus people

Considering the importance of supporter responsiveness within a supported decision-making process, the third research question was posed with a view to identifying and examining key factors underlying this responsiveness. These factors were clustered into five overarching domains, focus person’s attributes, supporter attitudes and perceptions, relational closeness, functioning and make up of circles of support, and characteristics of the service system. An exploration of these clustered factors helped concretize some of the mechanisms behind supported decision-making for people with severe or profound intellectual disability. Figure 12 depicts this characterisation of supported decision-making, highlighting that it is a bidirectional process between supporters and supported impacted on by a range of factors. These factors are summarised below.

5.2.1 Focus people’s attributes

The study found that supporters demonstrated greater levels of responsiveness when those they supported communicated intentionally rather than unintentionally. Although this lack of supporter responsiveness to people who communicate unintentionally is concerning, it is not surprising. As discussed in chapter two, in contrast to those who are more cognitively able, people who communicate unintentionally have a history of having their expressions of preference either ignored or misinterpreted resulting in restrictions to their self-determination (Burton-Smith, Morgan, & Davidson, 2005; Felce et al., 1998; Heller et al., 1999; Stalker & Harris, 1998).
No change in focus people’s communication intentionality was seen over the course of the study. This lack of developmental progress in terms of communication intentionality is typical of adults with severe or profound intellectual disability (Beukelman & Mirenda, 1998; Coupe-O’Kane & Goldbart, 1988; Siegel & Cress, 2002). Therefore, it makes little sense for interventions to focus on change in terms of a person’s ability to communicate intentionally. Rather, consistent with an ecological or social model of disability, the focus of change should rest on supporter responsiveness. This role of supporters to respond was found to be amenable to change through structured practice guidance, making the enablement of responsiveness, rather than focus people’s communication intentionality, a crucial strategy for supported decision-making. Therefore, these findings specifically highlight a need for focused attention to be paid to enhancing supporters’ responsiveness to the expressions of preference particularly for people who communicate unintentionally. Without this focus, the promises of Article 12 will remain a pipe dream for people with severe or profound intellectual disability and their supporters.

5.2.2 Supporters’ attitudes and perceptions

Drawing from the study’s pre and post interview, observation, and questionnaire data, it was found that supporters who believe those they support are capable of communicating, as well as making decisions, predominantly demonstrate greater responsiveness overall, than those who did not hold these beliefs. Despite the absence of statistical testing, it appears that pre and post intervention analysis revealed an increase across these attitudes and perceptions over the study. This suggests that the supported decision-making approach used in this study had an
impact on supporters’ perceptions regarding the communication and decision-making capabilities of those they supported.

These perceptions were found to be associated with several factors. Supporters were most likely to believe that someone they support was capable of making a decision when their communication was intentional as opposed to unintentional. Additionally, supporters were more likely to believe that someone they support was capable of communicating preference when a communication coordinator existed and communication assessment material was available.

5.2.3 Relational closeness

The data generated in this study showed a tendency towards greater supporter responsiveness to preference expression, within the context of intimate or very close relationships. However, this was not always the case, as evidenced prior to the intervention, when supporters who described their relationship as intimate or very close, also held a negative view of the decision-making and communication capability of those they support. This suggests a complex interplay between supporters’ responsiveness, relationship closeness and attitudes and perceptions, particularly relating to the decision-making and communication capability of those they support.

Despite this outlying data, generally the closer supporters’ reported their relationship to be with the person they were supporting, the more likely they were to be responsive to that person, in terms of acknowledging, interpreting and acting on their expression of preference. This finding highlights the
importance of relational closeness in responding to the expressions of will and preference of people with severe or profound intellectual disability.

Considering the important contribution relational closeness was found to have on supporter responsiveness, a characterisation of relational closeness for people with severe or profound intellectual disability was developed. This characterisation was drawn from descriptions within the qualitative data. Intimate or very close relationships between focus people and their supporters were characterised in the study’s data set by specific elements. These included characteristics outlined in the relational closeness continuum developed for the purpose of this study, as well as additional elements found within the qualitative data set. These additional elements were, 1) a knowledge of a focus person’s history and life story, 2) knowledge of the focus person “beyond their disability”, and 3) reciprocal enjoyment of activities together.

The study found that supporters who reported intimate or very close relationships with those they support, were more likely to have good knowledge of their history and life story than those who reported more distant relationships. An interesting finding was that supporters who reported and demonstrated this good knowledge of the focus person’s history, did not necessarily acquire this knowledge through relationship longevity, but through the stories and images that were shared about the person from people who had known them for a long time. Therefore, knowledge and understanding of a person’s history and life story, is not necessarily acquired through having a relationship over a long period, but through a process of listening to those who do have such a relationship. Additionally, participants in this study who
demonstrated a tendency and willingness to see the person they supported "beyond their disability", were more likely to report intimate or very close relationships with these people. In contrast, those who did not view the person they supported in this way reported relationships that are more distant. A third characteristic of relationship closeness identified in this study was engagement in activities that are mutually enjoyable. The study found that supporters, who reported intimate or very close relationships with those they supported, spent time engaging in mutually enjoyable activities together. In contrast, supporters who described their relationship as not close or distant described their time together as lacking pleasure and, particularly in relation to the use of behaviours of concern, stressful.

A factor relating to relational closeness was supporters’ paid or unpaid status. Supporters who were unpaid were more likely than those who weren’t to report relationships that were intimate or very close with those they supported. However, despite this, supporter’s paid/unpaid status did not appear to have an impact on supporter responsiveness. That is, unpaid supporters were found to be no more responsive to the expressions of preference of those they supported than paid supporters. Therefore, the factor that appeared to influence supporter responsiveness was the level of relational closeness, and not supporters’ paid or unpaid status. This finding suggests that regardless of supporters’ paid/unpaid role in a person’s life, supporter responsiveness is likely to be enhanced if relational closeness is increased.

5.2.4 Functioning and composition of circles of support

This study found that levels of collaboration and conflict within circles of support
were associated with supporter responsiveness to the will and preference of focus people. Specifically, when circles of support responded to focus people’s expression of preference collaboratively (via the use of video), they were observed to be more responsive than when they did so individually. Additionally, the more conflict that existed within circles, the less responsive individual supporters were found to be. The study has highlighted several scenarios where supporters’ engagement in conflict appeared to take precedence over responding to the expressions of preference of those they support. This was particularly evident in supporters failing to acknowledge/notice supporters’ expressions of preference, while they were either engaging in or conversing about conflict. The findings highlight the importance of collaboration and minimal conflict within circles of support.

Considering its value, data was collected regarding supporters’ opinions on characteristics that enabled collaboration. These were, supporters having adequate face-to-face time, ‘getting along’, and using video to collaboratively respond to preference (i.e. to acknowledge, interpret and act). Additionally, conflict within the supported decision-making process was explored. According to supporters, three elements drove the conflict that existed in circles of support. These included communication breakdown, perceived disrespect between service providers, and competitiveness.

5.2.5 Characteristics of the service system

Within the context of this study, the service system brought several challenges and enablers to the supporters’ role of responding to the will and preferences of those they support. Four characteristics of the service system were found to
impact on supporters’ responsiveness to the expressions of will and preference of those they support, and therefore to their role in the supported decision-making process. These characteristics were, 1) allocation of resources, 2) service providers’ duty of care, 3) commitment to occupational health and safety, and 4) system opposition to relational closeness between paid supporters and focus people.

In terms of resource allocation, staff identified time and staff availability as the most limited. A lack of time and staff were repeatedly blamed on supporters’ lack of responsiveness to focus people’s expressions of preference, particularly in relation to their ability to act on these expressions of preference. Although supporters’ recognized that they needed more time to spend with those they support in order to notice/acknowledge expressions of preference, they presented the act of interpreting this preference as relatively unproblematic. Rather, some supporters claimed that they knew what those they supported wanted, but they simply didn’t have the time or the staffing to implement many of these preferences. They described this lack of time and staffing as contributing to their feelings of being overburdened.

Supporters expressed concern in relation to their task of balancing their perceptions of duty of care and people’s right to choose to take risks. This balancing act is not new to those who provide support to people whose decision-making capability may be questioned. There is a large body of literature in this area, some of which has been presented and discussed in Chapter two. An interesting finding in this study was supporters’ tendency to facilitate risky decisions that challenge their perceived duty of care, when the person faced with
the decision used intentional as opposed to unintentional communication. This is exemplified in the comparison made between Kevin and Neil’s decision-making process. Although, they were both faced with the same decision (i.e. whether or not to have a gastrostomy), and they appeared to express the same preferences, only Kevin’s (an intentional communicator) preference was acted upon.

Supporters in this study were of the view that the system’s focus on occupational health and safety was “over the top”. Not only did supporters express this view, but the observational data also demonstrated it. There were numerous examples given throughout the study where paid supporters’ right to health and safety in the workplace was given precedence over the preferences of those they supported. Just as the challenges faced by service providers to balance duty of care and service users’ right to self-determination and risk taking is not new, neither is the balancing act they face regarding attending to the rights of their workforce and the rights to self-determination of those they support. These challenges were also identified in the literature discussed in chapter two.

A fourth system barrier demonstrated in this study’s data was service provider management’s tendency to discourage close relationships between paid supporters and service users. As discussed in chapter two, the value of natural and close relationships in the lives of people with severe or profound intellectual disability is far reaching and includes strengthened interconnectedness, community participation, life opportunity, and quality of life (Forster & Iacono, 2014; Pierce et al., 2010; Reinders, 2010; Schuengel et al., 2013; Sterkenburg, Schuengel, & Janssen, 2008). Moreover, this study has highlighted the value of relational closeness, to paid and unpaid supporters’ responsiveness to the will
and preference of those they support. Despite the value of close relationships, people with severe and profound intellectual disability have extremely small social networks, predominantly made up of paid support workers, other residents and family (Clement & Bigby, 2008; Kamstra et al., 2014a; Lippold & Burns, 2009). In the absence of unpaid relationships in the lives of people with severe or profound intellectual disabilities, a potential source of social closeness is between people with disability and their paid support workers. However, despite the possibilities it brings, the dynamic between service users and paid disability support workers brings with it multiple dilemmas, particularly in relation to paid support workers becoming more personally involved than what strict professional boundaries would dictate. These dilemmas were reflected in the examples provided by study participants, who described employers’ reluctance to support close relationships between paid supporters and service users. Despite the concerns, considering the importance of close relationships for people with severe or profound intellectual disability demonstrated in this study and the literature, a focus on how best to enhance appropriate relational closeness between supporters and those they support regardless of their paid status is warranted. This will be discussed in the proceeding section.

5.3 Implications of findings on policy and practice

The final research question, ‘what are the implications of this study’s findings on policy and practice relating to supported decision-making for people with severe or profound intellectual disability?’ is addressed in this section.

This study has provided evidence that supported decision-making is an effective mechanism for people with severe to provide intellectual disability to achieve
self-determination. Importantly, the study has shed light on how supported decision-making can be effectively implemented in the lives of people with severe or profound intellectual disability and their supporters. This evidence particularly focuses on the role of supporters’ responsiveness in this process. Based on this evidence, guidance is provided to governments, policy makers, families, and service providers, specifically focusing on actions for enhancing supporters’ responsiveness to the expressions of preference of people with severe or profound intellectual disability. This guidance is offered to inform policy development and practice in this area.

5.3.1 Emphasis on the universality of decision-making capability

As discussed in chapter two, the UN Committee on the Rights of Persons with Disabilities has expressed clear opposition to Australia’s interpretative declaration. This declaration allows for the use of substitute decision-making, rather than supported decision-making, in situations where a person is assessed as having no or limited decision-making capability, an assessment outcome typical for people with severe or profound intellectual disability. The Committee has articulated that while the declaration is in place, the Australian government is not recognising the universality of supported decision-making, and is not acting within the spirit of the Convention (Committee on the Rights of Persons with Disabilities., 2-13 September 2013). The Australian Law Reform Commission (ALRC) has mirrored the Committee’s concerns in its 2014 Inquiry and Report, *Equality, Capacity and Disability in Commonwealth Laws*. The Commission emphasises the universality of decision-making capability, explicitly
focusing on the relevance of supported decision-making for people with severe or profound intellectual disability.

The ALRC’s view, coupled with the study’s findings, calls for an emphasis on policy and practice guidance that aims to enhance supporters’ perception that decision-making capability is a universal construct. Within this study, this perception was increased through knowledge and attitude training, within the context of the supported decision-making intervention used. This study’s findings in particular, point to the value of this emphasis in enhancing supporter responsiveness to the will and preference of people with severe or profound intellectual disability, an essential component of supported decision-making for this population.

5.3.2 Embedding practice leadership within circles of support

The study’s findings evidence the value of policy and systems that enable the facilitation of practice leadership roles, in the form of communication coordination roles. A communication coordinator is a disability support worker who is “equipped with the skill, knowledge and attitudes to develop and support a culture of communication” within their residential or day service (Torresi & Muscat, 2009 p.4). The amount of resource attached to the role varies across service providers. However generally a communication coordinator is engaged in a range of activities including, the coordination of communication related documentation, basic assessment (e.g. *Triple C*), meeting facilitation, and importantly communication training and support.

Specific aspects of a communication coordinator’s role are relevant to
supporters’ responsiveness within the supported decision-making process, and therefore should be prioritized in the development, recruitment and professional development associated with these roles. These aspects of the role include,

1. Developing supporters’ positive perception of the capability of those they support to communicate (an important factor in supporter responsiveness), by enhancing understanding of the human communication continuum and the universality of communication through training, mentorship and assessment (e.g. *Triple C*).

2. “Weaving the ties that bind”, as described by a study participant. Within this study, where a communication coordinator role was a member of a circle of support, there was less conflict between supporters, and more collaborative behaviour, particularly when responding to those they support.

3. Leading/managing the supported decision-making process. Supporters spoke of the benefits of having someone, such as a communication coordinator, to manage/lead the supported decision-making process, specifically in organizing meetings, information, and communicating with members of the circle of support. One supporter described this role as someone to “pull it all together” and another described it as someone “to run the show”. Having someone available to complete these tasks was described by one supporter as enabling them to “focus on [their] job of responding to the guys”.

In terms of supported decision-making for people with severe or profound intellectual disability, an emphasis on these aspects of a communication
coordination role is likely to be beneficial. Therefore, service providers when developing, recruiting for, and supporting communication coordinator roles should consider them.

It is important to emphasise that this role, requires dedicated resourcing. Despite, supporters reporting that they valued the presence of a communication coordinator, they expressed concern regarding resourcing. They expressed feelings of being over burdened, which contributed to their reluctance to take on leadership and coordination roles, unless these roles were considered in their allocation of workload. This reluctance of disability support workers to take on such roles, due to feelings of being overworked, is reflected in the literature, discussed in Chapter two (Bigby & Atkinson, 2010; Bigby, Frederico, & Cooper, 2004; Iacono, 2010).

5.3.3 Building relational closeness

This study's findings suggest that regardless of supporters' paid/unpaid role in a person's life, supporter responsiveness is likely to be enhanced if relational closeness is enhanced. This finding supports the development of mechanisms that increase relational closeness for people with severe or profound intellectual disability, regardless of their paid/unpaid status.

As highlighted by Johnson and her colleagues there is a lack of understanding of the mechanics of relationship building for people with severe intellectual disability (Johnson et al., 2014a). As discussed in Chapter two, this lack of understanding extends to the mechanics of relationships for people with profound intellectual disability (Dobson, Upadhyaya, & Stanley, 2002; Griffiths &
Smith, 2015; Johnson et al., 2012b). The current study's findings not only highlight the importance of relational closeness between people with severe or profound intellectual disability and their supporters, but also provide some insights into what these relationships should look like.

Johnson and her colleagues' work, focused on relationship building with people with severe intellectual disability and their supporters, suggests a need for cultural change within the disability sector (Johnson et al., 2014a). The current study has highlighted the same need for services orientated to the needs of people with profound intellectual disability. Specifically, the study's findings emphasize a need to develop policy and practice mechanisms to increase relational closeness between those with severe or profound intellectual disability and those who support them, regardless of whether they are paid or unpaid.

It is important for those charged with disability policy, management, and service delivery relating to people with severe or profound intellectual disability to develop a respect and appreciation for the importance of close relationships, particularly for those with severe or profound intellectual disability. In contrast to the findings of Bigby and her colleagues, focused on decision-making with people with mild to moderate intellectual disability, relationship closeness appears particularly important for this group. While Bigby et al. have found that relationships are important in decision-making for their study population, they deemphasise the importance of closeness, stating, “the relationship does not have to be ‘excellent’ or ‘perfect’ but rather it needs to be ‘good enough’” (Douglas et al., 2015). It is important for those charged with disability policy,
management, and service delivery to understand the unique supported decision-making needs of people with severe or profound intellectual disability. This means that findings from studies focused on those with less severe cognitive disability (e.g. Douglas et al., 2015b) should not be generalised to people with severe or profound intellectual disability. For this population, a relationship that is “good enough” is not likely to be ‘good enough’.

Not only should those charged with providing and managing services within the disability support sector understand the value of relational closeness for people with severe or profound intellectual disability, they should develop an understanding of what such relationships might look like. This study’s findings have provided some insight into the components of relational closeness specifically for people with severe or profound intellectual disability and those who support them. It is important that these be considered in the development of policy, practice, recruitment and training, within the context of disability services for people with severe or profound intellectual disability. Relationships with the following components should be encouraged:

1. A supporter requires knowledge of a focus person’s history and life story;
2. A supporter requires knowledge of the focus person “beyond their disability”; 
3. Supporters and supported should enjoy activities together.

It is important for those engaged in the disability service sector to understand that knowledge regarding a person’s history and life story is not necessarily acquired through relationship longevity. Within the context of this study, the
sharing of historical and current stories, images, and video about the person being supported, by those who had known them for a long time, across multiple areas of their life, was found to enhance other supporters’ knowledge of the person. The SDM intervention used in this study, made use of multiple techniques for gathering and sharing this knowledge. These included, multi-sensory stories, multi-media profiles, books about me, personal history books, and video, some of which were housed online. As discussed in chapter two, these techniques have a growing body of practice and research based literature supporting their use (Acting Up, 2003; Bloomberg et al., 2004; Mencap., 2009; Rezzani, 2012; Scope., 2004a; Watson & West, 2011).

In addition, it is important for those engaged in the disability service sector to understand the importance of supporters “seeing a person beyond their disability”. This study’s data highlights this importance, associating supporters’ willingness to see the focus person “beyond their disability” with relational closeness, and therefore supporter responsiveness. Specifically, Lyng’s technique of encouraging supporters to see focus people “beyond their disability” was used in this study, and appeared to be valuable in increasing supporters’ appreciation of those they support as people with a diverse range of preferences, beyond those related to their disability.

