Developing an Understanding of Supported Decision-Making Practice in Canada: The Experiences of People with Intellectual Disabilities and Their Supporters

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Abstract

Supported decision-making has been promoted as the process and legal mechanism by which people with cognitive disabilities can be supported to become self-determining (Shogren, Wehmeyer, Lassman & Forber-Pratt, 2017a) and exercise their legal capacity (Committee on the Rights of Persons with Disabilities, 2014). Canada was the first country to develop legal mechanisms that allow for supported decision-making (Stainton, 2016) and there is little research, which explores how they are used in practice (James & Watts, 2014).

The aim of this research was to understand how people with intellectual disabilities were supported with decision making in the context of two legal mechanisms which create opportunities for supported decision-making in Canada, representation agreements and microboards. The research used a constructivist grounded theory methodology, interviewing and observing the decision making of seven people with mild to severe intellectual disabilities and 25 decision supporters. Thirty-four interviews and 104 hours of participant observation were conducted.

This research identified a common process of decision-making support, involving a dynamic interaction between the person's will and preferences in relation to a decision opportunity and their supporter's responses. This interaction was shaped by five influencing factors: the experiences and attributes the person and their supporter brought to the process; the quality of their relationship; the environment in which decision making occurred and the nature and consequences of the decision. The elements and influencing factors involved in the process were always the same, however because the nature of each and the way they interacted differed for each decision, the type of support provided and the outcomes observed varied significantly.

Not all decision-making support, provided in the context of these legal mechanisms that allow for supported decision-making, offered people with intellectual disabilities control and self-determination in their lives. How supporters responded shaped the extent to which the person's will and preferences directed the process, and the opportunities they had to exercise their legal capacity. The highly individualised and contextually dependent nature of the process of decision-making support has implications for the development of supported decision-making legislation, policy and practice.

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Statement of Authorship

Except where reference is made in the text of the thesis, this thesis contains no material published or extracted in whole or in part from a thesis accepted for the award of any other degree or diploma. No other person's work has been used without due acknowledgement in the main text of the thesis. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

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Publications and Presentations Arising from this Research

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Browning, M., Bigby, C., & Douglas, J. (2014, December). *Relationship as the foundation of supported decision-making practice.* Paper presented at 8th Disability Roundtable, Melbourne, Australia.

Browning, M., Bigby, C., & Douglas, J. (2013, October). *What can be learned about supported decision-making from British Columbia, Canada?* Paper presented at Supported decision-making Conference, Melbourne, Australia.

Browning, M., Bigby, C., & Douglas, J. (2012, October). *The development of supported decision-making.* Paper presented at 2nd World Congress on Adult Guardianship, Melbourne, Australia.

Chapter One:

Introduction, Aim and Thesis Overview

Introduction to the Problem

Supported decision-making describes the process of supporting a person whose decision making is impaired to make decisions whenever possible (Davidson et al., 2015). The broad aim of this process is to enable people with cognitive disabilities to exercise their legal capacity (Salzman, 2010) and determine their own lives (Bodnar & Coflin, 2003), through the provision of quality support and legal recognition of the interdependent nature of decision making (Browning, Bigby & Douglas, 2014, p.42). Supported decision-making is based on a set of guiding principles which “emphasize the person’s right to self-determination and autonomy, the presumption of capacity, and the right to decision-making supports to enable equality before and under the law, without discrimination on the basis of disability” (Bach, 1998, p.3). Internationally, there has been considerable support for the promotion and implementation of supported decision-making from a human rights perspective (Arstein-Kerslake, 2016; Carney, 2012; Dhanda, 2007; Dinerstein, 2012; Gooding, 2015; Lewis, 2010; Quinn, 2010).

The early conceptual and peer reviewed literature on supported decision-making was based on a set of assumptions about the benefits to people with cognitive disabilities (Bach, 1998; Bodnar & Coflin, 2003; Canadian Association for Community Living [CACL] Task Force, 1992; Minkowitz, 2010; Office of the Public Advocate (SA), 2012; Quinn, 2010; Weller, 2008). The assumed benefits included: eradicating (Minkowitz, 2010) and limiting (Office of the Public Advocate (SA), 2012) the need for adult guardianship; enabling people to enter into contracts who would otherwise be unable to do so (CACL Task Force, 1992) and limiting involuntary medical treatment of mentally ill patients (Weller, 2008). Authors also claimed supported decision-making would enable people with intellectual disabilities to choose the way they wanted to live their lives (Bodnar & Coflin, 2003), enjoy greater control and self-determination (Bach, 1998) and restore their dignity and personhood (Quinn, 2010). Overall, discussions have been slow to move from the assumed benefits of supported decision-making to practical considerations of how to implement supported decision-making in practice (Kerzner, 2011; Kohn & Blumenthal, 2014).

Over the last thirty years in Canada, a number of supported decision-making mechanisms have been developed which enable people with cognitive disabilities, such as intellectual disability, to be supported to make decisions by legal representatives or associations (Kerzner, 2011). These mechanisms, such as representation agreements in British Columbia, were the first attempts internationally to legally recognise supported decision-making (James & Watts, 2014). They provide recognition and status for families, friends and informal support networks (Community Coalition, 1994) to act as a bridge between people with disability and third parties (Gordon, 2012c). The legal recognition of supporters was sought because third parties, such as banks, had been questioning the authority of supporters to participate in dealings alongside the person with disability (Gordon, 2000). In British Columbia, disability advocates developed models of supported decision-making because they wanted a less restrictive legal alternative to adult guardianship which they perceived denied people with cognitive disabilities the right to determine their own lives (Gordon, 2000).

In Australia and elsewhere, many people with intellectual disabilities have had their legal right to make decisions removed by being declared incompetent and having a guardian and financial administrator appointed (Glen, 2015; Lord, Suozzi & Taylor, 2010; Rasmussen & Lewis, 2006). Quinn (2011) contends that when stripped of their legal capacity people with intellectual disabilities become non-persons and lose the ability to determine their own lives. In addition to formal mechanisms that deny people with intellectual disabilities the ability to control their own lives, there are occasions when informal support can be coercive and manipulative (Nonnemacher & Bambara, 2011). These formal and informal practices, once believed to be in the “best interest” of people with intellectual disabilities and the community, are now being challenged in light of increasing recognition of the human rights of people with disabilities (Committee on the Rights of Persons with Disabilities, 2014; Flynn & Arstein-Kerslake, 2014; Glen, 2015; Minkowitz, 2010).

In 2006, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) declared people with disabilities to be holders of rights and not objects of pity or charity (Kayess & French, 2008). The CRPD enshrined in human rights law that all people with disabilities must enjoy legal capacity on an equal basis with others and created an obligation for signatory parties, such as Australia, to provide people with disabilities with the support they may require to exercise their legal capacity (United Nations, 2006, Article 12). Supported decision-making as a legal alternative to guardianship has been promoted as the mechanism by which people with cognitive disabilities can be reasonably accommodated to exercise their legal capacity (Salzman, 2010).

Since the CRPD, legislative mechanisms that recognise supported decision-making developed in Canada have been endorsed as examples of best practice in supporting the decision making of people with disabilities (Stainton, 2016; UN Enable, 2006). However, very little is known about how decision making is supported in the context of these legal mechanisms (Bigby, 2016; Kohn, Blumenthal & Campbell, 2013; Kohn & Blumenthal, 2014). More recently, authors have started to question the claims made about the impact of supported decision-making in ensuring recognition of legal capacity in the absence of empirical evidence (Carney & Beaupert, 2013; Kohn et al., 2013; Law Commission of Ontario, 2014). Kohn et al. (2013) argue that

> ...there is currently insufficient evidence to know the extent to which (or the conditions under which) supported decision-making arrangements remedy the problems posed by the guardianship system. Specifically, there is a lack of evidence as to how decisions are actually made in supported decision-making relationships, as to the effect of such relationships on persons in need of decision-making assistance, or on to the decisions that result. (Kohn et al., 2013, p.3)

Given the presumed link between legislative mechanisms that recognise supported decision-making and furthering the rights of people with cognitive disability (Arstein-Kerslake, 2016), the lack of understanding regarding how decision-making support is provided in this context is highly problematic. There are very few studies that have explored how decision making is supported in a context that legally recognises supported decision-making (James & Watts, 2014; Malette, 2002; Nunnelley, 2015). The three studies that have occurred offer some insights into the provision of decision-making support. However, their narrow scope and limited methodological rigour limit the confirmability and transferability of their findings (Lincoln & Guba, 1985). In general, the small body of research exploring supported decision-making in Canada has focused on the broader use of legal mechanisms rather than understanding in any depth how decision making occurs within these contexts (Harrison, 2008; Pedlar, Haworth, Hutchison & Dunn, 1999; Nidus Personal Planning and Resource Centre, 2010a; Nunnelley, 2015; Rutman & Taylor, 2009; Women's Research Centre, 1994).

Similarly, in Australia a small body of research has started to shed light on how people with cognitive disability are supported with decision making (Bigby, Whiteside & Douglas, 2017; Knox, Douglas & Bigby, 2015; Knox, Douglas & Bigby, 2016a; Knox, Douglas & Bigby, 2016b; Watson, 2016). These studies have focused on the experiences of people with traumatic brain injury (Knox et al., 2015; Knox et al., 2016a; Knox et al., 2016b), severe or profound intellectual disabilities (Watson, 2016a) and of family members and workers in disability support services who provide decision support (Bigby et al., 2017a). While these studies offered greater understanding of the decision making experiences of participants, they did not occur in environments that legally recognised supported decision-making.

The development of practical knowledge regarding how people with intellectual disability can be supported to make their own decisions and control their own lives is essential to being able to realise the aims of supported decision-making (Browning et al., 2014). This research makes an important contribution to the gap in understanding how decision-making support is provided in a context that legally recognises supported decision-making. The use of observation as a research method, longer periods of participant engagement, and the participation of people with varying levels of intellectual disability have allowed this research to develop a richer understanding of decision making than previous studies exploring supported decision-making in Canada (James & Watts, 2014; Malette, 2002; Nunnelley, 2015).

Research Aim

In the context of a lack of evidence regarding how supported decision-making is realised in practice, the aim of this research was to understand how people with intellectual disabilities were supported with decision making in the context of two legal mechanisms which create opportunities for supported decision-making in Canada, representation agreements and microboards.

This research used a grounded theory methodology to gain an in-depth understanding of the experiences of seven people with intellectual disabilities and their supporters engaging in decision-making support. The research took place over an eight-month period and involved participants primarily in British Columbia, Canada. From interview and observational data, a common process of decision-making support was identified. The process involved a person with intellectual disability expressing their will and preferences in relation to a decision opportunity, and their supporter(s) responding by providing various forms of support.

Thesis Overview

This thesis consists of six chapters.

Chapter 1 has introduced the research problem, the aim of the research and provides an overview of how the thesis is organised.

Chapter 2 presents a critical review of the literature relevant to this research. It introduces the concept of supported decision-making, its beginnings in Canada, philosophy and principles. The chapter explores literature from a range of disciplines, which inform thinking about decision-making support. The chapter concludes with a review of the empirical research exploring models of supported decision-making and the process of decision-making support in both Australia and Canada.

Chapter 3 describes the research methods used in this research. It begins by explaining my decision to select constructivist grounded theory as the research methodology. It continues by outlining my methods and procedures including an overview of participant sampling, data generation and analysis. A description of research participants is also included.

Chapter 4 presents the research findings by exploring the role representation agreements and microboards played in the decision making of central participants. It goes on to describe the process of decision-making support used by all participants, providing a summary and diagram of the process. The first findings chapter concludes by explaining how a range of factors shaped the core elements of the process (the person's will and preferences and supporter's responses).

Chapter 5 explores the model of decision-making support in practice by examining three decision-making processes in significant detail. Each decision-making example illustrates the complexity of the process by showing how the influencing factors shaped the dynamic interaction of the core elements (the person's will and preferences and supporter's responses). The second findings chapter concludes by reflecting on how the decision-making examples demonstrate the dynamic, recursive and contextually dependent nature of the process of decision-making support

Chapter 6 discusses the key findings of the research and how they can be used to improve supported decision-making practice, policy and legislation. The thesis concludes by discussing the strengths and limitations of the study and directions for future research.

Chapter Two:

Supported Decision-Making

Literature, Research and Models of Practice

Introduction

In order to provide a rationale for the research described in this thesis, this chapter critically examines the literature that has informed knowledge in the area of supported decision-making. The chapter starts by examining the development of the concept of supported decision-making in Canada, its philosophy, principles and relationship to the CRPD. It explores the conceptualisation of supported decision-making after the CRPD and the important distinction between decision-making support and supported decision-making.

This second section of the literature review begins by exploring how thinking about intellectual disability has changed over time and how these changes have influenced whether people with intellectual disability are seen as capable of decision making. The theoretical and empirical literature from speech pathology, psychology and special education are examined to better understand how intentional communication, choice making and decision making are supported for people with a range of intellectual disabilities. Economic theories and empirical research on decision making (e.g., bias and information framing) and emerging insights from neuroscience (e.g., on the role of emotion and unconscious thought) provide a greater understanding of the factors which are known to be important when providing decision-making support.

Finally, the literature review examines decision-making support in the Australian context and supported decision-making in British Columbia, Canada. The scarce empirical literature which evaluates models of decision-making support and supported decision-making, and the limited insights they provide into the practice of supported decision-making are critically reviewed. The chapter concludes by identifying the significant gap in understanding supported decision-making practice in Canada and why this of interest in the Australian context.

Supported Decision-Making

Beginnings of the concept.

In seeking to explore how supported decision-making is realised in practice, it is important to understand where the concept came from and how it has evolved over time. Supported decision-making gained interest in Canada in the early 1990s in opposition to adult guardianship (CACL Taskforce, 1992; Bach, 1998; Gordon, 2000; Rutman & Taylor, 2009). During this time, the term supported decision-making was used to describe a process by which an individual was supported to discover their values, interests and talents in order to determine their own life (Bodnar & Coflin, 2003). Michael Bach (1998) believed supported decision-making was necessary to enable people with disabilities to become self-determining. It did this by removing the barriers that prevented people with disabilities exercising their right to make decisions and providing them with the support necessary to make decisions and communicate their choices (Bodnar & Coflin, 2003). Supported decision-making was a mechanism of obtaining equal legal rights for people with disabilities in the area of decision making.

Philosophy and principles of supported decision-making.

Supported decision-making is based on a set of principles (Bach, 1998) and the first clearly articulated principles of supported decision-making were written by the CACL Taskforce in their report on Alternatives to Guardianship in August 1992. The taskforce proposed supported decision-making be adopted as an alternative conceptual framework for decision making that challenged the belief "personal autonomy can only be exercised independently" (CACL Taskforce, 1992, p.2). The taskforce proposed a number of principles including:

(a) all adults have the right to self-determination and the right to make decisions affecting their lives with the support, affection and assistance of family and friends of their choosing;

(b) everyone has a will and is capable of making choices;

(c) a cornerstone of supported decision-making is the existence of a trusting relationship between a person giving support and a person receiving support; and

(d) the law must not discriminate on the basis of perceptions of a person's capacity or competence. (CACL Taskforce, 1992, p.6-7)

These principles challenged traditional views about autonomy and capacity by seeking legal recognition of the interdependent nature of decision making. They rejected the assessment of an individual's competence (mental capacity) and recommended assessing whether the decision-making process had been competent instead. These principles also challenged provincial governments to provide resources to help people with disabilities establish networks of support if they were isolated.

The philosophy and principles of supported decision-making remained largely unchanged during the 1990s and almost a decade later Bodnar and Coflin (2003) produced a manual for the Saskatchewan Association of Community Living which had a more practical focus to assist supporters in being able to apply the principles of supported decision-making in practice. The principles in the guide included an additional statement on decision making being about process and not outcomes and that the individual with a disability must be at the centre of the process of decision-making support. The overall purpose of supported decision-making remained focused on achieving self-determination and meaningful inclusion for the person at the centre of the decision-making process. The principles of supported decision-making were formally recognised in legislation in British Columbia in 2000 when the *Representation Agreement Act 1996* was enacted. This is discussed in more detail later in the chapter. The focus of supported decision-making underwent a significant shift when it was introduced to an international audience at the CRPD.

International platform through the CRPD.

The CRPD was the first human rights treaty of the 21st Century. It came about through the persuasive lobbying of non-governmental organisations, disability organisations and governments such as Mexico who believed there was a need to clarify the rights of persons with disabilities under international law (Mackay, 2007). The CRPD and Optional Protocol entered into force on 3 May 2008, having been developed over four years, and since then has 160 international signatories (as at 9 March 2017).

The purpose of the CRPD as articulated in Article 1 is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Kayess and French

(2008) suggest the CRPD “has been hailed as a great landmark in the struggle to reframe the needs and concerns of persons with disability in terms of human rights” (p.2).

The CRPD has been referred to as championing a paradigm shift which seeks to move societies away from viewing people with disabilities as passive objects of treatment and charity, towards a view that they are active subjects of their own lives with rights and dignity (Lewis, 2010). It seeks to achieve this shift by embracing the social model of disability and emphasising that full participation in society can be achieved by breaking down the barriers that prevent equal opportunity and respect for difference not by ‘fixing’ people with disabilities (Lord et al., 2010). The CRPD embodied the principle ‘nothing about us without us’ as it was the first time the drafting of a convention involved the people that would be affected by it (Harpur, 2012; Kayess & Finch, 2008; Lord et al., 2010).

The CRPD has 50 articles some of which are of particular interest when considering supported decision-making. It was during the drafting of Article 12 (Equal Recognition before the Law) that supported decision-making entered into the discussions of delegates at the United Nations. Supported decision-making was introduced as the mechanism through which States Parties could provide people with disabilities with the support they may require to be able to exercise their legal capacity as required in Article 12 paragraph 3. Another important section of the CRPD that has heavily influenced the promotion of supported decision-making is Article 5 (Equality and Non-discrimination). It discusses the need for States Parties to ensure they take steps to reasonably accommodate people with disabilities to promote equality and eliminate discrimination.

Integrating the ideas within Article 12 and Article 5 it can be said that just as people with physical disabilities need a ramp to ensure they are reasonably accommodated to access a building, supported decision-making is seen as the vehicle to reasonably accommodate people with cognitive impairment to exercise their legal capacity (Salzman, 2010). Therefore, States Parties who are signatories to the CRPD, such as Australia, now have a human rights obligation to ensure people with disabilities are provided with the support they need to exercise their legal capacity on an equal basis with others (Arstein-Kerslake, 2016). This obligation goes well beyond the provision of substituted decision-making (Bach & Kerzner, 2010) and has created an imperative internationally to review

(Australian Law Reform Commission [ALRC], 2014; Ontario Law Reform Commission, 2017) and amend legislation that involves substituted decision-making. Some examples of amended legislation include the *Adult Guardianship and Trusteeship Act 2008* (Alberta) and the *Assisted Decision-Making (Capacity) Act 2015* (Ireland).

Undue influence, persuasion and coercion.

Article 12 paragraph 4 of the CRPD addresses an important concern in relation to supporting people with cognitive disabilities to exercise their legal capacity through the provision of decision-making support. It states safeguards need to be in place to ensure all measures relating to the exercise of legal capacity must 'prevent abuse' and "respect the rights, will and preferences of the person, are free of conflict of interest and undue influence" (United Nations, 2006, Article 12, para 4). A number of authors have raised concerns that the dependency people with intellectual disability have on their supporters may increase the risk of abuse and undue influence occurring when engaging in supported decision-making (Arstein-Kerslake, 2014; Carney, 2015; Gooding, 2015; Series, 2015).

Many people with cognitive disabilities are dependent on the support of others to identify and express their conception of the good (Silvers & Francis, 2009), and their individual will and preferences (Series, 2015; Watson, 2016a). In the context of relationships of dependency, support with decision making has been characterised as "assistive thinking", whereby decision support acts as a cognitive "prosthesis" (Silvers & Francis, 2009, p.487). Support in this sense involves decision supporters co-constructing the person's will and preferences (Bach & Kerzner, 2010; Watson, 2016a). For some authors the idea of co-construction raises questions about the "ownership" of decisions (Series, 2015, p.86) and whether it is possible for supporters to strip the process of their personality and interests (Silvers & Francis, 2009, p.493).

While it is accepted that social influence shapes human agency to some degree (Carney, Tait & Touyz, 2008; Gooding, 2015) when influence is coercive it diminishes agency to a larger extent as it "dramatically closes down the size of the remaining decisional 'space' within which a person still retains the power of choice..." (Carney et al., 2008, p.9). Arstein-Kerslake (2014) suggests it is possible for the supported decision-making relationship to be an "empowering dependency" that produces results free of undue bias and influence (p.9). Series (2015) suggests an important question is “when does ‘influence’ threaten authentic agency” (p.86)? For her, and others, the answer lies in developing a better understanding the concept of ‘undue influence’ in the context of the new support paradigm (Series, 2015, p.86; Gooding, 2015, p.56).

The General Comment on Article 12 has proposed a definition of ‘undue influence’ that reflects a relational approach to autonomy. It suggests undue influence is evident when “the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation” (Committee on the Rights of Persons with Disabilities, 2014, p.5). This conceptualisation of undue influence, which focuses on interaction rather than the outcome of the decision-making process, reflects a new way of thinking about autonomy as “relational” (Series, 2015, p.88).

Relational autonomy is an umbrella term that describes seeing people as socially embedded and that their identities are formed within the context of,

> …intersecting social determinants, such as race, class, gender, and ethnicity. Thus the focus of relational approaches is to analyse the implications of the intersubjective and social dimensions of selfhood and identity for conceptions of individual autonomy and moral and political agency. (Mackenzie & Stoljar, 2000, p.4)

In this context, agency is understood “not as a matter of individual will” but the result of “complex and shifting configurations of power” (Mackenzie & Stoljar, 2000, p.10-11). It is unclear to what extent the reconceptualisation of autonomy and agency as relational, reflects the experiences of people with intellectual disabilities receiving decision-making support, and those of their decision supporters, as there is no empirical research which explores decision-making processes from this perspective.

In addition to undue influence, coercion has also been identified as a concern in relation to providing decision-making support in the context of supported decision-making (Carney & Beaupert, 2013, p.196; Kohn et al., 2013, p.1137; Gooding, 2015, p.57). Both undue influence and coercion have been conceptualised along a continuum (Largent, Grady, Miller, & Wertheimer, 2012) and can include formal and informal forms of leverage (Rathner, 1998). Undue influence has been referred to as a “milder form” of influence than coercion which is often associated with more formal threats of harm (Largent et al., 2012). Even so, informal coercion can include “request[s], reasoning, persuasion, barter, bargaining, gentle prodding, enticement, selective information, manipulation, deceiving, blackmail, threat and even various forms of physical force” (Rathner, 1998, p.186). There is little research that has explored the practice of supported decision-making to determine whether the fears held by legal professionals and practitioners with respect to coercion and persuasion are justified (Kohn & Blumenthal, 2014).

While deliberate coercion and undue influence are concerning, deference to others may also pose a risk to the person receiving support in a relationship of dependency (Arstein-Kerslake, 2014). The person receiving support may be worried that disagreeing with their supporter could mean losing support or even the support relationship (Arstein-Kerslake, 2014, p.9). While this type of deference would “subvert the goals of supported decision-making” there is little evidence to support how or when it happens (Gooding, 2015, p.57).

Conceptualising supported decision-making after the CRPD.

While supported decision-making was initially discussed as a legal alternative to substituted decision-making in Canada (Bach, 1998; Gordon, 2000) after the CRPD there was a much sharper focus on it as means of ensuring people with disability are able to exercise their legal capacity (Bach & Kerzner, 2010; Davidson et al., 2015; Flynn & Arstein-Kerslake, 2014) . The academic and grey literature on supported decision-making produced after the CRPD uses the term in two distinct ways: to describe a process of supporting a person with their decision making, and as a system that offers the process legal status (Browning et al., 2014). Supported decision-making is conceptualised as something that happens as a decision is being made (Quinn, 2010). It is a process of support directed by an individual (Kerzner, 2011) whose supporter explains issues and interprets their signs and preferences (UN Enable, 2006). In this sense, the process of supported decision-making is not only a means to realising legal capacity; it is also a means of realising autonomy or self-determination.

When conceptualised as a process, supported decision-making involves a range of practices and relies on a variety of relationships, which support individuals to exercise their legal capacity. The Australian Law Reform Commission proposed the following examples of strategies used in supported decision-making practice in Australia:

- effective communication, including in the provision of information and advice to a person and through ensuring that a person is able to communicate their decisions to others;
- spending time to determine a person's preferences and wishes;
- informal relationships of support between a person and members of their social networks;
- agreements or appointments to indicate that a relationship of support exists; and
- statutory relationships of support—whether through private or court/tribunal appointment. (ALRC, 2014, p. 51)

As well as being conceptualised as a process supported decision-making is also conceptualised as a system intended to replace guardianship (Inclusion Europe, 2008) and an alternative regime to substituted decision-making (Committee on the Rights of Persons with Disabilities, 2014). In this sense, supported decision-making is a legal status which protects a person's autonomy and legal capacity (Bach & Kerzner, 2010) by accommodating deficits in their decision-making capabilities (Kämpf, 2010; Advocacy for Inclusion, 2012). Therefore, supported decision-making can be described as a paradigm that legally recognises the process of supported decision-making (Flynn & Arstein-Kerslake, 2014). Arstein-Kerslake (2016) describes the support paradigm as "a system in which people work together to understand an individual's desires and choices and then provide the means for that person to exercise legal capacity and live life the way she or he chooses…" (Arstein-Kerslake, 2016, p.7).

An important distinction.

It is important to make a distinction between 'supported decision-making' and providing decision-making support. In the literature, the process of providing decision-making support has been referred to as 'support with decision making' (Browning et al., 2014), 'support in decision making' (Committee on the Rights of Persons with Disabilities, 2014) and 'support for decision making' (Douglas, Bigby, Knox, & Browning, 2015). Both the process of providing decision-making support and supported decision-making involve supporting a person who is unable to navigate decision making independently.

However, what distinguishes supported decision-making from generalised decision-making support is that the process is directed toward greater legal capacity for the individual being supported (Browning et al., 2014).

Supported decision-making requires the exploration of alternative ways of viewing capacity (Series, 2015) that enable people with cognitive disability to exercise their legal capacity (Committee on the Rights of Persons with Disabilities, 2014). This is done through the establishment of alternative legal frameworks or the reinterpretation of existing ones, which enable legal capacity to be seen as broader than just the assessment of an individual's mental capacity (Series, 2015). From this perspective, supported decision-making is about legally recognising the support offered, not by just legitimising the role of the supporter, but by formally acknowledging that the support offered changes the person's capacity. This is because supported decision-making redefines capacity as interdependent (Bach & Kerzner, 2010; Browning et al., 2014; Series, 2015; Watson, 2016b).

Reasonable accommodation is defined in Article 2 of the CRPD as "necessary and appropriate modifications and adjustments… to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms" (United Nations, 2006, Article 2, para 4). Such positive measures are needed because of the ongoing systemic discrimination against people with disabilities (Power, Lord & de Franco, 2013). Forms of reasonable accommodation such as building a ramp for a person in a wheelchair or providing information in plain language for a person with intellectual disability are already familiar to people who work in the disability sector. Similarly, reasonably accommodating the decision making of people with cognitive impairment should already be embedded in the practice of disability services. The concept of supported decision-making "moves beyond reasonably accommodating decision making and is about determining how to reasonably accommodate people with cognitive impairment in the exercise of their legal capacity" (Browning et al., 2014, p.42).

In Australia, there is a small, emergent body of literature that has explored the process of decision-making support (which will be explored in detail in the final section of this literature review). However, in the absence of legislation that recognises the legal personhood of people with cognitive disability, and the role of their supporters in enabling the exercise of their capacity, it was not possible to explore supported decision-making in the Australian context. The aim of this research was to understand how people with intellectual disability were supported with decision making in the context of legal mechanisms which allow for supported decision-making. Given the most internationally recognised legal mechanisms of supported decision-making are in British Columbia (Stainton, 2016; UN Enable, 2006), this research took place primarily in British Columbia, Canada.

Intellectual Disability and Decision Making

This section of the literature review begins by exploring how the concept of intellectual disability has changed over time. Currently, the empirical literature on supported decision-making is very limited. However, there is a large body of research, from a range of disciplines, which provide knowledge about supporting the decision making of people with intellectual disabilities. The theoretical and empirical literature from speech pathology, psychology and special education help to understand how intentional communication, choice making and decision making can be supported for people with a range of intellectual disabilities. Economic theories and empirical research on decision making (e.g., bias and information framing) and emerging insights from neuroscience (e.g., on the role of emotion and unconscious thought) provide a greater understanding of the factors which are known to be important when providing decision-making support.

Intellectual disability.

"The construct of intellectual disability is contained within the broader construct of disability" (Schalock et al., 2007, p.116). Therefore, as society's view of disability has changed so has its conceptualisation of intellectual disability. Since the 1970s there has been a shift from an individual, medical perspective to a structural and social perspective in which people with disabilities are viewed as being disabled by society rather than by their bodies (World Health Organisation, 2011). Intellectual disability was thought of as a form of internal, individual affliction until critical researchers challenged this understanding, exploring it is an interactional or social product (Goodley, 2011; Rapley, 2004). This led to an evolutionary change whereby intellectual disability is no longer considered a constant trait of the person but is recognised as the interaction between the person, their environment and the application of individualised supports (Schalock et al., 2007).

The terminology used to describe what we know as intellectual disability has undergone many changes. Cocks (1985) suggests this is because many terms which at first appear to have scientific or professional credibility develop associations with negative stereotypes and become derogatory. Terminology such as feebleminded, defective, idiot, moron and imbecile are examples of historical terms used to describe people with intellectual disabilities (Beirne-Smith, Patton & Kim, 2006). Such terms convey negative social expectations and ultimately increase the burden of the disability on the person (Cocks, 1985). Most recently, the term mental retardation has largely been replaced by the term intellectual disability (Schalock et al., 2007; Wehmeyer et al., 2008) as there had been increasing recognition that the term mental retardation reflected an out dated construct of disability, which located the disability of mental slowness solely within the person’s mind (Wehmeyer et al., 2008). Many professionals believed the term intellectual disability better represented the new social-interactional approach to disability, aligned with the current professional practice of psychologists that focused on functional behaviour, was less offensive to people with disability and was more consistent with international terminology (Schalock et al., 2007). However, some self-advocates such as People First UK, have not embraced the term intellectual disability as they find the label “disabling” (Hardie & Tilly, 2012, p.4).

The terms intellectual disability and developmental disability are used synonymously in Canada (CACL, 2013) though developmental disability is the more commonly used term. Legislation such as the *Community Living Authority Act 2004* in British Columbia uses the term developmental disability and defined it, according to the DSM-IV, as “significantly impaired intellectual functioning that: manifests before age 18; exists concurrently with impaired adaptive functioning and meets other prescribed criteria (Community Living Authority Act, 2004, Part 1). This research used the term intellectual disability because it is the most consistently used term internationally (Schalock et al., 2007), is the most widely accepted term in Australia (Wen, 1997) and, though not the dominant term in Canada, is also acceptable (CACL, 2013).

Definition.

In 2010, the American Association of Intellectual and Developmental Disabilities (AAIDD) defined intellectual disability in their 11th Manual as,

> Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18. The following five assumptions are essential to the application of this definition:
>
> 1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
> 2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioural factors.
> 3. Within an individual, limitations often coexist with strengths.
> 4. An important purpose of describing limitations is to develop a profile of needed supports.
> 5. With appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability generally will improve. (Schalock et al., 2010, p.1)

This definition has been criticised by proponents of the social model of disability (Gallagher, Connor & Ferri, 2014) and of professionals working with people with intellectual disability engaged in the criminal justice system (Greenspan, Switzy & Woods, 2011). Greenspan et al. (2011) suggest the concept of "risk unawareness" has been lost from discussions about intellectual disability as has the reality that cognitive impairments limit a person's ability to recognise, minimise and avoid social and physical dangers (p.247). They suggest the current definition of intellectual disability fails to recognise risk and vulnerability as central to the behaviour of people with intellectual disability and can be significant reasons why people with intellectual disabilities require supports and protections (Greenspan et al., 2011). Supporters who adopt this perspective of intellectual disability may bring with them assumptions about the person's inherent vulnerability and need for protection during the decision-making process.

Gallagher et al. (2014) criticise current definitions and thinking about intellectual disability for continuing to pathologise diversity and make arbitrary moral judgements about "the 'socialised' part of the disability from the 'biological' part" (Gallagher et al., 2014, p.1126). Article 2 of the CRPD suggests discrimination is any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise of all human rights. It is possible to argue that continuing to categorise and label people as 'intellectually disabled' builds negative cultural representations and is contrary to enabling people to exercise their human rights (for example, when the diagnosis of an intellectual disability justifies the appointment of a legal guardian resulting in the loss of legal personhood).

Supporters who adopt a perspective of intellectual disability, which is in line with the social model of disability, may be more likely to identify and potentially address the environmental factors that act as a barrier to the person engaging in decision making. This is because they recognise the significant role environmental factors such as low community expectations of people with intellectual disability, and how this can limit the opportunities people with intellectual disabilities are given to make decisions and participate in decision-making processes.

Intentional communication and preference making.

The start of any exploration of decision making, in the context of intellectual disability, must consider intentional communication and preference making. This is because preferences and choices are viewed as the building blocks of decision making, especially for people with significant intellectual disabilities.

> 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)

Interpreting communication is important for all people with intellectual disabilities, and research has tended to explore preference making for people with mild and moderate intellectual disabilities in the context of choice making (Harris, 2003; Hatton, 2004;

Jenkinson, 1993) or decision making (Powers et al., 2012; Shogren et al., 2015) which are explored in the following sections.

Understanding and interpreting the communication of people with severe and profound intellectual disability is critically important when we view what they communicate as the foundation upon which preferences, choices and formal decisions can be made. Problematically, there is a lack of knowledge about how people with profound and severe intellectual disabilities express their feelings and preferences (Petry & Maes, 2006). Often it is unclear whether the gestures and expressions made by the person are intentional. Even amongst professionals there is frequently disagreement regarding judging the intentionality of communicative acts (Carter & Iacono, 2002). There is an extensive body of research focused on developing assessment tools and measures to better understand the preferences of people with severe and profound intellectual disabilities (Cannella, O'Reilly & Lancioni, 2005). Kang et al. (2013) and Tullis et al. (2011) have further evaluated direct preference assessment as a valid way of identifying preferred items, environments, and other stimuli for people with severe and profound intellectual disability. These studies demonstrated the effectiveness of health professionals using a formal method to determine the preferences of people with severe and profound intellectual disabilities from a limited number of options (Kang et al., 2013).

Carter & Iacono (2002) suggest that for some individuals intentional communication may not be achieved independently and as a result a communication partner will be needed to assign intent to their preintentional signals. More recently, in keeping with the social model of disability, health professionals have embraced a collaborative view of communicative competence and have started to consider not only the skills of the individual but also the environment in which they are a part (Johnson, Watson, Iacono, Bloomberg, & West, 2012). In this context, communication partners supporting people with severe and profound intellectual disabilities must work to ensure they do not assign meanings that reflect their own hopes, fears and desires (Johnson et al., 2012). Research has shown there is a risk that communication partners overestimate their ability to interpret and assign intention to the communicative acts of others (Mostert, 2010). This research highlights a significant challenge for the practice of supported decision-making. When supporters need to interpret the communication of a person with intellectual disability, they will need to work diligently not to respond based on their own hopes, fears and desires. They may also benefit from checking with others that they are not overestimating their ability to interpret what the person is communicating.

Advocates of supported decision-making who work with people with significant intellectual disabilities (Bach & Kerzner, 2010; Watson, 2016a) have embraced the co-construction of communicative competence (seeing a person's communication ability as collaborative). For Bach & Kerzner (2010) the ascription of intention to communicative acts (signals) is the foundation of supported decision-making practice for people with high support needs. To ignore this aspect of decision making would result in the exclusion of people with severe and profound disabilities from determining their own lives and being able to exercise their human rights (Watson, 2016b).

Choice.

Given the aims of supported decision-making incorporate enabling control and self-determination (Bodnar & Coflin, 2003), promoting the person's right to autonomy (Bach, 1998) and enabling the exercise of their legal capacity (Flynn & Arstein-Kerslake, 2014), the empirical literature on choice making and decision making offers important insights when considering how decision making can be supported. Choice has been defined as "…making an unforced selection of a preferred alternative from two or more options" (Stancliffe, 2001, p.92). Choice making is psychologically powerful because in the process of choosing, people simultaneously express preferences and convey a sense of control in the situation (Savani, Markus & Conner, 2008). The impact of an intellectual disability on a person's ability to make a choice depends on whether choice making is seen as an internal, mental activity or as a socially mediated process (Harris, 2003). Just as the assessment of intentional communication has been reinterpreted to consider environmental factors, so choice making has been reinterpreted as more than just an independent mental process (Harris, 2003).

Research has demonstrated that opportunities for choice making increase according to the ability of people with intellectual disability and change according to the level of restriction in people's living environments (Hatton, 2004). The success of choice making relies upon not only having options but also being familiar enough with the options to be able to make a choice (Wehmeyer et al., 2007). People with intellectual disability have often been denied opportunities to experience different activities and develop the familiarity necessary to make choices.

Some literature suggests that personal preferences are the basis of choice making (Beamer & Brookes, 2001; Cannella et al., 2005). However, this idea has been challenged by research that suggests culture mediates a person’s ability to express preference in choice making. Savani et al. (2008) identified three core assumptions about preference and choice in North American and European contexts that “people (a) recruit or construct preferences to make choices, (b) choose according to their personal preferences, and (c) are motivated to express their preferences in their choices” (p.862). They conducted research to determine whether these assumptions could be applied in another culture (India) which values interpersonal responsibility over individual choice. They found that choices do not always reveal constructed preferences and that cultural context shapes the expression of personal preference (Savani et al., 2008).

This finding has implications for the practice of supported decision-making. The cultural background of people needing support, and the cultural context in which support is being offered, will likely influence the decision-making process. The North American/European notion of the primacy of personal preference may not be an appropriate way of thinking about providing support in other cultures that value interpersonal responsibility and a sense of familial obligation more highly.

Brown and Brown (2009) suggest choice making should begin from the developmental level of the person and move towards more and more complex choices as skills and environmental supports develop. To enable this development to occur they propose a four step strategy for integrating choice into daily practice for people with intellectual disabilities: (1) assess the acceptance of choice in the environment; (2) determine ways that opportunities can be made both broad and familiar; (3) determine ways that freedom, initiative and skills can be increased in choice making; and (4) increase the skill of support personnel and family members to encourage and support choice.

Brown and Brown’s (2009) model provides a number of important strategies to consider when wanting to increase decision-making opportunities for people with intellectual disability such as the benefit of providing regular opportunities to make choices and increase skill over time. In general, the research on choice making suggests the process of providing decision-making support may be affected by the cognitive ability, experience of the people receiving support and the opportunities they experience for skill development. It may also be effected by the cultural context in which these people live and how experienced the people who provide them with decision-making support are in supporting decision making.

Even though the terms 'choice making' and 'decision making' are sometimes used interchangeably in the literature they are often used in different contexts. Articles discussing choice are often focused on control (Parsons, Harper, Jensen, & Reid, 1997; Harris, 2003; Maes, Lambrechts, Hostyn, & Petry, 2007; Brown & Brown, 2009; Ferguson, Jarrett & Terras, 2010; Nonnemacher & Bambara, 2011) whereas those that consider decision making are more often focused on capacity and autonomy (Gunn, Wong, Clare, & Holland, 1999; Wong, Clare, Holland, Watson, & Gunn, 2000; Dukes & McGuire, 2009; Willner, Bailey, Parry, & Dymond, 2010a). The empirical and theoretical literature on decision making offers important insights in a range of areas including: the role of relationships, emotion and unconscious thought in decision making; self-determination as an aspect of decision making; and factors which have been shown to improve the decision-making capacity and skills of people with intellectual disabilities. This literature is explored below to better understand how these areas may influence the support provided to people with intellectual disabilities when making decisions.

Decision making.

Decision making has been primarily viewed as a cognitive process that is more complex than choice making although this distinction has been discounted by some as arbitrary (Harris, 2003). It has been studied from a number of different disciplines including economics, psychology and neuroscience who have sought to understand "our ability to process multiple alternatives and choose an optimal course of action in the face of characteristic uncertainty about the possible consequences" (Sanfey & Rilling, 2011, p.223). Research in the general population has shown decision making in general is influenced by a number of factors including neural processes (Yu, 2011), metacognitive knowledge (Colombo, Iannello, & Antonietti, 2010), affect (Anderson, 2007) risk (Slovic, Peters, Finucane, & MacGregor, 2005), heuristics and biases (Tversky & Kahneman, 2000). Little is known about how decisions are perceived by individuals (Niedermayer & Chapman, 2001) and few researchers have asked questions about how decisions are formed in the context of a person's life (Anderson, 2007).

A large body of research exploring the experiences of the general population has shown how a decision is represented or framed will influence the decision-making process (Beresford & Sloper, 2008; De Martino, Kumaran, Seymour & Dolan, 2006; Levin, Gaeth, Schreiber & Lauriola, 2002; Soman, 2004; Tversky & Kahneman, 2000). Researchers use the term loss aversion to describe a phenomenon where potential losses have more influence than gains when people are making decisions (Tversky & Kahneman, 2000). Experiments have shown that a difference between two options will have greater impact if it is framed as a difference between two disadvantages rather than as a difference between two advantages (Soman, 2004). Given framing can have such a strong impact on the outcome of a decision-making process, it would be possible either intentionally or unintentionally to manipulate a person's decision by the way a problem is presented (Beresford & Sloper, 2008). This body of research has implications for the practice of supported decision-making. It suggests that supporters will need to be aware of the way they chose to frame options available for consideration in the decision-making process. Those supporting decision making will need to consider the impact of their own values and attitudes when exploring a range of decision-making options with the person.

Relationships and decision making.

Decision making often occurs in the context relationships. Research conducted into the impact of specific types of relationships on the decision making of people with cognitive disabilities such as spousal (Knox et al., 2015), parental (Knox et al., 2016b), professional and familial (Björnsdóttir, Stefánsdóttir, & Stefánsdóttir, 2015; Fetherstonhaugh, Tarzia, Bauer, Nay, & Beattie, 2016; Watson, 2016a) have identified some important considerations in the provision of decision-making support.

Qualitative research exploring the experiences of 80 direct care staff supporting the decision making of people with dementia suggests getting to know the person is an important precursor to being able to assist them to make decisions (Fetherstonhaugh et al., 2016). This finding is corroborated by the doctoral work of Watson (2016a), who conducted an in-depth exploration of the decision making of 5 people with severe and profound intellectual disabilities. Watson (2016a) found that supporters who “reported intimate or very close relationships with those they support[ed] were more likely to have good knowledge of their history and life story” (p.338). This knowledge made supporters more likely “to be responsive to that person, in terms of acknowledging, interpreting and acting on their expression of preference” (p. 337). Decision making was most affected by the quality of the relationship between the person and their supporter, rather than the length (p.338) or type of relationship (p.339). Watson (2016a) reflected,

> …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. (p.339)

The relational space in which decision making occurred was shaped by the perceptions decision supporters had of the person they were supporting, such as whether they were seen “in a positive light” (Knox et al., 2015, p.11) or as an “adult” capable of decision making (Björnsdóttir et al., 2015, p.18). If the relationship “was poor, decision making was often also poor” (Knox et al., 2015, p.24). Lotan & Ells (2010) suggest it is critical to be aware of the asymmetrical power relationships between the person with a disability and those supporting them with decision making. As discussed previously, the dependence of people with intellectual disability on others, in multiple areas of their lives, will affect their ability to define their own thoughts, preferences and decision-making processes. This suggests supporters would benefit from becoming more aware of the complexities of the choice making process, and the potential barriers to decision making, which influence the process (Ferguson et al., 2010).

The complexity of informal caring relationships (Penning & Wu, 2016; Thompson, Kerr, Glynn & Linehan, 2014) can make decision making in these contexts complicated. Lashewicz, Mitchell, Salami & Cheuk (2014) conducted qualitative research exploring the extent to which the voices of adults with intellectual disabilities were heard within their family caregiving contexts. They found family caregivers can represent and facilitate the voices of their adult family members with intellectual disabilities in ways “that reflect intimate knowledge and skill at avoiding stress and anxiety” (Lashewicz et al., 2014, p.19). However, “entrenched roles” for both the care receiver and care giver can also “obscure” their voices (p.21-22) and diminish or negate their voices in conversation (Laschewicz et al., 2014, p.32). The complexity of informal caring relationships suggests it may be difficult for carers who are also decision supporters to hear the views of the person with intellectual disability when they make decisions together.

In the conceptual literature on informal care giving, Clough (2014) challenges the suggestion that decision-making support is ever unbiased in the family context. She suggests there are always a “plurality of interests” at stake in family life and it is unrealistic to expect family members to “divorce themselves from their own emotional ties and interests and view the interests of their relative in an objective unbiased manner” (Clough, 2014, p.140). She recommends legislation and policy must reflect the reality that caring relationships are interdependent and encourage dialogue about decision making which “does not ignore the realities of informal caring and perpetuate an unsophisticated approach to decision making in this context” (p.143). This has implications for professionals and organisations working with people with intellectual disability and their family members who provide decision-making support. Organisations facilitating and supporting families engaging in decision-making support need to consider it is highly challenging and possibly unrealistic for family members to provide objective, unbiased support.

Improving the decision-making capacity of people with intellectual disability.

Research into the experiences of people with intellectual disabilities making decisions, has shown they find it more difficult to comprehend (Wong et al., 2000) and weigh up information than the general population during decision-making processes (Willner, Bailey, Parry & Dymond, 2010b). However, it is possible to improve a person with intellectual disability’s capacity to make decisions if they are provided with information that is accessible, in size and form. Gunn et al. (1999) conducted research with 19 people with intellectual disabilities (as well as people with dementia and mental illness) to determine if a series of interventions could enhance their capacity to consent to a medical procedure. The interventions included: the presentation of information in smaller elements, the presentation of information in verbal and non-verbal formats and using tasks that depended less on verbal ability to assess the capacity of the person (e.g., physical demonstrations). They found these interventions were enough "to improve the capacity of a considerable proportion of people with learning disabilities to make a decision about a blood test" (p.287). The number of participants who were able to consent to the procedure was not stated specifically in the research findings.

Similarly, other studies have shown that the provision of specialised instruction has assisted a range of people with intellectual disabilities to perform more effectively in high risk situations (Wehmeyer et al., 2007) and improved their capacity to make sexuality related decisions (Dukes & McGuire, 2009). In a study, involving 24 participants with mild intellectual disability the use of visual aids improved their ability to integrate information from two different sources (Bailey, Willner & Dymond, 2011). This body of research suggests that when supporting people with intellectual disability with decision making the accessibility and presentation of information would likely have an impact on the person's ability to engage in the decision-making process.

Self-determination as an aspect of decision making.

An important goal of supported decision-making is enabling people with intellectual disability to be self-determining (Bodnar & Coflin, 2003). The literature on self-determination suggests decision making is one of a number of component elements to a self-determined life (Shogren & Wehmeyer, 2015) which also includes choice, problem solving, goal setting, independence and self-advocacy (Wehmeyer et al., 2007). Self-determination has been defined as "a quality or characteristic within a person who determines his or her own fate or course of action (Shogren et al., 2015, p.252). Therefore, self-determined people "are, in essence, actors in their own lives, rather than being acted upon" (Wehmeyer, 2014, p.178).

When people with intellectual disabilities are denied the opportunity to make decisions they become subjects in their own lives rather than actors. Historically, decision making has been withheld from people with intellectual disabilities on the grounds that they lack competence, have poor judgement and fail to meet a rational ideal of decision making (Jenkinson, 1993). Judgements such as these have denied many people with intellectual disabilities the ability to develop the skills necessary to determine their own lives and prevented them from developing their identity and confidence as decision makers (ACT Disability, Aged and Carer Advocacy Service [ADACAS], 2013).

A growing body of research exploring self-determination has demonstrated that training in decision making, self-advocacy, goal setting and attainment, as well as modifications to the environment to support these skills, leads to enhanced self-determination for people with mild to moderate intellectual disabilities (Nonnemacher & Bambara, 2011; Powers et al., 2012; Shogren et al., 2015; Wehmeyer & Abery, 2013). Nonnemacher & Bambara (2011) interviewed 10 adults with intellectual disabilities regarding the interpersonal or social supports they needed to be self-determined. These self-advocates identified five actions taken by supporters that impeded their self-determination: usurping decision making and control; controlling personal spending; being unapproachable or inaccessible; failing to follow through and obstructing or coercing the implementation of decisions. The self-advocates also identified five actions which supported their self-determination: expanding options and experiences to encourage choice; supporting access to people of authority; being approachable and accessible; listening without judgement and providing support for follow through.

While there has been a growing level of understanding regarding individual, relational and environmental factors that assist people with mild and moderate intellectual disabilities becoming self-determined, the literature on self-determination to date has paid little attention to the needs of people with severe and profound intellectual disabilities (Wehmeyer & Abery, 2013). This may be because researchers and practitioners in the field mistakenly believe people with high support needs “are not capable of anything more than simple choice making” (Wehmeyer & Abery, 2013, p.405). The development of the practice of supported decision-making may offer a way of exploring the experiences of people with severe and profound intellectual disabilities when exercising their self-determination by reducing the need to use proxy responders in the context of research (Wehmeyer & Abery, 2013). The current body of research on self-determination suggests for people with intellectual disability to be able to determine their own lives it is important they are provided with support that increases their skill making decisions and minimises the intention of supporters to usurp control and act coercively when supporting decision making.

Emotion.

Cognition researchers have explored the role of emotions in decision making which is of interest when exploring the range of factors that may shape supported decision-making. Anderson (2007) suggests emotions are necessary for decision making and can both help and harm the process. Emotions play a role in the way people determine the level of risk they are willing to accept as a consequence of their decision making and in many cases without emotions "there would be no decision of which to speak" (Anderson, 2007, p.198).

Slovic et al. (2005) examined two ways in which risk was identified and acted upon in decision-making processes. They suggest risk is either experienced as 'feelings' or through reasoned 'analysis' and their research concluded it is surprising to realise how often people depend upon feelings rather than reason when they make decisions.

The research exploring emotion in decision making encourages people with intellectual disabilities and their supporters to acknowledge and explore their emotions and feelings in the context of decision making rather than ignoring them or seeing them as external to the process.

Unconscious thought.

Conscious thought refers to the cognitive processes a person is aware of while attending to a task. More recently, neuroscientists have considered the role of spontaneous thoughts, including dreaming and mind wandering, in decision making (Christoff, Gordon & Smith, 2011). An emerging body of research has found unconscious thoughts play an important role in decision making (Dijksterhuis & Strick, 2016; Newell & Shanks, 2014). A series of five experiments by Dijksterhuis (2004) found unconscious thoughts led to clearer, more polarized and more integrated representations in memory. He concluded unconscious thinkers made the best decisions and recommended,

> …when faced with complex decisions such as where to work or where to live, do not think too much consciously. Instead, after a little initial conscious information acquisition, avoid thinking about it consciously. Take your time and let the unconscious deal with it… (Dijksterhuis, 2004, p.597)

If decision making is not only a rational and conscious process this may raise challenges when involving a supporter in the decision making of others such as people with intellectual disability. Understanding the role of emotions as well as how information is framed, the context in which it is discussed and the impact of any power imbalance in the decision-making relationship may also influence the experience of the person with a disability being supported in a decision-making process.

The next two sections of this literature review explore decision-making support in the Australian context and supported decision-making in British Columbia, Canada. These sections critically review the scarce empirical literature that evaluate models of decision-making support and supported decision-making, and the limited insights they provide into the practice of supported decision-making. The chapter concludes by identifying the significant gap in understanding supported decision-making practice in Canada and why this of interest in the Australian context.

Context in Australia

Supported decision-making in Australia.

In recent years, there has been growing recognition that adult guardianship legislation across Australia is out of date and in need of review (Chesterman, 2010; New South Wales Legislative Council Standing Committee on Social Issues, 2010; Victorian Law Reform Commission [VLRC], 2012; Australian Law Reform Commission [ALRC], 2014; Office of the Public Advocate (Qld), 2014; New South Wales Law Reform Commission, 2017). In this context, supported decision-making has been discussed as a legal alternative to traditional adult guardianship (Carney, 2012). Supported decision-making was a focus of the Australian Law Reform Commission’s report on ‘Equality, Capacity and Disability in Commonwealth Laws’ published in 2014 that recommended Australia adopt a set of national decision making principles to guide the reform of all Commonwealth, state and territory laws relating to decision making. The four principles were:

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

> 2) 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.
>
> 3) The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.
>
> 4) 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. (ALRC, 2014, p.64)

These decision-making principles are significantly aligned with the CRPD and to date the Commonwealth government is yet to act upon the principles or the report.

Disability groups, advocacy organisations and service agencies interested in the development of strategies to support decision making for people with cognitive disabilities have embraced the concept of supported decision-making. These organisations have developed material to explore the development of practice (Watson & Joseph, 2011), facilitated conferences (Victorian Advocacy League for Individuals with Disability [VALID], 2012; Office of the Public Advocate (Vic), 2013) and supported the development of trials of practice (Advocacy for Inclusion, 2012; Burgen, 2016; Community Matters, 2015; Wallace, 2012; Westwood Spice, 2015).

Australian financial and disability context.

Stainton (2016) has suggested supported decision-making should not be viewed in isolation from other systems and supports such as individualised funding or support brokerage when people require support to act on their choices. If new legal tools are adopted which allow for supported decision-making in Australia, they will only be as good as the service system and social environment available to the person needing support (Carney, 2012). Legal options become meaningless if the resources do not exist to realise the choices and decisions made by the person who is being supported (Carney, 2012). In the past advocates from the disability sector have questioned the viability of supported decision-making in a climate of limited resources, particularly when there are high numbers of people who are socially isolated and without natural supporters in Australia (Brayley, 2011; Browning, 2011; VLRC, 2012). However, more recently the introduction of the National Disability Insurance Scheme (NDIS), and the potential it brings to better resource the disability service sector in Australia, has offered some disability advocates hope that that the decisions made by people with intellectual disability may be better resourced in the future (Bigby, 2013).

The National Disability Insurance Agency (NDIA) has identified supported decision-making as key to fully realising its aims to enable people with intellectual disability to have choice and control over their financial packages and service delivery (ADACAS, 2013; Bonahady, 2016). Given the fast speed with which the NDIS is rolling out across Australia, the NDIA has been urged by researchers to stay abreast of research and practice developments as they emerge to inform the development of supported decision-making policy and practice guidelines in the context of the NDIS (Bigby, 2016, p.136).

Models of decision-making support in Australia.

Over the last seven years, a number of states across Australia have trialled models they refer to as supported decision-making. Table 2-1 on page 36 is a summary of the models of practice and the insights gained from them through formal and informal evaluation. In the table, the terminology used by each leading organisation is used. However, when summarising the collective contribution of these trials they are referred to as models of decision-making support because the support provided was not directed towards the exercise of legal capacity and occurred outside of the context of legal recognition.

These trials of decision-making support make an important contribution to the emerging body of knowledge about supporting people with cognitive disabilities to make decisions. All of the trials offer evidence that there were positive outcomes for decision makers when provided support with their decision making. Collectively, the projects identify some key challenges in the provision of decision-making support. These challenges include the difficulty of finding supporters for people who are isolated and in need of decision support; the persistent low cultural expectations of people with cognitive disabilities as decision makers and; as a result, the limited experience they have as decision makers. The projects also found it was resource intensive to set up and maintain supervised practice (Bigby, et al., 2017b). Bigby et al. (2017b) suggest the absence of information in the project evaluations means only “tentative conclusions can be drawn about the effectiveness of the programs and the design features that influenced their outcomes" (p.9).

The projects conducted to date have a few important gaps. They have not explored the experiences people with significant cognitive disabilities and high support needs because they have only recruited participants with mild-moderate intellectual disability, psychosocial disability and traumatic brain injury. Additionally, none of the projects have explored the decision-making processes of their participants in any detail nor the interactions between the person with cognitive disability and their decision supporters while decision making. While discussing support strategies in general, the project evaluations have not assessed how support was provided and the factors, which shaped decision making for participants. Therefore, while justifying further the need for support to be accessible to people with cognitive disabilities the project evaluations offer little guidance regarding the process of decision-making support.

Table 2-1: ***Models of decision-making support trialled in Australia***

Location	Organisation	Aim	Timeframe	Participants	Evaluation Findings
South Australia	Office of the Public Advocate (SA)	To assist people with a variety of cognitive disabilities who needed decision support to set up a non-statutory supported decision-making agreement with people already in their life.	2010-2012	The project resulted in 26 agreements being made over the two-year period for people with brain injury, intellectual disability, autism, and motor neuron disease.	An independent evaluation found there were specific benefits to the majority of the participants including increased confidence in themselves and their decision making, improvement in decision-making skills, growth in support networks and increased community engagement (Wallace, 2012).
South Australia	Health and Community Services Complaints Commissioner (HCSCC)	To train workers in disability agencies to establish and facilitate social support systems that support people with disabilities to make decisions. To build the capacity of the person (decision maker) to make decisions, the capacity of their family and friends (supporters) to provide support, and the capacity of staff from two support organisations (facilitators) to coach the supporters.	2013-2015	The project involved 8 trainee facilitators (5 completed the training) and 8 decision makers (7 completing the program) and an undefined number of supporters.	An independent evaluation found choice was improved for decision makers by using active, lateral problem solving and social capital to extend access to community options. When supporters and facilitators accepted the decision makers ‘expressed wish’ , believed in their capacity to develop decision-making skills and were willing to “rethink some aspects of traditional risk management policies” they were able to “release control that they had traditionally held” (Community Matters, 2015, p.6).

Australian Capital Territory	ACT Disability, Aged and Carer Advocacy Service (ADACAS)	To understand how people with a decision-making impairment or whose decision-making capacity is undervalued, might be supported to make more decisions. To work with the communities of the participant 'decision-makers' to build the capacity of the whole community to engage in supported decision-making.	2013	The project expanded on the first model developed in South Australia and was implemented with six people who experience psychosocial and intellectual disability.	An internal evaluation found "each person's capacity for self-determination was limited, not by their ability to make a decision, but by the support they received to exercise decision making" (ADACAS, 2013, p.5). A wide range of support was required, on a spectrum from formal to informal, and cultural change was important that normalises the active participation of people with cognitive disability in decision making (ADACAS, 2013).
New South Wales	NSW Department of Family and Community Services, Ageing Disability and Home Care, NSW Trustee and Guardian and the NSW Public Guardian	To explore a supported decision-making framework that included financial decision making. To produce tools and resources that could be used to educate the community about supported decision-making and to test those resources with people with cognitive disability receiving services from two of the three agencies involved.	2013-2014	The project recruited 26 participants who were supported by 19 supporters of whom 10 were paid staff, 7 family members, 1 friend and 1 paid advocate.	An independent evaluation found having a facilitator was crucial to the effectiveness of decision-making support. Barriers to participants' decision making were not intrinsic. They related to "social isolation (leading to difficulties with supporter recruitment), lack of power and familiarity with making decisions, low expectations by others, power imbalance and conflict of interest in relationships and the length of time that it takes for someone to be supported to become 'decision ready'" (Westwood Spice, 2015, p.13).

Victoria	Office of the Public Advocate (Vic)	To address an issue encountered in the NSW trial that many people wanting and needing support with their decision making do not have people in their lives who can offer this assistance. To trial using trained volunteers as decision supporters for people wanting decision support who are socially isolated.	2014-2015	The project matched 18 volunteers who were trained in the practice of supported decision-making with 18 people with 'mild to borderline' intellectual impairments who were experiencing social isolation.	An internal evaluation found most participants indicated improvement in their capacity for decision making and quality of life. The success of the project was "a pool of skilled volunteers" who were committed to spending many months developing a relationship with participants and persevering through many barriers when supporting them to make and act on their own decisions (Burgen, 2016, p.13). While resource intensive the provision of support addressed the neglect that appeared endemic in the lives of socially isolated participants (Burgen, 2016).
Victoria	Victorian Advocacy League for Individuals with Disability (VALID) and Office of the Public Advocate (Vic)	To address an issue encountered by National Disability Insurance Scheme that people with cognitive impairments were having difficulty planning and reviewing of their funded supports because they did not have support with their decision making. To match volunteers trained in the practice of support for decision making, with NDIS participants who wanted and needed this type of support.	2015-2016	The project matched 15 NDIS participants with 15 trained volunteers.	An independent evaluation by Deakin University found the relationships between OVAL Project volunteers and NDIS participants were highly valued by both parties. Participants valued having someone who was outside the service sector in their life. They perceived volunteers were on their side and would not tell them what to do. Volunteers expressed satisfaction that they were able to get to know their participant and offer them support to achieve their goals (Balandin, Frawley & Watson, 2016).

Research into decision-making support in Australia.

There are three pieces of exploratory empirical research that explore decision-making support in the Australian context (Bigby, et al., 2017a; Knox et al., 2013, 2015, 2016a, 2016b, 2016c, 2016d; Watson, 2016a). Knox (2016d) and Watson (2016a) both engaged in doctoral research and Bigby et al. (2015) conducted exploratory qualitative research that was commissioned by a community organisation. This overview summarises their research exploring the experiences of people providing and receiving support with decision making in the Australian context.

Bigby et al. (2017a) conducted an exploratory study into the experiences of family members and workers in disability organisations who were supporting people with intellectual disability with decision making. The study involved 11 family members (parents) and 12 workers (direct support & supervisory roles) who participated in individual interviews or a focus group. The qualitative data collected was analysed using an inductive thematic approach and grounded theory coding techniques. No criteria was given as to the quality or nature of the support given by supporters and the findings reflected a range of approaches to supporting decision making (Bigby et al., 2017a).

There were four ideas that underpinned the approaches of supporters. 1) Supporters thought of support for decision making as an integral part of their relationship with the person. 2) Supporters were unaware of “rights based approaches to decision making” but understood and endorsed the idea that people with intellectual disability have the right to make decisions about their own lives (p.16). 3) Supporters considered knowing the person was a “prerequisite” for providing support (p.8). 4) And supporters saw support for decision making as a process that was shared by many people involved in the person’s life.

While some supporters aimed to provide support that was “neutral” (p.10) at the same time they had to be “realistic” about available resources, support and the individual’s capacity (p.18). Managing this tension was one of the dilemmas supporters experienced in their role. They also had to balance the person’s “right to take risks” with their duty of care (p.14), “manage conflict” between supporters (p.14) and “seek assistance” when they felt support was beyond their role (p.16). Resolving these challenges proved “more difficult” for supporters than providing practical support (p.20).

Knox (2016d) explored the experiences of people with severe traumatic brain injury (TBI) and the people in their social support network participating in decision making. Her doctoral research resulted in five joint publications (Knox et al., 2013; 2015; 2016a; 2016b; 2016c) and her thesis (Knox, 2016d). The research used a constructivist grounded theory approach to explore the experiences of eight adults with TBI and eleven of their nominated decision supporters.

Knox (2016d) identified the support relationship provided the space in which decision making occurred. A number of factors facilitated a positive support relationship between the person with TBI and their supporters. These included knowing the person well, understanding the impact of the brain injury in the context of the person, trust, mutual respect, closeness, commitment to the long term nature of the relationship, honest and effective communication, sharing an appreciation of what was important to the person and taking a positive approach to risk (Knox, 2016d, p.3-4). The research provides evidence that positive relationships provide a vehicle for people with TBI to reinforce their self-concept post injury (Knox et al., 2016c), “increase their autonomy and exercise control in their lives” (Knox, 2016d, p.218). These findings echo the existing research on self-determination that demonstrates decision making is an important aspect of exercising control over one’s life (Shogren & Wehmeyer, 2015).

In the context of the support relationship, decision supporters created opportunities, provided advice, acted on the person’s behalf, motivated and acknowledged achievement, recruited others to join the person’s social network and provided support in relation to particular decisions (Knox, 2016d, p. 210-211). The goals, beliefs and previous experiences of the individuals within the support relationship “were reflected in the decision making space” (Knox, 2016d, p.208). This created a need for supporters to be able to reflect on their own values and identify what drove their approach to decision making (Knox, 2016d). This finding may have implications for decision supporters of people with intellectual disabilities who may benefit from becoming more aware of the values, beliefs and prior experiences they bring to the decision making process and how they might influence the way they provide decision support.

Knox (2016d) identified that the person’s need for decision-making support changed over time and in response to a range of different factors, such as the nature of the decision, its significance to the person and their familiarity with the issues involved. This resulted in decision supporters needing to approach "each decision as a new experience" and put aside their assumptions (Knox, 2016d, p.229). Research is yet to clarify the factors which shape the decision-making space of people with intellectual disability receiving decision-making support. Therefore, it is unclear whether the needs of people with intellectual disability change over time and in response to the same or similar factors as people with TBI when being supported with decision making.

Watson (2016a) conducted qualitative research which aimed to characterise supported decision-making for people with severe to profound intellectual disability and identify "the processes, enablers and barriers to supported decision-making practice" for this group of people (p.149). The research used an action research design to explore the implementation of 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). The intervention involved bringing people who cared for and about someone with a severe or profound intellectual disability together and forming a circle of support around them. Each circle of support was a case study that engaged in the intervention for a period of approximately six months each. The research involved five adults with severe or profound intellectual disability and thirty-five supporters, twenty-five of whom were paid staff (Watson, 2016a, p.176).

Watson (2016a) characterised supported decision-making for people with severe or profound intellectual disability as a complex, interdependent process with both parties contributing differently. The person contributed by expressing their will and preferences through a range of means including "facial expression, body language, gesture, physiological reactions, and sometimes behaviours of concern" (Watson, 2016a, p.356). The supporters contributed by responding to the person's will and preferences by "acknowledging, interpreting and acting on these expressions" (Watson, 2016a, p.356). Supporters needed to attend to all three tasks "collectively and often sequentially" in order to demonstrate "responsiveness" (Watson, 2016a, p.246).

Supporter responsiveness was shaped by five factors. The characteristics of the service system (e.g., balancing duty of care with the right to choice), the functioning and makeup of the circles of support (e.g., whether they were collaborative or involved conflict), supporters' attitudes and perceptions (e.g., of communication and decision-making capability), relational closeness (e.g., knowing the person's life history) and the intentionality of the person's communication (Watson, 2016a).