A third characteristic of relationship closeness identified in this study was supporters and supported enjoying activities together. Considering this finding, there should be a focus on ascertaining what activities people with severe or profound intellectual disability enjoy, and once understood, developing support systems that match supporters and supported based on mutual interests. Two
tools were developed within the context of this study, designed to develop an understanding of a person’s preferred activities. Both these tools are described in chapter three. Firstly, the Preferred activity analysis (Appendix 3.3), outlines a process for determining how a person prefers to spend their time, and what the common elements are across these preferences (Watson, 2010b). Secondly, the Exploration of options tool (Appendix 3.4) provides a process of exploring options based on a person’s perceived preferences (Watson, 2010a). Tools such as these are offered to those supporting people with severe or profound intellectual disability to help develop a clearer picture of how they prefer to spend their time. With this knowledge, support partnerships can be established based on mutual areas of interest, an important aspect of developing relational closeness. Participation in mutually enjoyable activities in the community can serve as a vehicle by which people with severe or profound intellectual disability can extend the number of close relationships they have with people outside of their support network. For example, a person and their supporter attending a community choir (an activity they both enjoy) may open doors to relationships with community members who share their passion for communal singing.

Although this study has provided evidence for developing policy and practice aimed at enhancing relational closeness between people with severe or profound intellectual disability and those who support them, systemic opposition exists to the development of such relationships, particularly when a supporter is paid. However, in the absence of unpaid relationships there is a need for the development of relational closeness between people with severe or profound intellectual disability and paid supporters. Despite this need, such a dynamic
between service users and paid disability support workers brings with it multiple dilemmas.

As evidenced by supporters in this study, the enforcement of such strict guidelines laid down in the name of professionalism, may lead to the development of relationships away from the spotlight, further adding to reasonable fears around abuse. Considering these concerns along with the importance of close relationships for people with severe or profound intellectual disability demonstrated in this study and the literature, a focus on how best to enhance appropriate relational closeness between supporters and those they support regardless of their paid status is warranted.

For people with severe or profound intellectual disability to have close and healthy relationships, the paid and unpaid relationships they have need to be permitted, visible, and not veiled under antiquated professional policy and attitudes that fail to acknowledge the fluidity of human relationships. There is a need for service providers to acknowledge the importance and existence of relational closeness for people with severe or profound intellectual disability, and develop systems that enable the development of such relationships that are highly transparent. Additionally, it is important for service providers to ensure that employees have understanding that appropriate, close relationships with those they support are central to their role. However, as articulated by Johnson et al., this is not likely to be achieved without modelling and training by management of good practice in terms of interaction and engagement (Johnson et al., 2014a). As exemplified in this study, this training does not need to be restricted to ‘the classroom’, but be provided through mentorship, supervision,
5.3.4 Building collaboration and reducing conflict between supporters

In this study, conflict was found to be evident between support groups from different agencies, specifically day and residential services. This conflict was related to communication breakdown, disrespect between agencies, and competitiveness. Although this conflict existed, value was found in supporters working collaboratively, particularly when responding to the expressions of preference of those they supported. Considering its value, the data was interrogated to gain insight into enablers for collaboration. These enablers were all related to supporters' roles, and included them, having adequate face-to-face time, 'getting along', and using video to collaboratively respond to preference.

It is recommended that policy developers and resource allocators, such as the National Disability Insurance Agency (NDIA), consider the importance of supporters spending ample and regular time together in the same physical location. The data presented in this thesis provides evidence that supporters spending time together physically, increases collaboration, reduces conflict between supporters, and enhances supporters' collective ability and confidence responding to the expressions of preference of those they support. It is recommended that this time together be scheduled regularly and alternate between different locations, so no one support group feels alienated. Considering the value found in this study of supporters collaboratively watching and responding to video of the person they support, it is recommended that within these meetings time be spent engaging in such an activity.
It is recommended that strategies be developed and resources allocated to building bridges between supporters, particularly those from different agencies. This may include the implementation of team building activities and training designed to increase social interaction and mutual respect between supporters. It is also suggested that service and workforce systems that allow for paid supporters to work across settings, be developed and piloted. Such arrangements may facilitate supporters developing an understanding of each other's role, with a view to increasing mutual respect.

Strategies to reduce communication breakdown between supporters should also serve to reduce conflict and increase collaboration. Such strategies may include the implementation of digital and social media communication systems, designed to facilitate online collaboration. However, as evidenced in this study, due to a lack of resources, supporters generally have limited access and knowledge of digital technology, adding to the difficulties they experience with collaboration. Considering the importance of collaboration, service providers, policy makers and resource allocators, such as the National Disability Insurance Agency, need to focus on closing the digital divide experienced by many Australians with disability and those who support them.

As previously discussed, within this study, where a communication coordinator existed within a circle of support, there was less conflict between supporters, and more collaborative behaviour, particularly when responding to those they support. However, despite their value, supporters were reluctant to take on such roles. This reluctance points to a need for service providers, policy makers, and most importantly resource allocators such as the NDIA, to incorporate dedicated
practice leadership roles such as communication coordinators into systems of service delivery.

5.3.5 A supported decision-making model of practice

A supported decision-making intervention, *People with severe or profound intellectual disabilities leading lives they prefer through supported decision-making: Listening to those rarely heard* (Watson & Joseph, 2011) was implemented, but not evaluated in this study. Rather it provided a lens through which to observe the phenomena of supported decision-making for people with severe or profound intellectual disability. This population generally has limited experience of decision-making and therefore it was necessary to provide a context in which it could be observed and explored.

Despite there being no intention to evaluate the intervention, the study provided some evidence of its efficacy, particularly in terms of supporters’ responsiveness, their perceptions of focus people’s decision-making and communication capability, and collaboration and conflict between one another. Several elements of the intervention have been identified as instigators of the positive change seen over the course of the study. These included, specific training activities focused on decision-making and communication universality, the presence of a practice leader in the form of a communication coordinator, the use of methods for collaboratively documenting and interpreting expressions of preference, and the extended time supporters spent together as part of the intervention process. These ingredients of the intervention provide guidance for the development of future supported decision-making practice models for people with severe or profound intellectual disability and their supporters.
At the centre of any future practice development in this area is a need to address the commonly misinterpreted concepts of self-determination, decision-making and supported decision-making when applied to people with severe or profound intellectual disability and their supporters. In response to this need, an alternative definition of supported decision-making, inclusive of and responsive to the unique needs of people with severe or profound intellectual disability and their supporters, is offered.

**Figure 25: A characterisation of supported decision-making for people with severe or profound intellectual disability**

This definition is based on the premise that decision-making is a universal construct that for those at the centre of this study can only be realised with significant support.
Further highlighting the unique nature of supported decision-making for people with severe or profound intellectual disability is the significant level of resource and support required to implement a SDM intervention with this population. The intervention used within the context of this study required circles of support to work together over a period of six months, attending at least two formal meetings, including one training workshop, documenting, and consulting with other circle members. The entire process was led by a skilled facilitator (Speech Pathologist). Within the context of this study, paid support staff were “backfilled” for the time, they spent engaged in the study, and the Speech Pathologist was not paid. Therefore, a replication of this intervention is likely to be particularly resource intensive. However, this issue of resource availability needs to be addressed if people with severe or profound intellectual disability are to realise the promises made to them via the UNCRPD.

5.4 Study limitations

The study’s research sample was small, made up of five case studies, comprising of thirty-eight participants in total. Although the data generated from these case studies is rich, the findings are necessarily limited in reach because of this small sample. Therefore, claims of pre and post intervention difference are weakened and therefore larger scale studies need to be carried out to confirm or refute the findings.

Data collection for this study was particularly time consuming, taking over two years. This extended period is typical of a study focused on people with severe or profound intellectual disability. For this population extensive observation and prolonged engagement is required, due to their inability to contribute through
interviews and focus groups. The time required for this extensive observation and prolonged engagement restricted the location of focus people to the researcher’s home state of Victoria. This meant that although participants were varied in terms of their service providers, they all received services from the same service system. Additionally, the sample was relatively homogenous in terms of culture and socio-economic status.

Although, positive change was seen over the course of the current study in terms of supporters’ skills, behaviour and confidence, the longevity of this change has not yet been addressed.

Due to these limitations, in order to provide confidence regarding the generalizability of the findings outlined in chapter four, further research is clearly warranted, a point discussed in the proceeding section.

5.5 Further research

As is the case for most research studies of this size, although the questions posed at the beginning, have largely been answered, additional questions have arisen. This has opened up a research agenda focused on supported decision-making for people with severe or profound intellectual disability and their supporters. This agenda is critically important if Australia and other signatory nations to the UNCRPD are to live up to their obligations under Article 12 of the Convention. These research questions are presented and discussed below.

5.5.1 What is an effective supported decision-making practice model for people with severe or profound intellectual disability?

As discussed, this study has implemented, but not evaluated, a model of
supported decision-making practice for people with severe or profound intellectual disability. Over the course of the study, insights were informally gathered regarding the model’s efficacy. These insights provide guidance for the further development of a supported decision-making practice model. An action research approach is suggested as a vehicle with which such a model can be conceived, further developed and evaluated for people with severe or profound intellectual disability.

5.5.2 What is the long-term impact of a supported decision-making approach such as the one used in this study, on people with severe or profound intellectual disability and their supporters?

This study did not explore the benefits arising from a successful supported decision-making process, for people with severe or profound intellectual disability. As previously discussed as a limitation, although, positive change was seen over the course of the current study, the longevity of this change was not determined. Therefore, future research, aimed at evaluating the maintenance of this change over time, is warranted. Findings from such research, coupled with findings from this study would provide further focus for the development of a supported decision-making practice model for people with severe or profound intellectual disability and their supporters.

5.5.3 What are the enablers and barriers to the three key elements of supporter responsiveness (acknowledgment, interpretation, action) within a supported decision-making paradigm for people with severe or profound intellectual disability?

One of the key contributions of the current study has been to characterise supported decision-making for people with severe or profound intellectual disability. This characterisation has emphasised the importance of supporters’
responsiveness to the expression of will and preference, within a supported decision-making paradigm. To date, there has been no deconstruction of the mechanics of this responsiveness. This thesis has made a considerable contribution to the field, by highlighting key elements of supporter responsiveness (i.e. acknowledgment, interpretation, and action). However, a deep interrogation of these elements was beyond the scope of this research. Such an interrogation with a view to further developing an understanding of supporter responsiveness is necessary, if people with severe or profound intellectual disability are to be included within supported decision-making practice. A research focus on the role of each of these elements, within the supported decision-making process for people with severe or profound intellectual disability, would go a long way to improving practice in this area.

5.5.4 What mechanisms enhance relational closeness for people with severe or profound intellectual disability?

As discussed, systemic opposition exists to the development of close relationships between paid supporters and those they support. However, as highlighted in the literature, and in this study, for many people with severe or profound intellectual disability, there is a clear absence of unpaid relationships in their lives. This absence points to a need for the development of relational closeness between people with severe or profound intellectual disability and paid supporters. Despite this need, such a dynamic between service users and paid disability support workers brings with it multiple dilemmas. These dilemmas stem from well-founded fears regarding the sectors’ need to safeguard people with disability from abuse. Considering these concerns along with the importance of close relationships for people with severe or profound intellectual

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disability demonstrated in this study and the literature, a research focus on how best to increase relational closeness between people with severe or profound intellectual disability and their supporters regardless of their paid status is warranted.

5.5.5 How can a supported decision-making practice model be applied to those with acquired cognitive disability (e.g. brain injury or dementia)?

People with severe or profound intellectual disability are not alone in their exclusion from self-determination movements and approaches such as supported decision-making. Therefore, the application of the intervention used in this study to other disability groups who communicate unintentionally or informally (e.g. people with acquired brain injury or dementia) is recommended.

5.5.6 How can a supported decision-making practice model be applied across cultures?

As discussed in chapter two, researchers have described a collaborative view of self-determination in non-western cultures, whereby it is best realized collectively rather than individually (Iyengar & Lepper, 1999b; Shogren, 2012). As the current study was carried out within a western predominantly individualist culture, it may be useful to explore how supported decision-making is applied in collectivistic societies, such as some parts of Asia and Indigenous Australia. Considering these cultures’ intrinsic collectivist approaches to decision-making, a dedicated supported decision-making approach, such as the one used in this study, may be less necessary.

5.5.7 What is the role of supported decision-making for people with severe or profound intellectual disability in Australia’s NDIS?

Another context in urgent need of research attention, is Australia’s NDIS. At the
scheme's heart, are the notions that system users should have the opportunity to express preference and have these preferences realized regarding the disability related services and supports they receive. Although there is no doubt that people with severe or profound intellectual disability will be significant users of the NDIS, to date, little attention has been paid to the unique decision-making needs of this group. Adequately responding to the needs of this group, within the context of the NDIS, requires an understanding of how supported decision-making, as described in this thesis, can be applied to individualised planning. The NDIS is currently in a trial or foundation phase, making the time ripe to engage in research in this dynamic area of practice.

5.6 Concluding statement

In a time when most people, including many with disability, are discovering and celebrating freedom and self-determination, people with the most profound intellectual disability are not necessarily enjoying these same entitlements. This exclusion mirrors self-determination movements of the past and present, such as self-advocacy, person centred practice, and individualised supports, dominated by people with mild, as opposed to more severe intellectual disability.

The UNCRPD (2008), specifically Article 12, has instigated a paradigm shift in the way people with intellectual disability are viewed in terms of their ability to lead self-determined lives. However, despite the legislative strength of this paradigm shift, there remains a lack of focus on the practice of decision-making and supported decision-making. This lack of focus is particularly evident for people with severe or profound intellectual disability who, due to their difficulties with communication and the interdependent nature of their lives, are faced with
unique challenges in terms of them leading self-determined lives. Arguably, it is these challenges that have driven Australia to retain its interpretative declaration in relation to Article 12, allowing for the use of substitute rather than supported decision-making in situations where a person is deemed incapable of decision-making, a scenario typical of those who are the focus of this thesis. This thesis has challenged this declaration, beginning with the premise that self-determination is not only a universal construct that is relevant for all citizens, but a key obligation of signatory nations to the UNCRPD. From this premise, arises an urgent need to understand supported decision-making for people with severe or profound intellectual disability, the central goal of this thesis.

Supported decision-making for people with severe or profound intellectual disability is characterized in terms of two distinct but interdependent roles. The role of the person with a disability (supported) is to express preference, while the role of the supporter or supporters is to respond to this expression of preference by acknowledging, interpreting and acting on this expression in some way. In harmony with the social model of disability, supporter responsiveness, as opposed to focus people's expression of preference, is the component of this dynamic amenable to change through structured practice guidance. This makes the facilitation of supporter responsiveness a crucial strategy in supported decision-making for people with severe or profound intellectual disability.

Acknowledging supporter responsiveness as crucial to supported decision-making for people with severe or profound intellectual disability, the author has identified key factors underpinning supporter responsiveness, illustrated in Figure 4.1. These factors are comprised of, supported people's communication
intentionality, supporters’ attitudes and perceptions specifically relating to perceptions of decision-making and communication capability, the functioning of circles of support, levels of relational closeness between supporters and supported, and characteristics of the service system.

This thesis makes a significant and timely contribution to policy, research and practice in supported decision-making. The study has demonstrated for the first time that although its implementation can be challenging and resource intensive, supported decision-making can be a powerful mechanism to affirm the right to self-determination for people with severe or profound intellectual disability. Characterising supported decision-making, and identifying underlying factors to its implementation, this thesis provides a strong focus for practice and policy efforts for ensuring people with severe or profound intellectual disability receive appropriate support in decision-making, a clear obligation of Australia under the UNCRPD.
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Appendix 3.1: Workshop evaluation

Feedback and evaluation

To assist me in making this workshop better, I would appreciate your feedback and comments.

1. Did this workshop meet your expectations?

   [ ] Not at all
   [ ] Not really
   [ ] Undecided
   [ ] Somewhat
   [ ] Very much

2. Did you find our time together today useful? Yes/Somewhat/No

If yes, how was it useful (tick as many or as few as you like)?

☐ It gave you time/space to reflect on your relationship with _________
☐ It gave you a break from your usual activities
☐ It provided you with a clearer understanding of what is meant by Supported Decision Making
☐ It enhanced your understanding of different methods of communication
☐ It enhanced your appreciation of the importance of working together when supporting someone who communicates informally
☐ It gave you some useful tools to help document _________’s preferences
☐ It gave you an opportunity to contribute your opinion regarding _________
☐ Anything else?

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________

If not, why wasn’t it useful?

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
3. As a result of our time together do you feel more confident in supporting __________ to express preferences?

   Not at all 1  Not really 2  Undecided 3  Somewhat 4  Very much 5

4. Do you feel today’s workshop catered to __________’s specific needs?

   Not at all 1  Not really 2  Undecided 3  Somewhat 4  Very much 5

5. As a result of participating in this project are there things you will change in the way you support __________ to make decisions?

   Not at all 1  Not really 2  Undecided 3  Somewhat 4  Very much 5

   One (or more) of the things you will change is

   ____________________________________________________________
   ____________________________________________________________
   ____________________________________________________________

6. Did you find the opportunities for group discussion useful?
6. Do you feel as though your opinions and views were 'heard' throughout the project?

7. Was the workshop facilitated well?

8. What parts of the workshop helped you the most? Why?

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
9. What parts of the workshop did you find least useful? Why?

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

10. After this project do you feel better able to support ________ through a decision making process?

Not at all 1  Not really 2  Undecided 3  Somewhat 4  Very much 5

11. After this project do you feel more prepared to support others who communicate informally through a decision making process?

Not at all 1  Not really 2  Undecided 3  Somewhat 4  Very much 5

12. Overall was this workshop useful?

Not at all 1  Not really 2  Undecided 3  Somewhat 4  Very much 5

Thanks so much for your time not only in filling out this questionnaire but also in participating in this project. Your input has been invaluable.

Jo
Appendix 3.2: Questionnaire about choice

A questionnaire about choice

Adapted from Hatton et al (2004)³

Please answer the following questions about opportunities X has to make choices in his life. Using the 3-point rating scale provided place a number from 1-3 in the box. Elaborate by giving some examples if you have some.

Rating scale:

1. X considered incapable of making choice in this area

2. Preferences are acknowledged, but final say generally rests with his supporters.

3. Preferences are acknowledged and are reflected in final decisions unless clearly inappropriate or dangerous.

In what ways is X supported in making choices with regard to the following areas of their life?

1. The content of his evening meal

2. The timing of his evening meal

3. Where he eats his evening meal

__________________________________________________________

__________________________________________________________

4. The leisure activities he takes part in indoors (e.g. TV, radio)

__________________________________________________________

__________________________________________________________

5. Going out (e.g. Pub, cinema)

__________________________________________________________

__________________________________________________________

6. The time he goes to bed in the evening

__________________________________________________________

__________________________________________________________

7. The clothes that he purchases

__________________________________________________________

__________________________________________________________

8. The clothes he wears each day

__________________________________________________________

__________________________________________________________
9. Keeping pets

________________________________________________________
________________________________________________________

10. Who he lives with

________________________________________________________
________________________________________________________

11. Where he lives

________________________________________________________
________________________________________________________

12. Who supports him?

________________________________________________________
________________________________________________________

13. His haircut and shave

________________________________________________________
________________________________________________________

14. His day time activities

________________________________________________________
________________________________________________________
15. His holidays

16. The time he spends in the bath or shower

17. The furnishings in his home

18. The furnishings in his bedroom
Appendix 3.3: Preferred activity analysis

Preferred Activity Analysis

A tool for the training ‘People Leading Lives they prefer through Supported Decision Making - Listening to those rarely heard’

Date: ________________________________

People filling out this form: ________________________________

This document is for the person’s ‘circle of support’ to work together on. Its purpose is to develop a picture of how the person prefers to spend her time and what the common elements are across these preferences.