In her analysis of supporter responsiveness Watson (2016a) found that eighty-four percent (n=15) of times a supporter was found not to respond to the person's expression of preference they were supporting, it was because they "had not acknowledged or noticed the person's expression of preference" (p.249). This has implications for trying to improve the quality of decision-making support with this population, through increasing supporter attentiveness to expressions of will and preferences. It is unclear whether supporter responsiveness is central to the decision-making experiences of people with mild to moderate intellectual disabilities as well as people with severe to profound intellectual disabilities.

Watson (2016a) identified the benefits of a communication coordinator to support circles by helping develop a positive perception of the person's ability to communicate and participate in decision making, manage conflict between supporters and provide a leadership role in "pulling it all together" (p.346). This finding mirrors those of other supported decision-making trials that benefitted from the involvement of a coordinator or facilitator (Burgen, 2016; Wallace, 2012; Westwood Spice, 2015).

Collectively, these three pieces of rigorous empirical research flag some challenges supporters faced providing decision support, and managing dilemmas and tensions during the decision-making process. They all suggest that providing decision-making support is complex, difficult work (Bigby et al., 2015) that can be "burdensome" for supporters (Knox et al., 2015, p.25). People with severe or profound intellectual disability rely on the responsiveness of their supporters to acknowledge, interpret and act on their will and preferences (Watson, 2016a). Similarly, people with traumatic brain injury rely on their supporters to assist them to "initiate" their involvement with decision making (Knox et al., 2015, p.26) and act as a bridge between participation and self-conceptualization (Knox et al., 2016c, p.1). Across all pieces of research the relationship between the person and their supporter was central to shaping supporter responsiveness (Watson, 2016a) and the person being able to exercise control over their lives (Knox, 2016d).

These studies also raise some important questions that require further investigation about the values, beliefs, goals and previous experiences of individuals within the support relationship and how they may be central to the decision making of people with intellectual disabilities as well as those with traumatic brain injury. If so, is the ability to reflect on these experiences and beliefs a significant factor, which shapes the decision-making process? Do supporters play an important role in initiating the supported decision-making process of people with intellectual disabilities? Is supporter responsiveness central to the decision-making experiences of people with mild to moderate intellectual disabilities as well as people with severe to profound intellectual disabilities? What are the factors that shape supporter responsiveness in British Columbia, in the context of having representation agreements and microboards?

Conceptual developments from research.

There has been one attempt to synthesize the learning from the early research conducted by Bigby, Whiteside and Douglas (2015b) and Knox et al. (2013; 2015) and characterise effective decision-making support for people with intellectual disability and brain injury. Bigby, Douglas, Knox & Browning (2015a) propose four empirically based propositions 1) orchestration by the primary supporter; 2) commitment to the person; 3) support principles and 4) strategy development. These propositions both challenge and embrace existing practice knowledge.

The proposition Bigby, Whiteside and Douglas (2015b) make that orchestration requires the primary supporter to have a relationship that is “good enough” (p.40) with the person which they define as one characterised by “trust, genuine positive regard, and honest interpersonal interaction” (Bigby, et al., 2015b, p.40) has been challenged by Watson (2016a). Watson (2016a) argues relational closeness is foundational to positive decision-making experiences for people with severe or profound intellectual disability and therefore for this population “a relationship that is “good enough” is not likely to be ‘good enough’” in practice (Watson, 2016a, p.349).

In contrast, when Bigby et al. (2015a) suggest support principles should shape the provision of support and include: the decision making agenda is set by the person receiving support; supporters need to be aware of their own values; and rights should be the touchstone for understanding and assessing risk. This assertion reflects the supported decision-making principles first articulated in Canada which point to the importance of the rights of the person to set the decision making agenda and take risks (Bodnar & Coflin, 2003; CACL, 1992).

In summary, the exploratory research conducted into decision-making support in an Australian context raises some important questions that are relevant to how people with a range of intellectual disabilities are supported with decision making. A close, positive support relationship, the importance of supporters demonstrating commitment to the rights of the person, and being responsive to their will and preferences seem to be central to good practice when providing decision-making support.

Context in Canada

Supported decision-making in British Columbia, Canada.

The province of British Columbia, Canada has the most well regarded examples of supported decision-making in law, policy and practice (James & Watts, 2014; Stainton, 2016; UN Enable, 2006). The most well-known example of supported decision-making in British Columbia is the use of representation agreements following the introduction of the *Representation Agreement Act 1996*. The use of representation agreements is the first of two models of supported decision-making explored in this research.

Representation Agreement Act.

In June 1993, the government of British Columbia passed the *Representation Agreement Act* as one of four pieces of legislation designed to protect the rights of people with disabilities. After long and complex political negotiations, the *Representation Agreement Act 1996* came into effect in February 2000.

The *Representation Agreement Act 1996* was created to offer British Columbians the ability to plan for future incapability and avoid the need for court appointed committeeship (the term used to refer to guardianship and financial management in British Columbia). However, a unique goal of the *Representation Agreement Act 1996* was to provide an alternative to the court appointment of a committee (guardian), for young people with developmental disabilities (intellectual disabilities), who were cared for by their families, at the time they became adults (Gordon, 2012a). There are a variety of people who utilise representation agreements including people with dementia, brain injuries and mental illness (Nidus Personal Planning and Resource Centre, 2012a; Stainton, 2016).

Defining representation agreements.

A representation agreement is a legal document available to adults in British Columbia for personal planning. It allows people to authorize one or more personal supporters to become representatives to assist in the management of personal affairs and if necessary make decisions on their behalf in the case of illness, injury or disability. The purpose of the *Representation Agreement Act 1996* is to provide a legal alternative to adult guardianship for adults who need help with decision making today and to enable people who are not in need of support to plan for a future when they might need assistance. Since the Act came into force over 5000 representation agreements have been voluntarily registered at the Nidus Personal Planning and Resource Centre in Vancouver (Nidus Personal Planning and Resource Centre, 2013).

Two types of representation agreements.

There are two types of representation agreements under the Act: section 7 and section 9 agreements. A section 7 agreement is designed for adults who need assistance with decision making about some or all aspects of their lives today because their competency to make decisions is in question. A section 9 agreement is designed for adults who may lose competency in the future. It has broader powers including major medical decision making and so a person must understand the type of decision covered by the agreement and the possible effects of giving these powers to a representative. Having a representation agreement does not remove decision-making rights from the adult. A representative's legal duty is to assist the adult with decision making. However, if they are unable to be supported to make the decision the representative may make the decision on the person's behalf. Section 7 agreements are required in order to receive funding from the Choice in Supports for Independent Living program and direct funding through Community Living BC (Nidus Personal Planning and Resource Centre, 2012b). A section 7 agreement is also necessary to establish a Registered Disability Savings Plan in British Columbia (Styan, 2012).

A different definition of incapability.

The *Representation Agreement Act 1996* has a different definition of incapability for section 7 agreements which allows people who may be considered incapable to make other contracts, such as a will or power of attorney, to nominate who they want to be able to assist them with decision making (James & Watts, 2014). The flexible definition of capability is considered one of the greatest strengths of the legislation as it shifts the burden of proof for incapability to others (Stainton, 2016) and challenges legal practitioners to develop new ways to understand how their clients with disability demonstrate capability and to respect the unique ways in which they communicate (Gordon, 2012c).

The *Representation Agreement Act 1996* clarifies the factors that must be considered in determining whether the adult is incapable of entering into a Section 7 agreement. They are:

- whether the adult communicates a desire to have a representative make, help make, or stop making decisions,
- whether the adult demonstrates choices and preferences and can express feelings of approval or disapproval of others,
- whether the adult is aware that making the representation agreement or changing or revoking any of the provisions means that the representative may make, or stop making, decisions or choices that affect the adult,
- and whether the adult has a relationship with the representative that is characterized by trust. (Section 8(2))

The test of incapability for section 7 agreements recognises the “shades of grey” (Kerzner, 2011, p.39) inherent in the process and moves away from the traditional all or nothing notion of capacity. “It was designed to provide a flexible arrangement where a person could be assisted to make decisions, substitute decision-making being a last resort” (Kerzner, 2011, p.39).

In their exploration of the *Representation Agreement Act 1996* in British Columbia, Rutman and Taylor (2009) suggest the relaxed definition of incapability allows attention to move away from competency and instead emphasises capability and the need people with disabilities have for support.

The role of the representative.

The duties of a representative are to act honesty and in good faith, exercise care, diligence and skill, and act within their authority (Section 16). When making a decision on behalf of an adult the representative must consult with the adult to determine their current wishes, and comply with those wishes if it is reasonable to do so (Section 16, para 2). Although the representative is able to make substituted decisions their first legal responsibility is to assist the adult to make their own decisions wherever possible (Nidus Personal Planning and Resource Centre, 2012b). Therefore, representatives are accountable to the adult, but may also need to provide information to a monitor, or the Public Guardian and Trustee. For this reason representatives need to keep records of everything they do acting as a representative (Nidus Personal Planning and Resource Centre, 2012b).

The role of the monitor.

The *Representation Agreement Act 1996* has a number of provisions to safeguard people from being exploited by their representative one of which is the appointment of a monitor (McClean, 2002). The legal duties of a monitor are separate and independent from the representative's decision making role (Nidus, 2012b). The role of a monitor includes determining whether the representative has been performing their duty appropriately by meeting with the adult and checking financial and other decision-making records (Section 20). If the monitor does not believe the representative has been complying with their obligations under the Act they are to try and resolve the matter with the representative. If this is unsuccessful, they are to report the representative to the Public Guardian and Trustee. Along with these formal duties, a monitor can also provide support with communication if it breaks down between any parties involved, including third parties (Nidus Personal Planning and Resource Centre, 2012b).

While the role of a monitor is considered a safeguard against abuse (McClean, 2002) there is no empirical research that has explored the role monitors play in safeguarding the decision making of people using representation agreements. Exploratory qualitative research has found some individuals engaging in supported decision-making with representation agreements lack clarity regarding the difference between supported and substituted decision-making (James & Watts, 2014). James and Watts (2014) argue “increased understanding of the roles of substituted and supported decision-making, particularly in the financial sector, can help staff to be vigilant and act appropriately if abuse or neglect is suspected” (p.78). Further research is needed to understand the conditions that safeguard people with intellectual and other disabilities who are supported with decision making in the context of using representation agreements.

Research into the use of representation agreements.

Although the *Representation Agreement Act 1996* has been enacted for seventeen years in British Columbia, there is scarce empirical research, which has explored how people with disabilities and their supporters use representation agreements (James & Watts, 2014). Table 2-2 on page 50 outlines the only four studies exploring the use representation agreements in British Columbia (Harrison, 2008; James & Watts, 2014; Nidus Personal Planning and Resource Centre, 2010a; Rutman & Taylor, 2009).

As a whole, these studies lack rigour. They are small, conducted over short periods and have a very limited scope. They are not published in peer-reviewed literature and the absence of information on aspects of their research design makes ascertaining the credibility and dependability of their findings difficult. None of the studies sought to understand the experiences of people making decisions with support in the context of having a standard section 7 agreement. Instead, the studies focused on preplanning for a time when an adult does not have capacity (the use of section 9 agreements), only the experiences of representatives and statistics regarding the number of agreements in place. While James & Watts (2014) conducted an “initial scoping of the issues” pertaining to the experiences of people using section 7 representation agreements (p.4), they concede their research findings were limited by only involving a small number of participants from British Columbia (10). Their research was unable to include observation of decision making because of the limited time involved (four months in total). The research conducted by James and Watts (2014) was commissioned by the Law Commission of Ontario to inform its ‘Legal Capacity, Decision-Making and

Guardianship' project. The project involved reviewing supported decision-making legislation across Canada, conducting telephone interviews with key informants from each province who had professional or practice expertise and interviewing people in British Columbia who had participated in supported decision-making personally.

The results pertaining to the experiences of people using representation agreements in British Columbia suggested being a supportive decision-maker (supporter) can be "a challenging and pressure filled responsibility" (James & Watts, 2014, p.10). Creating an agreement was difficult and expensive and social services and health care staff often had limited understanding of their use. In practice there seemed to be "a bit of slippage" between supported and substituted decision making with "representatives being engaged in both substituted and supported decision-making utilizing the same representation agreement, yet strongly characterizing their relationship as supportive in nature" (James & Watts, 2014, p.10). Informants participating in the research wanted greater clarification of what supported decision-making was and how to do it. They expressed there was a lack of education and resources available for practitioners, lawyers and the community more broadly on supported decision-making (p.54).

Table 2-2: ***Studies on the use of representation agreements***

Study	Aim	Peer Reviewed	Participants	Methods	Relevant Findings
Harrison, 2008	To determine the type of individuals that enter into section 9 representation agreements and explore their motivations for doing so.	No	48 capable representation agreement holders. 38 representatives of capable agreement holders 7 representatives of no longer capable agreement holders.	Interview over telephone using standardised questionnaire	Participants felt section 9 agreements were a good idea and a means of ensuring their wishes would be carried out should they become incapable of making their own health care decisions.
Rutman & Taylor, 2009	To explore how adults with Foetal Alcohol Spectrum Disorder (FASD) and their supporters use representation agreements as a tool for supported decision-making.	No	Two representatives who were each involved in helping an adult with FASD make and use an agreement.	Interview (method not explained)	The representation agreement gave legal status to supporters. It opened up doors to attend appointments and advocate more strongly for the person. Representatives felt they were treated more respectfully by staff because of the agreement.
Nidus Personal Planning and Resource Centre, 2010	Not stated	No	Quantitative analysis of 989 representation agreements made between 1 January 2006 and 30 June 2009.	Not stated	People from 19 – 99 years have made agreements. The highest percentage of agreements was made by 19-29 year olds. There is a need for qualitative research to understand the motivations and experiences of adults and their supporters making and using section 7 representation agreements.

James & Watts, 2014	To explore the lived experience of supported decision-making across Canada. The research was commissioned by the Law Commission of Ontario to inform its ‘Legal Capacity, Decision-Making and Guardianship’ project.	No	Ten interviews were conducted in British Columbia which involved decision makers, representatives and caregivers of decision makers.	Mixed methods Review legislation across Canada Telephone interviews with key informants	Being a supporter can be challenging and a pressure-filled responsibility. There is slippage between supported and substituted decision-making. Participants wanted greater clarification of what supported decision-making is and how to do it.

Microboards.

The use of microboards is the second of two models of supported decision-making explored in this research. In British Columbia, microboards were established to formalise networks of support and enable people with cognitive disabilities to have greater control over their own lives (Vela Microboard Association, 2013). To achieve this microboards adopt a person centred approach to planning and support (Malette, 2002) which is wholly in line with the philosophy and principles of supported decision-making in Canada (Stainton, 2016). Even though microboards allow for substituted decision-making (as representation agreements do), they are seen as a legal mechanism that allows for and promotes supported decision-making in British Columbia.

Development of microboards in British Columbia.

The first microboard in Canada was developed by David and Faye Wetherow in Manitoba in 1984 for their son (Wetherow & Wetherow, 2004). Its purpose was to establish a mechanism for direct individualised funding and to bring effective control of support services into the hands of their son and those closest to him (Wetherow & Wetherow, 2004). The first large scale application of the concept was by an organisation called the Vela Housing Society in British Columbia, which was a non-for profit society originally, formed to offer subsidised housing to people with developmental challenges in the Greater Vancouver area of British Columbia (Vela Microboard Association, 2013).

Early research evaluating Vela Housing Society's trial of microboards concluded that microboards benefitted the person being supported in many ways including: providing them with more choices, more opportunities and greater independence (Women's Research Centre, 1994). Microboards made it possible to "keep decision making and funding as close to the person as possible" (Women's Research Centre, 1994, p.4). Given the initial success of the implementation of microboards, the Vela Housing Society expanded their services and became the Vela Microboard Association. Since the early 1990s, they have supported the development of over 800 microboards throughout British Columbia. In 2013, there were over 600 active microboards in the province of British Columbia (Vela Microboard Association, 2013). Stainton (2016) believes microboards have proven to be "an effective vehicle for using individualised funding and sustaining a personal network" around an individual in a way which "enhances their decision-making ability" (p.8).

A microboard is defined as "a small group of committed family and friends that join together with a person to create a small non-profit society that will address the person's needs in an empowering and customized fashion" (Vela Microboard Association, 1997, p.2). In British Columbia, microboards obtain legal status through the creation of a society (board) under the *Societies Act 2015*. Societies must maintain official positions including the roles of president, vice-president, secretary and treasurer and keep accurate records of their regular meetings.

Research into the use of personal support networks in British Columbia and Ontario (such as microboards) identified three common purposes for their creation. (1) Individualised funding and service delivery, (2) friendship and community (and relatedly, security for when parents are gone), and (3) person-directed planning and facilitation (Nunnelley, 2015, p.20). While these purposes are different, they are often "rooted in common values, which may also be consistent with supported decision-making" (Nunnelley, 2015, p.29).

Vela Microboard Association (2013) suggest the purpose of any microboard must be to ensure the person becomes part of the fabric of the community and in doing so the microboard is safeguarding the person's future. Microboards assume the person at the centre has the capacity for self-determination and this capacity must be acknowledged, respected and demonstrated in all the dealings of the microboard (Vela Microboard Association, 2013). Members of the microboard must have a relationship with the person for whom the board is created and conduct their business in a spirit of mutual respect, cooperation and collaboration.

Microboard members facilitate the person's participation in community activities by providing the person with opportunities to give and receive in their community (Vela Microboard Association, 2013). All decisions made by the microboard must have regard for the person's "safety, comfort, and dignity, with consistent respect for his/her needs, wishes, interests and strengths" (Vela Microboard Association, 2013, p.1).

Early research conducted into the use of microboards suggested the most important function of the board was being directed by the wishes of the person (Women's

Research Centre, 1994). To be able to do this the board needed to resolve any questions regarding how to determine the views of the person. In reflecting on the challenges of doing this microboard members talked about,

> …the importance of remembering that, for some people, what's involved here is undoing years of limitations: of living in a group home, of dependency, of not having the chance to learn by making mistakes, and years of not being listened to or asked for an opinion. (Women's Research Centre, 1994, p.15)

Research into the use of microboards.

There is scarce empirical research that explores the use of microboards in British Columbia. Table 2-3 on page 56 outlines the only four studies (Women's Research Centre, 1994; Pedlar, Haworth, Hutchison & Dunn, 1999; Malette, 2002; Nunnelley, 2015) which explore how microboards have provided people in British Columbia with access to individualised funding, alternative forms of accommodation and person centred support. These studies offer little insight into the decision-making processes used in the practice of microboards and leave a host of unanswered questions regarding decision making in the context of a network of individuals.

The studies differ significantly in rigour. Three of the four are not published in peer-reviewed literature and lack a clear explanation of the credibility and dependability of their findings (Women's Research Centre, 1994; Pedlar et al., 1999; Nunnelley, 2015). Two of the four studies explore microboards as one of many forms of support available to people with cognitive disabilities across Canada (Pedlar et al., 1999; Nunnelley, 2015). While Pedlar et al. (1999) suggest microboards gave people with intellectual disabilities more control over their decision making than other models of support in Canada, the research offers little understanding of how the practices used by microboards led people with intellectual disabilities to feel more empowered. This seems to be the case because the researchers had an interest in the ideas behind the development of microboards rather than how they operated in practice (Pedlar et al., p.23). All of the studies involved participants with strong natural support networks and none of the reports problematize the situation of people without families and strong natural support networks.

The study by Nunnelley (2015) is the only research focused on microboards as a form of decision-making support. It had a brief data generation period (two and half months from start to draft report) which meant the researcher was not able to speak to people supported by networks such as microboards. This limited the capacity of the research to "speak to the more substantive and subjective elements of supported decision-making, for example whether it [wa]s experienced as empowering" (Nunnelley, 2015, p.4). The study concluded "empirical research that more comprehensively examines Vela Microboards in British Columbia" is needed (Nunnelley, 2015, p.107) to determine what the processes of support look like in the decision making of microboards and how people with intellectual disabilities are offered support with decision making within these contexts.

Table 2-3: ***Studies on the use of microboards***

Study	Aim	Peer Reviewed	Participants	Methods	Relevant Findings
Women's Research Centre, 1994	To describe the experience, accomplishments and needs of microboards as a basis for Vela Housing Society to reflect on their role and future.	No	Five microboards in urban and regional locations across British Columbia Vela staff, government officials and service agency representatives.	In-depth interviews Focus groups.	Microboards provided more choice, opportunity and independence for the person. Provided access to financial resources that increased options. The board being directed by the person could be difficult when the person had limited verbal ability.
Pedlar, Haworth, Hutchison & Dunn, 1999	To explore all support services available to adults with developmental disabilities across Canada.	No	801 service providers across Canada completed the questionnaire 141 participants were interviewed (52 adults with developmental disabilities, 26 family members, 63 staff & other support providers).	Questionnaire Face to face interviews.	People with microboards felt empowered and had a more integrated life in the community than participants receiving other forms of service support.
Malette, 2002	To provide a comprehensive description of the lives of three people with complex needs who had participated in the microboard project and achieved a "quality life"	Yes	Three microboards in Vancouver and Richmond Central participants, microboard members, friends, family members, members of Vela Microboard Society and the Community Living Branch.	Participant Observation for 50-100 hours Semi-structured and unstructured interviews with a range of participants.	Microboards gave people access to direct funding which enabled them to personalise their living arrangements and have more control over major life decisions such as housing and support.

Nunnelley, 2015	To examine decision making support being used in British Columbia and Ontario in the context of person support networks (which included microboards among others). The research was commissioned by the Law Commission of Ontario to inform its ‘Legal Capacity, Decision-Making and Guardianship’ project.	No	19 participants were interviewed seven of which were from British Columbia. The research did not include people who were support by personal support networks.	Literature review Semi-structured interviews Legal research into the laws that apply to personal support networks.	All participants reported they engaged in supported decision-making but were aware of other networks that slipped into substituted decision-making. Networks experienced challenges supporting the person’s wishes when there were concerns about safety and risk.

Overall Summary

While Canada led the development of the concept of supported decision-making (Bach, 2007), and the development of legal mechanisms which recognise the role of supporters (Stainton, 2016), little is known about supported decision-making practice in the Canadian context (James & Watts, 2014). Little research has been conducted to explore the decision-making processes used within the context of legal mechanisms such as representation agreements and microboards (Stainton, 2016), and the limited insights gained have been explored through the lens of theories such as person centred planning and empowerment (Malette, 2002; Pedlar et al., 1999). This literature review has demonstrated that there is a significant gap in understanding how supported decision-making is realised in practice for people with different levels of intellectual disabilities. The voice of people with intellectual disabilities is missing from the existing research on the use representation agreements and is very limited in the context of microboards.

Supported decision-making is heralded as the mechanism by which people with cognitive disabilities can be supported to maintain their right to legal personhood and be supported to exercise their legal capacity (Flynn & Arstein-Kerslake, 2014). It has been suggested that given the dearth of unanswered questions regarding how supported decision-making occurs in practice, empirical research is needed (Carney, 2017; Gooding, 2015; Kohn & Blumenthal, 2014) to assess "how well assisted decision making models work" and "whether the aims of legislation are being achieved" (Then, 2013, p.166). Given the human rights imperative to replace mechanisms of substituted decision-making with mechanisms of supported decision-making (Committee on the Rights of Persons with Disabilities, 2014) disability advocates are interested in empirical research that explores the efficacy and transferability of existing models of supported decision-making overseas (Bigby, 2016).

While there is an emerging body of qualitative research that explores the experiences of three groups of people engaging in decision-making support in Australia these studies did not occur in a legal context that allowed for supported decision-making. They have conducted exploratory work focused on understanding and conceptualising the experiences of people with traumatic brain injury (Knox, 2016d), severe or profound intellectual disabilities (Watson, 2016a) and of family members and workers in disability support services who provide decision support (Bigby et al., 2017a). These studies have begun to explore the process of providing support with decision making outside the context of legal recognition and raise a number of questions regarding the centrality of the support relationship, the impact of values, beliefs and prior experience and the importance of supporter responsiveness.

Similarly, the literature on choice and decision making also raise a number of questions regarding the impact of how information is framed, culture, emotion and relationships of dependency on decision making. The literature also suggests there is a need to further explore persuasion, undue influence and coercion in the context of supported decision-making relationships (Arstein-Kerslake, 2014; Carney, 2015; Gooding, 2015; Series, 2015).

Research Question

This research sought to develop an understanding of supported decision-making practice in Canada by exploring the experiences of people with intellectual disabilities and their supporters. The aim of this research was to understand how people with intellectual disabilities were supported with decision making in the context of two legal mechanisms which create opportunities for supported decision-making. The primary research question was:

> How are people with intellectual disabilities supported with decision making in the context of two legal mechanisms which create opportunities for supported decision-making in Canada, representation agreements and microboards?

Chapter Three:

Research Design

This chapter is divided into two sections: the first explains the approach I took to the research and the second outlines the methods and procedures. The chapter begins by explaining the theoretical framework for the research, which aligned with the nature of the research question and my position as a researcher. I provide an overview of grounded theory as the selected methodology and its congruence with a constructivist epistemology. The second section outlines the methods and procedures I used, including an outline of participant sampling, data generation and analysis. The chapter ends with a summary of the ethical considerations I made in conducting the research and the strategies I used to ensure research quality.

Approach

Social constructivism as a theoretical framework.

The aim of this research was to understand how people with intellectual disabilities were supported with decision making in the context of two legal mechanisms which create opportunities for supported decision-making in Canada, representation agreements and microboards. Given the relational and co-constructed nature of decision making, I employed a theoretical framework embedded in the socially constructed nature of knowledge: social constructivism.

Social constructivism approaches the nature of reality as multiple and constructed through our experiences and interactions with others (Creswell, 2013). From this perspective, reality is “co-constructed by the researcher and the researched” (Creswell, 2013, p.36). Constructivist researchers have the goal of “understanding the complex world of lived experience from the viewpoint of those who live it” (Schwandt, 1994, p.118). They do this by exploring how individuals interact and the processes which shape these interactions (Creswell, 2013).

Social constructivism recognises the values, knowledge, preconceived ideas, life experience and assumptions the researcher brings to the research context and how these affect both the research design and processes (Guba & Lincoln, 1989). My interest in supported decision-making emerged out of my professional experience trying to support people with disabilities to make decisions in Australia. These experiences led me to think of decision making and the provision of support as highly interactional and strongly influenced by the different perspectives of the people involved. These experiences meant the theoretical framework selected for this research would need to take into account the interactional nature of decision making and be able to explore the different viewpoints and perspectives of the people who engage in decision making support.

I consider myself a critical realist. I am epistemologically constructivist, and my ontology is more closely aligned with realism than relativism. In spite of my preference towards a realist way of thinking about knowledge, I determined social constructivism was the most appropriate framework for this research when developing the research design. I made this decision because the subject matter is so exploratory, decision making is such a relational, co-constructed concept and constructivist grounded theory (as a methodology aligned with social constructivism) had been used to explore decision-making support previously. I took measures to ensure I would be able to apply this framework consistently throughout the research process. For example, I engaged in reflexive practice facilitated through memo writing and regular supervision sessions. This process allowed my interpretation of data, analysis and the development of theory to be questioned and critiqued with my supervisors ensuring paradigmatic consistency. Therefore, a combination of personal beliefs and experiences led me to select social constructivism as the most appropriate theoretical framework for this research.

Selection of constructivist grounded theory as the research methodology.

Birks and Mills (2011) suggest grounded theory is appropriate to use when little is known about the area of study, when a process is embedded in the research situation, and a theory is sought that can explain the process. From the literature review, it has been established that little is known about how decision-making support is provided in British Columbia where legislation allows for supported decision-making. Given this lack of knowledge, the use of a grounded theory methodology supports the development of a theory to explain how people with intellectual disabilities are supported with decision making in this context.

Grounded theory is a qualitative research method designed to allow the researcher to constantly interact with the data through simultaneous collection and analysis (Bryant &

Charmaz, 2007). Initially, grounded theory was considered an inductive research process (Glaser & Strauss, 1968). Over time, constructivist grounded theorists have recognised the role of existing theory in shaping the development of core categories (Birks & Mills, 2011) and as a result, grounded theory has evolved to accept the role of both induction and abduction in data analysis (Charmaz, 2006). Abduction is a process whereby the researcher makes inferential leaps, considering all possible explanations for the observed data, and then tests the inferences until arriving at the most plausible explanation of the data (Charmaz, 2014). Grounded theory is an abductive method because it involves "reasoning about experience for making theoretical conjectures – inferences – and then checking them through further experience – empirical data" (Charmaz, 2014, p.201).

Constructivist grounded theory differs from other forms of grounded theory in that it does not see theory emerging from the data as separate from the scientific observer. Instead, theories are constructed "through our past and present involvements and interactions with people, perspectives and research practices" (Charmaz, 2006, p.10). A constructivist approach to grounded theory involves three things: 1) a sense of reciprocity between the researcher and participants in the co-construction of meaning and the development of a theory grounded in the experiences of participants and the researcher. 2) Relationships between the participants and researcher that recognise power imbalances and try to modify them; and 3) an understanding of the author's position when writing participants' stories (Mills, Bonner & Francis, 2006, p.9).

From a constructivist perspective interviews are contextual, negotiated and lead to a construction or re-construction of a reality (Charmaz, 2006). A researcher adopting this approach when interviewing seeks to counteract imbalances of power and establish a relationship of reciprocity with participants (Mills et al., 2006). Constructivist grounded theory has been criticised by Glaser (2002) as avoiding "the work of confronting researcher bias" in an effort to "dignify the data" (p.3). For Glaser (2002) the constant comparative method of data analysis ensures researchers resolve biases and correct their interpretation resulting in data becoming objective. For constructivist grounded theorists this type of objective account of the data is not possible because the story reflects the researcher as well as those being researched (Charmaz, 2000).

Constructivist grounded theory has been shown to be effective in developing theory to explain the processes of decision-making support used by people with severe acquired brain injuries and their decision supporters in Australia (Knox et al., 2015; Knox et al., 2016a; Knox et al., 2016b; Knox et al., 2016c). This prior experience seems to recommend it as a methodology to uncover new theory explaining how decision-making support is provided to people with intellectual disabilities in Canada.

Therefore, in this research I used a constructivist grounded theory approach because it aligned with the theoretical framework of the research (social constructivism) the epistemology of the researcher (constructivist) and it had been shown to be effective in developing theory to explain the processes of decision-making support used by people with severe acquired brain injuries and their supporters.

Perspective of the researcher.

Researchers conducting constructivist grounded theory studies need to locate themselves in the research because what they bring to the research process influences what they see (Charmaz, 2006) and how they interpret what they see (Creswell, 2013; Mills et al., 2006). The personal beliefs and professional experiences I brought to the research process influenced my selection of a research topic and the approach adopted. Therefore, it is important to understand the context behind my interest in the practice of supported decision-making and my motivations for wanting to explore how people engage in the process of providing support in a jurisdiction that legally recognises supported decision-making.

I developed an interest in the topic of supported decision-making through my professional experience working as a guardian of people with cognitive disabilities including people with intellectual disabilities, acquired brain injuries and psychosocial disabilities. Working for the Office of the Public Guardian in the state of New South Wales for five years, I made substituted decisions for people who were deemed as lacking the mental capacity to make legal decisions. Often, I saw the negative impact these appointments had on the self-esteem of people who were no longer recognised as legal decision makers by the law (in a variety of areas in their life). I supported a number of young clients who had never learned about decision making or received support to participate in decision making growing up. I found that by providing them with appropriate support, many of them were able to make decisions that they had been unable to make previously.

Whilst engaging in this work, I learned about the CRPD and supported decision-making as an alternative legal paradigm to substituted decision-making. Inspired by the concept as it resonated with the approach I was taking to my own work, I obtained a Churchill Fellowship to travel to Canada and England to meet with individuals, organisations and government agencies who understood about legal alternatives to substituted decision-making and supported decision-making. While in Canada, I was moved by the human rights philosophy underpinning the development of supported decision-making, and asked for current research exploring supported decision-making practice. However, practitioners were not aware of any research and suggested their focus had been on establishing legal mechanisms rather than supporting or evaluating how these were used in practice (Browning, 2011). I also found there were no resources to assist people engaging in supported decision-making to understand the process of providing decision-making support (Browning, 2011).

When I returned to Australia, I was involved in the development of a trial of supported decision-making practice in New South Wales. The agencies involved wanted to trial an alternative to substituted decision-making and the advisory group had questions about what to set up. No one understood what supported decision-making looked like in practice, and this lack of clarity motivated me to return to Canada to conduct this research.

Summary.

In line with the aim of this research, to explore how people with intellectual disabilities are supported with decision making in the context of two legal mechanisms which create opportunities for supported decision-making, I chose to use a constructivist grounded theory methodology. This decision was made because the methodology reflected the co-constructed nature of decision making, aligned with the theoretical framework of the research (social constructivism) and the epistemology of the researcher (constructivist). The next section of the chapter explores the methods and procedures used to recruit participants into the research.

Methods and Procedures

Participants.

I recruited two groups of participants: people with intellectual disabilities who were supported with decision making (known as central participants), and the people who provided them with support (known as decision supporters). In total, seven central participants and 25 supporters from their networks participated in the research.

Central participants.