As a team identify 10 activities/experiences that occur routinely in the person’s day. Select a range of preferred, non-preferred and neutral activities/experiences and order them on a scale of 1-10 with the most preferred being 1 and the most non-preferred being 10.

1. _______________________________________________________
2. _______________________________________________________
3. _______________________________________________________
4. _______________________________________________________
5. _______________________________________________________
6. _______________________________________________________
7. _______________________________________________________
8. _______________________________________________________
9. _______________________________________________________
10. _____________________________________________________

Watson 2010
Choose 2 preferred and 2 non-preferred activities/experiences. Complete the process for each of these.

Description of Activity

(Answer the following questions where they are relevant)

Activity

☐ Preferred
☐ Non-preferred

Describe the activity: is it visually stimulating; is it particularly noisy; does it involve smells; does it involve movement; does it involve tastes; does it involve touch; how long does the activity take; is it part of the person’s regular routine.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Does this activity involve travelling? Yes/No

If yes, describe the travel involved. Getting to the activity; travel as the activity itself; transport involved; length of time spent travelling.

Watson 2010
How would you describe the pace of the activity?

- Fast paced
- Moderately fast
- Neutral
- Moderately Slow
- Slow Paced

How physically demanding is the activity?

- Very Physical
- Somewhat Physical
- Not at all Physical

How repetitive is the activity?

- Very Repetitive
- Somewhat Repetitive
- Not at all Repetitive

How much structure and predictability is in the activity?

- High Structure
- Some Structure
- No Structure
- High Predictability
- Some Predictability
- No Predictability

Physical Environment:

Where does the activity generally take place?

---------------------------------------------

Watson 2010
Does the activity generally involve spending time in a particular climate/temperature? Yes/No
If yes, describe the climate

Is the environment in which the activity takes place particularly noisy or quiet? Yes/No
If so, describe the noise level surrounding the activity

Is the environment in which the activity takes place visually stimulating? Yes/No
If so, describe

Is the environment in which the activity takes place particularly smelly (either good or bad)? Yes/No
If so, describe

Social Environment
This activity involves lots of:

Social interaction Being left alone

Watson 2010
How many people are usually involved in this activity? Those participating in it do it...

<table>
<thead>
<tr>
<th>Alone</th>
<th>With 1-3 other people</th>
<th>With 4-10 other people</th>
<th>In a large group or crowd</th>
</tr>
</thead>
</table>

Does this activity involve the person spending time with a particular person? Yes/No
If yes, who? __________________________________________________________

Does the activity involve spending time with people of a particular age? Yes/No
If yes, what age? ______________________________________________________

Does this activity involve the person spending time with people of a particular gender? Yes/No
If yes, what gender? __________________________________________________

How does the activity require the person to engage with others?

- As the center of attention
- As just one of the crowd
- Seen but not heard
- As an observer

What level of physical contact does the activity involve?

- A lot of physical contact
- Moderate physical contact
- Very little physical contact

Is there anything else about this activity that you think contributes to the person’s enjoyment or non-enjoyment of it?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Appendix 3.4: Exploration of options tool

Exploration of Options: A Supported Decision Making Tool for People with Profound Intellectual Disabilities

A tool for the training ‘People Leading Lives they Prefer through Supported Decision Making - Listening to those rarely heard’ Watson and Joseph 2010

Date: ____________________________

Person/people filling out this form:

________________________________________

What is the decision the person is facing?

E.g. The ‘decision maker’ is living at home with her aging mother. It is time for her to explore alternative places to live. The decision she is faced with is ‘Where to live?’

________________________________________

________________________________________

________________________________________

What are all the options/choices?

E.g. To live in a government run residential unit with 4 people who the ‘decision maker’ doesn’t know. The unit is in a busy urban area very close to a tram line.

Option 1:

________________________________________

________________________________________

________________________________________

Watson 2010
Option 2:


Option 3:


Option 4:


Option 5:


Who is supporting the person to make this decision? What is their relationship?

<table>
<thead>
<tr>
<th>Support Person</th>
<th>Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

What are the practicalities that may impact on the options available?

E.g. Lack of appropriate accommodation


Watson 2010
Exploration of each option/potential choice

Support the person through a trial process of each potential choice. It may not be practical to fully trial each option, however, try to set up a scenario which best resembles the key elements of each choice.

E.g.: If one of the options to be explored is for the person to live in an urban setting close to a tram line, support the person to spend time near a tram line. Watch/listen to their reactions as the trams go past. Consider videoing these reactions to share with the person’s Circle of Support.

<table>
<thead>
<tr>
<th>Option/Scenario</th>
<th>Describe the person’s responses to this option/scenario</th>
<th>What does the person’s circle of support believe she is communicating through these responses?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>What sounds is she making?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>What facial expressions is she using?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>What is her body doing?</td>
<td></td>
</tr>
</tbody>
</table>

Note: If there is a concern regarding the person’s safety consider using a tool such as the Person Centered Risk Assessment (Kinsella 2000). This allows you as a group to balance each option in terms of its potential risk to safety and the level happiness it will bring to the person.

Watson 2010
Appendix 3.5: *The Triple C: Checklist of Communicative Competencies (CCC)* (Bloomberg, West, Johnson, & Iacono, 2009)

<table>
<thead>
<tr>
<th>Communication level</th>
<th>Description</th>
<th>Example items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unintentional passive</td>
<td>Behaviours produced in response to internal and external stimuli are assigned intent or meaning by a communication partner.</td>
<td>Shows an awareness of sounds, particularly voices. Visually follows slowly moving objects or people.</td>
</tr>
<tr>
<td>Unintentional active</td>
<td>Beginning attempts to act purposefully on objects, with behaviours assigned intention or meaning by a communication partner.</td>
<td>Reaches or moves towards familiar people in familiar situations. Reaches for or looks at an object to indicate preference/choice imitates novel behaviours. Uses people to get objects.</td>
</tr>
<tr>
<td>Intentional informal</td>
<td>Acting on the environment to create a specific effect, resulting in communication attempts through informal rather than symbolic means.</td>
<td>Imitates novel behaviours. Uses people to get objects.</td>
</tr>
<tr>
<td>Symbolic (basic)</td>
<td>Integration of information from each of the senses, trial and error to solve simple problems and uses conventionally understood symbols within limited contexts.</td>
<td>Gives or shows an object to a person to obtain an action. Follows a simple instruction out of routine.</td>
</tr>
<tr>
<td>Symbolic (established)</td>
<td>Solving of problems through thinking about them; the person had internal representations and can use symbols in a range of contexts.</td>
<td>Predicts cause/effect relationships. Uses photos, pictures or signs for choice making.</td>
</tr>
</tbody>
</table>

Reference: Copied with permission from authors (Iacono, West, Bloomberg, & Johnson, 2009 p.53)
Appendix 3.6: Expression of interest flyer

Do you support, love or care for someone with Profound Intellectual Disability?

Are you interested in participating in some research?

Research is being carried out by Scope and Deakin University as part of a PhD Project.

I am looking for people to participate in the trial of a training program. This training is designed to assist participants to best support those they care about with severe to profound intellectual disabilities to participate in decisions.

As part of the research a DVD will be developed.

Some people who participate in the research will need to consent to appear in the DVD, which will be used for training and research purposes.

If you would like to participate or want more information about the project contact:

Jo Watson

0439201921

jwatson@scopevic.org.au or jmwats@deakin.edu.au

scope
Appendix 3.7: A Plain Language Statement (PLS) (English)

INFORMATION FOR PARTICIPANTS

Supporting those rarely heard to live lives they prefer: Supported decision making for people who communicate informally

Why have you received this information?

You have received this information because you are an important person in ________’s life. Both you and ________ have been invited to participate in the ‘Listening to those rarely heard’ research project. You have been invited by Jo Watson. Jo is a Speech Pathologist and a research fellow with Scope. She is also undertaking a PhD at Deakin University.

This project involves the evaluation of an approach called supported decision making. This approach is about supporting people with severe to profound intellectual disabilities to live lives they prefer through decision making. Jo would like your help in evaluating this approach. Agreeing to participate in this project means both agreeing to be part of a training program and the research about it.

What is this project about?

As you know, people with severe to profound intellectual disabilities are highly dependent on those who know and love them. These people communicate informally. This means...

Plain Language Statement (Full study)
they are not able to use or understand formal communication such as print, sign, line
drawings or speech alone. It also means that they are usually unable to participate in most
decisions without support from those who care for and about them.

A circle of support is a group of people who support someone to live lives they prefer. They
may include family, friends or paid support staff. These people are likely to have different
roles in the person’s life. They may provide care, guidance, support and protection for
them, or simply be their friend. They are the people who provide support during decision
making. You have been identified as a member of __________’s circle of support.

A supported decision making approach is a way of helping people with intellectual
disabilities participate in decisions about their lives. This approach assumes that everyone
can participate in decisions with support. It draws from the idea that everyone has
preferences, and these preferences can be built up into decisions with support from those
who care for and about them.

The ‘Listening to those rarely heard’ project has a number of parts:

- A training workshop about supported decision making which will be run by Jo
  Watson with __________’s circle of support;
- Practical guidance and mentorship provided to circles of support in their use of a
  supported decision making approach after their attendance at the training;
- Research about the effects of this supported decision making approach on your lives
  and the lives of those you support.
What are the benefits of this project for those who take part?

Involvement in this project will give _______ and those who support him/her an opportunity to work through a decision ________ currently faced with.

_______’s circle of support will be guided through a process of supported decision making through a one off training and follow-up support over a period of several months. It is hoped that this project will:

1. Support __________ to participate in a decision about his/her life.

2. Strengthen _________’s ‘circles of support’ in their capacity to support him/her in making decisions in the future.

What are you and __________ being asked to do?

- Initially you are being asked to meet with Jo Watson. This meeting will be an opportunity for Jo to give you more information about the project and to answer any questions you may have. At this meeting you will be asked if you want to participate in this project. You may also be the person who is asked to consent on behalf of _______.

- You and __________ will have plenty of time to decide if you want to participate. You will not need to decide if you want to participate at the time of the meeting unless you want to.

- If you decide to participate, you will be contacted by Jo to set up some times to meet with both you and ____________.

At these meetings you will be asked to answer some questions about _________. These questions will be about how you perceive _________’s

- Communication
• Ability to express his/her preferences

• Behaviours of concern

• Relationships

• Quality of life

• Self determination

At these meetings you will also be asked questions about your understanding and confidence in supporting _______________ to make decisions.

At these meetings you will also be asked to identify who else (from __________’s circle of support) you believe should be invited to be part of the study.

At these meetings Jo Watson (Speech Pathologist) will carry out a communication assessment with _______________. This assessment will involve the collection of information about how _______________ communicates as well as how others communicate with _______________. This assessment will involve accessing _______________’s files in order to collect information about _______________’s communication, behaviours of concern and previous intervention. It will also involve spending time with _________ and his circle of support observing him in both his day and home environments.

❖ You will be asked to attend a training session. This session will ideally take place within one of _______________’s familiar environments. At the end of this session you will be asked to identify a particular decision for _______________ and his circle of support to work through over the next few months.

Plain Language Statement (Full study)
After the training session you will be asked to complete a questionnaire in which you will be asked about your experiences, both good and bad, during the training.

After the training session you and ___________ will be asked to continue working with Jo over a period of approximately 2 months. During this period Jo will provide support and mentorship to you, and ___________ around the making of a decision about ___________’s life. As this is a collaborative approach, the other members of ___________’s will also receive support. You will be guided through the supported decision making process that has been introduced to you during the training session. Contact with you during this time will be frequent. Jo will also be available to you by phone or in person at any time during the process you feel you need more support.

After this period of support you will be asked to answer the same questions you were asked at the beginning of the project. These questions will be about how you perceive ___________’s

- Communication
- Ability to express his preferences
- Behaviours of concern
- Relationships
- Quality of life
- Self determination

After the 2 month period of support you will once again be asked questions about your understanding and confidence in supporting ___________ to participate in decisions.
You will also be asked to complete a questionnaire regarding how you feel about the training and follow-up support as a whole.

- Once ________’s decision has been made Jo will not have any formal contact with ________ and his/her circle of support for approximately 2 months. This will give ________ time to experience the outcome of his/her decision.

- After this period of 2 months ________ and his/her circle of support will be visited by Jo Watson. During this visit Jo will once again ask you some questions about ________’s
  - Self determination
  - Quality of Life
  - Behaviours of concern

Jo will also spend time with ________ observing these aspects of his life.

- With your consent, you and ________ will sometimes be filmed throughout the project. This footage will not be publicly available, and will only be viewed and analysed by Jo Watson as part of her PhD project. After her PhD is completed this footage will be destroyed.

- With your consent, some conversations with ________ and others who know him well will be audio taped. These recordings will only be listened to by Jo Watson as part of her PhD project. After her PhD is completed these recordings will be destroyed.
Who is suitable to participate?

Not everyone will be suitable for this project. Jo is looking for 2-3 people with severe to profound intellectual disabilities who communicate informally and their ‘circle of support’ to assist her with this project. She would like these people to be facing a life decision that they need help working through. This may be as large a decision as where to live, or as small as what colour to paint their room. Jo will be able to help identify this decision.

What are the benefits of this project for others with intellectual disabilities?

Through the research, Jo will study participants’ experiences in using a supported decision making approach and the training package as a whole. This will allow her to further improve the package, so as to give other people with severe to profound intellectual disabilities greater control of decisions that impact his or her life. This will also provide circles of support with an evaluated tool to support people who in the past may have been excluded from decisions about their own lives.

Are there any risks associated with being involved in this project?

It is possible that some participants may experience some discomfort throughout the training component of the project. During the training, participants will be asked to have discussions about the future well being of the person they support. These discussions may stir up feelings of anxiety, guilt and worry. These same discussions may cause disagreement and perhaps conflict between participants as to how to best support the person they care about. Participants will be referred to a Psychologist if they feel a need to discuss any of these issues.
What about your privacy and confidentiality?

As mentioned, participants will be filmed periodically throughout the project. This footage will not be publically available. It will be viewed and analysed only by Jo Watson for evaluation purposes.

Any additional data collected for the research will be in the form of interviews, surveys, questionnaires and observational checklists. All of these will have any personally identifiable information removed. Jo Watson therefore will be the only person who will be able to identify the participants. All research findings presented in conference or journal papers will not include any identifiable information.

All research data will be stored on a password protected laptop only accessible to the researchers. This data will be destroyed within 5 years of the date it is gathered. Aside from Jo Watson and her supervisors none of this information will be disclosed to anyone or any organisation, except for the participants themselves.

What will be done with the results of the project?

The results of this project will be used:

- To further develop understanding of how best to support people with severe to profound intellectual disabilities to lead lives they prefer;
- To further develop a training package for supporters of people with Profound Intellectual Disabilities;
- To educate and further develop an understanding of how best to support people with severe to profound intellectual disabilities to live lives they prefer in conference presentations and journal articles;
• As part of Jo Watson’s PhD that, once examined, will be available to the public through Deakin University.

What if you give my consent now but change my mind later?
Participation in this study is completely voluntary. This means that if you do not wish to take part, you do not have to. You may stop participating at any time throughout the project by letting Jo know in person or in writing. If you decline or withdraw participation, there will be no impact on you or ________

How do you complain about anything to do with the project?
If you have any complaints about anything to do with the project or any questions about your rights as a research participant, then you can contact:

Michael Bink
Head of Research and Community Development – Scope
mbink@scopevic.org.au

Or

The Manager
Office of Research Integrity, Deakin University,
221 Burwood Highway, Burwood Victoria 3125,
Telephone: 9251 7129, Facsimile: 9244 6581; research-ethics@deakin.edu.au

Has this project been approved?
This project has been approved by the Research Ethics Committees of Scope and of Deakin University. The project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) which is produced by the National Health and Medical
Research Council of Australia. This statement has been produced to protect the interests of people who agree to participate in human research studies.

Will you and ____________ be paid for participation in this project?
No.

How can you find out more information?
If you would like any further information about the project or have anything you would like to discuss you can contact Jo Watson.

Jo Watson
Research Fellow (Speech Pathologist) – Scope
jwaston@scopevic.org.au
0439 201 921

Plain Language Statement (Full study)
THÔNG TIN CHO NGƯỜI THAM GIA ĐẾN ÁN
Hỗ trợ những Người Hiếm được Nghe đến để Sống Cuộc sống mà họ Thích:
Giúp Quyết định cho Người Giao tiếp bằng cách Khác thương

Tại sao quỹ viện nhận bạn thông tin này?
Rhonda là Cơ viên và Chất lượng (Quality Advisor) của Scope.

Đây ảnh gồm việc tạo lập tranh bố huấn luyện mới và việc hỗ trợ người có Khuyết tất Trị năng Trầm trọng (Profound Intellectual Disabilities) để họ sống cuộc sống theo như quyết định của họ. Nhân viên nghiên cứu mong được sự giúp đỡ của quỹ viện trong việc áp dụng thứ tranh bố huấn luyện này. Đây sẽ là các yếu tố mới mà do đó điều quan trọng là phải có thời gian nghiên cứu chúng. Đồng ý tham gia vào để anh này có nghi nhận và đồng ý dự phần vào việc được huấn luyện lên cuộc nghiên cứu.

Để anh này nghiên cứu người việc gì?
Như quỹ viện biết, người có Khuyết tất Trị năng Trầm trọng tùy thuộc vào nhiều vào những người biết hoàn cảnh của họ và thường yếu tố. Những người có Khuyết tất này giao tiếp theo id ki khác hoàn bình thường. Điều này có nghiệm và hồ không thể đúng hoàn toàn các lo giao tiếp thông thường như chỉ dùng các an bản, đánh hiệu, đường về hay ngôn ngữ mà thôi. Điều này cũng có nghiêm và hồ thường không thể
tự quyết định cho đa số sự việc khi không có sự giúp đỡ của những người chăm sóc và lo lắng cho họ.

Vòng Hỗ trợ (Circle of Support) là một nhóm người giúp cho người nào đó muốn sống cuộc sống mà họ thích. Đây có thể là thân nhân, bạn bè hoặc nhân viên hỗ trợ được trả lương. Những người này thường giúp các vai trò khác nhau trong cuộc sống của người được hỗ trợ. Họ có thể cùng việc chăm sóc, hướng dẫn, giúp đỡ và bảo vệ cho người được hỗ trợ hay chỉ đơn thuần động vai trò người bạn. Họ là những người hỗ trợ khi có việc phải quyết định. Quy vị đã được nhận định là thành viên của Vòng Hỗ trợ cho ____________.

Phương pháp Giúp Quyết định (Supported Decision Making) là cách giúp người bị khuyết tật có quyền quyết định cho chính cuộc sống của họ. Phương pháp này giúp định rằng mỗi người đều có thể tự quyết định khi được giúp đỡ. Phương pháp này giúp suy nghĩ lại mọi người đều có thể cơ bắp việc mà họ muốn thông qua tổ chức, và với sự hỗ trợ của một người chăm sóc và lo lắng cho họ, các số liệu này có thể được phát triển để trở thành các quyết định.

Để anh 'Lắng nghe những Người Hiếm được Nghe Đến' này gồm nhiều phần:
• Một chương trình huấn luyện nuôi dưỡng về phương pháp giúp quyết định, do Scope tổ chức.
• Phát hành một DVD với sự góp mặt của nhiều người đội tham gia để anh này.
• Cùng với hướng dẫn tư duy và cố vấn cơ kinh nghiệm cho những người trong vòng hỗ trợ và người có Khuyết tật Trí năng Tràm trong khi áp dụng phương pháp Giúp Quyết định, sau khi họ đã hoàn tất khóa huấn luyện;
• Nghiên cứu về ảnh hưởng của phương pháp Giúp Quyết định, do Jo Watson thực hiện như một phần của việc học để lấy bằng Tiến sĩ tại Đại học Deakin của anh ấy.

Để anh này mang lại lợi ích gì cho những người tham gia?
Tham gia vào đề án này sẽ giúp cho ______________ và những người hỗ trợ có cơ hội cùng nỗ lực để đạt được một quyết định cho việc mà Hoàng Hiền đang phải đối phó.

Hai Nguyen Statement (Practice Pilot)
Những người trong vòng hỗ trợ cho sẽ được hướng dẫn để thông qua tiến trình giúp quyết định, trong một khoảng thời gian chỉ tối cho một lần và sau đó sẽ được tiếp tục giúp đỡ thêm vài tháng. Chúng tôi hy vọng rằng để an nấy sẽ:

1. Giúp dat được quyết định về cuộc sống của mình.
2. Cung cấp khả năng cung vòng hỗ trợ của trong việc hỗ trợ để đạt được các quyết định trong tương lai.

Quy vị và sẽ được yêu cầu làm gì?

- Trước tiên quy vị sẽ được yêu cầu gặp hai nhân viên ở nguy của Scope, là Jo Watson và Rhonda Joseph. Buổi họp này sẽ tạo cơ hội để nhân viên để an cho quy vị biết thêm chi tiết về đề án và đồng thời giải đáp các thắc mắc của quý vị. Trong buổi họp quy vị sẽ được hỏi nếu quý vị muốn tham gia vào đề án này.

Quy vị cũng có thể là người được yêu cầu đi diễn cho để kỹ giấy tờ thuận. Quy vị và sẽ có nhiều thời gian để quyết định xem có muốn tham gia. Quý vị không cần phải quyết định muốn tham gia hay không trong buổi họp đầu tiên, trừ khi quý vị muốn quyết định ngay.

- Nếu quý vị quyết định tham gia, nhân viên sẽ dẫn cách các nguy hiểm về quy vị và sau đó.

Trong các buổi họp sau này quý vị sẽ được hỏi về câu hỏi về. Các câu hỏi này nhằm tìm hiểu nhận thức của quý vị về trên các phương diện:

- Giao tiếp
- Khả năng biểu lộ việc ura thông
- Cách hành xử trong lo ngại
- Mối liên hệ
- Phạm chất cuộc sống
- Tinh tự quyết

Trong các buổi họp này quý vị cũng sẽ được hỏi về sự hiểu biết và mức độ tự tin của quý vị trong khi hỗ trợ để dat được các quyết định.
Trong các buổi hợp nay quý vị cũng có thể được yêu cầu nhận định xem có người nào khác (trong số những người thuộc Vọng Hỗ trợ) mà quý vị nghĩ rằng nên được mời tham gia vào để an nấy.

Trong các buổi hợp nay Jo Watson (Speech Pathologist) sẽ thực hiện việc thẩm định khả năng Giao tiếp của [***]. Thẩm định này sẽ thu thập chi tiết về cách [***] giao tiếp với người khác cũng như cách mà những người khác giao tiếp với [***]. Thẩm định này sẽ gồm việc xem hỗ trợ từ [***] tại Scope để thu thập chi tiết về cách giao tiếp, các hành xử đáng lo ngại và biện pháp đối phó trước đây. Đồng thời đánh giá thể theo [***] và những người trong vồng hỗ trợ, đề quan sát trong cài một trường cứ một ngày sinh hoạt cũng như tại nhà.

- Quy vị sẽ được yêu cầu dự một buổi huấn luyện 3 tiếng đồng hồ. Chừng thời sẽ cố gắng tổ chức buổi huấn luyện này tại một nơi có một trường quay thuộc cho [***] khi buổi huấn luyện nhằm đặt, quý vị sẽ được yêu cầu nói lên một việc cụ thể nào đó cần phải quyết định, để [***] và những người trong vồng hỗ trợ cùng làm việc để đạt được một quyết định.

- Sau khi hoàn tất buổi huấn luyện 3 tiếng đồng hồ, quý vị sẽ được yêu cầu trả lời một băn cài câu hỏi về những ngiệm mà quý vị đã trải qua trong buổi huấn luyện, cả tốt lẫn xấu. Điều này sẽ giúp chúng tôi cải tiến việc thực huấn luyện.

- Sau khi hoàn tất buổi huấn luyện 3 tiếng đồng hồ, quý vị và [***] sẽ được yêu cầu tiếp tục làm việc với nhân viên để an thêm từ 3-6 tháng nữa. Trong thời gian này nhân viên sẽ tổ chức các buổi tập cung ứng sự hỗ trợ và cố vấn cho quý vị và [***] về phương pháp điều trị qua quyết định cho cuộc sống của [***]. Quý vị sẽ được [***] dần thông qua tiến trình giải quyết điểm này được trong buổi huấn luyện 3 tiếng đồng hồ. Chúng tôi sẽ liên lạc với quý vị hàng tuần trong thời gian này. Nhân viên sẽ và an các sẵn sàng tiếp chuyện với quý vị qua điện thoại hay gặp mặt bất kỳ lúc nào trong tiến trình, nếu quý vị cảm thấy cần được hỗ trợ thêm.

Sau thời gian hỗ trợ 3-6 tháng này, quý vị sẽ được hỏi lại các câu hỏi như lúc mới tham gia đến an. Các câu hỏi này nhằm tìm hiểu nhân thơ của quý vị về [***] trên các phương diện
- Giao tiếp
- Khả năng biểu lộ việc ura thich
- Cách hành xử đáng lo ngại
- Mối liên hệ
- Phạm chất cuộc sống
- Tinh tự quyết

Sau thời gian hỗ trợ 3-6 tháng nay, quý vị sẽ được hồi một lần nữa về sự hiểu biết và mức độ tự tin của quý vị trong khi hỗ trợ để đạt được các quyết định.

Sau thời gian hỗ trợ 3-6 tháng nay, quý vị cũng sẽ được yêu cầu trải một bản các câu hỏi về cảm tưởng tổng quan của quý vị về việc huấn luyện và hỗ trợ sau đó.

- Một khi quyết định của quý vị đã thành tựu, nhân viên để an sẽ không chứng thức liên lạc với quý vị và những người trong vòng hỗ trợ từ 2-4 tháng. Đây là để cho quý vị có thời gian quan sát các quan điểm và kết quả của quyết định của mình.

- Sau thời gian 2-4 tháng nay Jo Watson sẽ đến thăm viếng quý vị và những người trong vòng hỗ trợ 2-3 lần. Trong những lần thăm viếng này Jo sẽ tập hợp quý vị với quý vị trên những phương diện
  - Tính tự quyết
  - Phạm chất cuộc sống
  - Cách hành xử đáng lo ngại

Jo cũng sẽ đánh thời gian theo quý vị để quan sát các phương diện này trong cuộc sống của quý vị.

- Với sự thỏa thuận của quý vị, khi quý vị và Hoang sẽ được tham gia Như sớm trong suốt đợt đầu này. Một số hình ảnh sẽ được dùng trong việc sản xuất DVD để huấn
luyện; và sẽ phát hanh cho công chúng để giúp giáo dục họ về việc hỗ trợ người có Khuyết tật. Tri ngày Trâm trong dễ đạt quyết định. Phân nhỏ hình ảnh còn lại sẽ không công bố cho công chúng, và chỉ được Jo Watson xem và phân tích cho đến an ủy làng Tiến sĩ của cô. Sau khi có hoàn tất việc học ủy làng Tiến sĩ, các hình ảnh này sẽ được hủy xóa đi.

Với sự thỏa thuận của quý vị, một số đâu đối thoại với và những người biết nhiều số được ghi am lại. Các lời ghi am này chỉ được Jo Watson nghe như một phần của dễ an ủy làng Tiến sĩ của cô. Sau khi có hoàn tất việc học ủy làng Tiến sĩ, các lời ghi am này sẽ được hủy xóa đi.

Ai là người mà nhân viên đề an họ vong sẽ tham gia?

Đề an này sẽ mang lại lợi ích gì cho những người có Khuyết tật. Trâm Trâm khác?
Qua cuộc nghiên cứu này, nhân viên đề an sẽ��功 saturation quan về kinh nghiệm mà những người tham gia đã trải qua khi ứng dụng phương pháp giúp quyết định, và tron bố các việc liên hệ đến huấn luyện. Điều này sẽ giúp ho cá thiên tron bố huấn luyện, như đó giúp những người khác có Khuyết tật. Trâm Trâm trong được tư chi nhiều hơn trong các quyết định hành hướng đến cuộc sống của họ. Đồng thời cũng cung cấp một công cụ để huấn luyện gia lưu ích, cho những người trong vòng hỗ trợ để giúp người có Khuyết tật, những người mà trong quá khứ đã biết rằng làm việc tham gia việc tham gia của họ.

Có nguy cơ nào liên quan đến việc tham gia đề an này không?
Một số người có thể cảm thấy khó chịu đối với phán huấn luyện của đề an này. Trong bột huấn luyện, những người tham dự sẽ được yêu cầu thảo luận về sự an
lành trong tương lai của người mà họ đang hỗ trợ. Các cuộc thảo luận này có thể đa dạng nội dung, câu hỏi, cảm xúc chung và mỗi người có thể đưa ra những ý kiến, giao lưu thường giữa những người tham gia, về cách hỗ trợ nào tốt nhất cho người hoang mang cảm xúc. Những người tham gia có thể được giới thiệu gặp chuyên gia Tâm lý (Psychologist) nếu họ cảm thấy cần ban thảo thêm về các vấn đề này.

Việc nâng tư và chi tiết của quy vị được giải tỏa như thế nào?

Những hình ảnh nào không được dùng trong trò DVD sau cùng sẽ không được công bố cho cộng đồng. Chúng chỉ được các nghiên cứu viên xem và phân tích với mục đích đánh giá để an.

Các đề kiệu thu thập thông cho đề án này sẽ là các cuộc phỏng vấn, bản thân do vậy, bản trường kiến điểm và những điều cần quan sát. Mỗi chi tiết cần nhận được xóa đi từ các đề kiệu này. Do đó chỉ có các nghiên cứu viên là người có thể nhận được những người tham gia. Mỗi kết quả của cuộc nghiên cứu được trình bày trong các buổi họp báo hay tập san chuyên nghiệp sẽ không chứa đựng chỉ chi tiết để có thể nhận diện bất kỳ người nào.

Mỗi đề kiện nghiên cứu được lưu trữ với mục mà bảo vệ, trong may vi tính xách tay, chỉ có nghiên cứu viên mới xem được. Các đề kiện này sẽ được hủy bỏ trong vòng
5 năm kể từ ngày thu thập được. Ngoài các nghiên cứu viên ra, không có chi tiết nào được tiết lộ cho bất kỳ cơ quan nào hay người nào, ngoại trừ cho chính những người tham gia.

Kết quả của các đề an này sẽ được đứng làm gì?
Kết quả của các đề an này sẽ được đứng để:
- Phát huy thêm sự hiểu biết về cách tốt nhất để hỗ trợ người có Khuyết tật Tri năng Trầm trong để sống cuộc sống mà họ thích;
- Phát triển trọn bộ hướng dẫn cho những người hỗ trợ người có Khuyết tật Tri năng Trầm trong;
- Đề cương và phát huy thêm sự hiểu biết về cách tốt nhất để hỗ trợ người có Khuyết tật Tri năng Trầm trong để sống cuộc sống mà họ thích, qua các thuyết trình trong các buổi hội thảo và các bài viết trong các tập san chuyên nghiệp;
- Làm một phần của đề an đây bằng Tiến sĩ của cô Jo Watson, sau khi được chăm sóc, sẽ được Đại học Deakin công bố cho công chúng.

Nếu quy vị đồng ý tham gia nhưng sau đó đổi ý thì sao?
Tham gia cuộc nghiên cứu này hoàn toàn là việc tự nguyện. Điều này có nghĩa là nếu quý vị không muốn tham gia, quý vị không bị bắt buộc tham gia. Quy vị có thể ngừng việc tham gia bất kỳ lúc nào trong suốt tiến trình của đề án, chỉ cần cho biết bằng cách viết thư hay gặp nhân viên đề án. Nếu quý vị từ chối tham gia hay ngừng việc tham gia sau này, sẽ không có ảnh hưởng gì đến các dịch vụ mà quý vị đang tiếp nhận từ Scope.

Tuy nhiên, như đã đề cập trên, một khi đã DVD đã được dự kiến, quý vị không thể đổi ý vì đã nay đã được phát hành cho công chúng.
Appendix 3.9: Supporter consent form
Listening to those rarely heard: Supporting people with Profound Intellectual Disability to live lives they prefer.

Consent form for Supporters

Participation in this project is completely voluntary. You can decide not to take part at any time.

Please complete this form as soon as possible in the reply paid envelope.

By completing this form I agree that:

- I have read and understood the information provided about the Listening to those rarely heard project.
- I, as a significant person in __________’s life am happy to participate in the project.

Personal details - please print clearly

<table>
<thead>
<tr>
<th>Full name:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>The full name of the person with an intellectual disability for whom I support:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>My relationship with the person for whom I support: (e.g. sister, father, friend, advocate, disability support worker)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Preferred contact details:</th>
</tr>
</thead>
</table>

463
Appendix 3.10: Proxy consent form

Listening to those rarely heard: Supporting those with Profound Intellectual Disability to live lives they prefer.

Consent form for proxy on behalf of person with a disability

Participation in this project is completely voluntary. If you believe it is in Lisa’s best interest you can decide on her behalf not to take part at any time.

Please complete this form as soon as possible in the reply paid envelope.

By completing this form I agree that:

- I have read and understood the information provided about the ‘Supporting those rarely heard to live lives they prefer’ project.
- My relationship with Lisa is of a longstanding and close nature.
- I believe I am providing consent in the best interests of Lisa.
- To the best of my ability I am able to confirm that Lisa is happy to participate.
- I, as a significant person in Lisa’s life am happy to participate in the project.

Personal details of the proxy - please print clearly

<table>
<thead>
<tr>
<th>The full name of the proxy is:</th>
</tr>
</thead>
<tbody>
<tr>
<td>The full name of the person with an intellectual disability for whom I am acting as proxy is:</td>
</tr>
<tr>
<td>My relationship with the person for whom I am acting as proxy is: (e.g. sister, father, friend, advocate, disability support worker)</td>
</tr>
<tr>
<td>Preferred contact details:</td>
</tr>
</tbody>
</table>


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Appendix 3.11: Examples of unstructured field notes

even sitting he got up and was
told to wait. When Kim offered
him some water he stood up to
leave. When she forced him to
sit down and physically restrain
him he spat and bared his teeth
on the table. He cried loudly.
Kim: He has finished what he need
to do, and he can’t want to go,
just wants to leave. A woman
approached us saying "I thought
I recognized that voice " It was
a woman that knew him but he

He needed his glasses on. "Why setting stuff
with his legs and nearly relaxed. Sighs.
Then hit head (Self sham)progress
at lots of the time. At lot of noise
not tongue thrust and teeth grinding. Look
thing toward the window (lights).

Read when male staff made
interacted with. Right with moving
2 days with the package. Email to me.
Some footage that he task of. He
seems pretty lecture so it will be lovely
to see these stuff. 
Appendix 3.12 Structured observation form

Observational checklist

Participant: ____________________________
Observer: ______________________________
Observer’s level of participation: __________
Observational location/time: ___________

Description of X:
• X’s mood
• X’s health
• What is X doing?
• Are there any recent events that may affect X (e.g. long bus trip home)
People present:
- How many other residents are present?
- Description of other residents
  - Communication method/style
  - Behaviours of concern
  - Severity of intellectual disability
- Description of supporters
  - Who is present and what is their role?
  - Number and type of tasks engaged in at the time of observation - what are they doing?
  - How do they behave around, engage with X?
  - Do they make clear any attitudes about X?
What impact does participation or lack of participation in decisions by X have on X’s:

- BoC?
- Participation in a range of activities?
- Perceived Quality of life?
Communication

• How does X communicate?
• What communication resources are available and/or in use with/by X?
• How do supporters communicate/interact with participants?
• What examples of interaction occur?
• To what extent do supporters appear to understand X’s communication?
• To what extent do supporters appear to know the preferences of X?
Evidence of self determination

- Do X's preferences appear to be known?
- Are X's preferences acknowledged and acted on in any way?
- How does X appear/behave when preferences enacted/acknowledged?
- What decisions are made about X (e.g. what he eats etc.)?
- Is X involved in these in any way?
What factors appear to affect X’s participation/lack of participation in decisions and/or enactment of preferences?