Central participants were recruited through community-based services and service provider networks for people with intellectual disabilities in Vancouver, British Columbia. I contacted Planned Lifetime Advocacy Network (PLAN) and the Developmental Disabilities Association (DDA). These organisations support people with intellectual disabilities and their families by providing supported accommodation (DDA) and structured social support (PLAN). They also support families to learn about and create representation agreements in British Columbia. Additionally, central participants with microboards were recruited through contacts in the Vela Microboard Association, which is a not-for profit society that supports the development and implementation of microboards in British Columbia.

Initially, central participants were required to meet the following criteria to be eligible for the study however, the criteria changed as I conducted theoretical sampling:

1. Have an intellectual disability;
2. Live in metropolitan Vancouver, British Columbia or surrounds;
3. Be using a representation agreement (section 7) or microboard to support their decision making; and
4. Be able to communicate responses verbally or using augmented and alternative communication (AAC) during an interview.

In the context of this research the term ‘people with intellectual disability’ is used to describe people with significant impairment in their intellectual functioning who had difficulty in conceptual, social and practical adaptive skills for whom these difficulties started before the age of 18. The second criterion excluded central participants who lived a long distance from metropolitan Vancouver as time and financial constraints limited my ability to travel. For the purpose of the third criterion, in the context of this research the term ‘representation agreement’ is used to describe a legal document in British Columbia that allows a person to authorise one or more personal supporters to become representatives. As described in Chapter 2 representatives assist in the management of personal affairs, support decision making and if necessary make decisions on behalf of the person. This research only explored the use of Section 7 agreements.

In the context of this research the term ‘microboard’ is used to describe a small group of family and friends that join together with a person to create a small non-profit society that aims to address the person’s needs in an empowering and customised way. Microboards are expected to use a person centred planning approach to direct funding and make decisions about housing and support services for and with the person.

To satisfy the fourth criterion, the central participant was required to be able to: participate in an interview in English; understand the interviewer’s questions; and be able to provide responses, either verbally or using AAC. If the central participant required a supporter to be able to communicate, or feel comfortable, they were invited to participate in the interview also.

Consent process.

The first step in the consent process was establishing whether the central participant was literate and whether information could be conveyed in a meaningful way in a written format (Perry, 2004). Information was developed in plain language, with the addition of pictures. When presenting the information to central participants the process often required additional explanation from supporters who were able to link important concepts in the information to existing knowledge for the participant. This support greatly assisted central participants to be able to understand the research and provide consent. While all participants were presumed to have the capacity to provide consent, ethical guidelines required the researcher to assess the ability of potential participants to understand and appreciate the consequences of participating in the research. When assessing the ability of the person with an intellectual disability to provide informed consent, I asked the potential participant the questions listed in table 3-1 on page 68 which were adapted from questions developed by Dye, Hare and Hendy in 2007.

Table 3-1: ***Questions used to assess the ability of central participants to consent***

Question	Expected Response
1. What is this study about?	Participant provides at least a partial description of the study (e.g.,' you want to find out about how I make decisions with my microboard')
2. What would you be asked to do if you take part in the study?	Participant gives an answer that includes the researcher talking to them and observing them making decisions.
3. Will taking part in this study help you?	Participant gives an answer that is realistic (e.g., 'I will enjoy talking to you' or 'I want to tell people how they can help people with disabilities to make decisions.')
4. Will anything bad happen if you take part in the study?	Participant gives an answer that is realistic (e.g., 'I might get upset when talking about difficult decisions.')
5. Can you decide not to take part in the study?	Participant gives an answer that suggests they understand that they do not have to take part in the study and can withdraw at any time (e.g., I can say no if I want to stop.)
6. Do you want to take part in the study?	Yes or No.

If the central participant was able to answer these questions (with support), I obtained consent from the central participant. If the person was unable to provide consent I asked the decision supporter to provide proxy consent on behalf of the central participant. If the decision supporter was also invited to participate in the research, I conducted a separate consent process with the researcher to obtain their consent. If proxy consent was provided, I confirmed the central participant was indicating they assented to participation in the research process. This assent was evaluated throughout each interaction with the central participant.

Decision supporters.

Decision supporters were involved in the recruitment of central participants and were invited to participate in the research at the same time as central participants. All participants had a supporter that they relied upon heavily with respect to their decision making. These supporters are referred to as primary decision supporters. Usually the person's primary decision supporter was involved in the consent process. Either the central participant or their primary decision supporter identified other decision supporters who could be invited to participate in the research. Each central participant had between two and five supporters who participated in the research. It was a requirement that central participants agreed to the participation of their decision supporters in the research (either verbally or via assent).

Sampling and recruitment procedures.

A variety of sampling strategies were used to recruit these participants including purposeful and theoretical, as recommended when using a grounded theory methodology (Morse, 2007). Initially, I engaged in purposeful sampling to find participants using representation agreements and microboards who were engaging in decision making. The recruitment of participants in this phase involved sending letters of introduction from contacts in two disability organisations to establish contact with a first group of participants using representation agreements and microboards.

Written information was provided to central participants and supporters in plain language about the project (see Appendix A). Additional information was provided and questions answered over the telephone at the instigation of the potential participant. Potential research participants were provided with a consent form and stamped addressed envelope to return to the researcher.

Three central participants were recruited from this initial purposeful sampling (Jenny, Cecily and Reuben). In interviewing and observing these central participants and their decision supporters, a number of questions were raised about how familiar the concept of supported decision-making was to these families in British Columbia. There were questions about whether having a representation agreement or microboard shaped how people with intellectual disabilities were supported with their decision making. These questions emerged when Cecily and her decision supporters had never used their representation agreement in the many years it had been in place. Following on from the preliminary analysis of data, theoretical sampling was used to examine the tentative ideas emerging and refine them further (Charmaz, 2014).

Theoretical sampling led to the recruitment of central participants with differing levels of intellectual disability, types of relationships with their supporters, and use of their representation agreement or microboard. An additional three participants were recruited in this second sampling phase (Emily, Natalie and Betty) which involved being personally introduced by professionals who knew potential participants who met the specific sampling objectives (e.g., someone with a significant intellectual disability who had a range of supporter relationships). During this phase of recruitment, the eligibility criteria for central participants started to shift. For example, Emily who met a number of sampling objectives did not meet the initial eligibility criteria because she had limited verbal ability and was not able to be interviewed. Despite Emily's lack of verbal ability, I made the decision to include her as a central participant because of the significant experience Emily's primary supporter Peta had supporting Emily's decision making in the context of using both a representation agreement and microboard.

In interviewing and observing Emily, Natalie and Betty, and their decision supporters, a number of questions were raised about the limited role legal mechanisms appeared to be having on the process of decision-making support. In order to explore this emerging insight, theoretical sampling was used to select a central participant who could provide unique insights into understanding this concept, which seemed central to the development of the emerging theory (Morse, 2007). To explore the importance of having legal mechanisms in place I recruited a central participant and their support network who believed they were engaging in decision-making support aligned with the principles of supported decision-making outside the context of having a legally recognised representation agreement or microboard. This central participant lived in Ontario, a different province of Canada. The inclusion of this participant further changed the initial eligibility criteria, which only involved participants living in British Columbia.

In grounded theory studies it has been suggested sampling and data generation ceases when saturation is achieved for a certain category and ends for the study when all categories relevant to the emerging theory are saturated (Morse, 2007, p.231). Given the data generation period was necessarily constrained by the time and finances I had available, as a researcher living away from home, it may be more appropriate to say data generation ended when category and theoretical “sufficiency” were achieved (Dey, 1999, p.117). Theoretical sufficiency refers to the stage at which “categories seem to cope adequately with new data without requiring continual extensions and modifications” (Dey, 1999, p.117). Where saturation might imply the process of generating categories was exhaustive, theoretical sufficiency might imply it was “good enough” (Dey, 1999, p.117).

In summary, the central participants recruited differed according to a range of characteristics (see table 3-2 on page 73 for a summary of participant characteristics). They ranged in age from 28-59, had different levels of intellectual disability from mild through to severe or profound, and lived in different environments including alone, with a flat mate, with parents, in a group home and with a sibling. Five of the seven central participants were female and two male. Five central participants had representation agreements, three had microboards and two had both. One of the seven central participants did not live in British Columbia and had a circle of support that was not legally recognised.

The decision supporters who were recruited had a variety of roles in the central participant’s life. These included parent, friend, sibling, support worker, rehabilitation aide, support coordinator and niece. Two central participants had partners that were unable to be included in the research. One was because the family of the partner did not recognise the relationship and was unwilling to provide consent for him to participate in the research, the other was because of distance. One central participant had a family member who was a formal decision supporter but did not want them invited to participate in the research. The central participant did not consider the relationship positive and wanted to be able to discuss the difficulties they were having in the support relationship without fear of repercussions. I reassured the central participant anything said in the course of data collection would be confidential and respected the participant’s decision to exclude the decision supporter.

Table 3-2: ***Demographic information on central participants and their supporters***

Name	Age	Disabilities that influence decision making[1]	Status when included in research	Model of supported decision-making	Primary supporter	Other supporters in network
Jenny	50	Intellectual Disability (moderate)	Single, living with brother following death of her mother four months prior, attending day program	Representation agreement	Jack (brother, representative)	Jessica and Carly (nieces) Carla (day program support worker)
Cecily	49	Intellectual Disability (moderate)	Engaged, living in a group home with four other women, attending day program and drop in centre	Representation agreement	Shirley (sister, representative)	Lisa (key worker at day program) Dean (key worker at drop in centre)
Reuben	36	Intellectual Disability (moderate - severe)	Single, living with parents, engages in home based individualised skill development program	Microboard	Sarah (mother, microboard member)	Michael (father, microboard member) Alex (support worker)
Emily	36	Intellectual Disability (moderate – severe)	Single, living in basement apartment under parents' home,	Microboard	Peta (mother)	Sally (support worker,

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[1] The disabilities that influence decision making are reported as per the advice of the central participant and their supporters rather than assessment carried out by the researcher.

			engages in individualised program focused on community participation	Representation agreement		microboard member)
Natalie	28	Intellectual Disability (mild-moderate) Brain injury (stroke)	Single, living with parents in the family home, engaged in individualised rehabilitated and therapy based program	Microboard Representation agreement	David (father, microboard member, representative) Arleen (mother, microboard member, representative)	Annie (rehabilitation aide) Matthew (microboard member)
Brian	49	Intellectual Disability (severe – profound)	Single, living in his own home with a flat mate, receives individualised support to engage in community	Circle of support (not legally recognised in Ontario)	Ailsa (mother, facilitator of circle of support)	Veronica (circle of support member) Melissa (circle of support member) Ruby (support worker) Debbie (support coordinator)
Betty	59	Intellectual Disability (mild)	Engaged, living alone in own apartment, works in self advocacy	Representation Agreement	Terry (health care representative)	Jason (financial representative) Michaela (health care representative)

Introduction to central participants.

Jenny.

Jenny was a 50 year old woman with a moderate intellectual disability. Jenny lived with her brother Jack who was her primary decision supporter and representative. Jenny moved in with Jack four months prior to their involvement in the research following the death of their mother Beryl. Jack had three daughters who were grown up with their own families, two of whom participated in the research, Jessica and Carly. Jessica was the monitor for Jenny's representation agreement. Jenny had attended a day program for twenty years and Carla, her support worker, who was actively involved in supporting her decision making in this context was also involved in the research.

Cecily.

Cecily was a 49 year old woman with a moderate intellectual disability. Cecily lived in a group home with four other women and attended two day programs. Cecily was very close to her sister Shirley who visited her regularly at the group home. Shirley was Cecily's primary decision supporter and representative. Cecily was engaged to her partner David who did not participate in the research. In the first day program, Cecily was supported by her key worker Lisa who she had known for twelve years and in the second day program, her key worker Dean had also known Cecily for many years. Both key workers participated in the research.

Reuben.

Reuben was a 37 year old man with a moderate to severe intellectual disability. Reuben lived with his parents Sarah and Michael, who were microboard members, and his mother was Reuben's primary decision supporter. All three participated in the research. Reuben's parents were born in India and immigrated to Canada as newlyweds. Reuben and his brother were raised in Vancouver and adopted cultural practices from both countries. Reuben had a microboard that managed individualised funding which allowed him to engage in a home based individualised skill development program. None of Reuben's microboard members were able to participate in the research. Alex was a support worker who assisted Reuben with decision making in the context of his skill development program. Alex was interviewed and observed as part of the research. Two other support workers were also observed supporting Reuben with decision making (Brett and Elaine).

Emily.

Emily was a 36 year old woman with a moderate to severe intellectual disability. Emily lived in the basement apartment of her parent's home in Vancouver. Emily had both a representation agreement and microboard that were actively used by her support network. Emily's primary decision supporter was her mother Peta who was very familiar with the concept of supported decision-making. Peta was interviewed twice about her experiences supporting Emily with her decision making. Emily was also supported by a number of workers who helped facilitate her access to community including Sally and Libby. Both Sally and Libby were actively involved in an informal circle of support that helped facilitate Emily's busy social life. As participants in the research, Libby was observed supporting Emily with decision making and Sally was interviewed.

Natalie.

Natalie was a 28 year old woman with a mild-moderate intellectual disability. Natalie lived with her parents David and Arleen who were her primary decision supporters. Natalie had a representation agreement and microboard and her parents were her representatives and on her microboard. The microboard managed individualised funding which allowed Natalie to engage in an individualised rehabilitation and therapy based program. Following a stroke at the age of 16 Natalie required significant physical therapy to regain the ability to walk (short distances) and talk. Natalie's rehabilitation aide Annie, who had supported her for the last 12 years, provided her with decision support numerous times a week. Matthew, a friend of David and Arleen, who had known Natalie her whole life, also supported Natalie by his involvement as a microboard member. Both Annie and Matthew were interviewed and observed supporting Natalie as participants in the research.

Betty.

Betty was a 59 year old woman with a mild intellectual disability who identified as a self-advocate. Betty lived alone in a condominium which she owned. She had worked in a variety of roles as a self-advocate until she experienced a period of ill health in the last two and a half years. Betty had a representation agreement that she had changed a number of times. At the time of the research, Betty had three friends as her representatives: Jason (financial representative), Terry (health care representative) and Michaela (health care representative) all of whom participated in the research. Terry was Betty's primary decision supporter because they were spending significant amounts of time at medical appointments. Betty was engaged but her fiancé did not participate in the research.

Brian.

Brian was a 49 year old man with a severe or profound intellectual disability. Brian lived with a flatmate in a house they jointly owned in regional Ontario. Brian and his flatmate received twenty-four hour care from support staff such as Ruby, and his coordinator Debbie, who supported him with his daily decision making. Brian had an informal circle of support facilitated by his mother Ailsa who was his primary decision supporter. Brian was not able to make his own decisions but his mother, support staff and circle of support made decisions directed by his will and preferences. Veronica and Melissa were friends of Brian and Ailsa who belonged to his circle of support. They were involved in significant decision making such as the decision for Brian to purchase his own home.

Data Generation

Semi-structured interviews, participant observation and field notes were used as forms of data generation. I used semi-structured interviews to explore with central participants how they were supported with decision making, and how their decision supporters went about providing decision support in the context of having representation agreements and microboards. I also used participant observation to see how participants were supported with decision making in a variety of contexts adding another layer of understanding.

Semi-structured interviews.

Interviewing allows an in-depth exploration of a particular topic by eliciting each participant's interpretation of her or his experience (Charmaz, 2006). Semi-structured interviews were used to enable a balance between flexibility and structure (DiCicco-Bloom & Crabtree, 2006). Flexibility ensured participants were directing the telling of their stories (Mills et al., 2006) and structure provided a context that was supportive to people with intellectual disabilities (Prosser & Bromley, 2012). An interview guide was developed which outlined general topics and questions to prompt exploration of these topics during the interview process (see Appendix C). I approached the interviews without any fixed assumptions about the ability of central participants to understand questions and share their experiences (Booth & Booth, 1996). In practice, some central participants were unable to understand the complexity of the topics listed in the interview guide (e.g., they were unfamiliar with the term representation agreement or microboard). In these cases, time spent with the central participant helped me to be able to link these abstract concepts to experiences the person was familiar with, which assisted them to be able to share their stories. Ultimately, the interview guide served as an entry point for all participants to "share significant experiences and teach the researcher how to interpret them" (Charmaz, 2006, p.27).

Interview procedure.

I took time to get to know central participants and understand how they communicated independently, and with their supporters, during the process of seeking informed consent. In most cases, I interviewed the primary supporter prior to interviewing the central participant in an effort to gain more insight into the abilities and needs of central participants prior to their first interview (Prosser & Bromley, 2012). This additional information helped guide my approach during the first interview with central participants.

I tried to ensure the relationship I had with all research participants was reciprocal by being open about my own life and exchanging information about our personal experiences. The intention behind this openness was to share power in the research relationship (Mills et al., 2006). All interviews took place in a location of the participant's choosing which was private, comfortable and quiet (King & Horrocks, 2010). Locations included a bedroom, lounge room, office, community centre, meeting room and private booth in a restaurant. I started the interviews by asking general questions about the participant's life and experiences of decision making. The interviews with central participants started with a period of 'free narrative' where the person with an intellectual disability was free to share their story and experiences in their own language

(Bull, 2010). They were encouraged to talk by saying things such as “tell me more about that” (Gudjonsson & Joyce, 2011, p.19). When we finished the ‘free narrative’ I asked the participant open-ended questions for more detail on the information provided and lastly closed questions if necessary (Bull, 2010). During the interviews, I tried to utilise the guidelines proposed by Prosser and Bromley (2012) to simplify questions for participants. They recommend using short words and sentences, active verbs and speaking in the present tense. They also recommend avoiding questions about abstract concepts, jargon and figurative language (p.114-115). I worked hard to ensure the questions posed to all research participants were short, simple and unambiguous (Perry, 2004).

Booth and Booth (1996) identified four potential challenges when interviewing people with intellectual disabilities: “inarticulateness; unresponsiveness; a concrete frame of reference and difficulties with the concept of time” (p.55). While I did experience these challenges in interviewing central participants, the incorporation of some structure into the interviews, and anchoring topics of discussion to familiar events assisted some participants who had difficulty with the concept of time (Prosser & Bromley, 2012). Slowing down the communication and allowing adequate time for responses also assisted participants to engage in the interview process more successfully (Bull, 2010). All interviews were audio recorded and transcribed verbatim to help me remember the views expressed by participants and enable data to be coded and analysed line by line.

I conducted 34 interviews in total, five central participants and seven primary supporters were interviewed twice. In addition to the perspective of primary supporters, single interviews were conducted with 16 other supporters. After conducting the first interviews, I engaged in periods of participant observation that allowed me to see decision making in practice. The second interview provided me with the opportunity to ask about specific events and actions that were observed and gather more focused information than generalisations or abstract opinions (Maxwell, 2012). Interviewing combined with extended periods of observation and casual conversation generated rich data on the experiences of central participants being supported with decision making. The triangulation of observations and interviews provided “a more complete and accurate account than either could alone” (Maxwell, 2012, p.107).

Two central participants with severe intellectual disabilities were unable to be interviewed because they were not able to express themselves in an interview setting either verbally or non-verbally with support. A decision was made to include these participants even though they did not meet the initial inclusion criteria because both central participants and their support networks met other important criteria. For example, Emily was recruited because her mother had experience supporting her with decision making in the context of having both a microboard and representation agreement. In a previous study, involving people with severe intellectual disability, Johnson, Douglas, Bigby, & Iacono (2011) found that developing an understanding of people with complex communication needs through observation enabled the researcher to establish credibility as an interviewer and ask more appropriate and focused questions of the person's supporters. The second interview conducted with Brian's primary supporter Ailsa provided an opportunity for me to discuss practices that were observed and revisit concepts discussed in the first interview in light of what was discovered during the period of observation.

Reporting on interview data.

When interview data is described in the research findings the pseudonym of the person interviewed is used to designate who is being quoted. The following system is used I: Natalie 2, p.10. "I:" indicates data was obtained from an interview with Natalie the number following the name indicates it was the second interview completed with Natalie (e.g., I: Natalie 2, p.10). "10" indicates the quote referred to was taken from page 10 of the interview transcript.

Participant observation.

After the initial interviews, I engaged in a period of participant observation with central participants and their supporters. While interviewing provided a way of understanding the participants' perspective on decision making, observation of decision-making processes allowed me to explore "theory in use" (Maxwell, 2012, p.106). The length of each period of observation depended on the willingness and availability of research participants. I engaged in over 100 hours of observation across all seven networks.

Table 3-3: ***Data generated for each central participant***

Central participant	Activities observed	Number of hours	Participants interviewed (times)
Jenny	Preparing lunch with brother, choosing activities at new day program, making burgers at home with family, performing on stage, visiting local gardens, ordering food at a restaurant	20	Jenny (2) Jack (2) Jessica (1) Carly (1) Carla (1)
Cecily	Engaging in art class, bowling with friends, having coffee at café with sister, shopping at Costco with group home staff, catching the bus with partner.	20	Cecily (2) Shirley (1) Lisa (1) Dean (1)
Reuben	Borrowing books at library, selecting meal at McDonalds, cleaning at voluntary job, serving afternoon tea, developing literacy skills, cooking curry, recycling cans at local depot	16	Reuben (2) Sarah (2) Michael (1) Alex (1)
Emily	Making breakfast, getting dressed, afternoon tea with family[2].	2	Peta (2) Sally (1)
Natalie	Engaging in speech therapy, shopping for a present, ordering food at restaurants, discussion at microboard meeting,	20	Natalie (2) David (2) Arleen (2)

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[2] While Emily and her network remained research participants, family difficulties prevented the researcher from being able to contact Peta and arrange a similar number of participant observation sessions to other central participants and their networks.

	interacting with band members, catching the bus		Annie (1) Matthew (1)
Brian	Interacting with doctor in emergency department, shopping at two dollar store, choosing a meal at home and out in a restaurant, visiting community nurse for minor procedure, choosing bed time, expressing disinterest watching television	14	Ailsa (2) Debbie (1) Veronica (1) Melissa (1) Ruby (1)
Betty	Preparing for a doctor's appointment, cooking a meal, catching Skytrain, walking around local community, meeting friends, having coffee with her representatives.	12	Betty (2) Terry (1) Jason (1) Michaela (1)

Table 3-3 on page 81 outlines the amount of time spent observing each central participant, the type of activities observed as well as the participants who were interviewed in relation to each central participant.

Participant observation allowed me to understand how social relationships were arranged and "discern the principles by which decisions [we]re made" (Angrosino, 2004, p.162). I engaged in a wide variety of activities with family members and friends observing decision making in the context of their everyday lives. Activities included spending time at home, eating out in restaurants, attending doctor's appointments, day programs and shopping outings. I attended a musical, annual microboard meeting, art class, bowling alley, family burger night and a variety of therapy sessions. Decision making was observed on crowded buses, in cluttered family rooms, familiar coffee shops, sterile medical rooms, and gardens lit with thousands of sparkling lights.

I engaged with central participants and their supporters by taking a more active role in casual interactions (e.g., family dinners) and less during formal interactions (e.g., doctor's appointments). Gold (1958) characterises four roles a researcher can have when engaging in field work ranging from a “complete participant” to a “complete observer”. The two roles in between these extremes, “participant-as-observer” and “observer-as-participant” (p.217), more accurately describe the changing role the researcher in this study played while observing decision making. Central participants and decision supporters were aware at all times of the presence of a researcher however, different environments and situations required more or less active involvement. My experiences during observational periods supported the discovery of Johnson et al. (2011) taking a more active role as a participant, while observing people with intellectual disabilities in their home environment, allowed family members to include the researcher more fully in their interactions and relieved feelings of discomfort.

Observation was greatly assisted by engaging in small talk as a way of building trust and ensuring interactions did not become too threatening (Hammersley & Atkinson, 2007). Small talk provided a neutral ground so that central participants and decision supporters did not feel as if they were being pumped for information. I also tried to gauge how much self-disclosure was helpful and beneficial to the research. While sharing personal information can engender feelings of reciprocity, researchers sometimes need to downplay personal beliefs or political sympathies to be tactful (Hammersley & Atkinson, 2007). My previous trip to British Columbia, Canada made me aware that many disability advocates in Canada find the concept of adult guardianship abhorrent. This knowledge made me cautious about sharing too much about my previous working life until I had developed rapport with central participants and their networks. While I did tell central participants and decision supporters about my working background if asked, in most cases I contextualised my research in terms of my interest in learning from the expertise of research participants as a student.

Field notes.

During periods of observation, I wrote field notes in an attempt to capture everything that occurred during the interactions. It has been suggested in the context of participant observation that if it is not written down, it never happened (Taylor & Bogdan, 1998). Therefore, it was critical that I did everything possible to remember the events and conversations that occurred during the time in the field as accurately as possible. First, I recorded jot notes in a small note book while in the field. Words or phrases that I wanted to be able reproduce verbatim were written in this note book, dated and if possible the time noted. Second, I translated the jot notes into field notes as soon as possible after the events took place. I was aware that notes “get cold” and detail can be lost the longer the interval between the period of observation and writing the detailed field notes (DeWalt & DeWalt, 2011, p.165). I attempted to write up field notes the same day as the period of observation. They included descriptions of people, events, and conversations as well as my feelings, actions and responses to what I had observed (Taylor & Bogden, 1998). They also included the physical context of the environment as well as the behaviour and non-verbal communication of participants (DeWalt & DeWalt, 2011). Over the course of the data collection period, over 170 pages of typed field notes were generated that described a broad range of decision making experiences and the rich contexts in which they took place.

Participant observation is an iterative process in that researchers read and reread field notes to search for things they did not understand or need more information on so as to direct their future data collection. In this sense, the writing of field notes is “simultaneously data collection and analysis” (DeWalt & DeWalt, 2011, p.159). Alongside observation field notes I also wrote memos which recorded the thoughts, feelings, insights and ideas developing in relation to the research project as a whole (Birks & Mills, 2011). The process of writing memos facilitated analysis of data as it was both “a methodological practice and a simultaneous exploration of processes in the social world of the research site” (Lempert, 2007, p.245).

Reporting on observational data.

When observational data is described in the research findings the pseudonym of the person is used to designate which central participant was being observed. The following system is used for example, F: Cecily, p.45. “F:” indicates data was obtained as a field note from a period of participant observation. “Cecily” clarifies the period of observation related to Cecily and her decision supporters and “45” indicates the section of data referred to was taken from page 45 of the typed field notes.

Ethical Considerations.

The Australian Code for the Responsible Conduct of Research states researchers must comply with the ethical principles of integrity, respect for persons, justice and beneficence (National Health and Medical Research Council, 2007). Justice demands fairness in the distribution of the benefits and burdens of research, while beneficence relates to the researcher's responsibility to secure the wellbeing of participants (King & Horrocks, 2010). Respect for persons demands that individuals participate in research voluntarily. As a result, researchers seek the consent of people to participate having had adequate information about the purpose of the research, what will be required of them, what impact participation might have on them or others and what impact not participating might have (Perry, 2004, p.117). This means "dealing with people as free to choose, but also acknowledging more vulnerable people's rights to be protected" (King & Horrocks, 2010, p.106).

Informed consent.

For people with intellectual disabilities there are potential ethical problems in seeking voluntary informed consent as it in these processes that they are most obviously vulnerable. This could be as a result of cognitive limitations in expressive and receptive communication and in some circumstances limited experience in decision making in their own best interests (Griffin & Balandin, 2004). A number of authors have described the difficulties they experienced in seeking informed consent from people with severe and profound intellectual disabilities to participate in research (Johnson et al., 2011; Stalker, 2010). They discuss the importance of taking time, providing information in various formats and developing a relationship of trust. People with more significant intellectual impairment are likely to need someone to decide for them whether or not they should participate in research (Griffin & Balandin, 2004).

The models of decision-making support studied in this research are about enabling people with intellectual disabilities to be involved in significant decisions which affect their lives. The literature discussing these models suggests at times the support offered leads to the person making the decision and at other times their supporter makes a substituted decision on their behalf (Nidus Personal Planning and Resource Centre, 2010). Importantly, the support offered enables the person to have greater control and involvement in the decision-making process and allows decision making to be more accessible to people with cognitive impairment. Therefore, the process of seeking consent from central participants for this research necessarily involved the support they required to be able to make an informed choice to participate. I ensured where necessary the person with an intellectual disability had the support of someone of their choosing, usually their primary decision supporter, to assist them to understand all relevant information on the research.

The researcher assumed each participant was capable of providing informed consent, however two central participants (Brian and Emily) were unable to understand and appreciate the consequences of participation in the research with support. For these participants their primary supporters provided proxy consent. When proxy consent was provided the person with an intellectual disability still needed to assent to their participation in the study (Griffin & Balandin, 2004, p.70). Assent was demonstrated by the participant being open to my presence in their life, happy to be observed and wanted to communicate their ideas about decision making to me. Therefore, the process of obtaining and confirming consent from participants was an ongoing process throughout the data collection process. All participants, and their proxies, were aware they could withdraw from the study at any stage of the research process.

Risk of harm.

Consideration of the potential risks involved in any research project is critically important when the research involves vulnerable populations (Iacono & Murray, 2003). Research can exploit vulnerable groups within society and contribute to their disempowerment and oppression (Swain, Heyman, & Gillman, 1998). While this research was not conducting scientific experimentation with predictable side effects, there were some risks explored in the literature on conducting research with people with intellectual disabilities that are relevant to this project.

First, the observational component of this research involved spending time in the central participant's home. Conducting research in a person's home environment may be intrusive for participants and awkward for researchers (Cartwright & Limandri, 1997; Johnson et al., 2012; Stalker, 1998). Previous research has discovered the role of a participant observer is less intrusive than a non-participant observer in the home environment (Cartwright & Limandri, 1997; Johnson et al., 2011). The discomfort of observing in the home environment can also be reduced by researchers communicating openly on the purpose of the visits (Johnson et al., 2011) and remaining mindful they are guests in the home of participants (Cartwright & Limandri, 1997; Stalker, 2010). Therefore, I adopted the role of participant observer and worked to ensure there was open communication about the purpose and goals of each observational visit. I sought to respect the privacy and privilege of being invited into the homes of participants at all times by trying to put participants at ease.

A second risk was that participation in the research touched on sensitive topics. People with intellectual disabilities want to be respected by taking part in research that includes them, promotes their wellbeing and social value, and allows their lives to be improved (McDonald & Kidney, 2012). The way researchers handle the disclosure of sensitive information is critical to research participants feeling safe and respected. Griffin and Balandin (2004) suggest it is critical to recognise if a person is becoming distressed during an interview and provide appropriate support. This could be taking a break from the research process and asking if the participant is comfortable going on with the conversation (Cartwright & Limandri, 1997), listening to the person share their story (Swain et al., 1998) or facilitating access to appropriate professional counselling (Griffin & Balandin, 2004).

Two central participants discussed experiences of abuse while being interviewed and communicated signs of distress. At the first sign of distress, I suggested a break and paused the interview. The participant was provided with reassurance and emotional support. After a short period the participant requested continuing with the interview and communicated later, she felt she had benefitted from the opportunity to share her experience and feel heard. The participant identified several professionals she could speak with if she wanted to discuss her feelings further. The second participant expressed significant anger about experiencing abuse in her childhood. Her supporter had not seen the participant express anger about her experiences previously. Both the researcher and supporter followed up with the participant in the days and weeks after the interview to check on the participant's wellbeing. The participant showed no ongoing signs of distress and the disclosure seemed to deepen the communication and respect between the person and their supporter.

Confidentiality and anonymity.

Privacy, confidentiality and anonymity are linked to the underlying principle of respect for persons (King & Horrocks, 2010). Privacy involves protecting the right of research participants to choose what and to whom they disclose information, confidentiality requires shielding data from public or unauthorised scrutiny by storing it securely and anonymity entails de-identifying any information which is disseminated (Griffin & Balandin, 2004, p71).

All forms of data collected in this research were de-identified to ensure the anonymity of research participants (interview transcripts, field notes and memo writing). All research participants were given a pseudonym and participant lists, consent forms and pseudonyms were stored separately from the interview transcripts, field notes and researcher's personal journal.

Throughout the study, written information was stored in a locked filing cabinet in the researcher's office and then room 305a Health Sciences 2 building at La Trobe University upon return to Australia. Coded digital audio recordings and typed interview transcripts were stored as secure computer files on the researcher's laptop which was password protected. A back up of the data was also stored on an external hard drive which was password protected. Following the completion of the study and five years subsequent to publication, written records will be archived securely in the Archive Room in Health Sciences 3 (located opposite room 105) at La Trobe University.

Ethical approval.

Prior to the commencement of data collection, ethical approval for this research was obtained from the La Trobe University Human Ethics Committee (approval number: HEC13-047; see Appendix B).

Data Analysis

A grounded theory study must go beyond description of what is happening in the social setting and offer a conceptually abstract explanation of the phenomena under investigation (Holton, 2007). The development of an explanation or theory occurs by implementing specific data analysis methods. Grounded theory researchers engage in concurrent data generation and analysis which is known as "constant comparative analysis" (Birks & Mills, 2011, p.94). This method of data analysis involves comparing "data with data, data with category, category with category, and category with concept" (Charmaz, 2006, p.187). It is this process of induction and abduction (Reichertz, 2007) that allows the development of theoretical understanding, which is grounded in the experiences of participants.

This research used constructivist grounded theory methods as interpreted by Charmaz (2006). Data analysis occurred over a number of years and involved the use of initial, focused and theoretical coding. Initially, interview transcripts and field notes were coded by looking at each word, line and segment of data and developing preliminary "in vivo" codes (Charmaz, 2006, p.56) that best captured the actions and incidents in the data. Initial coding used the terms as described by research participants to capture their ideas (e.g., "skin in the game"). These short, simple codes were written quickly in the margins of typed transcripts and field notes (see Appendix D), though there were instances where it took time to find codes that fit specific pieces of data well (Charmaz, 2006). For example, some simple codes that initially referred to supporter "influence" were later categorised as a range of supporter "responses".

I used post it notes of in vivo codes and stuck them to a wall to assist in the comparison of data across the seven central participants. As categories emerged (e.g., the support relationship) sub-categories became evident such as the one pictured below (e.g., knowing the person). This picture captures some initial codes across all central participants that related to the support relationship. Seeing these initial codes together led to recognition that deep personal knowledge was an important element of the support relationship.

Figure 3-1: Photograph of in vivo codes being categorised

After initial coding, I moved on to develop focused coding which was more selective and conceptual than initial coding. Focused coding establishes an analytic direction that tries to synthesize and explain larger segments of data (Charmaz, 2006) and involves grouping codes to form categories. Categories are “multi-dimensional and may consist of a number of sub-categories that together explain the broader concept” (Birks & Mills, 2011, p.98). Categories can be linked together and compared to one another. In this phase of data analysis, I compared codes across interviews and support networks to “compare people’s experiences, actions and interpretations” (Charmaz, 2006, p.59). I used mind mapping, diagramming and reflective memo writing to assist in the development of categories (see Appendix E). For example, comparison between the experiences of central participants led to the identification of focused codes, such as “equality”, “respect”, “knowledge” and “trust” which together formed categories such as “values brought to the support relationship” and “characteristics developed within the support relationship”. See table 3-4 on page 92 for an example demonstrating the coding process. It illustrates how segments of data were coded, analysed and categorised to reach a specific theoretical construct.

After focused coding, I engaged in theoretical coding which sought to find the relationships between the categories I had developed. Theoretical coding was about conceptualising how the categories related to each other as hypotheses to be integrated into a theory (Charmaz, 2006). Theoretical codes are integrative and help tell “an analytic story that has coherence" (Charmaz, 2006, p.63). This phase of the data analysis allowed me to see the connections between focused codes and categories which in the example provided was the "quality of the support relationship". The development of theoretical codes was both an exciting and frustrating process. Finding the analytic story took time and plenty of dead ends as connections were made, explored and discarded when they did not hold up to interrogation across the data as a whole. For example, "need" was an early theoretical code used to describe the contribution of the central participant in the process of decision-making support. However, it was discarded when it was found not to encompass the experience of all central participants who were actively engaging in decision making. The expression of will and preferences ended up better reflecting the initial contribution of central participants.

Table 3-4: ***Example of the coding process: Quality of the support relationship***

Segment of data	In vivo code	Focused code	Category	Theoretical construct
"You don't make decisions with respect to Brian that you would not consider making with respect to yourself"	Same standards	Equality	Values brought to the support relationship	Quality of the support relationship
"I'm a service to him and he's a service to me"	Reciprocity			
"He's just like everybody else"	Like everybody else			
"There are things he won't do but you don't put him in a behaviour modification program to make him do it. You should accept"	Accepting preferences	Respect		
"She does have the right to make decisions and I can't force her to do things, go somewhere, or try something new"	Can't force her			
"I think the important thing for her in the decision-making process is that her essential self is known"	Essential self known	Knowledge	Characteristics developed within the support relationship	
"You do have to know Emily to understand her choices"	Knowing to understand choices			
"If we are helping him to make his decision we should know him, what his wants are"	Knowing the person's wants			
"I feel like we have this trusting relationship and she's not going to let me walk all over her"	Trusting the person to speak up	Trust		
"I was very cautious about not being convincing… because I know that Betty trusts me so much"	Not being convincing			
"If I ask Cecily to do things compared with other staff she will most likely do it. I think the length of relationship determines that as well as the level of trust"	Trust shaping influence			

The grounded theory product.

The aim of this research was to understand how people with intellectual disabilities were supported with decision making in the context of two legal mechanisms which create opportunities for supported decision-making in Canada, representation agreements and microboards. The product of this research was the identification of a common process of decision-making support, which is outlined in Chapter 4. The process of decision-making support was characterised by a dynamic interaction between expressions of the person's will and preferences in relation to a decision opportunity and their supporter's responses. This interaction was shaped by a range of individual, relational, decisional and environmental factors.

Assessing the quality of this research.

I applied the four quality criteria proposed by Charmaz (2014) to evaluate the quality of this constructivist grounded theory research: "credibility, originality, resonance and usefulness (p.337-338). Table 3-5 on page 96 outlines the methods used to address each of the four criteria. A number of these methods and how they were applied are described below.

Peer debriefing and manuscript review. *(Credibility)*

I participated in regular face to face meetings with my supervisors throughout the entire research process including via skype for the eight months I was in Canada. These meetings provided an opportunity to engage in debriefing and review my position as a researcher in relation to the emerging data (Lincoln & Guba, 1985). Supervision was also the place where the emerging theory could be interrogated and working manuscripts reviewed for methodological coherence. These sessions were helpful in keeping my interpretation of the data "honest" (Lincoln & Guba, 1985, p.308).

Memo writing. *(Originality)*

Memo writing occurred throughout the entire process of this research project including the design, collection of data, analysis and development of the theory of supported decision-making practice. Memo writing is an essential methodological process that enables the creation of a grounded theory (Lempert, 2007) through allowing me to keep track of my developing thoughts about the data (Stern, 2007). I engaged in memo writing during each phase of the research process to reflect on my position, values, beliefs and reactions in response to the data and emerging theory. I chose to write memos spontaneously as ideas emerged such as when I experienced challenging feelings in the course of the research process. Several examples of memos are included in Appendix E.

Personal journal. *(Credibility/Originality)*

I brought a host of assumptions and a particular perspective to the research process. In an attempt to become more aware my own subjectivity and biases I engaged in reflexive journaling. Birks and Mills (2011) define reflexivity as "an active process of systematically developing insight into your work as a researcher to guide your future actions" (p.52). They recommend using a personal journal to keep an ongoing written record of the analysis of the impact and outcome of the researcher's actions, thinking and feelings. I also used the personal journal to keep a map of the research activities and decisions taken during the research process, which provides an important audit trail (Birks & Mills, 2011). Together with memo writing, journaling advanced my thinking about the emerging theory (Charmaz, 2006; Lempert, 2007).

Method triangulation. *(Resonance)*

Triangulation is a method that ensures the credibility and dependability of research findings (Lincoln & Guba, 1985). There are many kinds of triangulation (Richards & Morse, 2013) and the one used in this research was method triangulation. Method triangulation is "the checking of inferences drawn from one set of data sources by collecting data from others" (Hammersley & Atkinson, 2007, p.183). I triangulated data generated from semi-structured interviews with the data generated from periods of participant observation which enabled me to gain a deeper and clearer understanding of the context of decision making and the participants being studied (Taylor & Bogdan, 1998).

Prolonged engagement and persistent observation. *(Credibility)*

Another method used to address research credibility was spending a prolonged period engaged in the research context of Vancouver, Canada. I lived in Vancouver for eight months, which allowed me to experience the culture in which research participants lived and build their trust over time. This was important because it is not possible to understand phenomena such as supported decision-making without reference to the context in which it is embedded (Lincoln & Guba, 1985). Prolonged engagement helped me to become aware of the “multiple influences” involved in the lives of research participants and the decision making of people with intellectual disabilities (Lincoln & Guba, 1985, p.304). Alongside prolonged engagement, persistent observation assisted me to uncover which influences “were most relevant” to their decision-making processes (Lincoln & Guba, 1985, p.304).

Chapter Summary

This qualitative research aimed to better understand how people with intellectual disabilities were supported with decision making in the context of two legal mechanisms which create opportunities for supported decision-making in Canada, representation agreements and microboards. This chapter has outlined the approach used to conduct this research and explained why a constructivist grounded theory methodology was employed to best answer the research aim. In the following chapter, the findings of this research are explored which outline the process of decision-making support that was discovered and factors which influenced it.

Table 3-5: ***Assessing the quality of this research (Charmaz, 2014)***

Criteria	Description of criteria	Strategies applied
Credibility	The research has achieved familiarity with the setting or topic The data is sufficient to merit the claims There are strong logical links between observations and categories Strong logical argument between the data, argument and analysis	• Prolonged engagement (8 months in Vancouver) • Persistent observation (104 hours observation) • Method triangulation • Audio recording of interviews and verbatim transcription • Personal journal • Member checking in second interviews • Interviews with community leaders • Peer debriefing in regular supervision, scrutiny of transcripts and field notes
Originality	Categories offer fresh, new insights Analysis provides a conceptual rendering of the data The grounded theory challenges, extends or refines current practice	• Personal journal • Memos • Documents outlining coding, emerging categories across central participants and the development of theoretical constructs • Recording of joint analysis and supervision sessions
Resonance	The categories portray the fullness of the studied experience The grounded theory makes sense to research participants	• Method triangulation • Memo writing and personal journal • Sampling of central participants with a range of intellectual disabilities
Usefulness	Analysis offers insights that people can use and sparks further research Research contributes knowledge	• Rich description of research assumptions • Comparison with the literature • Description of study limitations

Chapter Four:

Research Findings

Uncovering the Process of Decision-Making Support

This chapter starts by exploring the role representation agreements and microboards played in the decision making of central participants. It goes on to describe the process of decision-making support used by all participants, providing a summary and diagram of the process. The chapter explains how a range of factors shaped the core elements of the process (the person's will and preferences and supporter's responses). The second findings chapter (Chapter Five) goes on to examine three decision-making examples, which illustrate how the complex interaction of the influencing factors shaped the dynamic, recursive interplay between the core elements.

The Role of Legal Mechanisms

These research findings explore how people with intellectual disabilities were supported with their decision making in the context of two legal mechanisms which create opportunities for supported decision-making in Canada, representation agreements and microboards. Before outlining the process of decision-making support that was discovered, it is important to understand the role representation agreements and microboards played in the decision making of central participants. Three of the seven central participants in this research had microboards (Natalie, Reuben, Emily) and five of the seven had representation agreements (Jenny, Cecily, Natalie, Emily, Betty).

Most central participants and their supporters, when reflecting on their decision making, did not identify these legal mechanisms as a significant environmental factor that shaped their experience. Legal mechanisms were most often discussed in relation to resolving practical problems faced by supporters such talking with lawyers (F: Jenny, p.11-12), banks (I: Jason, p. 1) or doctors (I: Terry, p. 4) on behalf of the person with intellectual disability. Peta discussed needing a representation agreement to be able to set up a Registered Disability Savings Plan for her daughter Emily because she was not seen as a person with legal capacity.

> …because Emily doesn't have legal capacity it [the RSDP] is in my name and she's the beneficiary. Now I had to have an agreement in order to do that, that is why it's been a lot harder in other provinces to open one. (I: Peta 2, p.17).

When participants discussed the establishment of representation agreements and microboards decision supporters always initiated creating them (I: Jason, p.1; I: Shirley, p.9-10; F: Reuben, p.8; I: Jessica, p.11; F: Natalie, p.2). There were many reasons decision supporters set up representation agreements and microboards, most of which related to the person's future welfare rather than supporting the decision making of people with intellectual disabilities.

For parents, microboards created a "safety net" which gave them peace of mind that there were other people involved in their child's life who would support them "when we drop dead!" (I: Peta 2, p.21; F: Natalie, p.2). Microboards also enabled parents to access individualised funding which gave them the capacity to meet the unique needs of their child (I: Sarah 1, p.8; I: Peta1, p.1). During the first observational period with Natalie and her family, Natalie's father David mentioned that the microboard they had for Natalie had an upcoming meeting.

> David explained that the microboard itself is merely a formality to them receiving the funding they need to support their daughter. "To get government funding required having a microboard back then." As such, David wanted me to know that the AGM "merely rubber stamps what is going on". (F: Natalie, p.1)

For other supporters, representation agreements took away the fear they experienced dealing with professionals when they realised "how little power" they had as a family member (I: Peta 1, p.8) and gave them "the right to say something" (I: Shirley, p.9-10). When Shirley described the circumstances that led to the creation of a representation agreement for her sister Cecily seeking power and the authority to be involved in decisions made by government on Cecily's behalf were a motivating factor.

> When I got the representation agreement another one of the motivators was there was a change in government policy and they were doing some very quick decisions about placements and changing home situations. And there was a huge uproar in the province and I remember going to a meeting about that and it really affected me. They were trying to put some people who they thought could maybe manage in a home with one adult rather than a group home or live on their own and that made me think that I needed to be more involved and have a little bit of power. (I: Shirley, p.14-15)

Representation agreements were also seen by some supporters as a preventative measure to ensure government bureaucrats were not able to take over the lives of people with intellectual disabilities when they as supporters were no longer around (I: Peta 2, p.8). There was only one central participant Betty, and her representatives (Jason, Terry and Michaela), who discussed the presence of a representation agreement in the context of supporting Betty's decision making.

Betty was an articulate self-advocate whose parents had initially set up her representation agreement (I: Jason, p.1). Over time, Betty had changed her representatives to reflect her own preferences regarding being supported with health care and financial decision making (I: Betty 2, p.12). Betty had based the selection of her representatives on their availability to assist her (I: Betty 1, p.16), their helpfulness (I: Betty 2, p.10), and whether they listened to her and respected what she had to say (I: Betty 2, p.11). Betty had removed a health care representative from her agreement because she did not listen to her requests and would tell her what to do (I: Betty 2, p.11).

Betty's experience having and directing the use of her representation agreement differed significantly from Jenny's experience of having one. A representation agreement was made for Jenny when the disability organisation that supported Jenny and her mother Beryl suggested the family create one at the same time they created Beryl's will (I: Jack, p.9). Jenny's brother Jack was made her representative for health care and financial decision making (I: Jack, p.9) and Jack described the agreement in the following way "it just says that I speak for Jenny, emotionally, financially and through all her affairs because she can't make those decisions (I: Jack, p.9-10).

Jack used the representation agreement when he engaged a number of lawyers on Jenny's behalf (F: Jenny, p.11). He wanted to use Jenny's inheritance to buy out his ex-partner's share of their home (F: Jenny, p.11-12). Jack had not told Jenny about how he intended to spend her inheritance nor included her in the decision-making process because he believed "she had no idea about money" (F: Jenny, p.11). While the presence of the representation agreement created the opportunity for supported decision-making, the way Jack interpreted his role and his perception of Jenny's capacity to engage in decision making resulted in him excluding her from important decisions that had significant consequences in her life.

The experiences of participants in this research suggested the presence of legal mechanisms such as representation agreements and microboards played a very limited role in shaping how central participants were supported with their decision making. The reasons supporters initiated and created these legal mechanisms seemed to reflect how they were used in practice. The mechanisms were most often created to solve problems faced by supporters (e.g., communicating with banks and lawyers on the person's behalf) who were trying to ensure the future welfare of central participants (e.g., by accessing individualised funding or preparing for the death of their parents). It was only rarely that the presence of legal mechanisms and the way in which they were discussed related to how people with intellectual disability were supported to make decisions (e.g., Betty's experience being supported by Terry, her health care representative at a doctor's appointment). Even though the presence of legal mechanisms was not a factor which substantially shaped the decision making of central participants, this research has identified a range of individual, relational, decisional and environmental factors, which were observed to influence how they were provided with decision-making support. These factors were central to the model of decision-making support which emerged from the data and are explored in this and the next chapter of the thesis.

Identifying the Process of Decision-Making Support

All central participants involved in this research had multiple decision supporters. However, when engaging in a particular decision-making process most participants were supported by one person. While there were a few occasions when more than one supporter was directly involved in the decision-making process (for example, both parents), the majority of processes were defined by one person being assisted by one supporter. The language used when describing the process of decision-making support reflects this reality. For ease, the term 'supporter' is used but it is important to recognise that in a limited number of cases the term supporter represents more than one supporter.

From engaging in observation, and discussing the experiences of seven people with intellectual disabilities and their support networks, a common process of decision-making support was identified. This process started when a decision opportunity arose in the person's life (person with intellectual disability being supported) and was explored with their decision supporter. In relation to this decision opportunity, the person expressed their will and preferences and their supporter responded in a variety of ways. There was a dynamic interaction between the person's will and preferences and the responses of their supporter during the process. This interaction was influenced by five factors: 1) the experiences and attributes the person brought to the process; 2) the experiences and attributes their supporter brought to the process; 3) the quality of their support relationship; 4) the environment in which decision making occurred and 5) the nature and consequences of the decision.

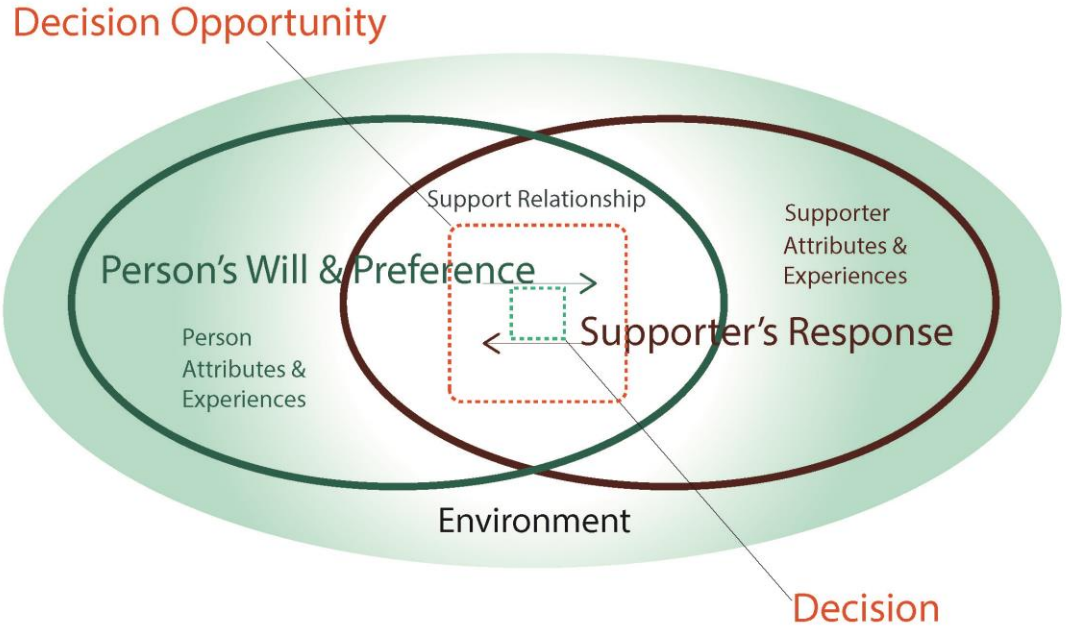

Figure 4-1. Diagram of the model of the process of decision-making support.

Defining the Process of Decision-Making Support

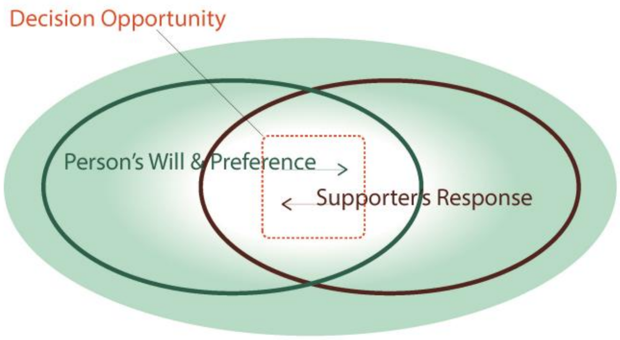

Figure 4-2. The starting point and the two core elements of the process.

The starting point: a decision opportunity.

The starting point of the process of decision-making support was the emergence of a decision-making opportunity within the interaction between the person and their supporter. Decision opportunities could be created by the person, their supporter, other people or triggered by environmental factors. The emergence of a decision opportunity did not always lead to a decision-making process. Some decision opportunities were explored, some needed to be negotiated and others were shut down.

Two core elements of the process.

The person's will and preferences.

Will and preferences refer to the desires, goals, priorities, likes and dislikes of a person. The person's key role in the process of decision-making support was to express their will and preferences in relation to a decision opportunity. These could be expressed verbally and through idiosyncratic non-verbal communication such as eye gaze, vocalisations and gestures.

The supporter's responses.

The response of the supporter was how the supporter reacted to the person's will and preferences. Often supporter responses involved the provision of support directed towards helping the person form, explore, clarify, and express their will and preferences in the decision-making process. Sometimes supporter responses involved the provision of support directed towards changing and disregarding the person's will and preferences which could result in the supporter taking over the decision-making process.

Defining the Five Influencing Factors that Shaped the Process

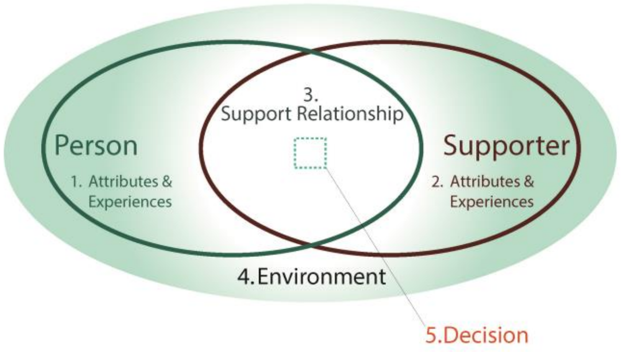

Figure 4-3. The five influencing factors that shaped the process of decision-making support.

The influencing factors outlined below shaped the core elements of the decision-making process and the interactions between them. Variations in these factors resulted in significant diversity in the duration and outcomes of the decision-making processes observed.

(1) The experiences and attributes the person brought to the process.

The person brought to the decision-making process their will, which was shaped by their unique experiences, values, beliefs, hopes and dreams. These experiences and attributes defined who they were as individuals. Each person had specific preferences shaped by their previous life experiences, goals and priorities, and came to the decision-making process with a range of abilities (e.g., communication, cognitive), personality traits (e.g., confidence, agreeability, motivation), likes and dislikes and in various states of emotional and physical health.

(2) The experiences and attributes the supporter brought to the process.

The supporter brought to the decision-making process their expectations, which were similarly shaped by their unique experiences, values, beliefs, needs, hopes and dreams.

These experiences and attributes defined who they were as well as what they wanted for the person they were supporting. The supporter came to the decision-making process with values and beliefs regarding their role as a supporter and with preferences about the outcome of the decision-making process. Each supporter came to the decision-making process with specific values (e.g., equality, respect), goals and priorities (e.g., independence, inclusion), abilities (e.g., to actively listen) and personality traits (e.g., openness, attentiveness, tendency to be controlling).

(3) The quality of the support relationship.

The relationship between the person and their supporter was important because it was the context in which the dynamic interaction between the person's will and preferences and the supporter's responses occurred. The quality of the support relationship contributed to shaping the person's readiness to express their will and preferences and the supporter's willingness to hear and respect those preferences. The quality of the support relationship was influenced by how well the person and supporter knew each other, trusted each other and shared their power (viewed one another as equals, respected each other).

(4) The environment.

The environment in which decision making occurred had both an immediate, direct impact on the process and a broader influence. Environmental factors such as time, the availability of resources (e.g., services, paid supports), the accessibility of information and financial limitations directly shaped the process of decision-making support. In addition, the priorities of government, community attitudes about disability and the nature of congregate care were environmental factors which had a broader influence.

(5) The nature and consequences of the decision.

If the proposed decision was highly complex, it could make understanding the potential consequences of the decision difficult. This complexity could change the intensity of support the person required from their supporter. If the decision was perceived to involve risk for the person or the potential for serious adverse consequences, it often shaped the openness of the supporter to explore the decision opportunity. When the decision had potentially serious consequences for the person's supporters or other third parties this also contributed to shaping how supporters responded to the person's will and preferences during the process of decision-making support.

Summary of the Process of Decision-Making Support

The process of decision-making support started when a decision opportunity emerged in the context of the relationship between the person and their supporter. Often the relationship the person had with their supporter was developed over years or decades. Over time, they had established patterns of relating to one another which tended to enable or constrain the opportunities the person had to make decisions.

Most often, the person and their supporter were interested and open to exploring the decision opportunity. If the person and/or their supporter lacked interest in the decision opportunity, it could stall or stop the decision-making process entirely. When the decision opportunity was explored, sometimes the decision to be made was clear but sometimes it needed time to be clarified throughout the process. There were times when the decision changed entirely and therefore started a new decision-making process.

In response to the emergence of a decision opportunity, the person expressed their will and preferences. Sometimes the person was able to do this independently, and at other times they needed significant support to be able to identify and communicate their will and preferences in relation to the decision. Whether the person had experience making decisions and the type of experiences they had expressing their preferences (e.g., whether they were accepted or ignored) contributed to shaping their understanding of the decision and their ability to express their will and preferences in relation to it. The values (e.g., equality, respect), beliefs (e.g., about the person's ability to communicate their will and preferences) and abilities (e.g., self-awareness) the supporter brought to the process shaped their ability to listen, enable and respect the 'voice' of the person.

After the person expressed their will and preferences, the supporter responded to them. Sometimes the supporter responded by immediately accepting the person's will and preferences as a decision. Sometimes the supporter immediately disregarded the person's will and preferences and took over the decision-making process. Often the process was more complicated and there was a dynamic interaction between the person’s expressed preferences and the supporter’s responses. The duration of the dynamic interaction (between various expressions of will and preference and responses) varied depending on the five influencing factors shaping the process.

Supporters used a wide variety of strategies and approaches when supporting the person during the decision-making process. The range of responses was mediated by how the supporter perceived the person’s expressed will and preferences which was influenced by their values, beliefs, priorities and needs. During the decision-making process, there were times when the supporter’s response changed as their perception of the person’s will and preferences changed. In fact, the supporter’s response could change several times within one decision-making process.

The process of decision-making support ended when the decision opportunity was resolved. Most often, this was because the supporter accepted the person’s will and preferences as their decision. Sometimes this acceptance came after a period of clarifying the person’s will and preferences. At other times, the supporter accepted the person’s will and preferences after they influenced the person to change them to align with what they thought was best. Occasionally the process ended because the supporter took over the decision-making process and closed the decision opportunity for the person.

A Decision Opportunity

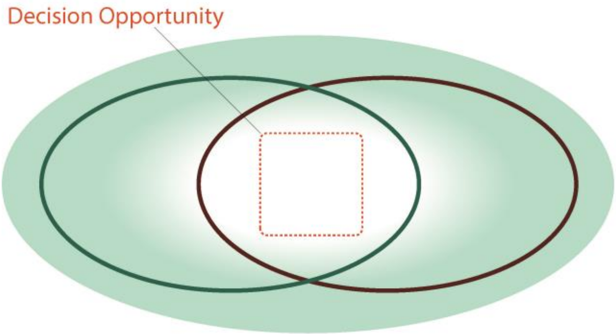

Figure 4-4. A decision opportunity emerges within the support relationship.

Each process of decision-making support started when a decision opportunity emerged within the context of the relationship between the person and their supporter. Some decision opportunities were created when the person and the supporter interacted with other people. For example, Betty and her representative were told by her doctor she had cancer and she would need to make some decisions about her treatment options. Other decision opportunities were created by the person when they said or did something that communicated their need for a decision to be made. For example, when Brian started crying during catheterisation his support worker recognised he was in pain and that a decision opportunity had emerged around how to meet his health needs. The supporter created other decision opportunities, when they identified a need the person may not have considered. For example, Matthew wanted Natalie to decide where she might like to live, if her parents were no longer able to look after her.

Decision opportunities were not always evident and sometimes the supporter needed to provide help to “expand” the person’s “awareness” that there was a decision that could be made (I: David 2, p.22). At other times, the person raised an issue “over and over and over” in the hope that it would be acknowledged and treated as a decision opportunity by the supporter (I: Darren, p.8). Whether an opportunity was explored or ignored was determined in the interactions between the person and their supporter.

Previous life experiences contributed to shaping how sensitized the person was to recognising and initiating decision opportunities. If the person’s attempts to communicate their needs and preferences had been largely ignored for most of their life, it could result in a lack of confidence to speak up and create opportunities for decision making. For example, Jenny's ability to initiate and explore decision opportunities was significantly affected by her experiences with her mother. Jenny's mother was described as exhibiting "controlling" behaviour and having very "limited" expectations of Jenny (I: Carly, p.1, p.23, p.5). Her mother's personality and beliefs meant whenever Jenny attempted to assert herself (e.g., expressing anger about being denied access to her computer and television) her requests were dismissed and ignored (F: Jenny, p.10). Years later Jenny remained reluctant to speak up and initiate decision opportunities even when strongly encouraged to do so by other family members (I: Carly, p.5). In contrast, when the person came to the process with a history of empowering experiences, having their concerns heard and respected, it fostered their confidence and ability to explore decision opportunities. This was the case for Natalie who had always been encouraged "to use her voice" by her parents and support staff (I: Annie, p.1). When Natalie raised concerns about issues in her life (e.g., disliking the approach of her doctor), her parents listened and recognised her attempt to create a decision opportunity (F: Natalie, p.6). Over time, these experiences resulted in Natalie having greater confidence to recognise and initiate decision opportunities with other people in her life.

Sometimes the supporter created and promoted decision opportunities for the person because they believed a change might be in the person's best interest. In these situations, supporters brought new options and ideas to the attention of the person. For example, Lisa proposed on numerous occasions that Cecily try swimming for the first time with other residents because she believed exercise would help her heart condition (I: Lisa, p.10) and Annie suggested Natalie try the low fat option at Starbucks because of her increasing weight gain (I: Annie, p.8).

There were other times when the supporter closed off decision opportunities because they believed an option was not in the person's best interest. For example, when Betty proposed opening a savings account to save for a holiday, her trustee refused to discuss her suggestion (I: Betty 1, p.3). The trustee believed it was better for Betty to ask her directly for the money and refused to discuss other ways of managing her money (I:

Betty 1, p.3). The trustee's response closed off any opportunity for Betty to decide how she wanted to save for her holiday.

Community attitudes about people with disability sometimes prevented the emergence and acknowledgement of decision opportunities. A number of central participants spoke about being excluded and denied a voice in important decision-making processes because of the negative beliefs of community members. For example, Brian was asked to leave a volunteer job because the company who had taken over the video store "didn't want someone like Brian working there!" (F: Brian, p.10). And Natalie was overlooked while out, with her mother, shopping in a wheelchair for the first time. Her mother expressed she was angry with the local storeowner because she knew, and had interacted with Natalie, prior to acquiring a physical disability "it's her ankle that's broken her brain still works!" (I: Arleen 2, p.12).

In these situations, when the person was excluded and ignored, they were denied opportunities to make decisions about important aspects of their lives including how they spent their time and money. However, through the advocacy and assistance of the person's decision supporters, in many cases the negative impact of community beliefs were mitigated and the person was able to explore decision opportunities.

Summary

This section has illustrated that the process of decision-making support started with the emergence of a decision opportunity. Whether or not decision opportunities were acknowledged and explored by the person, their supporter and third parties was influenced by a complex interaction of individual, relational, environmental and decisional factors. The following section explores how five influencing factors shaped the first core element of the decision-making process, the expression of the person's will and preferences.

The Person Expresses their Will and Preferences

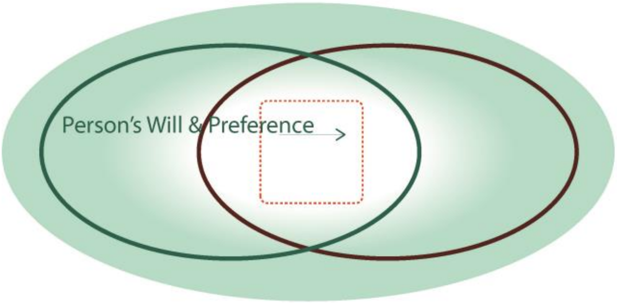

Figure 4-5. The person expresses their will and preferences in relation to the decision opportunity.

The first core element of the decision-making process was the person expressing their will and preferences in relation to the decision opportunity. Sometimes the person expressed their will and preferences verbally and sometimes it was through idiosyncratic non-verbal communication such as eye gaze, vocalisations and gestures. During the decision-making process, the person's will and preferences were constantly being shaped by the five influencing factors and the responses of the supporter.

The experiences and attributes the person brought to the process shaped their willingness and ability to express their will and preferences. Similarly, the supporter's experiences and attributes shaped their ability to hear and respect the voice of the person (i.e., their response). The quality of the support relationship shaped the person's comfort and discomfort expressing their thoughts and feelings. The quality of the relationship also improved or diminished the ability of the supporter to help the person understand the decision. Environmental factors such as the accessibility of information, community expectations and the rigid structure of congregate care as well as the person's awareness of the decision and its consequences could significantly change the person's will and preferences.

(1) Experiences and attributes of the person.

Experiences.

When the person had limited life experience, it limited their ability to form their will and preferences. It could also shape their understanding of the options and their confidence to express their will and preferences. Brian used non-verbal communication to express his will and preferences, which needed to be interpreted by his supporters. Brian's mother Ailsa explained how as a child Brian communicated where he wanted to keep his toys.