- Environment
- Staffing levels
- Staff attitudes
- Staff confidence
- Staff skills
- Staff knowledge/history
- Resources present
- Nature/focus of decision
- BoC
Supporters’ confidence/skill/knowledge

- How do supporters communicate with/to X?
- Do supporters appear to know X’s communication modes and meanings?
- Do supporters appear to ‘know’ X’s likes/dislikes/preferences?
- Do supporters appear to ‘know’ other residents likes/dislikes/preferences?
- Are communication attempts identified/acknowledged/responded to for X?
- Are communication attempts identified/acknowledged/responded to for other residents?
- Is X supported to participate in decisions/choices?
- Are other residents supported to participate in decisions/choice?
Behaviours of concern

- What behaviours are observed?
- What do they appear to mean?
- Frequency
- Severity
- Impact on X, others in environment, environment
### Appendix 3.13: Responsiveness observation template

<table>
<thead>
<tr>
<th>Supporter</th>
<th>Expression of preference</th>
<th>Acknowledgment of preference expression</th>
<th>Interpretation of preference expression</th>
<th>Acting on expression of preference</th>
<th>Responsiveness/responsive?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Niall</td>
<td>Walking slowly in the mall.</td>
<td>Supporter moved to his side of the table. The adult next to him held his hand.</td>
<td>Supporter said, “I know you are having a big meal.”</td>
<td>Supporter continued, “...and it’s not quite time to go. I need to finish my tea. I’ve had some in there, but a bit longer, maybe?”</td>
<td>Responsive</td>
</tr>
<tr>
<td></td>
<td>Walking leaving the supermarket and running outside.</td>
<td>Supporter said to Niall, “You need to walk, something we need.”</td>
<td>Supporter continued, “He’s had enough, poor boy. He has done well to keep it going. He needs to have some time outside.”</td>
<td>Supporter continued addressing the staff, “He’s had enough, poor boy. He has done well to keep it going. He needs to have some time outside.”</td>
<td>Responsive</td>
</tr>
<tr>
<td></td>
<td>Talking loudly after being asked to be quiet.</td>
<td>Supporter did not acknowledge preference expression.</td>
<td>No interpretation,</td>
<td>Supporter purchased ice cream, saying, “He usually likes them, don’t ya mate?”</td>
<td>Unresponsive</td>
</tr>
<tr>
<td></td>
<td>Screaming loudly while in the shower.</td>
<td>Supporter said, “Stop it!”</td>
<td>Supporter continued, “He’s had enough, stop crying, he’s still in there.”</td>
<td>Supporter went to bathroom and assisted Niall to complete his shower and get dressed.</td>
<td>Responsive</td>
</tr>
</tbody>
</table>
### Appendix 3.14: Angela’s pre intervention responsiveness data

<table>
<thead>
<tr>
<th>Supporter</th>
<th>Acknowledgment</th>
<th>Interpretation</th>
<th>Action</th>
<th>Overall Responsive/Unresponsive characterisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>A2</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>Responsive</td>
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<tr>
<td></td>
<td>√</td>
<td>√</td>
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<td></td>
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<td>X</td>
<td>X</td>
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</tr>
<tr>
<td>A4</td>
<td>X</td>
<td>X</td>
<td>√</td>
<td>Unresponsive</td>
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<td>X</td>
<td>X</td>
<td>√</td>
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## Appendix 3.15: Conflict template

A tool for recording incidents of conflict and conflict scores for each circle of support. This template allows for the calculation of a ‘conflict score’ for each circle of support, calculated by counting instances of conflict pre and post intervention. An ‘incident of conflict’ was defined in the following ways:

1. A disagreement that affected the flow of a workshop, focus group or discussion.
2. A conflict considered significant enough by supporters to report it to the facilitator/researcher, but not necessarily discussed openly.
3. Conflict evidenced through an email between circle of support members.
4. Conflict observed during an observation session.
5. Conflict identified in focus group or interview transcripts not already reported above.

<table>
<thead>
<tr>
<th>Circle of support</th>
<th>Stage of research (pre or post intervention)</th>
<th>Description of conflict</th>
<th>Conflict score pre-intervention</th>
<th>Conflict score post-intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angela</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neil</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Nathan</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Yuri</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kevin</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
Appendix 3.16: Interview guides

**Pre intervention individual interview**

Questions asked before training session two members of circle of support individually.

Some of these same questions will be asked to members of the circle of support during training session. The data gathered within the context of an individual and collaborative context will be compared.

Some of these same questions will again be asked of supporters, both individually and collaboratively at the end of the research for pre-post comparison.

1. How long have you known X?
2. Who is important in X's life?
3. Tell me about how decisions about X are made?
4. How much do you agree with the statement: X is able to participate in a decision about his/her life?

![Rating Scale]

5. How confident are you in understanding X's preferences?

![Rating Scale]

6. How confident are you in supporting X to make a decision that reflects their preference?
FINAL Pre intervention individual interview data collection tool (interview schedule)

7. What is your understanding of the human communication continuum and how it applies to X?

8. Using the communication continuum how would you describe X’s communication (unintentional/intentional informal/formal).

9. Would you say that X’s preferences are usually reflected in the decisions made about him?

10. If not, why do you think this is the case? If so, why do you think this is the case?

11. When faced with a decision is X given the opportunity to explore options?

12. Are any documentation tools used to help with the decision making process? (e.g. communication profile, log book of reactions to various options)

13. What is important to and for X?

14. Think about a decision X is faced with. Describe what you think your role is in supporting him to participate in that decision?

15. Describe X’s communication.
   a. How do you know what X likes/dislikes/wants?
   b. How do people who don't know X well know what he/she likes/dislikes/wants?
FINAL Pro intervention individual interview data collection tool (interview schedule)

c. What do you think would help X communicate more successfully?

16. Does X use any behaviors that are concerning to you?

17. What do you think X is communicating through his behavior?

18. I am going to show you a short video of X. I want you to answer the following questions:

I. What are your initial reactions
II. Is X communicating in this clip?
III. What does this clip tell us about X’s preferences?

19. What did participation in decision-making look like for X today?

20. Do you have any specific concerns about X’s health or safety at the moment?
Post training individual interview

*Post-training individual interview*

Questions asked at the end of project to members of support circle individually

Over the past 4 months, we have been working together to help X participate in a decision about his life. It is now time to reflect on what this process has meant for X.

1. Tell me what you think the outcomes of this process have been for X?

2. Let’s look at the decision-making framework. At what phase of the cycle are we at in terms of supporting X to participate in a decision?

![Decision-making framework diagram]

3. What factors have hindered the process?

4. What factors have helped the process?

5. This project is about self-determination. People who are self-determined are able to live lives they prefer, where possible. On a scale from one to 5, with 1 being ‘not at all’ and 5 being ‘very much’, how self-determined do you think X is?
Post training individual interview

6. How confident are you in identifying X's preferences?

7. How confident are you in working collaboratively with X's circle of support to help him/her participate in a decision that reflects his preference?

8. Think about another decision X is faced with. Describe what you think your role is in supporting him to participate in that decision?

9. Let's talk about X's behaviour of concern. Do you think this process has had any impact on his behaviour? If so, how?

10. As a result of this process, do you believe you have a better understanding of X? If so, how?

11. As a result of this process do you think X is now better able to participate in decisions about his own life? If so, how?

12. What is your understanding of the human communication continuum and how it applies to X?
Post training individual interview

13. Using the communication continuum how would you describe X's communication (unintentional/intentional informal/formal).

Person specific questions:

These questions have been developed specifically for individual case studies to follow-up on particular aspects of their data collected at earlier stages of the research.

The following are questions asked specifically in relation to Yuri.

1. It is clear that some conflict has existed between those involved in Yuri’s life, specifically day and residential services staff. After out time together, do you think you are getting along better? If so, is Yuri benefiting from this? If so how?

2. One of the things I have noticed about Yuri’s circle of support is how well you all seem to know each other. Do you think knowing each other is helpful in terms of reducing the conflict that exists?

3. Chris, you told me that the idea of exploring options with Yuri was challenging for you, because you wouldn’t know what to try with him. Do you feel more equipped and more confident now to explore options with Yuri? If so, what helped?
Appendix 3.17: Focus group questioning guide

**Focus group questions (general guide)**

Questions asked at the beginning of supported decision-making process and at the end to all members of circles of support for pre-post comparison. Some of these same questions will have already been asked of each member of the circle of support individually prior the training. Some of the data gathered within the context of an individual and collaborative context will be compared.

1. I am going to show you a short video of X. I want you to answer the following questions:
   
   I. What are your initial reactions
   II. Is X communicating in this clip?
   III. What does this clip tell us about X’s preferences?

2. What did participation in decision-making look like for X today?

3. Does X participate in decisions about his/her life? If so, how?

4. People who are self-determined are able to live lives they prefer, where possible. On a scale from one to five, with one being ‘not at all’ and five being ‘very much’, how self-determined do you think X is?

5. What barriers do you think exist for X in becoming more self-determined?

6. What do you think would help X become more self-determined?

7. As a group, how confident are you in identifying X’s preferences?
8. How confident are you in working collaboratively with X's circle of support to help him/her participate in a decision that reflects his/her preference? (Rating scale 1-5)

9. As a group, how confident are you in supporting X to make a decision that reflects their preference?

10. What does X like to do? If X could spend his/her time in anyway what do you think he/she would choose to do?

   Number these in order of preference.
   1. Look at things (e.g. bright colours etc.)
   2. Feel things (e.g. different textures and temperatures)
   3. Taste things (e.g. sweet/sour)
   4. Listen to things (e.g. singing/music)
   5. Move (e.g. move/dance)

11. What is important to X?

12. What is important for X?

13. Think about a decision X is facing. Describe what you think each of your roles is in supporting him/her to participate in that decision?
14. Describe X’s communication.
   a. How do you know what X likes/dislikes/wants?
   b. How do people who don’t know X well know what he/she likes/dislikes/wants?
   c. What do you think would help X communicate more successfully?

15. What do you think X is communicating through his/her behavior?

16. Do you have any concerns about X’s safety at the moment?
Appendix 3.18: An outline of the *Listening to those rarely heard* workshop structure

**People leading lives they prefer through supported decision making**

“Listening to those rarely heard”

**Workshop outline and facilitator’s notes**

Facilitator’s notes:

Suggested points to make:
- welcome!
- This workshop is designed around the individual needs of both you and Tom;
- We will explore how you as a team can support Tom to build a decision based on what we know about his preferences;
- Contribute your thoughts and ideas freely;
- We are all here for the same reason, that is, to support Tom live a life he prefers;
- None of us can or should be doing this alone.

Suggested activities:
- Direct participants to read the booklet’s ‘introduction’ in their own time. They may have time to read this material while they are waiting for the workshop to begin.
- Note: The booklet guides training facilitators and participants through the workshop. This workshop has been developed for a group of people who know someone with a severe to profound intellectual disability well. It is designed to be focused around someone who may be facing a particular decision, either now or into the future. The package should be tailored to the needs of those using it.
- Tom, a fictional character, is referred to throughout this booklet, as well as within the accompanying PowerPoint presentation.
- Tom has a severe to profound intellectual disability, and his story is used to exemplify how a supported decision making approach can be used. In order to make the workshop relevant, participants are invited to replace “Tom” with a person they are supporting, and to focus on that person throughout the workshop.
Slide 2
Who this workshop is designed for...

- People with a stroke
- People with learning difficulties
- People with physical disabilities
- Support workers and other professionals working with difficult clients

Facilitator's notes:
Suggested question:
Is there anyone else that should be on this list?
Suggested activities:
Record any other suggested people on a whiteboard/butcher's paper, to be referred to throughout the workshop.

Slide 3
We would like this workshop to...

- Highlight the value of making decisions as a family.
- Explore some tools and resources designed to support decision-making.
- Provide support for families, using a framework developed by Scope.

Facilitator's notes:
Suggested question:
Is there anything else you would like on this list?

Slide 4
“Listening to those rarely heard” introduction

Facilitator's notes:
- Watch the ‘introduction’ component of the video by clicking on the image;
- Alternatively play the ‘introduction’ section of the video on a standard DVD player.

Listening to those rarely heard - Workshop outline and facilitator's notes
Watson & Joseph, 2011
Facilitator notes:
Suggested points to make:
The term Profound/Severe intellectual disability describes someone who might:
• Need a lot of support;
• Communicate using behaviours considered challenging;
• Communicate using facial expression, body language, and sounds;
• Sometimes withdraw or fall asleep because the things around him/her don’t make sense;
• Have significant health needs.
Suggested activities:
Group discussion about terminology.
Reference notes:
Over the last two decades, the use of labels for people with intellectual disabilities has been generally discouraged, for fear of their individuality being buried within stereotypes. However, there is now growing support for the careful and respectful use of labels, particularly for people with severe to profound intellectual disabilities. There is increasing support for the notion that, for people with severe to profound intellectual disability to achieve true inclusion, individual difference needs to be named as the means by which they can become ‘visible’ and can obtain the supports and the resources they require. Sheridan Forster, an Australian-based speech pathologist and researcher says people with severe to profound intellectual disability “deserve the dignity of being named, counted and recognized for who they are, what they need, and how they might be a unique part of our community” (Forster, 2010 p.33).
Slide 6

Facilitator's notes:
Suggested questions to ask:
- Is there anything else you would like to add to this list?
Suggested activities:
- Record these points, and anything additional offered by the group on a whiteboard/butcher's paper, to be referred to throughout the workshop.

Slide 7

Facilitator's notes:
Suggested actions:
- Watch the video about Frances.
Suggested questions to ask:
- What decisions do you think Frances may be faced with now and into the future?
- What do you think some of her preferences might be around these decisions?
- How do you know what Frances prefers?
- How does she tell you?

Slide 8

Facilitator's notes:
Suggested points to make/actions:
- Think about a decision you have made in the past (large or small);
- Reflect on and discuss the process you went through to make that decision;
- Record discussion on the whiteboard, drawing out the following typical decision making process:
  - Identify decision to be made
  - Listen to yourself/friends/family
  - Learn about the options
  - Document
  - Decide
- How collaborative was your decision making?
Note: This process will be discussed in the next slide.

Listening to those rarely heard - Workshop outline and facilitator's notes

Watson & Joseph, 2011
Typical decision making process...

- Identify decision
- Listen to yourself
- Listen to others
- Learn about the options
- Document
- Decide

Facilitator's notes:

Suggested points to make:
This process has been developed from what the literature has to say regarding how a typical decision is made.

We get by with a little help from our friends

Facilitator's notes:

Suggested activities/points to make:

- Ask participants to read the story in their booklets 'We get by with a little help from our friends', or alternatively tell them a similar story based on your own experience. If you are concerned about the group's levels of literacy read the story in the booklets aloud to the group;
- Make the point... Dave goes on to remind his readers that he did not make it through the evening because he could stand up, he made it through the evening because he was held up. When he couldn't make a decision alone, he had to rely on someone he trusted to get him through the day;
- Facilitate a discussion asking these questions:
  - How many times do you make it through your day because someone helps you?
  - How many times when you have wanted to yell at your boss has a co-worker given you the time and space to let out steam?
  - How many times when you have felt unloved has someone given you a smile or a wink that has completely changed your day?
  - How many parents have been saved from harming their children because they can pick up the phone and let out a stream of forbidden words to an understanding friend?
  - Who are these people to you? They are your support network.
Slide 11
Facilitator’s notes:
Suggested actions:
- Note down your support network;
- Facilitate discussion.
Suggested points to make/questions to ask:
- Who are these people?
- Think about the depth of your support network and contrast it with Tom’s.
Note: You are likely to find that the support network varies, but is quite similar. Family, friends, co-workers, ministers, some may put God on the list as someone to talk to in times of decision making.

Slide 12
Facilitator’s notes:
Suggested points to make:
- Humans need each other;
- Supported decision making is about recognizing, validating and supporting the important role those who know and love us play in decision making;
- This role is particularly important for those with severe to profound intellectual disabilities, like Tom.
Suggested actions:
Group discussion if time permits.

Slide 13
Facilitator’s notes:
Suggested points to make:
- We all turn to those who know and love us for support in making decisions that are difficult for us;
- Some people, like Tom, simply need a lot more support than others;
- Sometimes it may be beneficial to formalize this support, but not always.
Suggested actions:
Group discussion about the value of formalizing a support network for Tom.
Note: Tom may or may not currently have a well established support network.
Facilitator's notes:
Suggested actions/points to make:

- Read the first paragraph in the section titled 'Tom's decisions' in booklets;
- As a group answer the questions listed;
- Facilitator record this discussion on whiteboard/butcher's paper, drawing out the following information:

1. Decisions Tom maybe faced with:
   - Involvement in everyday decisions. For example, what to eat and what to wear?
   - Involvement in decisions about his support and services. For example, where to live, how to spend time?
   - Involvement in decisions about his local community. For example, what services there should be?
   - Involvement in decisions about national policy. For example, taking part in government consultations?

2. How are these decisions made currently?
   - Ask participants to think about how Tom has made decisions in the past;
   - How does this differ from the way you make decisions?

Note: The main difference that should emerge during this discussion is that Tom simply needs more support.

3. Role of 'circles of support':
   - Listening and interpreting Tom's preferences and building these up into decisions;
   - Breaking down the very real attitudinal and system barriers that exist to ensure Tom's decisions are heard and realized.
**Slide 15**

**Supported decision making**

Recognising the value of people working together

**Facilitator's notes:**

**Suggested actions:**

- Turn to section in booklet titled 'Supported Decision Making' framework;
- Ask participants to read this section.

**Note:** If the facilitator is concerned about participants' literacy and therefore their ability to read and comprehend what is written simply read the content aloud.

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**Slide 16**

**Supported decision making**

The starting point is not a best world, but the question: For what, for whom, and how? In the context of decision making, where are the preferences? Preferences can be built up. This expression of preference makes it possible to make the decision. From this perspective, where someone stands is a question of their own preferences and more generally of their personal circumstances.

**Facilitator's notes:**

**Suggested actions:**

Read to group and discuss the notion of decision making capacity.

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**Slide 17**

**Supported decision making framework**

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**Facilitator's notes:**

**Suggested actions**/Suggested points to make:

- Scope has developed a model of Supported Decision Making;
- It is a framework designed to gather a consensus view on what Tom may be communicating, or what is in his best interests, and from there collaboratively make a decision;
- This decision obviously should not be set in stone;
- It may be useful to use a structured process like this when there is a decision to be made, and there is uncertainty about what Tom is feeling about it;
- It may also be useful when there is a difference in opinion, as it can allow everybody to have their say, and to be clear about their own agendas;
- This process may also provide a clearer picture of Tom's preferences;
- This picture is sometimes necessary to

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help express to authorities and funding bodies what people with intellectual disabilities may need in terms of services and supports;

- If these perceived preferences are documented Tom’s voice can become clearer and louder;

- It is essential that this documentation is not ‘set in stone’ and is reviewed regularly, as preferences, perceptions and circumstances can and will change over time;

- A more detailed version of the Supported Decision Making framework is set out in the booklet.

Suggested actions:
Group discussion.

Facilitator’s notes:
Have a break if this is an appropriate time.

Facilitator’s notes:
Suggested points to make:
Communication is fundamental to hearing people’s preferences.
Suggested actions:
Direct participants to the sections in the booklets titled ‘Communication’, and either read this aloud or ask group to read the material themselves.
Slide 20

Facilitator’s notes:
Suggested activity:
Take it in turns to tell the group what you would like for dinner WITHOUT USING SPEECH, writing or drawing.
Suggested questions:
• What communication methods did you resort to?
• Did you use or want to use behaviours of concern?
• Was all your communication intentional?
• Did you use symbols to communicate (e.g. signs/pictures)?
• What functions of communication did you use? (requesting, protesting, commenting, answering)

Slide 21

Facilitator’s notes:
Suggested points to make:
• Communication develops along a continuum, beginning at the earliest stage of communication;
• It usually progresses through a series of stages;
• Most people move through these stages to become functional and independent communicators by the age of 5;
• A small percentage of people who have profound intellectual disabilities do not make this transition;
• Tom maybe one of those people.
Suggested activities:
Group discussion

Listening to those rarely heard - Workshop outline and facilitator’s notes
Watson & Joseph, 2011
Facilitator's notes:
Suggested points to make:
Summarise what is meant by ‘unintentional communication’:

- The person does not appear to communicate intentionally, however they do indeed communicate;
- The person communicates using behaviour (e.g. body language/vocalisations);
- They rely on others to notice and give meaning to that behaviour (sometimes this involves best guessing);
- The person does not appear to understand speech;
- People who know the person well tend to respond instinctively to their behaviour doing their best to ensure their needs are met;
- The sharing of knowledge of a person and their communication is very important.

Suggested activities:
Ask participants to think about Tom while you are running through this.