> …he had drawers and boxes to put things in but he chose his cupboard, which was under my husband's recliner in the living room. And that's where he liked to keep his things. And at night he would put them under there and in the morning he would go and take them out. So he wasn't into boxes and the things we decided he should put those toys in… (I: Ailsa, p.9)

Brian communicated in his own way where he wanted to keep his toys and his parents demonstrated respect for his will and preferences by listening to and accepting them.

In contrast, Betty shared about her experience living in a group home in her twenties and going off to work one morning without making her bed. When she returned the staff told her,

> …the Ministry came by, the big wigs, like Dad's office, saying why didn't you make your bed? So I was punished for a whole week because I didn't make my bed. So to this day I make my bed, usually… I still worry about that. That was almost thirty years ago, thirty-five years ago. And I still, someone says you shouldn't have to, but I do I worry about it constantly. (I: Betty 2, p.17-18)

This experience continued to have a significant impact on Betty's decision making 35 years after the incident. The fear of punishment stayed with her long after she moved out of the group home and created ongoing insecurities that shaped her ability to do what she preferred. Even though Betty was quite capable of articulating her will and preferences, she talked about having a fear of getting in trouble if she said the wrong thing. "…If I don't say yes will I get in trouble. Not now, but I'm just thinking back over the years and I would think that. I am going to get in trouble for not agreeing to do that" (I: Betty 2, p.17). Although Betty was in many respects a strong self–advocate, previous experiences had left her with a fear of saying or doing the wrong thing which hampered her ability to express her will and preferences and engage in the decision-making process.

Attributes.

Each person brought a complex mix of attributes to the decision-making process and this mix of attributes contributed to shaping the person's ability to express their will and preferences.

Natalie, for example, was a passionate lover of nature who valued self-expression and freedom. She demonstrated this in the way she dressed, the places she liked to visit and her politics. Natalie's rehabilitation aide suggested Natalie "is quite political, and... we would buy little stickers or little badges on politics and she would put them on her chair because she wants to express how she feels and that's her choice…" (I: Annie, p.6). Natalie's beliefs about herself changed according to how she was feeling at any given moment. Sometimes she had positive beliefs about her life and felt accomplished. At other times, she doubted herself saying things like "I don't know much about myself" (I: Natalie, p.1). When Natalie was young, decision making was nearly impossible because she would become overwhelmed (I: Annie, p.2). Annie described Natalie as a very shy person who lacked confidence (I: Annie, p.1). Natalie said, "most of the time I let my Dad say for me because I'm shy" (I: Natalie, p.21). Annie was aware that Natalie needed support to build her confidence in making decisions.

> A lot of her decision making is based on me building up her self-confidence and her ego, and learning to listen to herself and to know that you can make a good decision and a good choice. Because if you're not feeling confident about yourself it's really hard to believe in yourself to make a choice. (I: Annie, p.3)

Natalie believed she was no good with money (I: Natalie, p.9) and that decision making about money was "always hard for people who have Down syndrome" (I: Natalie, p.9). Although Natalie's ability to process information and understand the consequences of budgeting was limited, her confidence played a central role in shaping her ability to express her will and preferences.

Natalie had a stroke when she was a teenager, which affected her memory and created issues with fatigue when concentrating on tasks (I: Matthew, p.1). Natalie's mother

Arleen knew that around bedtime Natalie could develop “unrealistic ideas about things” because of fatigue (I: Arleen 1, p.10). For the most part Natalie knew her own limitations, however during these times she was less able to identify her need for support and ask for help when she needed it (I: Arleen 1 p. 10). Natalie’s state of physical health and wellbeing affected her ability to express her will and preferences and engage in the decision-making process at certain times of the day.

Natalie also wanted to make people happy and tended to be “a people pleaser” (I: Annie, p.5). Annie had seen in the years they had worked together that,

> If she likes you she wants to please you and make you feel happy so you have to be aware of that when you are with her and or suggesting things or asking questions because she might give you the answers that you are looking for. So it’s, yeah that can happen quite easily. And I am always aware of that. (I: Annie, p.5)

Natalie brought all of these attributes with her to the process of decision-making support: her passion for politics and the environment; a history of self-doubt and shyness; beliefs about her own ability to make decisions; wavering confidence; memory loss; a moderate level of intellectual disability and a tendency to be a people pleaser. Often these personal attributes made it difficult for to her express her will and preferences and meant her supporters needed to provide specific types of support (e.g., exercising caution when expressing their own preferences to counter her tendency to be a people pleaser).

(2) Experiences and attributes of the supporter.

Experiences.

Supporters came to the decision-making process with previous experiences that shaped how they went about providing support to the person to express their will and preferences. When Ailsa employed staff to work with Brian, she was mindful of their prior experience supporting people with disability. She had learned over time the training staff received from the disability sector influenced their ideas about her son, and more often than not, “those ideas were limiting” (F: Brian, p.1).

> I have to be careful how I say this. It is hard for some staff who have had training because you are trained to have an expectation that you are going to help him achieve something that you see as a certain standard, and I don't think that's what needs to be done. We have to try and identify what Brian's standard is and reach that for him. You know help him to reach that, not our standard. (I: Ailsa, p.9)

Over time, Ailsa came to view previous experience working in the disability sector as a liability when employing staff to work with Brian. This view was because she had seen staff come in with certain expectations and "a list of things you have to do" rather than "getting to know" her son and figuring out what he wanted to do (F: Brian, p.1). Previous experience often resulted in staff having set ideas that limited their motivation to listen to Brian and want to understand his will and preferences (I: Ailsa, p.9).

Attributes.

Each supporter brought a complex mix of attributes to the decision-making process. Certain attributes such as openness, attentiveness and self-awareness shaped the ability of supporters to listen, enable and respect the voice of the person. When the supporter was open and attentive to what the person expressed, it helped the person find their voice and made them more likely to communicate their will and preferences. When the supporter was focused on their own goals and priorities, they could be closed to hearing what the person was communicating. Some supporters recognised their support could influence the person's will and preferences and developed strategies to try and minimise their influence. Other supporters used this awareness to try and change the person's will and preferences to align with their own goals and priorities for the person.

Sarah brought a range of attributes to the process of decision-making support. When she found out her son, Reuben, had Down syndrome she felt responsible for his disability, which led to feelings of guilt.

> In the beginning, it was guilt. It was guilt. It was totally guilt because I was feeling responsible. I have two children one is doing fine and the other one is not. So somewhere, something I did wrong. It is not going right and that was the guilt, I had it from the day he was born. (I: Sarah 1, p.1)

Sarah believed her experience of guilt motivated her to ensure her son had the support he needed to live a good life (I: Sarah 1, p.2). Sarah’s goal for Reuben was that he would live semi-independently in the future (I: Sarah 1, p.1). She believed his greatest needs were safety and the development of life skills (I: Sarah 1, p.1). To this end Sarah and her husband Michael sold their family home and moved to a gated community where they were preparing Reuben to live as independently as possible (F: Reuben, p.1). Five days a week Reuben engaged in an intensive skill development program which was directed toward helping him acquire important life skills such as accessing the library, gym, shops and doctor (F: Reuben, p.1). Reuben had little say over the development of the program,

> …he has to follow that one. He can make small decisions that I don’t want to do this one, but he can’t say I don’t want to learn this skill. Because those are the list of important skills for anybody in the routine of daily life so he has to keep up with those. (I: Sarah 2, p.6)

Sarah had strong preferences about her son Reuben’s life that she attributed to her family’s Indian cultural heritage. She explained,

> …this is my culture I don’t want my son to be introduced to girls because we believe in arranged marriage and I don’t want my son to drink. I don’t want my son to smoke. I don’t want my son to do drugs so I am going to tell you please don’t show him things wherever it is happening that is your job to protect my child. (I: Sarah 1, p.19)

Sarah wanted her son Reuben to “learn Indian ways” (I: Sarah 1, p.18) and asked staff to respect their culture in the way they provided support (I: Sarah 1, p.19). Decision making regarding Rueben’s social life was significantly impacted by his family’s cultural beliefs.

> …he doesn’t go out on his own. He goes with us. If we are going to relatives or friends he goes with us. And any activity we do he does with us… outside the house he hasn’t got any life. But we are giving him plenty of life. Activities like go to movie. Just the other day he went with his brother to a game. Things like shopping or visiting friends. All those sort of things which we do together. And this is the way of our culture. It is a cultural thing. (I: Sarah 2, p.1)

Sarah's beliefs about her son Reuben's need for protection meant he didn't access the community independently or develop friendships outside his family network (I: Sarah 2, p.1). These beliefs limited the opportunities Reuben was given to express his will and preferences and determine his own life. Sarah's beliefs about his cognitive ability also shaped the support she provided him when expressing his will and preferences.

> You know he is an adult but his mentality is not up to his age level. So you have to, at a certain point, put your foot down and say this is not for your safety. You have to you know. My older son, I don't make any decisions for him. I don't tell him what to do. But if Reuben is saying "it is 12 o'clock mum I am going out" I have to say "no this is the wrong time you can't go out you can't do it." But if my older son wants to go out that is his decision. He [his brother] is an adult he can make decisions. But at certain points you have to put your foot down. But we are hoping that he [Reuben] is independent, semi-independent. And we don't need to be making, he can make his own decisions. (I: Sarah 1, p.17)

Sarah brought a complex mix of attributes including her cultural values, beliefs and perception of Reuben's cognitive abilities, which contributed to shaping her openness to recognising and supporting his will and preferences.

Openness and attentiveness.

When supporters came to the decision-making process with the attribute of openness, they were curious about the person and invested time and energy getting to know them and their communication.

Veronica's brother Ryan moved to an institution called "Rideau" when he was a child because it was the only place in the area that could assist him with toilet training (I: Veronica, p.27). When allegations of abuse in the institution became known Veronica supported Ryan to share his experiences even though she understood it would take her family down a difficult path.

> I knew this was going to take us down a path and there are all sorts of discoveries down that path, the life experiences. But he will just start to talk, "ha gag a ga Veronica" this is how he talks. We need to figure out a sign. "What are you talking about?" And we would go through, then he would do this (gestures), and

> I'd go "Redo?" "Yeah." "Ok, so can we make a deal when you want to talk about Redo can you do this?" (I: Veronica, p.27)

Veronica supported Ryan to develop clearer ways of talking about his experiences at Redo. She was open to his communication and as a result, over time Ryan became stronger and more able to express his will and preferences "…because he knows we will listen to him" (I: Veronica, p.27).

There were times when the supporter was not open to the person's will and preferences because they had strong ideas about what they thought was best for the person. Elaine was a support worker who assisted Rueben to develop his literacy skills. Sarah referred to Elaine as "a military mistress" who had a disciplined approach to teaching her son (F: Reuben, p.11). One morning during their literacy skill development program Elaine asked Reuben if he wanted to move on to another task. However, she was not open to his response.

> R: "No." E: "Yes." R: "No." E: "Yes." R: "No." Elaine said "Who's going to win?" Reuben replied "Me." Elaine shut the conversation down yelling "NO ME!" (F: Reuben, p.15)

Elaine was often not open to Reuben's expressed will and preferences because she had already decided what the outcome of their interaction needed to be. Elaine refused to take no for an answer because when she wanted Reuben to work she could "get him to work" (F: Reuben, p.15). While Elaine accepted her role was to support Reuben to develop life skills, she saw his growing independence (seen in clear expressions of will and preference) as problematic. The following is an extract from observational field notes which describe an interaction between Elaine and Rueben's mother Sarah.

> Sarah went on to share about Reuben taking the initiative to make a smoothie this morning independently. She felt he was so proud of himself. Sarah turns to Elaine and says "Monster Reuben is coming out" with a big smile on her face. "You guys are getting this monster and the long term goal is for the monster to come out and for him to be independent." Elaine replies to Sarah "But we have to tame the monster." (F: Reuben, p.17)

Elaine perceived Reuben's growing independence was something that needed to be controlled. Her interactions with Reuben demonstrated she felt a need to control the outcome of their decision-making processes and in doing so she became closed and unresponsive to his expressed will and preferences.

Attentiveness to the person's will and preferences was often linked to the expectations and beliefs supporters brought to the decision-making process. An experienced supporter talked about the difficulty he had hearing his daughter express she wanted to become a yoga teacher because it did not align with his perception of her abilities.

> John had talked once about the fact that he didn't hear Karen when she had said she wanted to become a Yoga teacher. He was talking about how he didn't hear her maybe because her voice was so quiet or maybe because he in his own mind couldn't imagine that being a reality or a possibility. (I: Michaela, p.17)

If the supporter did not believe the person was capable of achieving something it made it easier to dismiss their will and preferences.

Self-awareness.

When supporters were self-aware they recognised the influence they could have over the person's expressed will and preferences. Sometimes supporters used their awareness to try and shape the person's will preferences and at other times, they used it to try and mitigate their influence.

When Dean spoke about his interactions with Cecily at her day program, he described in detail the strategies he used to encourage her to participate in an activity. Dean was very aware of how he could influence Cecily's will and preferences.

> …if I ask Cecily to do things, because I have a longer rapport with her compared with other staff, she will most likely do it. So I think the length of relationship determines that as well as the level of trust. And also your approach too. For me, I'm very soft when I approach Cecily. I always start off with a hug or a pat on the shoulder. After that I will ask her if she wants to do something. "I'm going to go out with this group would you like to come?" So there is a higher chance of her saying yes, right? Compared to another staff with a different approach. It

> depends on what she is used to, what she likes, and the length of time she knows that individual. (I: Dean, p.5)

Dean understood that because of the level of trust in his relationship with Cecily, and his knowledge about how to communicate with her, he was able to influence her to participate in activities.

When Annie spoke about her interactions with Natalie, she was aware there was a strong likelihood that she could influence Natalie's decision making so she employed strategies to try and remain neutral, and minimise her influence on Natalie's decision making.

> I have to be really careful and be aware that I don't put my preference on to her. So I always try to remain neutral. Many times she will ask, "what would I do?" Or "what do I think?" Or "what would I like?" You know and then I will just joke around with her. And I'm like "it doesn't matter what I like, I'm a vegetarian what do I know?" I just throw it out left field and then she is redirected and we laugh and we joke and we go back to it again in a few moments when she is not as stressed out and she feels calm again. And then I present to her again, "ok we have to make this choice, let's look at it again" and that seems to work. (I: Annie, p.4-5)

The strategies Annie employed such as encouraging Natalie to express her view first (I: Annie, p.6) and redirecting her attention when stressed (I: Annie, p.5) demonstrated her self-awareness and attentiveness to Natalie's needs. Annie understood that to be able to minimise her influence over Natalie's decision making she needed to analyse the way she went about providing support.

> You need to self-analyse. Self-awareness is really important in the work that I do because I can influence anybody without saying a word. And people who have developmental disabilities are sensitive to that. So it's really important to be aware of what you are saying, and how you are saying it, and what your body language is too. Because that can influence the person you are working with or supporting. (I: Annie, p.6)

Therefore, there were a number of important attributes supporters brought to the decision-making process which shaped the person’s ability to express their will and preferences. Attributes which contributed to assisting the person to express their will and preferences included openness, attentiveness and self-awareness (in most cases). Others which contributed to diminishing the person’s ability included having limited beliefs about the person’s capability and coming to the interaction with a specific outcome in mind.

(3) Quality of the support relationship.

Research participants had a range of relationships including familial (fiancé, siblings, parent/adult child, cousins), professional relationships (speech therapist, rehabilitation aide, key worker, group home staff), and friendships (microboard members, previous colleagues, previous support workers). In the model of the process of decision-making support, the relationship between the person and their supporter is referred to as ‘the support relationship’. The quality of each support relationship also varied. Quality in the support relationship was influenced by knowledge, trust, equality and respect. While each relationship type had natural advantages and disadvantages in developing knowledge, trust, equality and respect, high quality support relationships were observed across all relationship types.

The quality of the support relationship contributed to shaping the person’s readiness to express their will and preferences and the supporter’s willingness to hear and respect those preferences. It improved or diminished the openness of the person and their supporter to being influenced by one another. The perception the person and supporter had of each other (e.g., as equals to be respected) shaped the quality of their relationship which was an important influencing factor that shaped the process of decision-making support.

Knowledge.

The knowledge the person and supporter had of each other shaped the nature of their relationship. Knowledge was more than having specific information about the person, it meant knowing a person’s “essential self” and having “knowledge between people” (I: Michaela, p.1). To develop knowledge required “being part” of each other’s lives (I: Ailsa, p.5) and spending time together (I: Betty 2, p.15). Sometimes getting to know someone took a long time (I: Ailsa, p.6; I: Peta 1, p.6) but sometimes it was possible relatively quickly when there was intentional effort (F: Jenny, p.11). While some participants felt most known by family members (I: Natalie, p.19), others felt more connected to friends (I: Betty 1, p.15) and partners (F: Cecily, p.2). For some participants having particular supporters in their life for a long time did not necessarily result in a strong sense of being known or understood (I: Betty 2, p.11; I: Jenny, p.6).

When the supporter spoke about knowing the person they discussed having “a deep understanding of the person’s vision of their life” (I: Jason, p.10), knowing their “likes and dislikes” (I: Peta 1, p.6), as well as their “needs” (I: Shirley, p.9). This knowledge seemed to come through “trying things” (I: Ailsa, p.8) and “lots of lived experience” (I: Penny, p.1). For some supporters, part of getting to know the person was developing an understanding of how the person communicated (I: Sally, p.2), their “unique language” (I: Ailsa, p.8) and how to interpret their particular gestures and signs (I: Ruby, p.6). Knowing each other meant having shared experiences and developing an understanding of the things that were important to each other over time (I: Betty 2, p.15; I: Peta 1, p.24). For the person, knowing their supporter made asking for support easier (I: Betty 1, p.1) because they knew their will and preferences were valued. Natalie expressed this confidence in her father David when she was asked about whether she had expressed her preference to continue with her music therapy to which she replied “he knows I love music too much to go without it… he knows me” (I: Natalie, p.15).

When the supporter knew the person well, they understood the unique way the person expressed their will and preferences and how to support the person to clarify these. For example, it was not possible to ask Emily a question and “expect her to say yes or no”, she would show preferences for things in her own way (I: Sally, p.2). Sally developed an understanding of Emily and her preferences “over time” (I: Sally, p.2) discovering she would often agree to the last option presented to her.

> She never chooses the first thing so we realised that if you flip the choices and then she chooses the first thing that is really what she would like because that’s not the last choice anymore. So if I say to her “do you want eggs or oatmeal” and she still says “eggs” then I know that she actually wants that. But you don’t know that right away. (I: Sally, p.6)

When the person and supporter knew each other really well the supporter was able to support the person to communicate their will and preferences more clearly. Shirley learned that Cecily could only respond to questions about her preferences if they were phrased in a way that she could “grab onto” (I: Shirley, p.21). Shirley needed to link the concept to something Cecily was already familiar with and could understand. Shirley reflected “when I want her to think about something and give me her opinion or preference I do now spend more time thinking of how I’m phrasing the question” (I: Shirley, p.20).

When the person felt their supporter did not know them well, it could lead to a reluctance to go to them for support and express their will and preferences. Betty explained that her cousin Harriet was appointed administrator of the family trust (trustee) however she chose not to go to her when she needed support with her finances. “I don’t go to my cousin because I don’t feel I can… like my friends Sharon and Jason know me a lot better than she does” (I: Betty 1, p.1). Betty chose to share preferences with her friends Sharon and Jason who knew her well and would not “treat her like a child” (I: Betty 1, p.1).

Trust.

Trust shaped the quality of the support relationship. Trust grew out of respect that was built (I: Peta 2, p.4) or diminished (I: Betty 2, p.5) through shared experiences. Trust was the foundation of being able to influence each other and as a result carried with it a responsibility to act with integrity (I: Terry, p.5; I: Annie, p.10). The level of trust in relationships changed over time and could be broken when people acted with disrespect (F: Natalie, p.26, I: Betty 2, p.11).

Sometimes when there was trust in the support relationship, it gave the supporter confidence the person would speak up if they were not happy with their support. Michaela had confidence that Betty would not let her take over the decision-making process because she knew Betty was a strong self-advocate and trusted her ability to stand up for herself.

> …So I don’t try intentionally to be so careful about [influencing her] because I feel we have this trusting relationship and she’s not going to let me walk all over her. She is a strong woman… (I: Michaela, p.6)

While at times Betty’s confidence expressing her will and preferences wavered, she demonstrated her ability to push back against others who tried to impose their preferences on her (I: Betty 2, p.11; I: Betty 1, p.10). Trust built over time, and through shared experiences, helped Betty develop the ability to challenge her supporters when they were not listening to her.

Some supporters felt a weight of responsibility because they knew the person trusted them and could be influenced in the decision-making process. These supporters tried to respect the trust the person had in them by acting ethically. When supporting someone to express their will and preferences, Terry spoke about the importance of “not being convincing” in the way she presented information (Terry, p.5) and Arleen spoke about the importance of “providing all the information” relevant to a decision (F: Natalie, p.7).

While trust could be built over time, it could also be diminished through action or inaction. During a period of observation, Natalie’s father David shared about an experience Natalie had in hospital that eroded her trust in the staff who were supporting her.

> David explained Natalie had had to have surgery for a hernia a couple of years ago. She had had to have anaesthesia that she didn’t take to well. She did not like the loss of control when she was under anaesthetic and found the use of IV medication traumatic. It seemed to cause her pain particularly because the hospital staff insisted on inserting the IV into her left arm even after they were told that her left side is hypersensitive. One nurse would not pass the message on to another and even though they meant well they eroded the trust that Natalie had in hospital staff. (F: Natalie, p.26)

Over time, Natalie’s trust in hospital staff diminished when they consistently ignored her expressed will and preferences to have medication administered in a way that prevented her experiencing significant pain.

Equality and respect.

Equality is the state of being equal in status, rights or opportunities. In support relationships based on equality, the supporter identified with the person and saw them as “just like everybody else” (I: Sarah 1, p.5) focusing on how they were both similar and the experiences they shared as fellow human beings (I: Shirley, p.6; I: Annie, p.4; I: Ailsa, p.9). When support relationships were founded on “equal humanity” supporters challenged if the person’s status was “questioned on the basis of what they look[ed] like or what they [could] do” (I: Ailsa, p.1). Equal support relationships were characterised by reciprocity, “I’m a service to him and he’s a service to me…” (I: Ruby, p.1) and mutual friendship “we are friends and it’s a friendship where she needs more from me…” (I: Sally, p.10). When support relationships were not characterised by equality the person was seen as “so different” (I: Betty 2, p.10) and not entitled to the same rights (F: Jenny, p.12; F: Brian, p.7; I: Betty 2, p.10; I: Peta 1, p.27).

High quality support relationships were characterised by reciprocity, mutual friendship and respect for the preferences of the person. When the supporter saw the person as an equal and treated them with respect, they were open to the person’s will and preferences. Terry described her relationship with Betty as “very reciprocal” and based on “friendship” (I: Terry, p.11). When Terry provided Betty with support she conceptualised herself “as a sounding board” not there to solve the problem but “to listen and Betty figures it all out” (I: Terry, p.2). Terry saw Betty as the decision maker and that her role was to provide Betty with the support to understand relevant information in order to be able to make her decision (I: Terry, p.2). She enjoyed hearing Betty’s opinions and sharing her own with respect to her health care decision making (I: Terry, p.3). This openness and freedom for Betty to express her will and preferences was indicative of the equality and reciprocity that often characterised their support relationship. Reciprocity and mutual friendship was observed in number of other support relationships such as Cecily and her support worker Dean. When interviewed Cecily described her relationship with Dean in terms of reciprocity and his acknowledgement of her relationship with her fiancé David.

> I: If you had a problem who would you go to, who would you speak to?
>
> C: I’d talk with Dean.
>
> I: So if you had a problem you would talk with Dean. Why Dean?
>
> C: I talk with Dean and Dean talks to me. I talk to Dean and Dean takes me and David out for coffee. (I: Cecily, p.5)

Dean described his relationship with Cecily in terms of the trust between them that had been built over many years (I: Dean, p.5) and the respect he had for her preferences.

"Here at the day program Cecily speaks her mind, and sometimes we want her to be more active in the activities here and we also respect her decision not to…" (I: Dean, p.4).

Jenny and her brother Jack, who was her financial and health care representative, had a very different type of support relationship. Jack had a history of excluding and dismissing Jenny's preferences from significant decisions such as determining whether she would purchase half of their shared home (F: Jenny, p.8) and purchasing new furniture (F: Jenny, p.9). This exclusion also occurred regularly when supporting Jenny with everyday decisions about meal preferences (I: Jack, p.2) and household duties (I: Jack, p.5; F: Jenny, p.3). For example, when Jenny said she didn't like eating the crust of pizza Jack refused to accept her expressed preference.

> …now she won't eat pizza crust, she only eats the middle and throws it away which does not happen in my house so we have a fight. And the only good thing about it is that she knows she can't win, I'm very strict with that, and she knows it but she'll try all the time… if you think I'm going to give her pizza and cut around the whole outside and just give her the middle, that's not going to happen. I think it's the best part actually… (I: Jack, p.2)

Jack refused to accept Jenny's preferences and responded by trying to coerce her into eating the crusts.

> I watched her and she ate all around it and she got half way through it and I said that she was going to eat the crust and she threw it down and said "I'm not" and I said "you are, you will" and she did. She ate the whole thing so we're good. She will try it again, she will eat it next time and then she'll try and slough it off and then I will catch her, I know what to look for and how to correct her. (I: Jack, p.2)

The poor quality of the relationship between Jack and Jenny was a significant factor which contributed to shaping Jack's tendency to disregard Jenny's will and preferences.

(4) The environment.

Environmental factors such as time constraints contributed to shaping the ability and willingness of the person to express their will and preferences. As a support worker, Sally recognised she was responsible for ensuring she and Emily achieved their goals for the day, which at times meant keeping to a schedule. Sally explained that because of time pressure there were occasions she made decisions for Emily instead of supporting her to express her will and preferences. Speaking in relation to choosing from two good breakfast options Sally explained,

> …sometimes you do [make a decision for her]. You are on your own schedule. The time schedule does not matter to her. Sometimes for the sake of moving the day along you do make those choices. (I: Sally, p.6)

Some supporters suggested medical appointments were a context where the person needed time and support to ensure they could adequately express their will and preferences. Experience as a support worker had taught Lisa to arrange longer medical appointments for the people she supported. She did this because she knew they needed more time to process the information they were being provided which in turn enabled them to be able to express their treatment preferences. She explained “I would let the doctor know in advance, I am bringing in so and so, and you need to book a longer appointment (I: Lisa, p.3). More time also allowed the health professional to be able to provide information in a way that was meaningful to the person. Terry, Betty’s health care representative explained,

> …the doctors have been pretty good at making things more plain language… when I am in an appointment with her, there are times when I know I don’t understand so I am assuming that Betty’s not understanding and I need them to clarify. (I: Terry, p.3)

Betty was aware that in the past she had agreed to things because she had not “been given enough time to think about it” (I: Betty 2, p.17). As such, when a decision opportunity emerged in a context where time was limited, it could significantly limit the ability of the person to understand the situation and express their will and preferences.

(5) Nature and consequences of the decision.

If the person did not understand the nature and consequences of the decision, it could influence their will and preferences. Natalie was often unaware of how decisions and specific options might affect her in the future, and this had implications when expressing her will and preferences in relation to a decision opportunity. For example, when

Natalie was asked if she would like to go bowling with friends her mother made sure Natalie was aware that it would mean getting up at 9am to get there. Waking early in the morning was extremely difficult for Natalie so while she was interested in catching up with her friends, Natalie did not want to go badly enough to have to get up at 9am (I: Arleen 1, p.11). Gaining a greater understanding of the consequences of the decision (going bowling) changed Natalie's will and preferences.

Similarly, one afternoon during a shopping trip Natalie expressed she wanted to purchase a book for her mother as a Mother's Day gift. Natalie had been deliberating over a range of gifts for a number of weeks and Annie was supporting her to decide whether to spend the money on this particular gift or something else. After a long period of deliberation,

> Natalie still wasn't sure so Annie asked her "how much money do you have left?" She counted it and said "$60." Annie said, "I know you are definitely going to need $40 for dinner and a beer." Hearing this Natalie decided to wait and not buy the Jazz Gypsy book for her Mum. (F: Natalie, p.30)

When Natalie realised purchasing the book for her mother would mean not having as much money for her meal, it helped clarify her will and preferences.

Summary.

This section has demonstrated that all five influencing factors shaped the persons' will and preferences including their ability and willingness to express them during the process of decision-making support. The following section explores how the five influencing factors also shaped the second core element of the decision-making process, the supporter's response.

Supporter Responses to the Person’s Will and Preferences

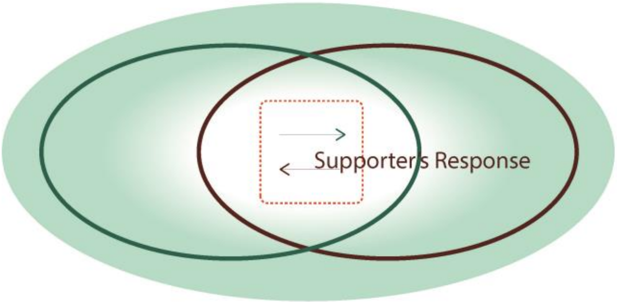

Figure 4-6. The supporter responds to the person’s will and preferences in relation to the decision opportunity.

The second core element of the process of decision-making support was the supporter’s response, which was also shaped by the five influencing factors. Changes in the influencing factors (e.g., increased risk to the person) and/or changes in the person’s will and preferences often resulted in changes to the supporter’s response.

As with the first core element, the experiences and attributes the person and supporter brought to the process of decision-making support shaped the supporter’s response. There were particular attributes that contributed to shaping the supporter’s response such as the person’s cognitive ability and motivation, and the supporter’s goals and priorities. When supporters had specific goals and priorities that did not align with the person’s will and preferences, they sometimes responded by trying to change them to align with what they believed was best for the person. Knowledge of the person allowed the supporter to respond to the person’s will and preferences in the broader context of their life and understand why they prioritised certain things. A lack of knowledge sometimes resulted in the supporter being unable to provide meaningful support to the person during the decision-making process. Environmental factors such as community attitudes and organisational expectations created pressure for supporters to limit the person’s exposure to risk. At times when the supporter knew others would judge their support, they acted cautiously when responding to risks. The subjectivity of assessing risk meant there were times when different supporters responded to the same risk differently.

(1) Experiences and attributes of the person.

Experiences.

The person's previous experience, or inexperience, sometimes contributed to shaping how the supporter responded during the decision-making process. For example, Carla questioned Jenny's preference to join in an activity because she had never tried it before. Carla explained, "How can you say yes to something you've never experienced, you don't know" (I: Carla, p.2-3). Similarly, when the person had participated in an activity before, their previous performance could be used to evaluate the reasonableness of their current will and preferences.

> So when we would swim I would push her to her limit swimming because I knew she could do it. I had done it before with her, she's had really good results swimming laps and I know she could do well. (I: Sally, p.2-3)

Attributes.

The person brought particular attributes to the process of decision-making support such as their cognitive ability and motivation that contributed to shaping how their supporter responded to their will and preferences. The cognitive ability of the person had the potential to limit their understanding of the nature and consequences of the decision and the circumstances in which decision making was taking place. Lisa explained her response to Eddie's preference to remain seated in his own faeces was shaped by her understanding of his cognitive ability.

> A lot of times someone like Eddie who has severe Autism he doesn't process things like that so would it really be fair to only focus on his preference? His preference to sit cross legged in that chair and not move all day long. Is that practical? It's not… I don't always know what is in my best interest until I've made the mistake but I can filter that information after I've done it and go oh geez I've got to suffer the consequences of that decision whatever they might be… It's not fair for me to assume that they are going to be able to make those same evaluations and assessments on themselves so again if I am going to arm

> them with information I need to make sure they are getting what I am saying. Everybody can nod and not hear a word you are saying… (I: Lisa, p.10)

When Eddie communicated he wanted to remain sitting in his own faeces, Lisa perceived this in light of his limited understanding of the consequences of doing so to his own health and his limited capacity to evaluate the outcome and learn from his “mistake”. Eddie’s limited cognitive ability led to her questioning the feasibility of his will and preferences and ultimately disregarding them.

Each person came to the process of decision-making support with differing levels of motivation. Some supporters questioned the person’s will and preferences because the person was generally perceived to lack motivation and needed to be pushed to improve their quality of life (I: Jack, p.3) and expand their world (I: Arleen 2, p.22).

Sally questioned whether Emily was “intrinsically motivated by things” because she would be happy to sit on the couch or lay in bed “for the long part of the day” (I: Sally, p.3). She believed without external encouragement and motivation, Emily would be extremely inactive and have a very low “quality of living” (I: Sally, p.3). Sally believed it was her role to help Emily “find things” that allowed “her to be motivated to live life to the fullest” (I: Sally, p.3). Emily’s lack of motivation shaped how Sally responded to Emily’s expressed will and preferences. When Emily expressed she wanted to cease an activity (I: Sally, p.2), or not commence an activity (I: Sally, p.3), Sally felt she needed to “push her” (I: Sally, p.2) in an effort to motivate her to do something that was “important for her” (I: Sally, p.3). Sally responded by clarifying or testing Emily’s expressed preferences in an effort to expand her levels of activity and improve her quality of life. A significant factor that contributed to shaping Sally’s response to Emily’s will and preferences was her perception that Emily lacked intrinsic motivation.