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Facilitator's notes:
Suggested points to make:
To summarise what we mean by ‘intentional communication’:

- The person intentionally communicates;
- They may not use or appear to understand formal/symbolic communication like speech, sign, pictures or words;
- They may use communication methods like gesture, eye gaze, facial expression and sometimes behavior;
- They appear to understand that in order to get what they want, they need to involve another person.

Suggested activities:
Ask participants to think about Tom while you are running through this.
Facilitator's notes:
Read to group:
Frank spends most of his time in a wheelchair. At times he yells loudly and hits his leg with his fist. He does this, regardless of who is present. People, who know him well, believe that this means he is uncomfortable in his wheelchair and needs a change of position. When they help move him to his favourite bean bag, he usually smiles broadly and stops yelling.
Suggested questions to pose and discuss:
- Is Frank communicating intentionally or unintentionally?
- How do you know?

Facilitator's notes:
Read to group:
When Jason comes home he usually goes to the dining room and paces in front of the kitchen door, flapping his arms and yelling. He does this without looking at anyone else. His family believes this means he wants some afternoon tea. They give him some afternoon tea. He stops pacing and flapping his arms and eats. Once finished eating he then paces near the back door, frequently stopping to look outside and to bang on the door. His family interprets this to mean that he wants to go outside. If the weather is ok, they open the door so Jason can go outside. His family believes they have interpreted Jason's communication accurately if he runs around the backyard laughing.
Suggested questions to pose and discuss:
- Is Jason communicating intentionally or unintentionally?
- How do you know?
Facilitator’s notes

Suggested activities:

Read to group:
Sarah is 29 years old and has an intellectual disability. She enjoys the weekly drama session she attends at her day service. She participates by copying other group members. Sarah particularly appears to enjoy hanging out with Emma the woman who runs the session. At the beginning of the session Sarah looks around the room. Once she finds Emma she will sit next to her. If Emma is not already sitting down Sarah will approach her and stand next to her until the session begins. She will often take her hand and guide her to a chair. Once Emma is sitting down she will sit next to her. If someone else sits next to Emma, Sarah will often cry and push that person.

Suggested questions to pose and discuss:
- Is Sarah communicating intentionally or unintentionally? How do you know?
- Is she communicating formally or informally? How do you know?

Facilitator’s notes:

Suggested activity:
Ask participants to imagine that today you are 80 and you have dementia. You are not considered by those around you as a competent decision maker. You need to go to a nursing home.

Suggested questions to pose and discuss:
- What do you think is important for those making the decision about where you live to know?
- Reflect on Tom and the decisions that are made about him.
  a. What drives the decisions that are made about him?
  b. Are his preferences heard?
Facilitator’s notes:
Suggested actions:
• Discuss Tom’s communication together;
• Turn to the section in your booklets titled ‘Tom’s Communication’;
• These questions have been designed to develop a collaborative picture of how Tom communicates;
• As a group discuss these questions and record on whiteboard/butcher’s paper.

Facilitator’s notes:
Suggested points to make:
• We haven’t got time to unpack the communicative function of Tom’s behaviours of concern in detail during our time together. However, it is worth exploring what purpose (or function) any behaviours of concern have for Tom?
• Although there are many reasons why a person may use behaviours of concern, it may be helpful to consider the function in relation to the following four categories:
  - Social attention - ‘I am lonely, could someone come and have a chat’
  - Tangibles - ‘I want that bottle of lemonade’
  - Escape - ‘Get me out of here’
  - Sensory - ‘I don’t like the texture of that blanket you just put around me’
• The Motivation Assessment Scale (Durand & Crimmins, 1986) is a tool to help us do this. This is a tool you might like to use together over the next few months. It can be found in the ‘other useful information’ section of the booklet.
Facilitator's notes:
Suggested points to make:
- Self determination is a term that is used a lot;
- We hear it in discussions around people who have traditionally not been heard, such as in indigenous societies;
- It means different things to different people. However, fundamentally, it is about humans having control over their own lives through decision making and choice;
- Self determination is a fundamental human right;
- There are a range of factors that can limit self determination generally for people with severe to profound intellectual disabilities.
Suggested actions:
- Whiteboard/butcher's paper discussion about factors that limit self determination. Draw out the following points:
  - Traditional view of decision-making competence;
  - A general lack of resources;
  - Risk phobia;
  - Outdated perceptions of 'duty of care';
  - Service cultures and staff value judgments;
  - OH&S policy which is in conflict with the preferences of those with disabilities;
  - Lack of knowledge and clarity about legal rights and systems;
  - System barriers that prevent choice. Sometimes choice is reduced to a 'fixed menu';
  - Assumptions that people cannot be supported to make decisions;
  - Challenges with 'hearing' and responding to people who communicate unintentionally and informally;
  - A lack of resources/frameworks for supporting decision making.

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Facilitator's notes:
Suggested points to make/questions:
- What does self determination mean to you?
- Are you self determined?
- In what parts of your life are you able to demonstrate this self determination?
- What barriers stand in your way?

Slide 32

Facilitator's notes:
Suggested activities:
Turn back to the 'Supported Decision Making Framework' section in booklets and begin the process of working through a decision with Tom.

Slide 33

Facilitator's notes:
Suggested Activities/Points to make:
- Turn to section in booklet titled 'Supported Decision Making Framework';
- As a group work through the following from the 'Identify Decision Together' section;
- Ask a participant to take notes;
- Is there a decision to be made?
- Is the status quo ok or not?
- Who is this decision important to?
- Why is it important?
- Identify the options, considering what new possibilities and opportunities exist for Tom.
- Be clear about what everyone's hopes, assumptions and agendas are.
Facilitator's notes:

- Watch the 'Identify Decision Together' component of the video by clicking on the image;
- Alternatively play the 'Identify Decision Together' section of the video on a standard DVD player.

Note: Pause the video when Anne talks about Laura's ability to make decisions. She says she wouldn't be able to make a decision about where to go on a holiday. Ask participants to remember that, because you will discuss it in more detail later.

Facilitator's notes:

Suggested Activities/Points to make:

- Turn to section in booklet titled 'Supported Decision Making Framework';
- As a group work through the following from the 'Listen Together' segment;
- Ask a participant to take notes;
- Listening is the key to supporting someone through a decision making process.
- Listen to Tom's sounds, cries, laughter, scratches, smiles, grimaces, tapping, shouts and silences. Discover what is important to him by following his eyes to the things that interest, excite or perhaps scare him.
- Discover what Tom enjoys by 'listening' to his behaviour. Where does he like to go? Who does he like to be with? What sensory activities does he enjoy? What is it about these places and people he appears to enjoy?
- Spend relaxed time simply 'being with' Tom without any particular agenda. Allow Tom to take the lead in the interaction. Respond to his behaviours using eye contact, facial expression, vocalizations and imitation. This form of 'being with someone' is sometimes called 'intensive interaction'. It allows a person to communicate their preferences at their level.
- Listen to others who know and love Tom. They are most likely to know how he expresses his preferences and are likely to know his history and stories, too. Our identities exist in our stories.
- Discover who Tom is beyond his disability. If he had control over his life,
what clothes do you think he would wear? What music do you think he would enjoy? What food do you think he would eat?

Facilitator’s notes:
Suggested points to make:
- People have so much to tell us about who they are through their sensory preferences;
- These preferences can form the building blocks of decisions.

Facilitator’s notes:
Suggested actions:
- Turn back to the section in booklets titled ‘Tom’s communication’;
- Look at question 7 again. This question is designed to tell us about Tom’s sensory preferences;
- A Sensory Profile (Dunn 1999) can help us do this as well. Has Tom ever had one of these?
- Show an example of a sensory profile if you have one available. Suggest that it might be helpful to talk to an Occupational Therapist about this;
- Come to a consensus about what sensory experiences make Tom happy.
Facilitator’s notes:
Suggested points to make/questions to pose:
- Think about Tom’s history. If he was able to tell his story, what would he say?
- What do these stories when pieced together, tell us about Tom’s preferences?
- Share a quote by Nicola Grove: “Stories are important! They nourish our imagination, fill our dreams, entertain and inspire us. We use stories every day of our lives - every time we see friends, visit the doctor, return something we have bought, explain key facts to policemen, solicitors, teachers, social workers and ticket collectors. Stories are the way we make sense of what has happened and so they are critical to our sense of who we are. Our identities exist in the stories we tell ourselves and others” (Grove, 2009).

Facilitator’s notes:
Suggested actions:
Read paragraph below about David. David is 20 years old and has profound disabilities. He has cerebral palsy, is partially sighted, and cannot speak for himself. Some weekends he goes to respite care to give his family a rest from the heavy physical demands of caring for him. Respite also gives him some time out from his family, which he seems to enjoy. One day David went on a visit to the butterfly house with his respite care team. The staff member who was pushing his wheelchair didn’t realise how big the butterflies were and freaked out. He threw his jumper over his head, screamed and ran, leaving David alone in his wheelchair. David laughed all the way home.
Suggested questions to pose and discuss:
- What does this story tell us about David and his preferences?
- What stories can we share about Tom that help us get to know him?
Facilitator's notes:
Suggested actions:
- Watch the 'Listen Together' segment of video by clicking on the image;
- Alternatively play the 'Listen Together' segment of the video on a standard DVD player.
Note: Pause video when Anne talks about Laura not liking the snow, and therefore as a family they would not take her there.
Point to make:
Think back to when Anne said Laura couldn't make a decision. What is Anne saying here? Do you think she is saying that Laura can make a decision about where to go for a holiday? The reality is that Laura is dictating where everyone goes on holiday.

Facilitator's notes:
Suggested points to make/questions to pose:
- We all have activities/tasks in our lives that we really enjoy and activities that we despise;
- Spend some time thinking about these activities;
- What is it about these activities that you love them or despise them?
- Are these characteristics reflected in other activities you enjoy or don't enjoy?
- Based on this list what other activities should you have more of in your life?
- How would this influence your decision making in the future?
Suggested activities:
- Ask each participant to develop a list of activities that make him/her happy/unhappy;
- What is it about these activities that make you happy/unhappy?
- Based on this information ask them to define activities they should have more/less of in their life.
Facilitator’s notes:
Suggested Activities/Points to make:
- Turn to section in booklet titled ‘Supported decision making framework’;
- As a group work through the following from ‘explore the options together’, segment;
- Ask a participant to take notes:
  - We all need information about options to make decisions.
  - We need it in a way we are likely to understand.
  - Tom is most likely to understand his options when he is able to experience them first hand and when they are presented in the here and now.
  - The ‘Preferred Activity Analysis’ (Watson 2010) is a tool that may help explore the activities Tom appears to enjoy/not enjoy. It can be used to discover what other activities might involve the elements Tom is indicating he enjoys or doesn’t enjoy?
  - This information can then be considered when identifying options.
  - Allow Tom to feel, taste, listen to and in other ways explore his options. ‘The exploration of options’ form (Watson 2010) is a tool that may help explore and record this information.
  - Tom is likely to need a LOT of time to explore his options.

Suggest that circles of support may want to complete the forms over the next few months, TOGETHER. If appropriate, this could take place within the workshop.

Note: Both the ‘Preferred Activity Analysis’ (Watson 2010) and ‘The exploration of options’ form (Watson 2010) can be found in the booklet.
Facilitator's notes:

Suggested activities:

- Turn to section in booklet titled 'Supported Decision Making Framework';
- As a group work through the following from 'Explore the Options Together' segment;
- Ask a participant to take notes:
  - We all need information about options to make decisions.
  - We need it in a way we are likely to understand.
  - Tom is most likely to understand his options when he is able to experience them first hand and when they are presented in the here and now.
  - The 'Preferred Activity Analysis' (Watson 2010) is a tool that may help explore the activities Tom appears to enjoy/not enjoy. It can be used to discover what other activities might involve the elements Tom is indicating he enjoys or doesn't enjoy.
  - This information can then be considered when identifying options.
  - Allow Tom to feel, taste, listen to and in other ways explore his options. 'The Exploration of Options' form (Watson 2010) is a tool that may help explore and record this information.
  - Tom is likely to need A LOT of time to explore his options.
- Suggest that circles of support may want to complete the forms over the next few months, TOGETHER. If appropriate, this could take place within the workshop.

Note: Both the 'Preferred Activity Analysis' (Watson 2010) and 'The Exploration of Options' form (Watson 2010) can be found in the booklet.
Facilitator’s notes:
Suggested Activities/Points to make:
- Watch the section of video titled ‘Document Together’ by clicking on the image;
- Alternatively play ‘Document Together’ segment of the video on a standard DVD player;
- Refer participants to the examples of documentation tools in booklets;
- Show examples as well if some are available.

Facilitator’s notes:
Suggested Activities/Points to make:
- Turn to section in booklet titled ‘Supported Decision Making Framework’;
- As a group work through the following from the ‘Document Together’ segment;
- Ask a participant to take notes;
- A person’s voice can become very loud when information about their communication is gathered and documented properly. Record detailed information about how Tom communicates in different situations with different people and at different times. Use a range of communication profiling tools, such as communication passports, sensory happiness charts and multimedia profiles.
- Once documented this information is not set in stone. Preferences change and therefore it is important to review this information regularly.
- Documentation is important should evidence be required as to how the decision was reached.
Facilitator's notes:
Suggested points to make and discuss:
- Multimedia profiling is a communication tool;
- It enables people through the use of video and computers to gather and share information about themselves;
- It helps overcome barriers to communication by establishing a powerful presence, real or virtual;
- It's proved an accessible and effective way to focus ideas, convey messages and show the evidence that can so often make a difference for people who don't communicate using speech.
Suggested activities:
Direct participants to 'Multimedia Profiling' fact sheet from Mencap in booklets.

Facilitator's notes:
Suggested activities:
Show video of Francis.
Suggested points to make/questions:
- Although this is not technically a Multimedia profile, it is one way to document information about someone;
- What does this video tell us about Francis in terms of his preferences?
- If a decision was to be made for him regarding where he might go on a holiday what would you take into account?

Facilitator's notes:
Suggested activities:
- Watch the section of video titled 'Make Decision and Act on it Together' by clicking on the image;
- Alternatively play the 'Make Decision and Act on it Together' segment of the video on a standard DVD player.
Facilitator's notes:
Suggested Activities/Points to make:
• Turn to section in booklet titled 'Supported Decision Making Framework';
• As a group work through the following from the 'Make Decision and Act on it Together' segment;
• Ask a participant to take notes;
• Base the decision around all the information gathered about Tom's preferences.
• Ensure that any decision made reflects Tom's moral and legal rights.
• Check that no particular agenda is driving the decision.
• Keep in mind that the choice may not reflect what is important for Tom, but what is important to him.
• Think about how to balance Tom's need to take risks with safety. The Person Centred Risk Assessment (Kinesella 2000) might be useful. This is in the 'More information' section of the booklet.
• Obviously Tom will need support to act on the decision. As you know there are often many attitudinal and system barriers in people's way. Tom is likely to need a great deal of your support to hurdle these.

Facilitator's notes:
Suggested points to make/questions:
• We cannot talk about decision making without reflecting on risk;
• Decision making is inherently risky;
• Think about a time in your life where you felt you were taking a risk;
  o How did you make your decision?
  o Who did you talk to?
  o Who did you consult?
  o What support did you get before, during and after?
  o What did you get out of this experience?
  o Share your story with the group.
Facilitator's notes:
Suggested points to make/questions:
• When I ask myself why I feel ok about taking risks, I think about the supports I have around me that I trust will catch me if I fall and scaffold me if I need it;
• Do the people we support have this support?
Suggested actions:
Read the poem on back cover of booklet.

Facilitator's notes:
Suggested points to make and discuss:
• When making decisions it is important to remember that sometimes what is important for us is not necessarily important to us;
• Discuss examples in participants’ own lives.

Facilitator's notes:
Suggested actions:
• Offer the opportunity to get together again in a few months for an informal catch up;
• Between now and then ask participants to explore with Tom the decision discussed today using the supported decision making framework;
• Ask participants what the next step is going to be, and delegate some roles and responsibilities.

Listening to those rarely heard - Workshop outline and facilitator’s notes
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Appendix 3.19: Example of written narratives generated collaboratively during workshops using Lyng’s (2007) technique of viewing the focus person beyond their disability

Angela is feisty. She loves being with people. She makes us laugh A LOT. If there were no constraints on her life, we think she would be a cheerleader.

Yuri is a gentle soul. He is peaceful and kind. He loves to meditate. He also loves soft cool music. He loves good music too.

Neil is funny! He is a happy man. He loves fast cars and anything related to them. He loves the speed, the smell, and the fumes. He is a nice man with a kind heart.
## Appendix 3.20: The Questionnaire about Choice compared to Hatton et al.’s (2004) Resident Choice Scale

<table>
<thead>
<tr>
<th>Resident choice scale (Hatton et al., 2004)</th>
<th>Questionnaire about choice (used in this study) adapted from Resident choice scale</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Instructions:</strong></td>
<td><strong>Instructions:</strong></td>
</tr>
<tr>
<td>In what ways is the person supported in making choices with regard to the following areas of their life?</td>
<td>Please answer the following questions about opportunities X has to make choices in his/her life. Using the three point-rating scale provided place a number from one to three in the box. Elaborate by giving some examples if you have some.</td>
</tr>
<tr>
<td><strong>Rating Scale:</strong></td>
<td><strong>Rating Scale:</strong></td>
</tr>
<tr>
<td>1. Nothing mentioned/resident considered by staff member to make incapable of making choice in this area;</td>
<td>1. X considered incapable of making choice in this area;</td>
</tr>
<tr>
<td>2. Some procedure(s) mentioned but unlikely to give person much real choice;</td>
<td>2. Preferences are acknowledged, but final say generally rests with his/her supporters;</td>
</tr>
<tr>
<td>3. Some procedure(s) mentioned through which person can express preferences but final say does not rest with person;</td>
<td>3. Preferences are acknowledged and are reflected in final decision unless clearly inappropriate or dangerous.</td>
</tr>
<tr>
<td>4. Procedures in place for person to express preferences and these are the final say unless clearly inappropriate or dangerous.</td>
<td>In what way is X supported in making choices with regard to the following areas of his/her life?</td>
</tr>
</tbody>
</table>

<p>| Question 1: The content of their evening meal? | No adaptation |
| Question 2: The timing of their evening meal? | No adaptation |
| Question 3: Where they eat their evening meal? | No adaptation |
| Question 4: The leisure activities they take part in indoors (e.g. T.V., radio) | No adaptation |
| Question 5: Going out (e.g. Pub, cinema)? | No adaptation |
| Question 6: | No adaptation |</p>
<table>
<thead>
<tr>
<th>Question</th>
<th>Adaptation</th>
</tr>
</thead>
<tbody>
<tr>
<td>The time they go to bed in the evening?</td>
<td>No adaptation</td>
</tr>
<tr>
<td>The clothes that they purchase?</td>
<td>No adaptation</td>
</tr>
<tr>
<td>The clothes that they wear each day?</td>
<td>No adaptation</td>
</tr>
<tr>
<td>Household routines (e.g. shopping for food, household rotas)?</td>
<td>Deleted</td>
</tr>
<tr>
<td>Keeping pets?</td>
<td>No adaptation</td>
</tr>
<tr>
<td>Who they live with?</td>
<td>No adaptation</td>
</tr>
<tr>
<td>Where they live?</td>
<td>No adaptation</td>
</tr>
<tr>
<td>Recruitment of staff?</td>
<td>Changed to: Who supports them?</td>
</tr>
<tr>
<td>Staff performance review?</td>
<td></td>
</tr>
<tr>
<td>The firing of unsuitable staff?</td>
<td>Deleted</td>
</tr>
<tr>
<td>Involvement with girlfriends or boyfriends?</td>
<td></td>
</tr>
<tr>
<td>Their haircut?</td>
<td>Changed to: Their haircut and/or shave?</td>
</tr>
<tr>
<td>Their daytime activities?</td>
<td>No adaptation</td>
</tr>
<tr>
<td>Holidays: Where they go, who they go with, and when they go?</td>
<td>Changed to: Their holidays?</td>
</tr>
<tr>
<td>Question 20:</td>
<td>No adaptation</td>
</tr>
<tr>
<td>The time they spend in the bath or shower?</td>
<td>Deleted</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>---------</td>
</tr>
<tr>
<td>Their employment</td>
<td>Deleted</td>
</tr>
<tr>
<td>Access to a private area?</td>
<td>Deleted</td>
</tr>
<tr>
<td>Moving home in the future?</td>
<td>Deleted</td>
</tr>
<tr>
<td>The furnishings in their home?</td>
<td>No adaptation</td>
</tr>
<tr>
<td>The furnishings in their bedroom?</td>
<td>No adaptation</td>
</tr>
<tr>
<td>Personal possessions?</td>
<td>Deleted</td>
</tr>
</tbody>
</table>
Appendix 3.21: Example of ‘marked up’ transcript

Record 7

FULL TRANSCRIPT

Facilitator: Decision-making for people who were often not listened to. I can't remember.
Participant: Listening to those rarely heard.
Facilitator: Rarely heard, I think that's where we're at now isn't it?
Participant: On yes or maybe hearing from...
Facilitator: Yes, so that's the name that we're at now and we're still -- and every time we do it, it changes a little bit and Jo's now sort of become the face of this project, which is great. She needs to be and she's off conferencing all around the world, telling everyone about how fantastic this is and it is fantastic, but it's just really common sense.
Participant: Yes it's not rocket science.
Facilitator: Yes so that sort of -- so that's why I pushed myself in. Because for me, well I've been working on it for years. It's really nice to see that it actually works, and so for me that's [overtalking].
Participant: No, you better, we actually need [0.57.2] because yes despite what Adrian says, she does work a lot with Scope service users, so, you know her role is to really hear their voice and be a bit of a bridge, hey Yung?
Facilitator: Well I think we will start without --- she's heard a lot of this stuff before and what I'll say Yung, is if you don't feel like being here, that's cool. You know, you just let us know and we'll take you out if you've had enough of all these people. Okay, so everyone knows each other? Given us a nice intro, which is terrific. Today what we're going to be doing is coming together -- we've only got two and a half hours, we just don't have time.
Participant: You're still missing someone.
Facilitator: We're missing two, but that's all right because we knew Petra was going to be late and Sally's coming -- have you met Sally?
Participant: Yeah.
Participant: Yeah.
Participant: Might have done.
Facilitator: She's what we call a...
Participant: [Overtalking]
Facilitator: Yes. Have you met Sally?
Participant: No.
Facilitator: So she'll be here and she knows all about communications; so that's...
Participant: [0.02.18.3].
Facilitator: Yes, she is. So what we thought we’d — with this, the model of this training is for everyone who knows somebody well to come together and really discuss what people might be telling us through their preferences. It’s very difficult for Yuri to tell us what his preferences are, and we know that, don’t we Yuri? It’s a bit of a challenge to be able to get your message across.

Participant: That’s why we need Petra to be here, because she has supported Yuri for 30 years.

Facilitator: Yes.

Participant: Wow, that’s hugely [overtalking].

Participant: So did she — when he came as a kid to...

Facilitator: Yes; so she is — that’s terrific. Because Petra has been an important part of your life and she was telling me that the other night actually, how well she knew you. Sometimes someone like Petra, in someone’s life — she might not be able to say — she might not agree when I say ‘wow you just know him so well and you knew what he was communicating there and it was so subtle’ Sometimes people aren’t aware of their skill around that and how powerful that can be.

So all of us here have a really important role in Yuri’s life. We don’t often come together though, to really explore and — you know Cybil might say, Yuri when you, you know how you breathe loudly sometimes, what sometimes we call that, you know, the puff and puff, a little bit of that — Cybil might say, when she sees that at Melba or parties, that that means that you aren’t very comfortable in your chair; you, or you want somebody to get out of your face, you just want to be left alone; and Sharee might say, here at Lilydale, ‘well I don’t think a bit of action means that he’s hungry.’

So what I do is, you know, we organise some morning tea or we give you a drink. So what we’re doing here is interpreting differently and that’s okay, because communication has different roles in different environments. But it’s really important that we come together and we’re consistent about that. Seems really easy to say ‘come together and do that’; it’s really hard. All your roles are really challenging, you’re really really busy. You know, when I’ve been at [0:04:47.0] from here, it’s go, go, go, you know. It’s toileting, it’s getting dinner ready, it’s showering, it’s all of those things.

Certainly here I don’t have to say, you know, here everything is just so flat; chat, you know, we’ve got so much to do. So it’s easier said than done. So today, what — and next week because we’re going to have Part one today and Part two at Melba we’re going to sort some of the ways that we might be able to communicate a little better around what Yuri’s needs are, okay? As you know, there’s another chap from Melba and he’s also here at — hello, we’re just talking about...

Participant: Sorry.

Facilitator: That’s all right. We’re just talking about — that’s all right — come through — we’ve been talking about him. Sally, this is Adrian.

Participant: Yeah, we’ve met.
### Appendix 3.22: Examples of analytical memos from Dedoose (2012)

<table>
<thead>
<tr>
<th>Title</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>A summary of Yuri's post intervention feedback from Yuri's post choice questionnaire</td>
<td>It needs to be compared to his pre.</td>
</tr>
<tr>
<td>Ageing carers 4</td>
<td>Suzie when talking about another client he knows so many people, he's mum and dad take it all on themselves. It doesn't have to be that way. They are getting older. His support network could be so much easier.</td>
</tr>
<tr>
<td>Ageing carers 3</td>
<td>I'm getting older, I think I will just take Angela with me. I think it would be easier that way.</td>
</tr>
<tr>
<td>Annual and sick leave</td>
<td>Non paid supporters can't go on leave!</td>
</tr>
<tr>
<td>Changes in professional roles</td>
<td>The changing contexts of professional practice. Traditionally, the helping professions operated in controlled environments – hospitals, clinics, institutions, community service centres.</td>
</tr>
<tr>
<td>Collaborative decision making 3</td>
<td>Decisions are made by those who show up - C.J. from West Wing</td>
</tr>
<tr>
<td>Competition</td>
<td>There seems to be a competition as to who has the best relationship with Nick. Who has known him the longest, who he enjoys spending time with.</td>
</tr>
<tr>
<td>Conflict 2</td>
<td>Conflict is such a clear theme particularly for Nathan. An analysis of the interviews so far demonstrates that a lot of time is spent in conflict with others in the circle.</td>
</tr>
<tr>
<td>Decision making framework 0</td>
<td>We spoke about the order of the model. It is clear that we can approach the model in 2 ways - reactively (where a decision is thrust upon us) or proactively (where preferences are observed and built into decisions. What kind of decision-making model?</td>
</tr>
<tr>
<td>Decision making process being time consuming</td>
<td>Decision making process being time consuming a barrier time I mean</td>
</tr>
<tr>
<td>Decisions around intentionality</td>
<td>Reflection: them more time you spend with someone the more you appreciate the intonerality of their communication.</td>
</tr>
<tr>
<td>Developing a circle of support 7</td>
<td>It's about taking all the loving relationships in people's lives and transforming them into a future good life for someone with a disability. PLAN refer to it as 'weaving the tissue that binds'.</td>
</tr>
<tr>
<td>Email</td>
<td>As we discussed when we crossed paths last week Jo, this seems like useful analysis. However, you may yet collapse some categories into higher order ones into which these micro detail ones might be grouped (eg: characteristics of CDS.</td>
</tr>
<tr>
<td>Exploring options 1</td>
<td>Fascinating irony. When we look at where most of the time was spent it was around exploring options. Yet people felt uncomfortable do that, felt like they were treating the person like a guinea pig.</td>
</tr>
<tr>
<td>Facilitator being in focus person's life for my sake or not wanting to let go has got me thinking about what the literature has to say about longitudinal studies and the impact on researchers. I think it is important not to ignore that!</td>
<td></td>
</tr>
<tr>
<td>Family stress</td>
<td>I called the case manager and said if you don't come and get this child I will beat the living day lights out of him.</td>
</tr>
</tbody>
</table>
### Appendix 3.23: Selections of entries from coding table/book

<table>
<thead>
<tr>
<th>Step 1: Topic area (derived from research question)</th>
<th>Step 2: Descriptive codes (Parent codes)</th>
<th>Examples of data used to generate these parent codes</th>
<th>Step 3: Analytical codes (Child codes)</th>
<th>Examples of data used to generate these child codes</th>
<th>Step 4: Developing themes</th>
<th>Step 5: Focused questions asked of the data based on developing themes</th>
<th>Step 6: Answers to these questions and developing conclusions</th>
</tr>
</thead>
</table>

**Characterizing decision-making support**

Focus person expresses will and preference unintentionally.

Focus person expresses will and preference intentionally.

Focus person expresses will and preference using behaviour.

- **“He screamed and splashed the shower water [expression of preference using behaviour] [expression of preference using vocalisation]. I came into the shower cubicle thing and asked him if he had finished; he smacked me over the head [expression of preference using behaviour]!”**

- **“Look, spitting again [expression of preference using behaviour of concern], does it stop? ... The spitting [expression of preference using behaviour of concern] is usually when he is”**

- **Expression of preference acknowledged**

- **Expression of preference interpreted**

- **Expression of preference acted upon.**

- **“He screamed and splashed the shower water [expression of preference acknowledged]. I came into the shower cubicle thing and asked him if he had finished; he smacked me over the head [expression of preference interpreted]; be smacked me over the head”**

- **“Look, spitting again [expression of preference acknowledged], does it stop? ... The spitting is”**

Focus people’s role within the process of supported decision-making is to express will and preference. This expression of preference takes many communicative forms. In order for this expression of preference to contribute to the supported decision-making process it needs to be acknowledged, interpreted and acted on.

1. Can focus people’s role within the supported decision-making process to express will and preference be manipulated?

2. If so how?

Focus people’s expression of will and preference as observed by the researcher does not change. What does change though is supporters’ responsiveness to these expressions.

This finding is consistent with the social model of disability that places...
Focus person expresses will and preference using behaviour of concern.

Focus person expresses will and preference using facial expression.

Focus person expresses will and preference using head/eye movement.

Focus person expresses will and preference using gesture.

distressed about something”.

“Sometimes if he’s interested, his head is down but his eyes are up (expression of preference using head/eye movement)"

“He is hungry. That is an anxious look (expression of preference using facial expression)”.

He communicated... that he was hungry and wanted a chest massage... with the humming and that (expression of preference using vocalization)... there’s something about the pitch of that noise... the pitch of hum (expression of preference using vocalization), the speed of his huffing and puffing (expression of preference using physiological changes).

“If he doesn’t like something he won’t eat it (expression of preference using behaviour)”.

usually when he is distressed about something (expression of preference interpreted)”.

“See, look at him. When he’s hovering around the kitchen like that (expression of preference acknowledged), he’s usually hungry. He’s saying give me my dinner now (expression of preference interpreted)... so we know we have to get our skates on (expression of preference acted on)”.

the onus of change on supporters rather than the person with a disability.
Focus person expresses will and preference using vocalisation. Frantic! He screams (expression of preference using vocalizations), and he stiffens, his whole body (expression of preference using body language). It’s the tone and the people who know him well, it’s about the tone and you can hear... and oh yes, he goes all pale, you know his face, he goes so pale (expression of preference using physiological changes).

Focus person expresses will and preference using physiological changes (e.g. breath, facial tone, muscle tone)

Supporter responds to focus person’s expression of will and preference by acknowledging their communication.

Supporter responds to focus person’s

| Focus person expresses will and preference using vocalisation. | Frantic! He screams (expression of preference using vocalizations), and he stiffens, his whole body (expression of preference using body language). It’s the tone and the people who know him well, it’s about the tone and you can hear... and oh yes, he goes all pale, you know his face, he goes so pale (expression of preference using physiological changes). | Field note: Yuri is watching television, vigorously gouging his eyes. Researcher: “What’s going on here then, what’s he telling us?” (Yuri gouging vigorously) Supports: I don’t know, he’s always here when I start my shift, watching the box, seems to relax him you | 1. Did supporters’ responsiveness to focus person’s expressions of preference change over the course of the study? 2. What characteristics do those | 1. A comparison of observational and reported data collected at various time points throughout the study revealed supporters’ responsiveness to focus person’s expressions of preference increased over the course of the study. |

Supporters’ role within the process of supported decision-making is to respond to focus person’s expression of will and preference. This responding is characterised by three key elements, acknowledgment, interpretation and action. Unlike focus people’s expression of preference, supporters’ responsiveness can be manipulated and therefore the responsibility

| Supporter responds to focus person’s expression of will and preference by acknowledging their communication. | He’s either telling us he’s bored, he doesn’t like it, he wants to move or it’s an onset of the psychosis. (Interpreting expression of preference) Because when the psychosis starts it might start with that and it will get more vigorous, and then there’s other things that come into play like the noises and ‘woo-woo’ and the shaking (Acknowledging expression of preference) but Not acknowledging expression of preference | Acknowledging but not interpreting or acting on expression of preference. Supports: I don’t know, he’s always here when I start my shift, watching the box, seems to relax him you | Supports’ role within the process of supported decision-making is to respond to focus person’s expression of will and preference. This responding is characterised by three key elements, acknowledgment, interpretation and action. Unlike focus people’s expression of preference, supporters’ responsiveness can be manipulated and therefore the responsibility | 1. Did supporters’ responsiveness to focus person’s expressions of preference change over the course of the study? 2. What characteristics do those | 1. A comparison of observational and reported data collected at various time points throughout the study revealed supporters’ responsiveness to focus person’s expressions of preference increased over the course of the study. |
Supporter responds to focus people's expression of will and preference by acting on it in someway.

Otherwise it's probably he's bored, he wants music, wants to move (interpreting expression of preference).

"Hey, look at him, when he's hovering around the kitchen like that (acknowledging expression of preference), he's usually hungry. He's saying give me my dinner now (interpreting expression of preference)... so we know we have to get our skates on (acting on expression of preference)."

If he wants food (interpreting expression of preference) he goes to the pantry (acknowledging expression of preference) and its as simple as that, and like if he wants to go somewhere (interpreting expression of preference) he'll go and get any keys, he'll bring the bag, he'll grab your hand (interpreting expression of preference). He let's you know. If he wants to go to know, when he gets off the bus. Doesn't care what's on. Seams happy enough... He doesn't give us much grief. O'ya want a cuppa (looking at researcher)? I'm having one (Not acknowledging of expression of preference). Of enhancing decision-making support should lie with supporters not focus people.

There are variations however in supporters demonstrating all three of these roles. Supporters demonstrate multiple examples of acknowledging focus people's expressions of preference, however less examples of interpretation of these expressions of preference and even less of them acting on these who are unresponsive to focus people's preferences share?

1. What characteristics do those who are responsive to focus people's preferences share?

2. Supporters who are unresponsive to focus person's expression of preference generally,
   - Have a poor understanding of the communication continuum;
   - Perceive the focus person as having no/limited communication and decision-making capability;
   - Have needs (e.g. OHS, workload) that appear to 'trump' those of the focus person;
   - Report that they have limited time and resources with which to "really study,

3. What characteristics do those who are unresponsive to focus people's preferences share?
sleep (interpreting expression of preference), he'll just go to his room
[acknowledging expression of preference]

The bubbles stopped, and Larry, looked at Nathan, waiting for him to communicate. Nathan looked back at him, for a couple of seconds. He stopped smiling and began spitting. Larry said, “ah, we’ll turn them back on mate I know I know.” [acknowledging expression of preference]. Larry asked me to turn them on [acting on expression of preference].

“He’s helped us come to a decision about whether or not he gets an Ipad [acting on expression of preference]. If we hadn’t seen him staring at that video [interpreting expression of preference], I mean, did you see his face [acknowledging expression of preference]”.

“Head back like that, that

3. Supporters who are responsive to focus people’s expression of preference generally,
- Understand the communication continuum;
- Have a positive perception of focus people’s decision-making capability;
- Describe their relationship with the focus person as intimate or very close;
- Supporters engage in the process of preference identification collaboratively rather than individually.

listen” to the focus person.
certainly tells us stuff, oh yea and the chair rocking (acknowledging expression of preference). It usually means, get me out of here, or do something (interpreting expression of preference). Come on mate let’s go outside (acting on expression of preference).
Appendix 3.24: Pre and post intervention average score across eighteen questions on the *Questionnaire about Choice* for each of the thirty-three supporters

Raw data generated from the *Questionnaire about Choice* completed by thirty three supporters pre and post intervention. Text coloured red represents a negative perception of the capability of focus people to participate in decisions. Text coloured green represents a positive perception.

<table>
<thead>
<tr>
<th>Supporter</th>
<th>Pre-intervention</th>
<th>Post-intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angela 1</td>
<td>2.8</td>
<td>3</td>
</tr>
<tr>
<td>Angela 2</td>
<td>1.1</td>
<td>1.9</td>
</tr>
<tr>
<td>Angela 3</td>
<td>1.4</td>
<td>1.5</td>
</tr>
<tr>
<td>Angela 4</td>
<td>1.1</td>
<td>1.8</td>
</tr>
<tr>
<td>Angela 5</td>
<td>1.3</td>
<td>2</td>
</tr>
<tr>
<td>Angela 6</td>
<td>2.2</td>
<td>2.6</td>
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<tr>
<td>Angela 7</td>
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<td>Angela 8</td>
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<td>Neil 4</td>
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<td>Name</td>
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<td>Value 2</td>
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<td>---------</td>
</tr>
<tr>
<td>Neil 7</td>
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<td>No data</td>
</tr>
<tr>
<td>Nathan 1</td>
<td>2.7</td>
<td>3</td>
</tr>
<tr>
<td>Nathan 2</td>
<td>2.9</td>
<td>3</td>
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<td>Nathan 3</td>
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<tr>
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<tr>
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<tr>
<td>Kevin 4</td>
<td>2.2</td>
<td>3</td>
</tr>
</tbody>
</table>
Appendix 3.25: Data generated from the question “on a scale of one to five, how much do you agree with the statement X is able to participate in decisions about his/her life?”

Raw data generated from the question “on a scale of one to five, how much do you agree with the statement X is able to participate in decisions about his/her life?” asked of ten supporters during pre and post intervention interviews. Red = negative perception. Green = positive perception.