(2) Experiences and attributes of the supporter.

Experiences.

The experiences supporters had in their lives contributed to shaping how they responded to the person’s expressed will and preferences. In the previous section, when discussing the support relationship, Jack refused to accept his sister Jenny’s preference not to eat pizza crusts. When asked why it was important that Jenny ate the crust, Jack talked about his experience growing up in a family with limited money.

As a child Jack regularly ate the same meal for days because the family budget had been tight and it was more economical to cook in bulk and eat leftovers (I: Jack, p.5). Jack's response to Jenny's preference not to eat the crusts of bread or pizza (I: Jack, p.2) was shaped by the value he placed on frugality and "not wasting good food" (I: Jack, p.5; I: Jack, p.1) which he attributed to these formative experiences growing up.

Attributes.

The supporter brought their values, beliefs, priorities and abilities to the process of decision-making support which contributed to shaping their response to the person's will and preferences. Ailsa was conscious of the values and beliefs that shaped the approach she took to supporting her son Brian. She highly valued equality and respect and when her son expressed his will and preferences she expected his supporters to be attentive to and accept what he communicated. Trying to force Brian to do something he didn't want to do was disrespectful and something she would not tolerate.

> There are things he won't do but you don't put him in a behaviour modification program to make him to do it. You should accept. If there's something I don't want to do I'm not going to do it. *Laughs.* But we force people with disabilities to do all sorts of things that deep down that they wouldn't want to do. (I: Ailsa, p.8)

Ailsa believed acceptance of Brian's expressed will and preferences was linked to recognition he had "the same status as a human being and also as a citizen" (I: Ailsa, p.1). She believed when supporters went into the decision-making process without respect for the person, and what they communicated, they would make decisions based on their own values and experiences and "what you need to be able to do is try and get inside Brian's shoes for a little while and think about what it looks like to him" (I: Ailsa, p.6). Ailsa's values and beliefs shaped her response to Brian's expressed will and preferences and created in her a willingness to accept them.

Different supporters conceptualised their role differently and these beliefs contributed to shaping how they perceived and responded to the person's will and preferences.

When Lisa believed her role was to “help guide [Cecily] in a more healthy direction” (I: Lisa, p.1), she perceived Cecily’s will and preferences were something to be shaped or “tweak[ed]” (I: Lisa, p.12). When Terry believed her role was to “be a sounding board” (I: Terry, p.2), she perceived Betty’s will and preferences were to be “listen[ed] to” while Betty “figure[d] it all out” (I: Terry, p.2). When Annie believed her role was to “always try and remain neutral” (I: Annie, p.4-5), she perceived Natalie’s will and preferences were vulnerable to being influenced “so it’s really important to be aware of what you are saying, and how you are saying it” (I: Annie, p.6).

Jack’s beliefs about his role as a supporter, to ensure Jenny didn’t get the decision “wrong” (I: Jack, p.13), meant he perceived Jenny’s will and preferences as something to be “corrected” (I: Jack, p.2). Because of these beliefs when Jenny expressed her will and preferences, Jack often refused to accept them because he thought they were uninformed. For example, when Jenny refused to eat curry Jack was unwilling to accept her preference because he believed that she had been indoctrinated by their “bigoted” mother (I: Jack, p.4). Even when Jenny tried curry and expressed “she absolutely hate[d] it” he continued to “make her eat it” (I: Jack, p.4). Jack used coercion to try and change Jenny’s preferences regarding eating curry. He explained,

> …that’s what I instil, you don’t like it, that’s dinner! And I served it three times and I know she dreads it, she just absolutely hates it here, picking at it, she knows what to do to appease me... So do I make her eat it? I still will make it and it still will be the dinner, I still will serve it, she doesn’t have an option, she has to eat it, but I make sure there’s more salad or buns or something else that she likes with it… (I: Jack, p.4)

Jack perceived Jenny’s will and preferences through a lens of right and wrong, and he responded by disregarding her expressed will and preference (to not eat curry). Jack assessed the ‘rightness’ of Jenny’s preferences according to his own preferences (enjoyment of eating curry). He explained, “many times I give her the opportunity to make a decision and if she gets it right, yay, if she gets it wrong, I have to take a step back and explain why” (I: Jack, p.13). When the supporter believed a specific outcome was right for the person they often responded by trying to align the person’s will and preferences with their preferred outcome.

Each supporter brought beliefs about the decision-making ability of the person to the decision-making process, which contributed to shaping how they responded to the person's will and preferences. Arleen had a strong belief that her daughter Natalie was capable of making decisions and that her intellectual disability did not prevent her from knowing what was best for her life.

> …some people have an attitude of I am the grown up and I know better. And this person has Down syndrome and they don't know so I have to tell them. No, [I have seen this is not true] there were times when she was right and we were wrong. (I: Arleen 2, p.23)

In contrast, when supporters came to the decision-making process with limited beliefs about the person's capability to make decisions it sometimes created a perception that their will and preferences were not valid and could be disregarded. Sarah's limited expectations about her son's mental capacity (I: Sarah 1, p.17) and ability to make financial decisions (I: Sarah 1, p.17) led to his exclusion from conversations about his microboard, and his preferences about his skill development program being disregarded (F: Reuben, p.3).

The understanding supporters had of the concept of supported decision-making also contributed to shaping how they responded during the process of decision-making support. For a number of decision supporters supported decision-making was about primarily enabling the person to make their own decision. Terry was clear that she was "not making the decision" and her role involved bringing "her wisdom to the table too" (I: Terry, p.2). Jason believed supported decision-making was "mostly helping people to make a decision" which involved "providing information, it's helping make sense of the information, and it's providing advice in terms of direction (I: Jason, p.5). In supporting the person to make their own decision, Michaela thought of the assistance she provided as a cognitive prosthesis.

> I like the idea of the prosthesis where you are just an extension, you are kind of an accommodation to someone in the same way a wheelchair or a crutch would be used to help someone physically. (I: Michaela, p.1)

A small number of decision supporters believed supported decision-making could also involve making decisions for the person. When asked what Ruby understood supported decision-making to mean she answered “if I was to become incapacitated and I couldn’t make decisions for myself, and for what was good or bad for me, that someone would have to do that for me” (I: Ruby, p.7). Ailsa, the mother of Brian who had a severe intellectual disability, conceptualised supported decision-making as shared decision-making for people who would never be considered to have capacity to make decisions independently.

> It was clearly a way of making the proper decisions in the best interest of an individual who was unable to do that on his or her own behalf. And it was shared rather than substitute because the person always had to be part of that process. The person’s presence provided his or her share and the commitment of the other people provided the capacity. (I: Ailsa, p.1)

At times, supported decision-making was seen as a vehicle to enable the person to live their life to the fullest (I: Sally, p.14) by asking them “what do you want?” (I: Dean, p.3). Although in some circumstances supporters felt they needed to “guide” and “steer” the person

> …in a way that you are not steering them away from what they want but try to let them see that maybe there is a compromise. There is a halfway point that we can reach so that certain goals that you want can be accomplished, and I wouldn’t say the parents’ wishes, but realistically you will benefit from these decisions you make. (I: Dean, p.3)

Dean, a staff member at a day program, understood his role engaging in supported decision-making involved ensuring the person’s will and preferences were “realistic” and certain goals that others may have for the person “can be accomplished” (I: Dean, p.3). The perspectives supporters had about the concept of supported decision-making influenced how they perceived their role as a decision supporter and subsequently how they responded to the person’s will and preferences. Supporters that understood it was their role to support the person to make their own decision by providing information and impartial advice were less likely to try and change the person’s will and preferences than those who felt responsible for ensuring the person’s will and preferences aligned with the goals of others.

(3) Quality of the support relationship.

Differences in the quality of the support relationship contributed to shaping how the supporter responded during the process of decision-making support. Often when the supporter had a relationship with the person that was characterised by deep personal knowledge, trust, equality and respect they were more accepting of the person's expressed will and preferences. When the relationship lacked deep personal knowledge (e.g., not understanding the person's goals and priorities) or lacked respect it could result in the supporter ignoring, disregarding or trying to change the person's will and preferences.

Peta shared about the decision making of a young woman with an intellectual disability for whom she was an advocate. The Public Trustee supported this young woman to manage her finances. One day the young woman made a request to the administrator to purchase a bird but her administrator disregarded her will and preference because he did not understand the young woman's goals and priorities.

> I was her facilitator, her mentor, and she lived alone, she was very capable but the public trustee was involved because of money and this woman wanted a bird that she could teach to talk and the public trustee said no. And I'm thinking, a bird, why would they say no? They don't know her. They wouldn't know what that means in her life. (I: Peta 2, p.23-24)

The knowledge the supporter had of the person created an important context to understanding and responding to their expressed will and preferences. As well as knowledge, respect was an aspect of relationship quality that contributed to shaping whether the supporter attempted to change the person's will and preferences during the decision-making process.

Betty chose her representatives based on the quality of her relationship with each of them (e.g., knowledge of one another and personal closeness) rather than the length or type of relationship (e.g., familial) (I: Betty 2, p.15). Her health care representative Terry reflected on Betty's reasons for choosing friends rather than her brother as her health care representative.

> I think Betty has been so wise in choosing the friends this way and choosing the representatives where she knew she probably wouldn't have gotten that from

> her brother. Right, her brother would have been always steering her in the direction, which he thought was wisest. Where we just support Betty in her decision. We bring the information to her, we tell her the pros and cons of what we think but she still really is the person who is making the decision where I think perhaps with her brother it would be. Well you should do this, and this is why and all this sort of stuff. And Betty would do that and I think she is wise enough to know that her brother and or other people could do that with her. And she has chosen people that will not do that with her. (I: Terry, p.5)

Betty's friends respected her right to make decisions and provided her with support to clarify her preferences by providing information and support to understand her options. They accepted Betty's wishes and did not try and change them to align with what they thought was best. The quality of their relationships significantly contributed to shaping how they responded to Betty's preferences.

(4) The environment.

Environmental factors such as financial constraints, community attitudes and organisational expectations contributed to shaping how the supporter responded to the person's will and preferences. Environmental factors sometimes created pressure for supporters to limit the person's exposure to risk and there were times when supporters responded cautiously knowing their support would be judged by others.

At times the person's financial situation contributed to shaping how the supporter responded to the person's will and preferences. Betty had inherited a trust fund from her parents that provided her with an income that would be challenging for her to spend in her lifetime (I: Jason, p.4). Given her affluence, her financial representative Jason believed it was not necessary to "sweat the small stuff" as far as Betty's spending was concerned (I: Jason, p.12).

In contrast, Natalie's income was the disability support pension ($900 per month), $350 of which went towards rent (I: David 2, p.19). When Natalie expressed a preference to buy a shirt that was about $12 her mum wanted her support worker Annie to check it wasn't too small before they went ahead and purchased it (I: Arleen 2, p.17). If the shirt was more expensive than $12, her mother became involved in the purchase herself (I:

Arleen 2, p.18). The limited funds available to Natalie played a role in whether her parents tried to change her will and preferences when purchasing specific items.

The financial situation of the supporter could also shape their response to the person's will and preferences. Peta had seen decision opportunities limited by the financial situation of her friends and she, and her husband, had tried hard to ensure money did not limit their capacity to respond to their daughter's will and preferences.

> She does ask to go to shows and stuff… I try not to let money inhibit too much what she does, she does get her disability pension and it is hers. I have friends who have all these hard and fast rules about you see one movie a month and eat out for lunch once a week, well Emily is 36 and I don't want to put those rules on her, whatever friends and staff want to do, I want her to be able to take part in without having to worry too much. We're lucky we can afford to accommodate that, not everybody can. (I: Peta 2, p.15)

The rigid structure of congregate care settings often prevented staff from being able to accommodate and support the preferences of the person. The need to meet organisational requirements also shaped how supporters in these environments responded during the process of decision-making support. When Betty moved into a group home, the weekly cleaning routine stopped her from being able to continue a long-standing family tradition. Sundays had always been a family day for Betty (I: Betty 2, p.19) when she would travel from wherever she was to spend time with her parents.

> …I can remember the staff saying when we moved in that that was one of the rules. That the five or four of us had to clean the whole house from top to bottom on a Sunday, and you couldn't go out until we got it all done. So it wasn't like we had a choice in the matter. (I: Betty 2, p.19)

There were times when the supporter experienced pressure from their employer to support the person to align their will and preferences with organisational goals and priorities. When supporting Cecily at her day program, Dean felt he had to encourage Cecily to do activities that were more physical (I: Dean, p.4). While Dean respected Cecily's preferences to go for coffee and create art, his response to her activity planning was shaped by the goals and priorities the day program had for her (more physical activity). Dean responded by trying to shape Cecily's will and preferences to align more closely to the program's goals. He did this by linking activities he knew Cecily preferred such as going for coffee with non-preferred activities such as walking (I: Dean, p.4).

(5) Nature and consequences of the decision.

If the decision was perceived to involve risk or the potential for serious adverse consequences, it contributed to shaping how the supporter responded to the person's will and preferences. Supporter responses were also shaped by the potential consequences of the decision on the person, themselves and third parties.

People identified and perceived risk differently and there were often differences in the way various supporters responded to the person's will and preferences as a result. Betty described a frustrating decision-making process she had been involved in with her friend Dale. Betty expressed her desire to take Dale out for a walk in the community to Dale's support staff. When discussing the proposed decision, some support staff said "oh no, you can't do that, something might happen" (I: Betty 2, p.2). Betty was clear that she would return to the group home if "something happened" and could call for assistance using her cell phone if necessary (I: Betty 2, p.2). "But you see we got mixed messages. Some staff said 'sure, you could do that', and then others would say 'that's a risk for her'. So who do you believe?" (I: Betty 2, p.2).

Different support staff perceived the risks to Dale being out in the community with Betty differently. These differences in the perceived risk resulted in different responses. When Betty's will and preference (to take Dale for a walk) was perceived to have serious adverse consequences it resulted in the request being denied (I: Betty 2, p.2).

A number of supporters talked about risk as a difficult and complex aspect of responding to the will and preferences of the person. For Jason there was a tension between "paternalism" (I: Jason, p.12) and "the right to take some risks" (I: Jason, p.13) and he was unsure "where you draw the line" (I: Jason, p.13) when responding to the person during the process of decision-making support. Betty had expressed a desire to have complete control over her money and Jason expressed his concern about the long-term consequences of getting rid of financial management.

> I think a parent's worst fear would be ok let's give Betty all her money and if she blows it and gets taken advantage of well that's her life to live. If she ends up back on disability benefits or on the street or whatever well that's just the

> consequences of making your decisions kind of thing. I think that's where there is a parental attitude that's involved in it. You wouldn't let that happen to your child if you could prevent it. So why would you let it happen to anyone else solely for the purpose of self-determination. (I: Jason, p.11)

Jason acknowledged that while self-determination and supported autonomy were very important, he believed vulnerability and the consequences of certain decisions could justify overriding or disregarding the person's will and preferences in certain circumstances.

Many supporters felt comfortable disregarding the person's will and preferences, if acting on them could mean serious health problems with long-term consequences. A number of supporters expressed it was part of their role to support the person to align their will and preferences with healthy options (I: Dean, p.4; I: Lisa, p.1; F: Reuben, p.7; I: Penny, p.11; I: Alec, p.8; I: Sally, p.3; I: Peta 2, p.16). For example, limiting their choices to only healthy options. However, there were some supporters, who despite perceiving the risks involved and long-term consequences of poor health choices, valued the person's right to make decisions that were not healthy. These supporters assisted the person to make health decisions that would likely lead to poor health outcomes (I: Lydia, p.2; I: Annie, p.7; F: Natalie, p.10) and resisted significant community pressure to intervene and "protect" the person from risk (I: Lydia, p.6). For example, Annie accepted Natalie's preference to cease swimming even though it would likely have a negative effect on her limited mobility (I: Annie, p.7).

When responding to the person's will and preferences, sometimes the supporter had regard to the consequences of the person's preferences on themselves and others. While out having coffee one day Cecily told her sister Shirley she wanted a cell phone (F: Cecily, p.15). Some years ago, Cecily had owned a cell phone and had used it to contact "people all the time" (I: Shirley, p.13). Shirley believed if Cecily had another phone, she would be calling her and staff "at all hours" (I: Shirley, p.13). Even though Cecily asked to have a cell phone on many occasions (F: Cecily, p.7; F: Cecily, p.15; I: Shirley, p.13) her requests were dismissed. When asked if she thought Cecily could have another cell phone Shirley responded,

> I don’t think so and the reason I say that is because when you’re in a group home if one gets a phone then why can’t all of them have a phone and then how do the staff monitor them, so I think it’s a logistics thing. (I: Shirley, p.13)

There would be consequences for staff if Cecily was to obtain a cell phone. It could lead to other residents also wanting a phone and difficulties for staff in monitoring their use. It was the potentially negative consequences of Cecily’s proposed decision on her supporters that led to them ignoring her expressed will and preference.

Chapter Summary

This section has demonstrated that all five influencing factors shaped the response of the supporter to the person’s will and preferences during the process of decision-making support. This first chapter of the research findings has outlined a conceptualisation of the process of decision-making support that involved two core elements (the person expressing their will and preferences and their supporter responding) in relation to a decision opportunity. These core elements were constantly being shaped by five influencing factors: the experiences and attributes the person and their supporter brought to the process; the quality of their support relationship; the environment in which decision making occurred and the nature and consequences of the decision.

The second chapter of the research findings illustrates how the five influencing factors shaped the dynamic interaction of the person’s will and preferences and the supporter’s responses during the process of decision-making support. By exploring three decision-making examples in detail the following chapter explores the complex, dynamic interaction of factors which shaped the process of decision-making support.

Chapter Five:

Research Findings

The Process of Decision-Making Support in Practice

The second chapter of the research findings explores the model of decision-making support in practice by examining three decision-making processes in significant detail. Each decision-making example illustrates the complexity of the process by showing how the influencing factors shaped the dynamic interaction of the core elements (the person's will and preferences and supporter's responses). The chapter concludes by reflecting on how the three decision-making examples demonstrate the dynamic, recursive and contextually dependent nature of the process of decision-making support.

Decision-Making Example One: Is Emily Ready to Go?

The following decision-making example explores an interaction between Emily and her supporter Sally at the swimming pool. The example shows how the five influencing factors shaped the expression of Emily's will and preferences, Sally's responses and the dynamic interaction between them. The interaction was shaped by:

(1) the attributes and experiences Emily brought to the process including her love of swimming and lack of intrinsic motivation;

(2) the attributes and experiences Sally brought including her respect for Emily's preferences and beliefs about her role to motivate Emily;

(3) their support relationship of which a strong feature was their accumulated knowledge of one another gained over ten years;

(4) the environmental pressure Sally experienced to uphold the values and expectations of Emily's family (her employer) to "push" Emily to be healthy and finish what she started, while ensuring she didn't become stressed in the process; and

(5) the judgement Sally made about the poor quality of life Emily would have if she wasn't extrinsically motivated to engage in physical activity such as swimming.

It was the complex interaction of all of these factors that shaped Sally's response - initially to try and change Emily's will and preference (pushing Emily to swim a few more laps) and eventually accepting her preference to stop.

Person's experiences and attributes.

Emily.

Emily was described by her mother as an easy going, loving and happy (I: Peta 1, p.5) 36 year old woman. Emily lived in a self-contained apartment in the basement of her parent's three-storey home in Vancouver. Emily loved looking nice (I: Peta 1, p.5), catching up with friends for coffee, swimming laps in the pool and watching her favourite TV show - the Price is Right (I: Peta 1, p.6). Emily was not someone who was "intrinsically motivated" (I: Sally, p.3). She would be happy to spend most of the day sitting on the couch watching TV or lying in bed (I: Sally, p.3). She understood her day as "chunks of activities" rather than time (I: Sally, p.4) and thrived on routine and knowing what to expect (I: Sally, p.2).

One of the activities Emily first tried was swimming because her mother wanted to ensure she would always be safe in the water. It was not a choice Emily made (I: Peta 2, p.11). It was something she "had to do" and her mother believed it "worked out" because Emily loved swimming laps and wanted to continue doing it (I: Peta 2, p.11). Swimming was part of Emily's weekly schedule of activities (F: Emily, p.3), even though sometimes she could be reluctant to participate (I: Peta 1, p.11). Her mother Peta explained,

> …she and I are so in sync, I love to swim and I hate going swimming if you know what I mean. I hate going there, I hate getting my bathing suit on, I hate being cold, but once I'm in the water I absolutely love it and I think she's very much the same so once she is in she loves it but the whole idea of it is, so I think that's a lot of it cause when she has been pushed a little bit she's been fine… (I: Peta 1, p.11)

Emily used a mixture of expressions, vocalisations and body language to communicate her preferences. Her communication had to be interpreted by her supporters and it wasn't always straight-forward. Often when Emily was given two options to choose from, she would "choose the last option" (I: Sally, p.6). Through experimentation her supporters learned if you "flip the choices and she still chooses the first thing that is really what she would like" (I: Sally, p.6). If she didn't have a preference she would choose the last option each time because "it really didn't matter to her" (I: Sally, p.6).

Emily engaged in regular volunteer work doing administrative tasks at a community organisation (F: Emily, p.3) and physical work at a friend's horse stable (F: Emily, p.2). She had a wide and active circle of friends despite being quite limited in her verbal communication. This social network was the result of intentional, proactive support by her family since she was very young (I: Peta 1, p.2). Her family had prioritised social connection and inclusion over other life goals like independence.

When Emily's mother Peta realised her daughter wasn't going to develop certain skills like the ability to read and write she decided to focus on supporting her daughter to develop friendships that could actively assist her to participate in community life (I: Peta 2, p.9). Peta wanted the people helping Emily with her decision making to know her deeply (I: Peta 1, p.24), love her (I: Peta 2, p.19) and share the same values and priorities as her family (I: Peta 2, p.24).

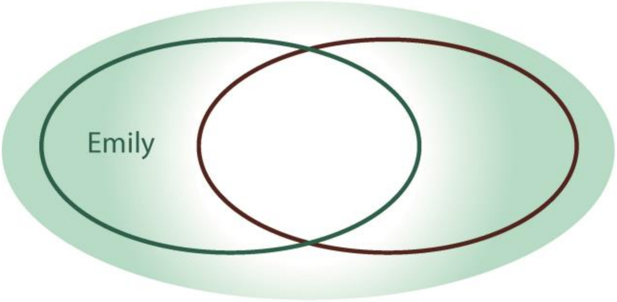

Figure 5-1. Emily brought her prior experiences and unique personal attributes to the process of decision-making support.

Supporter's experiences and attributes.

Sally.

Sally was one of the support workers who regularly spent time with Emily. They had met through a mutual friend who had done some work with Emily and recommended Sally consider joining her support team (I: Sally, p.1). Right from their first meeting there was an instant connection "where we kind of got each other" (I: Sally, p.1). Emily would laugh with Sally and she had assumed this was a common thing until Peta clarified "she never giggles or laughs with other people, I think you are the first one outside her family" (I: Sally, p.1).

Over the ten years they had known one another, Sally's perspective on people with disability had changed. Being with Emily had taught her not to define people with disabilities by their disability. She saw Emily "as a friend first and not as a person who require[d] support" (I: Sally, p.15). She was aware other support workers approached supporting Emily in a functional way but she rejected seeing her "as a thing to move along through the day" (I: Sally, p.10). Sally conceptualised the support she provided as "holistic", catering to "all sides" of Emily including her emotional and relational well-being (I: Sally, p.9). Sally believed an important part of her role was finding things that motivated Emily to live her life to the fullest (I: Sally, p.3). She believed without this type of support and accommodation the "quality of living for Emily would be very low" (I: Sally, p.3).

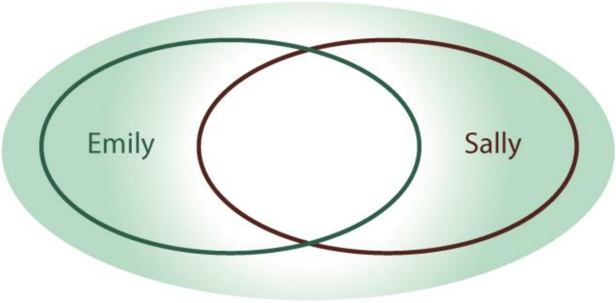

Figure 5-2. Sally brought her prior experiences and unique personal attributes to the process of decision-making support.

Support relationship.

Emily had the ability to sense people in her own way (I: Sally, p.1) and connected with Sally's calm, easy going nature (I: Sally, p.1). Emily trusted Sally and demonstrated this by anticipating their time together (I: Peta 1, p.6), wanting to share important life events (I: Peta 1, p.21) and being open to receive her support when anxious and feeling vulnerable (I: Sally, p.5).

Over time, Sally learned the way information was provided to Emily about her day was important. Knowing about an upcoming activity could be very motivating but it also had the potential to prevent Emily from being able to remain engaged in something she was already enjoying (I: Sally, p.4).

Sally and Emily shared a love of laughter, family and travel that allowed them to develop “quite a special friendship” (I: Sally, p.1). The relationship was reciprocal, mutual and unique (I: Sally, p.10). It asked more of Sally than her other friendships, because of Emily’s support needs, but she also received a lot from the relationship (I: Sally, p.10).

> I think [Emily] just helps you to slow down. I mean Emily is not a fast person, she doesn’t move fast, she doesn’t do anything fast accept drink her coffee very fast, but she helps you to live in the moment more because you can’t go any faster than that and that’s fine. (I: Sally, p.10)

Sally was confident making choices for and with Emily because she knew her well (I: Sally, p.15). She believed when making decisions with someone who has difficulty expressing their own preferences “relationship is pretty key” (I: Sally, p.15). Over the ten years they had been friends Sally had developed an understanding of how Emily made decisions.

> …the way Emily makes decisions isn’t by saying yes or no necessarily. I think she shows preferences for things in her own way which she communicates. So it’s not something where you can ask her a question and expect her to say yes or no. It’s being with her and understanding who she is and through that over time you understand what she prefers. And it’s not a fast decision-making process it’s over time. So when it comes to things like making decisions for her in her life it’s not going to be asking Emily a simple, what we would believe are simple questions. It would be understanding her. Developing a relationship with her. It is the only way you would get to know what it is that she wants to do. And it’s the only way we can help her make decisions. (I: Sally, p.2)

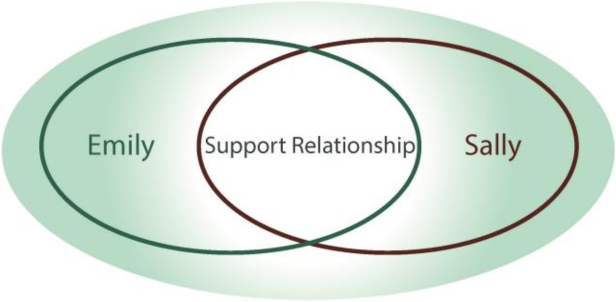

Figure 5-3. Emily and Sally developed their relationship over ten years.

Environment.

The values, goals and priorities of Emily's family influenced the support Sally provided to Emily (I: Sally, p.12). There were a number of values and beliefs that were central to their family culture: the importance of all family members being respected and treated equally (I: Peta 2, p.19), the importance of health and exercise (I: Peta 2, p.16), the importance of finishing what you start (I: Peta 2, p.15), and the need to push people sometimes to do things that they don't want to do (I: Peta 1, p.21). These family values and beliefs influenced the approach Sally took to providing support.

When supporting Emily with her decision making at the pool, Sally was aware that Emily's family wanted her to exercise and as a result Sally felt she should try to "maximise" her participation in physical activity (I: Sally, p.3). There was a clear directive from Peta that just because Emily expressed she wanted to move on didn't mean that the activity was necessarily over (I: Peta 1, p.11). It was important to "push her a little bit" and see if "she falls for it" however "if she doesn't you've got to listen to her" (I: Peta 1, p.11).

Sally knew that if Emily was "anxious" or "feeling unwell" she needed to "lessen her anxiety" (I: Sally, p.5), because if Emily became distressed in public it was "no fun for anyone" (I: Sally, p.5). Peta did not want attention brought to Emily in public when she was not expressing herself "in a very calm manner" (I: Sally, p.5). There was a fine line Sally needed to walk between pushing Emily and ensuring she didn't become anxious or distressed. If there were a risk that pushing Emily would compromise how she was seen in public, Sally would just “check it off and try again next time” (I: Sally, p.5).

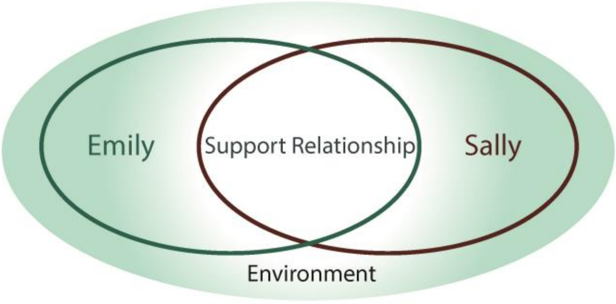

Figure 5-4. The goals and priorities of Emily’s family shaped the decision-making environment.

Decision.

Decision opportunity.

Sally took Emily to the local pool regularly, swimming laps and going in the hot tub together (I: Peta 1, p.11). Some days she would have “a really good swimming day and she could just keep going” and other days “she would not want to swim any laps at all” (I: Sally, p.3). Sally regularly provided support to Emily regarding her participation in swimming. Sally recalled one day in which Emily had been happy to initially participate in swimming but had started to express her desire to leave the pool after only swimming twelve laps (I: Sally, p.3). Emily said to Sally “time to go see mum” which was one of a number of ways she could communicate “I’m done” (I: Sally, p.3). Sally perceived Emily needed support deciding whether to continue participating in swimming and just because Emily communicated it was “time to go see mum” did not necessarily mean that the activity was over (I: Sally, p.3). Sally interpreted Emily’s communication as creating a decision opportunity. She needed to clarify her will and preferences as to whether she wanted to continue swimming any further.

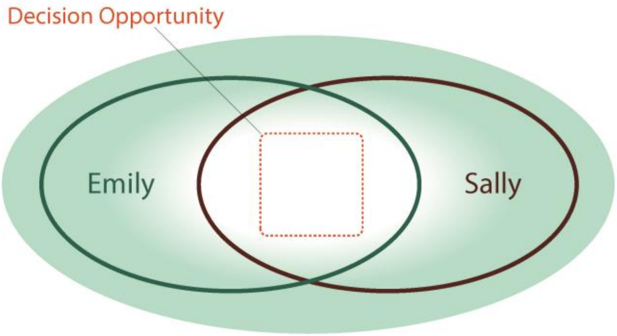

Figure 5-5. A decision opportunity emerged regarding whether Emily wanted to continue swimming in the pool.

Nature and consequences of the decision.

Sally needed to consider the nature and consequences of participating in swimming for Emily. She was aware of Emily's intrinsic lack of motivation to participate in exercise and the importance of her engaging in activities such as swimming to ensure she maintained good health. Sally believed that without external motivation to participate in exercise the long term consequences would be a "quality of living for Emily" that was "very low" (I: Sally, p.3).

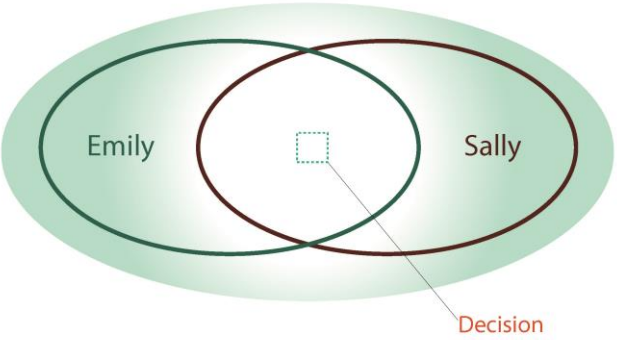

Figure 5-6. The decision to continue swimming had consequences for Emily's quality of life.

Dynamic interaction between Emily’s will and preferences and Sally’s responses.

Sally knew how many laps Emily was capable of swimming and felt it was appropriate to push her because she “knew she could do it” (I: Sally, p.3). Sally’s perception of Emily’s need for support had been informed by years of swimming together and as a result Sally knew Emily’s “capabilities” and what she could “manage” (I: Sally, p.3). She felt it was important to push her in this instance because she knew “exercise wasn’t her favourite thing” but that it was “important for her and for her family that she does” it (I: Sally, p.3). There was also a chance that Emily could be “testing” her as child tests one parent who may “give in a little quicker than the other” (I: Sally, p.3).

Sally suggested to Emily “we are just going to do this many more” laps. She made sure she was in the pool with Emily and able to observe “the way she looks”, “feels in the moment” and “the things she is saying” (I: Sally, p.3). Sally became aware through Emily’s family that Emily could only be pushed so far and then she would “put on the brakes” if she wasn’t interested (I: Peta 1, p.9). Emily was not a passive recipient of support and knew how to end an activity if she didn’t want to do it (I: Sally, p.5; I: Peta 1, p.10). It was not often that Emily really put her foot down but when she did it was important to listen because she was obviously “trying to tell” her supporters “something” (I: Peta 1, p.11).