<table>
<thead>
<tr>
<th>Supporter</th>
<th>Pre-intervention</th>
<th>Post-intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angela 1</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Angela 2</td>
<td>3</td>
<td>4</td>
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<td>4</td>
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<td>Neil 2</td>
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<td>No data</td>
</tr>
<tr>
<td>Nathan 1</td>
<td>4</td>
<td>4</td>
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<td>3</td>
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<tr>
<td>Kevin 1</td>
<td>3</td>
<td>5</td>
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<tr>
<td>Kevin 2</td>
<td>3</td>
<td>4</td>
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</tbody>
</table>
Appendix 3.26: Supporters’ perception of decision-making capability pre-intervention (triangulated data)

<table>
<thead>
<tr>
<th>Supporter</th>
<th>Scaled interview question (Rating 1-5)</th>
<th>Questionnaire about Choice (Rating 1-3)</th>
<th>Perception of decision-making capability of focus person Pre-intervention</th>
<th>Bar graph illustrating each circle’s distribution of positive and negative perceptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1</td>
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![Inconclusive, Negative, Positive graph](image)
Appendix 3.27: Possible conclusion

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<th>Date</th>
<th>Conclusion</th>
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<td>January 15th, 2010</td>
<td>This is a reflection at this early stage of the research on what my conclusions might be. What is it I expect of the study? What are some possible conclusions?</td>
</tr>
<tr>
<td></td>
<td>1. Everyone can participate in decisions with support.</td>
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<tr>
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<td>2. Those who know someone well are most likely to understand their preferences.</td>
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<td></td>
<td>3. Everyone needs unpaid support in their lives, because paid supporters have a conflict of interest and find it hard to be objective.</td>
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<td>4. A process of supporting someone to make a decision generally has 5 key consecutive phases as reflected in the SDM framework.</td>
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<td>5. Communication is central to a supportive decision making process.</td>
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<td>6. If we can increase someone's self-determination, their behaviors of concern will decrease.</td>
</tr>
</tbody>
</table>

This is a reflection at this early stage of the research on what my conclusions might be. What is it I expect of the study? What are some possible conclusions?

1. Everyone can participate in decisions with support.
2. Those who know someone well are most likely to understand their preferences.
3. Everyone needs unpaid support in their lives, because paid supporters have a conflict of interest and find it hard to be objective.
4. A process of supporting someone to make a decision generally has 5 key consecutive phases as reflected in the SDM framework.
5. Communication is central to a supportive decision making process.
6. If we can increase someone's self-determination, their behaviors of concern will decrease.
Appendix 3.28: Audit trail example

During each training session get each member to reflect out loud if they want. This really adds to the participatory nature of the process – adds to the action research elements.

Interesting objections to the collection of data – filling out forms (e.g. Ann). This points to a lack of enthusiasm around a research culture and also possibly more threatening to the SDM process itself is the lack of commitment to documentation. Need to be creative about alternative documentation. Tech?
Appendix 3.29: Example of summary email used in the process of member checking

Hi everyone,

Could someone please pass this email onto [redacted] and [redacted] should we expand this list to anyone else?

Sorry it has taken me a while to get back to you all after our workshop the weekend before last. Things have been rather distracting here in [redacted] since then. It's a very sad community this week.

Thanks so much for a wonderful day last Saturday, your input and commitment to [redacted] is just so wonderful. I'm hoping [redacted]'s hip is ok, and that he and [redacted] didn't have to spend too many hours at the hospital.

In terms of follow up from the day here is a summary and some next steps as promised.

1. **Sensory profile.** As we discussed, I think it would be beneficial to further develop a clearer picture of [redacted]'s sensory preferences. To this end could those of you who have time please complete the sensory profile I gave you? [redacted] has some copies if you don't have one.

2. I would like us to further explore [redacted]'s spitting behavior using the motivational assessment scale which [redacted] so beautifully completed during the workshop. I think [redacted] is communicating a few things through his spitting, which I have discussed below. I would appreciate your thoughts around my interpretations. If we are able to get to the bottom of what [redacted] is communicating through this behavior we may be able to respond by giving him a more appropriate way to have his sensory needs met.

i) He enjoys the tactile sensory experience. I think he enjoys the experience with his tongue and lips in his mouth and also with his fingers when it makes its way to the floor/table.

ii) I think as [redacted] described, he enjoys the attention that the behavior provides him with. As supporters you are forced to provide him with attention when he spits.

iii) I also think that [redacted] has learnt to use this behavior to express his frustration around not having/getting/doing something that he wants.

3. **Decisions to work through with [redacted].**

i) Should [redacted] have a psychological assessment with a psychiatrist such as Dr. [redacted]? We have all agreed that [redacted] would benefit from a thorough medical review, particularly in terms of his psychological health. He is also on a lot of medication, and we think this should be reviewed. We are particularly concerned about his episodes of crying. [redacted] will look at this further week a view to getting an appointment with Dr. [redacted].

ii) Considering what we find out about his sensory preferences and preferred activities in general, what activities should [redacted] continue to participate in? What activities should he stop participating in? What additional activities should he try?

iii) Should a multimedia profile be set up for [redacted] to assist in consistent fluid communication between his supporters?

4. **Where to from here?**

i) Could as many of you as possible complete the sensory profile for [redacted] as well as the preferred activity analysis I have given you. Once you have completed them, do you mind passing them to [redacted] for me to analyze.

ii) Once I have these, we can explore and discuss these further either via this email group or in person. We flagged getting back together on a Thursday evening. What are people's thoughts around this?

iii) I would really appreciate your feedback around the workshop. I have attached an evaluation, which I forgot to give you, for anyone who feels like they would like to complete it. It really would be appreciated.

iv) Could you all please take a look at the options of a multimedia profile for [redacted]. I have attached a handout about the concept. Also have a look at Multi me, the web based tool we are already using with one gentleman at [redacted] (www.multime.com).

v) Can we leave the medical review/psychiatry assessment in your hands?

Please feel free to use this list to communicate about [redacted] and his support. It is a good way to keep in touch.

Sorry for the long-winded e-mail. I really did think it was going to be a quick one, but when it comes to [redacted] there really does seem to be so much to say!

If there is anything you disagree with in this email please let me know.

jo
Appendix 3.30: A simplified description of the process used to develop child codes, using one parent code as an example

<table>
<thead>
<tr>
<th>Focused topic area</th>
<th>Parent (descriptive) code</th>
<th>Example of extracts tagged with this parent code</th>
<th>Query</th>
<th>Answer to query</th>
<th>Child (analytical) code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Characterizing supported decision-making for people with severe to profound intellectual disability</td>
<td>Characterizing the role of others in decision-making</td>
<td>Quote: “He communicated to us all that he was hungry and wanted a chest massage [Acknowledging and interpreting expression of preference] [Acknowledging expression of preference] [Supporters collaborating to support decision making], you know with the humming and that [Acknowledging expression of preference]. We responded you know [Acknowledging].”</td>
<td>What similarities and differences exist across the data extracts?</td>
<td>Throughout the data set tagged with the parent code “characterizing the role of others in decision-making”, there are multiple examples of supporters responding to focus people’s expressions of preference by engaging sequentially in the process of responding to expressions of preference by acknowledging, interpreting and/or acting on the expressions of preference of those they support. There are differences</td>
<td>Supporter responding to expression of preference by acknowledging, interpreting and acting</td>
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<td></td>
<td></td>
<td></td>
<td>What occurs rarely in this data set?</td>
<td></td>
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<tr>
<td>Interpreting and acting on expression of preference</td>
<td>What events occur sequentially in this data set?</td>
<td>however in supporters demonstrating all three of these roles. Supporters demonstrate multiple examples of acknowledging focus people’s expressions of preference, however less examples of interpretation of these expressions of preference and even less of them acting on these expressions.</td>
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<tr>
<td>Acknowledging and interpreting expression of preference</td>
<td>What correlations exist in this data set?</td>
<td>Supporters demonstrated multiple examples of responding to expressions of preference collaboratively. A consistent variable across these examples was that the focus person’s communication was assessed according to the Triple C as unintentional and informal. Multiple examples of positive perceptions of the capability of focus people to participate in decisions was seen across this preference but not interpreting or acting on it.</td>
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<tr>
<td>[Acknowledging expression of preference]</td>
<td></td>
<td>Positive perception of the capability of focus people to participate in decisions.</td>
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<tr>
<td>I guess that’s a decision. We wouldn’t have made the decision to stop for lunch unless he let us know.”</td>
<td></td>
<td>Negative perception of the capability of focus people to participate in decisions.</td>
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<tr>
<td>FP descriptors: Y, PO, RU, UI, BF</td>
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<tr>
<td>Supporter descriptors: YS, P, C, D5, 8 years, SDPW</td>
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<tr>
<td>“Yeah, we bounced things off each other. We were collaborating to support decision making, until we came</td>
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</table>

What events occur sequentially in this data set?

What correlations exist in this data set?

however in supporters demonstrating all three of these roles. Supporters demonstrate multiple examples of acknowledging focus people’s expressions of preference, however less examples of interpretation of these expressions of preference and even less of them acting on these expressions. Supporters demonstrated multiple examples of responding to expressions of preference collaboratively. A consistent variable across these examples was that the focus person’s communication was assessed according to the Triple C as unintentional and informal. Multiple examples of positive perceptions of the capability of focus people to participate in decisions was seen across this preference but not interpreting or acting on it. Positive perception of the capability of focus people to participate in decisions. Negative perception of the capability of focus people to participate in decisions.
up with what we thought he was saying with the humming and rocking and that”

[Acknowledging and interpreting expression of preference] [Acknowledging expression of preference]

FP descriptors: Y, PO, RU, UI, BF

Supporter descriptors: Y6, P, NC, RS, 3 years, 5DPW

Quote: “Because in Summer at the end of the year we sometimes go to a beach house in Rosebud, and Nathan comes with us all.”

Paid supporters being willing to extend their relationship with focus people beyond their paid role

FP descriptors: Na, P&U, @HF,

Supporter perception that people with severe/profound ID are unique and misunderstood

Supporters collaborating to support decision-making

Supporters not collaborating to support decision-making

data set. Where these examples occurred there were also examples of supporters collaborating to support decision-making as well as responding to expressions of preference, acknowledging, interpreting and acting. Supporters who demonstrated these positive perceptions also demonstrated a tendency to take into account focus people’s history and life story when supporting decision-making.

Examples of supporters holding negative views of the capability of those they support to participate in decisions were evident and were accompanied with views that there was a misunderstanding of this group in terms of their ability to be self-determined.

Paid supporters demonstrated focus people to participate in decisions
II, AxP, ISP

Supporter descriptors: Na4, P, UR, C, SH FH Comm, 3 years, 4-5DPW

Quote: "I'm not sure you know him, do you. He can't tell us what he wants. We just decide shit for him. [Negative perception of the capability of focus people to participate in decisions] You know, no offence but we have all these programs and stuff, but at the end of the day, people don't know who we're dealing with here [Negative perception of the group]. They just can't communicate. It's different for them, they can't tell us what they want, so we just have to examples of willingness to extend their relationship with those they support beyond their paid roles when providing decision-making support throughout this data set. These examples were most prevalent for focus people who had an ISP rather than block funding. There were also system barriers impacting on the development of these relationships.

Paid supporters being willing to extend their relationship with focus people beyond their paid role

Paid supporters having to answer to service providers rather than responding to preferences of those they support

System barriers reducing relational closeness between supporter and
get on with it and make decisions that we think are best for the guys

**Negative perception of the capability of focus people to participate in decisions**

**[Perception that this group is unique]**

*FP descriptors: Y, PO, RU, UI, AxA, BF*

*Supporter descriptors: Y6, P, NC, RS, 3 years, 5DPW*

Supported

Supporters taking into account focus people’s history and life story when providing decision-making support.
Quote: “I guess coz he’s not getting paid he doesn’t have to suck up to anyone [Paid supporters having to answer to service providers]. He’s here only because he wants to be, only because he loves Nathan [Loving focus person]. He wouldn’t admit that though! I guess he keeps us honest.”

FP descriptors: Na, P&U, @HF, II, AxP, ISP

Supporter descriptors: Na3, UP, VC, SH & Comm, 3 years, 4-5 DPW.

Email from manager of day service: “I have also been concerned that a traditional interpretation of professional...”
boundaries reduces choice and control, blocks community participation and is unfit for a world of personalised services. System barriers reducing choice. System barriers reducing relational closeness between supporter and supported. In the real world, multiple roles and relationships overlap and we need a way to safeguard these overlapping relationships, rather than wasting effort on a futile attempt to keep people safe by shutting people out of informal relationships. Paid supporter: being willing to extend their relationship with focus people beyond their paid role.

FP descriptors: K, PO, RU, II, AxA, ISP

Supporter descriptors: K3, P,
UR, I, RS, 20 years, 5 DPW.

Quote: “He has nobody in his life that loves and cares for him, except paid staff. There is a different quality to what we do, than other paid workers” [Paid supporters being willing to extend their relationship with focus people beyond their paid role]

FP descriptors: K, PO, RU, II, AxA, ISP

Supporter descriptors: K4, P, UR, I, DS, 6 years, 5 DPW.

Quote: “You know that Kath, the casual who was here before. She lives next door. And I said to her how would you feel...”
about having a street party. And she said, wow that would be awesome. Because she has a daughter, and she wants her to get to know others in the street, because the daughter gets along so well with Yuri, and so it’s great.

Paid supporter: Being willing to extend their relationship with focus people beyond their paid role.

FP descriptors: Y, PO, RU, UI, AxA, BF

Supporter descriptors: Y2, P, I, RS&DS, 1 year, SDPW

Quote: “[It was] decided that the pair’s relationship was wrong, that such a friendship was ‘unprofessional’ and crossed the boundaries of what was acceptable. So, they
ordered to stop. No more meals with the family, no more days out, or festive fun" [Paid supporters being willing to extend their relationship with focus people beyond their paid role]

[System barriers reducing relational closeness between supporter and supported] [Paid supporters having to answer to service providers]

FP descriptors: A, P&U, @HF, II, AxP, BF
Supporter descriptors: A6, P, UR, C, DS, 15 years, 2DPW

Email correspondence: "I can say that if I did not love the adults in the group home I work in, I wouldn't still be there after 5 years. For these 5 adults I am one of a handful, a very small handful who know them well, understand how to best support them to make decisions, and
above all love them, and who can walk away from love"

[Loving focus person]
FP descriptors: N, P&U, RU, UI, AxA, BF
Supporter descriptors: N3, P, UR, VC, RS, 5 years, 5 DPW

Quote: “So many people put their two cents in. But love, it really was Neil running the show, you know. It was all about him, all about him. It was everything that we all know he wanted, coz you know, we know him love we have known him all his life. [Supporters collaborating to support decision-making]. And Dave reminded me, you know his cousin, the one with the hair, you know the one, anyway he reminded me about the jelly slice that he loved before the peg when he was teeny tiny. So
we had to have that after didn’t we, with a cuppa you know. He would have loved it” [Taking into account focus person’s history and life story] [Positive perception of the capability of those they support to participate in decisions]

FP descriptors: N, P&U, RU, UI, AxA, BF

Supporter descriptors: NS, UP, I, FH, 42 years, 1 DPM

Quote: “If we deny his capability then what’s the point of us paying attention to his preference, because when you think about it by saying he has no capability we are saying he doesn’t have preferences” [Positive perception of the capability of those they]
Support to participate in decisions.

FP descriptors: K, PO, RU, II, AxA, ISP

Supporter descriptors: K2, P, C, DS, 20 years, 5 DPW.

Field note: Kevin hangs around the kitchen while dinner is being prepared. This is acknowledged, and interpreted by Sam [support worker] as Kevin wanting dinner. [Acknowledging and interpreting expression of preference] [Acknowledging expression of preference] [Positive perception of the capability of those they support to participate in decisions]
<table>
<thead>
<tr>
<th>FP descriptors: K, PO, RU, II, AxA, ISP</th>
<th>Supporter descriptors: K3, P, UR, I, RS, 20 years, 5 DPW.</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Quote: &quot;He has choice over what he gets up to mostly. If he doesn’t want to do something he makes it clear with his body language&quot;</td>
<td>[Acknowledging and interpreting expression of preference] [Acknowledging expression of preference]</td>
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</tr>
<tr>
<td>FP descriptors: K, PO, RU, II, AxA, ISP</td>
<td>Supporter descriptors: K3, P, UR, I, RS, 20 years, 5 DPW.</td>
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<tr>
<td>Quote: &quot;I now see after this&quot;</td>
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<td>Discussion that he is able to make his preferences clear. It's the staff that have to recognise that he is communicating to us and then act on it.</td>
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<td>Acknowledging, interpreting, and acting on expression of preference</td>
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<td>Positive perception of the capability of those they support to participate in decisions</td>
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</table>

FP descriptors: K, PO, RU, II, AxA, ISP

Supporter descriptors: K1, P, D, DS, 1 month, 1 DPW.

Quote: “We didn’t have a choice. We knew he didn’t want...”
that breathing tube again... He hated it last time... Do you remember? I have some photos at home I’ll show you, he hated it, didn’t he Max?” [Taking into account focus person’s history and life story] [Positive perception of the capability of those they support to participate in decisions]

FP descriptors: N, P&U, RU, UI, AxA, BF

Supporter descriptors: NS, UP, I, FH, 42 years, 1 DPM.
Appendix 4.1: Summary of relevant descriptive statistical and demographic data relating to individual supporters and circles of support

<table>
<thead>
<tr>
<th>Supporter</th>
<th>Angela</th>
<th>Neil</th>
<th>Nathan</th>
<th>Yuri</th>
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Paid/unpaid

Perception of decision-making capability

Pre-intervention

554
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<th>Perception of decision-making capability</th>
<th>Pre-intervention</th>
<th>Post-intervention</th>
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<tr>
<td>Percentage of supporters who viewed focus people's decision-making capability positively within each circle</td>
<td>38%</td>
<td>43%</td>
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No data as Neil died before the end of the study
<table>
<thead>
<tr>
<th>circle</th>
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<td>Relational closeness</td>
<td>Intimate</td>
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<td>Responsiveness</td>
<td>Pre-intervention</td>
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<td>Post-intervention</td>
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<tr>
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<td>No data as supporters not observed</td>
</tr>
<tr>
<td>View that focus person can communicate</td>
<td>Pre-intervention</td>
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<td>View that focus person can communicate</td>
<td>Percentage of interviewed supporters holding the view</td>
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<td>Percentage of interviewed supporters holding the view that focus people can communicate</td>
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559
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<th>Value placed on a collaborative as opposed to an individual approach to responding to preference (Scale 1-5)</th>
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560
Average rating interviewees gave to how much they value a collaborative as opposed to an individual approach to decision-making support

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<th>Pre-intervention</th>
<th>4.5 (positive)</th>
<th>2 (negative)</th>
<th>4.5 (positive)</th>
<th>2.5 (negative)</th>
<th>1.5 (negative)</th>
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Value placed on a collaborative as opposed to an individual approach to responding to preference (Scale 1-5)

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<th>+</th>
<th>+</th>
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<td>Conflict within circle of support (Incidents of conflict)</td>
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<td>4</td>
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<td>Communicatio of person being supported</td>
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<td>Unintentional</td>
<td>Intentional</td>
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<tr>
<td>Existence of a group coordinator or facilitator</td>
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