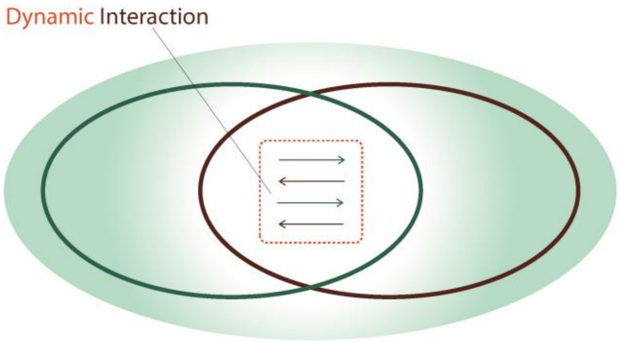

Figure 5-7. There was a dynamic interaction between Emily’s expressions of preference and Sally’s responses.

Resolution of the decision opportunity.

Sally respected Emily's communication and when she eventually made a comment about lunch it was clear she was ready to go. They both stopped swimming immediately and left the pool together (I: Sally, p.3).

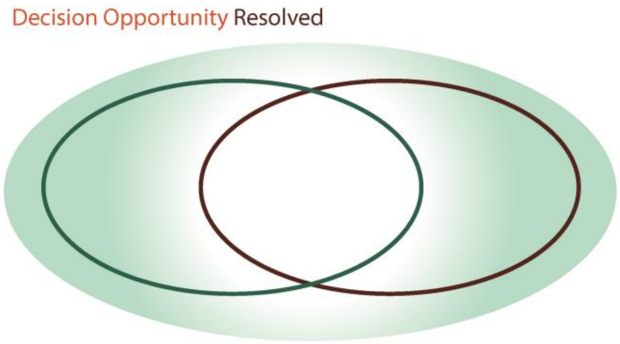

Figure 5-8. The decision opportunity was resolved when Sally accepted Emily's expression of will and preference as her decision.

Reflection on the decision-making process.

It was the complex interaction of the core elements and influencing factors that shaped Sally's responses during the decision-making process and Emily's influence over the outcome. The interaction between Emily's lack of motivation, the expectations of her family and the consequences of her not engaging in physical activity shaped Sally's desire to change Emily's will and preferences. While Sally believed it was appropriate to try to "push" Emily at times, she ultimately respected Emily's will and preferences. The quality of their relationship meant when Emily clarified her will and preferences Sally accepted them. Throughout the process of decision-making support, how Sally responded changed Emily's influence over the decision-making process. Initially, when Sally responded by seeking to change Emily's will and preferences, she reduced Emily's influence over the outcome of the decision-making process and later when she accepted her will and preferences she increased her influence.

Decision-Making Example Two: Does Natalie Want To Quit?

The following decision-making example explores a series of interactions between Natalie and her rehabilitation aide Annie who needed to determine whether Natalie wanted to continue swimming as a form of physical therapy. The example illustrates how the five influencing factors shaped the expression of Natalie's will and preferences, Annie's responses and the dynamic interaction between them. The interactions were shaped by:

(1) the attributes and experiences Natalie brought to the process including positive experiences growing up having her autonomy respected, her current weight and health issues, her history of indecisiveness and her tendency to be a people pleaser;

(2) the attributes and experiences Annie brought including her desire to help Natalie find her voice and develop her ability to make decisions and her understanding of her role as a rehabilitation aide to motivate Natalie;

(3) their support relationship which was characterised by deep knowledge, mutual respect and trust;

(4) the environmental pressure Annie experienced including the expectations of Natalie's parents who were Annie's employer and the important link between Natalie's rehabilitation program and her individualised funding; and

(5) the nature and consequences of the decision which were potential financial losses, if Natalie did not meet the requirements of her individualised funding and the physical effects of her not exercising, such as weight gain and immobility.

It was the complex interaction of all of these factors that shaped Annie's response to accept Natalie's will and preference to cease swimming in the short term and clarify her will and preferences regarding alternatives for the future.

Person's experiences and attributes.

Natalie.

Natalie was a 28 year old woman who was passionate about the environment and using technology. Natalie referred to her parents David and Arleen as guardians as she believed “nature” was her real parent (I: Natalie, p.2). Natalie experienced a significant amount of ill health in her younger years. She was born with Down syndrome and when she was three years old was diagnosed with Leukaemia. After a period of chemotherapy she was cleared of the condition though she continued to be “tortured a lot” by her chemo burn (I: Natalie, p.17).

When Natalie was 16 years old she had a stroke which resulted in left sided paralysis and significant speech, vision and memory impairments (F: Natalie, p.1). After six months of intensive and ongoing rehabilitation she relearned to walk and talk. Despite years of therapy Natalie relied on an electric wheelchair to travel medium to long distances in the community.

Natalie’s rehabilitation aide Annie explained that when she first met Natalie after the stroke “she was shy, insecure and scared” (I: Annie, p.1). There were times when Natalie lacked confidence in her ability to communicate her needs and preferences saying things such as “I don’t know much about myself” (Natalie, p.1). During these times of insecurity Natalie would let others speak for her (Natalie, p.18). Her mother Arleen reflected:

> She was very shy and part of the difficulty is that she speaks very softly and she has the usual problems that people with Down’s have articulating certain sounds. And then, of course having the stroke made it worse. So a lot of the time people don’t understand what she is saying. So that makes it sometimes difficult for her to communicate. But also because she was really shy she would tend to let us talk for her. (I: Arleen 1, p.9-10)

There were other times when Natalie expressed confidence in herself saying things like “I have never been normal. Who would want to be normal?” (F: Natalie, p.23) When she was feeling confident, she would communicate in a way that was self-assured and focused on her abilities saying things like “I’m very good at drumming” (I: Natalie, p.2).

Natalie grew up in a home environment that respected her wishes and where she was supported to make her own decisions (F: Natalie, p.7). Natalie had been given opportunities to learn through experience, which had allowed her to define her own limits (I: Arleen 1, p.10; F: Natalie, p.15). David and Arleen advocated for Natalie to be seen as capable, and demanded that others respect her will and preferences (F: Natalie, p.7).

Natalie had always been an “indecisive person” who needed a lot of support and encouragement to make big and small choices in her life (I: Annie, p.1). She was a “people pleaser” (I: Annie, p.5) who often felt “overwhelmed about making a decision” (I: Annie, p.2). In situations where Natalie could not decide between two options, her supporters would assist her to go through the “pros and cons of each” (I: Annie, p.2). Natalie often needed to have complex decisions broken down into smaller bounded choices and to be asked questions in order to clarify her will and preferences (I: Annie, p.1). Over the years, Natalie had developed a greater ability to push through her uncertainty in the decision-making process although she continued to need support with her decision making (I: Annie, p.4).

Over the last few years Natalie had experienced “quite a large weight gain” (I: Annie, p.9) and was no longer able to stand “on a regular scale” to be weighed. She needed to be taken to a hospital environment to determine the extent of the weight gain and this had not occurred despite encouragement from her physical rehabilitation aide Annie (I: Annie, p.9). Members of her microboard were concerned about the long term effects of the weight gain on Natalie’s wellbeing especially with her history of stroke (I: Matthew, p.11).

Supporter’s experiences and attributes.

Annie.

After Natalie’s stroke, David and Arleen employed Annie as a rehabilitation aide to implement physiotherapy and occupational therapy programs, support Natalie to access the community and develop her life skills (I: David 1, p.1). Annie took an “all encompassing” approach to her rehabilitation work with Natalie treating “the whole person” (I: Annie, p.1). This involved motivating Natalie using music and humour, helping her find and use her voice, and doing physical therapy (I: Annie, p.1; F: Natalie, p.16). Annie believed swimming was very important for Natalie because it was “a place for her to get a cardio workout” that was easy “on her joints, because she can’t walk. I mean she can walk but it’s at a slow pace and she gets hip pain… So it goes without saying that swimming is very, very important [for her health]” (I: Annie, p.7).

Annie was implicitly trusted by Natalie's guardians who had given her "more and more freedom over the years" (I: David 1, p.4). Annie believed her role as a supporter was to "always try and remain neutral" being careful not to put her "preference on to" Natalie (I: Annie, p.4-5). She was aware her word choice and body language could "influence" Natalie when providing support (I: Annie, p.6). Annie tried to reduce her influence by using "self-analysis" (I: Annie, p.6) and becoming clearer about her own "preferences" and "views" in relation to the proposed decision (I: Annie, p.6). Annie was strategic about the way she elicited Natalie's views to minimise her influence on Natalie's will and preferences.

> I didn't know how she felt about things so I was very careful not to tell her what I was thinking or feeling or what my stand was on anything. I always allow her to express her view first. And it was difficult because sometimes she would not want to do that because she was feeling insecure and she would rather hear what I thought before she said what she thought. So again, it's like gentle persistence in saying "no tell me what you think I'm really interested in what you have to say" "I don't know that guy, who is that guy, what Councillor is that?" I would get her to explore her feelings and what not. (I: Annie, p.6)

However, there were times when Annie had to support Natalie to accept the limits set by her guardians when making decisions and in these situations she understood the way she presented something mattered. She had learned over time "if I can make it seem like something is more of her idea, then it's more readily welcomed" (I: Annie, p.1).

Support relationship.

Natalie and Annie had known one another for over eleven and a half years (I: David 1, p.1) and in that time developed deep knowledge, respect and trust in one another (F: Natalie, p.16). Annie had become one of the "three primary decision makers" in Natalie's life, taking on a "big sister role" (I: David 1, p.1). Natalie saw Annie as her therapist, friend and family member and when they were together, Annie moved between these roles constantly (F: Natalie, p.14). It had taken a couple of years to determine whether her own "ways", "style" and "philosophy" meshed well with Natalie and her guardians (I: Annie, p.2). A "good fit" was "crucial" to the success of "any kind of therapy" (I: Annie, p.2) and Annie was pleased when early on it became evident her therapy was "working" (I: Annie, p.2).

A familiar ease existed between Natalie and Annie when they spent time together (F: Natalie, p.14). They knew a lot about each other which was evident in their conversations. When out doing a therapy session in the park one afternoon, Natalie and Annie spoke about their dinner plans. Natalie was going to Whitespot with her guardians and said "I know what Annie would order if she was coming… A veggie burger!" Annie laughed because she was right. "She does know me very well"" (F: Natalie, p.15).

Annie respected Natalie's feelings and took pains to act consistently and with integrity. "I always like to be where I say I am going to be so she can always trust in that. And if I'm not there she worries that something's happened because she knows that I'll always be there" (I: Annie, p.10).

Environment.

Annie tried to create a decision-making environment that was casual and laid back (I: Annie, p.1) because Natalie experienced "pressure" from her guardians and it was important there wasn't "too much on both sides" (I: Annie, p.1). Annie walked a line between supporting Natalie to make her own decisions "she does have choices" and supporting Natalie to accept the boundaries her guardians set "we just have to work within what mum and dad said" (I: Annie, p.1). Natalie's decision-making environment consisted of "a team of people" (I: Annie, p.2) with differing views.

The decision-making environment was shaped by the family's financial situation and the conditions upon which Natalie received individualised funding. Most of Natalie's support needs were paid for by a package of funding, brokered by her microboard, which was initially obtained to help pay for physical rehabilitation after her stroke (I: David 1, p.2). Her guardians were aware that years later she was engaging in maintenance work, although it could be argued there were continued improvements in her function even if it was very slow (I: David 1, p.2). Concerned about the ongoing stability of Natalie's funding, the family researched and discovered the health department had an obligation to provide for Natalie's health and safety and they would consider the exercise she was supported to do by Annie as important to maintaining her health (I: David 1, p.2). David explained,

> …if Natalie wants to go swimming for instance she is getting therapy from the rehab aide who will stand over her while she is swimming. The rehab aide also helps her in the shower and makes sure she gets down the stairs and into the pool safely. Now we're talking health and safety and that falls within the purview of the health department. So we can still definitely justify the funding that she is getting… (I: David 1, p.2)

It was important to David that Natalie maintain her health through exercise, such as swimming and he encouraged her to find forms of exercise she enjoyed (F: Natalie, p.10). David was also aware of Natalie's need to receive ongoing financial support from the government to ensure she could live the life she wanted in the community. Her current package of individualised funding required him to demonstrate that funded activities such as swimming contributed to her long-term health and safety.

Decision.

Decision opportunity.

Since the stroke, Natalie had been participating in swimming regularly, but about a year ago she started making excuses week after week such as "I don't want to go I'm cold" or "I'm tired." Natalie expressed concern that "the roof's going to leak" (I: Annie, p.7). When the weather was warm, it was "too nice out I don't want to go swimming" and when it was raining, "I don't want to be in the pool it's going to rain on me" (I: Annie, p.7). When Annie examined Natalie's will and preferences over the last year (numerous rejections to the offer of going swimming), she was wondering if Natalie wanted to stop participating in swimming as a form of therapy. Annie identified a decision opportunity and wanted to find out if Natalie still wanted to participate in swimming.

Nature and consequence of the decision.

Natalie was largely unaware of the consequences to her of ceasing swimming as a form of physical therapy. However, Annie was highly aware of the detrimental health consequences. Natalie's weight gain meant most activities including walking gave her hip pain and swimming was the only way for her to get a cardio workout that was easy on her joints (I: Annie, p.7). Further weight gain increased Natalie's risk of stroke and of becoming immobile. There were also financial consequences to Natalie not engaging in physical therapy as her individualised funding was linked to her participation in activities that contributed to her health (I: David 1, p.2).

Dynamic interaction between Natalie's will and preferences and Annie's responses.

Annie asked Natalie whether she still cared about the goal they had set regarding her participation in swimming as a form of therapy. "Do you still care about this?" (I: Annie, p.7). Annie asked in a "casual and easy" way that was not "intimidating" (I: Annie, p.7) and Natalie responded by saying she still liked swimming. Annie responded by seeking to clarify Natalie's will and preference and asked additional questions to try and understand why she kept making excuses rather than going swimming.

Natalie explained that the pool Annie had been taking her to leaked when it rained (I: Annie, p.7). Annie acknowledged the pool "was never meant to be an indoor pool. It was built a long time ago as an outdoor pool and it has a tarp over the top. And the tarp has thinned in certain areas so when it is raining outside you get these little drips" (I: Annie, p.7). Natalie said when she was stretching at the end of the pool she would feel rain drip on her and Annie agreed "that's annoying" (I: Annie, p.7). When Annie asked Natalie about the winter time she said "the pool's cold" and Annie empathised saying "I know it's too cold for me to swim in winter. You have got to swim very fast to stay warm" and she knew Natalie didn't swim very quickly (I: Annie, p.8). Then they explored why Natalie didn't want to swim indoors in summer and it was because "it's so nice out outside!" (I: Annie, p.8). In conclusion Annie summarised,

> So when it's really nice out you don't want to go swimming and if it's really cold out, like snow storm day, you don't want to swim because it's cold, and if it's raining outside you don't want to go swimming at the pool because you don't want to be rained on inside is that correct? And she said yes that's correct. And I said 'ok so when do you want to go swimming?' And we decided partly cloudy days. *Laughs.* (I: Annie, p.8)

After clarifying Natalie's will and preferences Annie accepted them. Her perception was that giving Natalie more options would help to clarify what she was going to do if she didn’t want to go swimming “because of x, y or z” (I: Annie, p.7). Natalie had already communicated she would like to go swimming in the indoor pool on cloudy days and no longer go there in winter. From here Annie supported Natalie to explore the possibility of going to an outdoor pool in the summer where they could do some personal training outside as well as play ball in the pool and generally have fun (I: Annie, p.8). When it was raining, Annie suggested she could plan some alternative therapy options from which Natalie could choose each week (I: Annie, p.8).

Resolution of the decision opportunity.

Natalie decided she was not going to return to the indoor swimming pool during winter and was excited to try other therapy options until the weather improved (I: Annie, p.8). Annie asked Natalie to communicate the decision they reached together to her guardians as it was important they know “where we are at” which would allow everybody to stay “on the same page” (I: Annie, p.8). Natalie’s father David respected the decision Natalie had made not to return to the indoor swimming pool in winter. During a home visit he talked about Natalie’s change in plan.

> The conversation turns to exercise and David tells me that Natalie used to go swimming on Tuesdays. There is a local pool that used to be outdoor that was covered with a vinyl roof. However, in recent times the roof has started leaking and the heater doesn’t work adequately for Vancouver winters. As a result it is really unpleasant in winter and Natalie has stopped going for the time being… David said “we are trying to think of other ways of exercising, perhaps involving a chariot and whips.” He looks at Natalie and winks at me. “That’s not funny!” And they banter backward and forward. (F: Natalie, p.10)

Reflection on the decision-making process.

It was the complex interaction of the core elements and influencing factors that shaped Annie’s responses during the process of decision-making support and Natalie’s influence over the outcome. The interaction between Annie’s values and beliefs, which defined her role as a supporter, their respectful and trusting relationship, and Natalie’s tendency to be a people pleaser influenced Annie’s desire to clarify Natalie’s will and preferences. While Annie understood how important ongoing physical therapy was for Natalie’s health and wellbeing, and in spite of legitimate concern regarding the consequences of not exercising on Natalie’s weight, mobility and possibly her individualised funding, Annie responded by accepting Natalie’s will and preference to cease swimming. Throughout the process of decision-making support how Annie responded, seeking to clarify and then accept Natalie’s will and preferences, increased Natalie’s influence over the outcome of the decision-making process.

Decision-Making Example Three: Does Cecily Want To Try Swimming?

The following decision-making example explores a series of interactions between Cecily and her support worker Lisa who was trying to determine whether Cecily would like to try swimming. The example illustrates how the five influencing factors shaped the expression of Cecily's will and preferences, Lisa's responses and the dynamic interaction between them. The interactions were shaped by:

(1) the attributes and experiences Cecily brought to the process including her love of routine and resistance to changing her daily patterns;

(2) the attributes and experiences Lisa brought including how she thought about her role to "help guide" Cecily to make the best possible decision;

(3) their support relationship which developed over many years and involved deep mutual knowledge and trust;

(4) the environmental pressure Lisa experienced trying to respect Cecily's will and preferences while meeting the needs of everyone in the group home; and

(5) the nature and consequences of the decision which were the serious consequences of Cecily not engaging in regular exercise and its impact on her heart condition.

It was the complex interaction of all of these factors that shaped Lisa's response to push Cecily to participate in swimming and how she went about changing her will and preferences over time.

Person's experiences and attributes.

Cecily.

Cecily was a 49 year old woman who valued many things: "her fiancé David, and the engagement ring he gave her which she kept in a special box in her bedroom, going out for coffee with her sister Shirley on the weekend and Harry Mandel from Deal or No Deal." (F: Cecily, p.1). Cecily loved her routine (I: Shirley, p.2) which included spending time with her friends at day program and the four women with whom she lived in her group home. Despite attempts by staff and family to encourage Cecily to try new things, she often preferred to stick with her existing weekly routine (I: Shirley, p.2).

Cecily was described as “a bit of a loner”, valuing time in her room knitting or writing on the computer rather than the common areas of her home (I: Lisa, p.8). When Cecily was comfortable with someone she was able to clearly express her preferences and the things that were important to her (F: Cecily, p.19). For example, Cecily had always wanted to be a secretary and expressed a desire to answer the phone at her day program to the manager Earle. Because of their conversation, this goal was added to her day program plan (I: Shirley, p.14).

While she was growing up Cecily’s father had limited expectations of her ability. There had been disagreement between her mother and father about whether she should have access to an education. Her sister Shirley explained,

> …my mother insisted on carrying the child and my father wanted nothing to do with it, it was very unpleasant for the first year after she was born, he just ignored the whole thing. He was very old school and he was afraid the relatives would not understand it and make fun etcetera and he always felt that any kind of education for her and kind of treatment would be worthless. (I: Shirley, p.4)

Cecily’s mother fought for Cecily to receive an education and she attended the first special preschool, elementary and high school in Vancouver (I: Shirley, p.4). When she was younger Cecily had been quieter and unable to express herself very well (I: Shirley, p.6), but over time she had matured and become more confident living in a supported environment (I: Shirley, p.6).

> She probably is more verbal now, more outgoing, more confident than she was six or seven years ago. She’s been in this home where there’s, it’s all women, she was with men and women before when she was younger and different homes until there was a change needed for whatever reason. But this home has been really good for her and there’s a lot of stimulation… (I: Shirley, p.1)

A number of years ago Cecily moved into the group home, where Lisa worked, because “her weight was getting a little out of control” and there were concerns about the effect of weight gain on her “heart condition” (I: Lisa, p.2). At the group home Cecily was able to be supported to monitor her weight and change her food preferences: “I’m on a diet” (F: Cecily, p.4).

Supporter's experiences and attributes.

Lisa.

Lisa fell into working as a disability support worker and "accidently found [her] niche" (I: Lisa, p.12). While it was not encouraged that she become friends with the people she supported, she believed "when you are that close to somebody for that many years how can you remain detached? (I: Lisa, p.12). After many years working with Cecily, Lisa thought of her as a friend who was very important to her (I: Lisa, p.12).

Lisa attempted to treat the people she supported in the group home as she would like to be treated in the same situation (I: Lisa, p.12). When she was supporting a client she would ask herself if the person was her sister or mother would she want them to be treated this way (I: Lisa, p.12). With respect to decision making, Lisa wanted to empower people with disabilities to make decisions for themselves but acknowledged this could be "challenging, tricky and downright frustrating because you really just want what's best for them" but often "they're just not getting that" (I: Lisa, p.2).

Lisa believed her role as a supporter was to help Cecily be all that she "should and can be" and it was in this context that she provided support.

> …I can tweak here, tweak there, talk to you about this, talk to you about that. Know when to be quiet and back off, you've had enough. Because we're all different, every single one of us, we're not so different in the fact that we are all different. We all like different things, need different things, want different things and that's the reality, you know. (I: Lisa, p.12)

Her role was to shape and frame information, tweaking things so that the person she was supporting would make the best decision. She tried to "empower" Cecily to make decisions and "help guide her in a more healthy direction" (I: Lisa, p.1). These beliefs about her role significantly shaped the support she provided Cecily when deciding whether or not to participate in swimming.

Support relationship.

In her role as a support worker, Lisa learned the importance of knowing the person you were supporting with decision making, which meant developing "rapport" and "knowing who they are, their likes and dislikes" (I: Lisa, p.4). Cecily and Lisa had known each other for over twelve years (I: Lisa, p.1) and during this time Lisa developed a strong understanding of how Cecily comprehended information and the importance of breaking down processes into “little steps” (I: Lisa, p.4). She had seen what a great support Cecily’s family was to her (I: Lisa, p.1) and how much she loved coffee and eating out in restaurants (I: Lisa, p.1).

Over the years Lisa had learned Cecily’s particular responses and the little cues that helped to understand what she wanted when she couldn’t say it. Lisa had learned through experience that sometimes when Cecily said no she didn’t really mean no.

> …when I first got to know her saying no, “do you want to go to Red Robin for dinner or do you want to go to Pizza Hut?” “No, no, no, no.” So I’m thinking no, no meaning she doesn’t want to go out to dinner at all. So we’ll forget that. But I got to know that that’s not what she means at all. Her first response tends to be no, or I can’t, I can’t. Everything’s critical, I can’t, I can’t. And I would get worried. But I learned through building rapport with her that it’s not always what she means. She could mean I can’t go right now. Or I want to finish my knitting, or I haven’t had a shower. But I learned that going out for dinner is a highlight for her. So no doesn’t mean no in that regard. So these are little things you learn with all of them. (I: Lisa, p.1)

Lisa understood Cecily’s ‘no response’ to be “a protective mechanism” that was her “way of maintaining control” (I: Lisa, p.4). Cecily wanted to maintain her routine to feel in control and Lisa believed there were times when saying no was “fine” (I: Lisa, p.4). However, she also believed there were times when certain things “needed to happen” (I: Lisa, p.5).

Cecily was very familiar with Lisa and she particularly enjoyed their time together when Lisa took her out for coffee (Cecily, p.2). Cecily was unable to discuss whether she trusted Lisa but her willingness to seek support from her in the day program environment when feeling insecure (F: Cecily, p.1), and introduce her as someone important in her life (F: Cecily, p.2), suggested she knew Lisa well and trusted her support.

Environment.

As a staff member working in the group home environment, Lisa was under pressure to demonstrate she was meeting Cecily's health needs adequately.

> …in a licensed group home there are a lot of concerns. I mean you have to have documentation for finances, health care. It's neglect if they don't go to the dentist or they don't see a doctor when they are sick and Cecily has a heart condition and so these things have to be addressed and kept on top of and you have to show that you are keeping on top of it through the documentation. (I: Lisa, p.1)

Lisa needed to ensure she was meeting "certain standards" (I: Lisa, p.2) and had to walk "a fine line" (p.9) between respecting individual choices and values and meeting her obligations as an employee of the organisation. It was also challenging to balance meeting the needs of individuals against the impact it had on everyone else in the group home. The reality was "it is a group home. It's not just Cecily's home" (I: Lisa, p.9).

In response to this pressure, Shirley stated Lisa had developed the ability to frame conversations in a way that would get Cecily "to do something that she didn't want to do" (I: Shirley, p.8). She had figured out "little ways to make things happen that need to happen" (I: Lisa, p.5).

Decision.

Decision opportunity.

When Cecily was reviewed by her heart specialist, Dr Key recommended changes to her diet and that she commence regular exercise such as swimming. As a result of this appointment, Lisa believed swimming was "the only exercise" Cecily was "going to benefit from. She cannot walk long walks. Nothing fast paced. Nothing. Swimming is the best thing for her" (I: Lisa, p.11).

Cecily's group home went on a weekly outing to the local swimming pool and out for dinner afterwards as a group (I: Lisa, p.10). Not long after her appointment with Dr Key, Lisa approached Cecily to see whether she would like to join other members of the house to go swimming. Lisa created a decision opportunity for Cecily to see whether she would like to join other residents in the group home going swimming each week.

Nature and consequences of the decision.

Lisa was very aware of the serious consequences of Cecily not engaging in regular exercise and the impact it could have on her heart condition (I:Lisa, p.11). If Cecily decided to join the group, it could have a very positive effect on her overall health.

Dynamic interaction between Cecily's will and preferences and Lisa's responses.

In response to Lisa's proposed decision, Cecily's will and preference was "adamant" she said "no God no, oh God no" (I: Lisa, p.10). Cecily did not want to go swimming.

Lisa's initial response to Cecily's will and preference was to accept her reluctance to go swimming. She said "heard no and we accommodated that in the beginning" (I: Lisa, p.10). She recognised that "maybe it was too much and she wasn't ready for that. No problem" (I: Lisa, p.10). On this first attempt to involve Cecily in the swimming group, Lisa took other clients swimming and another staff member stayed behind with Cecily. "They worked it out so someone still got the pleasure of it" (I: Lisa, p.10).

While initially, Lisa accepted Cecily's refusal to participate in swimming (expressed will and preferences) over time her response changed. Lisa became frustrated that Cecily was reluctant to change her regular routine and try something new.

> And a lot of time for Cecily she will say no without knowing what she is saying no to. You know. I didn't ask you to cut off your finger we're going swimming and then out for dinner. (I: Lisa, p.10)

Lisa perceived Cecily was "missing out on a great outing" (p.10) and she wanted to push her to be able to benefit from it. She also saw her decision was having negative consequences on other residents in the group home "because now the staff have to separate" (p.10). Lisa no longer accepted Cecily's 'no' and responded by providing support that was directed toward actively changing it. Lisa started to help guide Cecily "in a more healthy direction" (I: Lisa, p.1) and employed a number of strategies to change her mind.

Initially Lisa tried verbally encouraging Cecily to reconsider joining the swimming group with no success (I: Lisa, p.10). She reiterated she would get to go out to dinner afterwards which she knew was one of Cecily's preferred activities. When this was unsuccessful she pushed harder saying,

> Just come with me, put your bathing suit on, if you decide you don't want to get in the water, don't get in the water. But at least come with me and put your bathing suit on. And then if you don't want to go you can sit with the life guard. (I: Lisa, p.10-11)

Lisa explained that after "a few turns" they got their "ok" and Cecily was willing to get into her bathing suit and join the group at the pool. Lisa praised her "beautiful bathing suit" and kept "building it up, building it up" (I: Lisa, p.11).

Resolution of the decision opportunity.

So eventually Cecily was at the swimming pool with her bathing suit on and surprised everyone when she swam "like an Olympic star" (I: Lisa, p.11). She was a strong swimmer who participated without "needing any prompts or praise. Once she got in she just did her laps no problem" (I: Lisa, p.11). Lisa was shocked at the change in Cecily's attitude. After that initial push to participate, Cecily would willingly get her swimming bag ready, with her perfumes and her shower gels, without any problem (I: Lisa, p.11).

Reflection on the decision-making process.

It was the complex interaction of the core elements and influencing factors that shaped Lisa's responses during the process of decision-making support and Cecily's influence over the outcome. The interaction of Cecily's resistance to changing her routine, their mutual knowledge and trust as well as Lisa's beliefs about her role were weighed against the consequences of Cecily not participating in swimming. There were consequences for Cecily (heart condition); Lisa (not meeting organisational expectations); and other group home residents/staff (inconvenience). Throughout the process of decision-making support how Lisa responded trying to change Cecily's will and preferences, reduced Cecily's influence over the outcome of the process.

Reflecting on the Three Decision-Making Examples

All three decision-making examples had a number of similarities. They all involved decision opportunities exploring participation in swimming. Each of the central participants was female and their decision making was supported by paid staff who were also female. The quality of these support relationships was generally high as they were characterised by mutual knowledge, trust and respect that had developed over many years working together.

Alongside these similarities there were also some significant differences between the examples. Each of the participants had different values, beliefs, goals and priorities which they brought to the process. Participants experienced different environmental challenges including financial dependence on government benefits and pressure from organisational expectations and different consequences in making their decisions such as reduced mobility, increased risk of heart complications and poor quality of life.

Reflecting on the three decision-making examples, it is possible to see how contextually dependent the process of decision-making support was in practice. The involvement of specific elements and influencing factors were always the same, however because the nature of each and the way they interacted differed for each decision, the type of support provided and the outcomes observed varied significantly.

The three decision-making examples demonstrate the dynamic nature of the process of decision-making support. Sometimes the interactions between the person and their supporter changed the person’s will and preferences (e.g., Cecily) and sometimes they didn’t (e.g., Natalie). Sometimes the interaction resulted in the person clarifying their will and preferences and articulating their decision more clearly (e.g., Natalie understanding why she didn’t want to swim). There were also times when the interactions changed the supporter’s response (e.g., Sally trying to push Emily to continue swimming and later accepting her preference to leave the pool). The various changes that occurred during the process of decision-making support were the result of the complex interaction of the influencing factors shaping the core elements (the person’s will and preferences and the supporter’s responses).

The dynamic nature of the process meant some decision opportunities were resolved quickly while others took longer. This was because the interactions at the heart of the process varied in length significantly. For example, Emily's interactions with Sally all occurred during one swimming session whereas, Cecily's interactions with Lisa occurred over many months.

The process of decision-making support was not linear. Rather, it was a recursive process whereby the views of the person and their supporter bounced backwards and forwards constantly being shaped by variations in perspectives and circumstances. This process is best demonstrated by the dynamic interaction between Cecily's will and preferences and Lisa's responses. Initially, Lisa accepted Cecily's reluctance to participate in swimming but a range of factors including organisational pressure and concerns about Cecily's heart led her to change her perspective. Cecily's preference not to go swimming became unacceptable, and Lisa made numerous attempts to change her mind and coerce her into trying swimming. Lisa employed a range of support strategies to try and change Cecily's mind using verbal encouragement, linking swimming to a preferred activity (eating out) and telling her what to do. The recursive interaction only ceased once Cecily agreed to try swimming.

The way supporters responded during the dynamic interaction led to variations in the outcome of the process for the person. When Annie supported Natalie to clarify her will and preferences by asking questions, acknowledged her concerns, provided her with more options, and then accepted her preferences as her decision, it increased Natalie's agency in the process. When Annie accepted Natalie's will and preferences, even though it might have had a detrimental impact on her health and mobility, she allowed Natalie's will and preferences to direct the process. Whereas, when Sally questioned Emily's preference to cease swimming, told her to swim twenty more laps and jumped into the pool to swim alongside her, although it was done in an effort to motivate her to improve her health, Sally's actions decreased Emily's agency in the process. Later when Sally accepted Emily's preference to cease swimming and leave the pool her agency increased. The extent to which Emily's will and preferences directed the process of decision-making support changed throughout the dynamic interaction.

Chapter Summary

This chapter has explored three decision-making examples that demonstrate the process of decision-making support in practice. By reflecting on these examples, it is clear that how people with intellectual disabilities were supported with decision making involved a complex, dynamic and multifactorial process. The interaction at the heart of the process, the person expressing their will and preferences and their supporter responding, was recursive and shaped by the complex interaction of five influencing factors. How supporters responded to the person's will and preferences shaped the agency of the person in the process and the extent to which they directed the outcome.

In the discussion, the research findings are examined in relation to the existing body of knowledge on undue influence and agency, as are the broader implications of these findings to the current body of knowledge on supported decision-making practice.

Chapter Six:

Discussion and Conclusion

Discussion

This research sought to develop an understanding of supported decision-making practice in Canada by exploring the experiences of people with intellectual disabilities and their supporters. The aim of the research was to understand how people with intellectual disabilities were supported with decision making in the context of two legal mechanisms which create opportunities for supported decision-making in Canada, representation agreements and microboards. A grounded theory methodology was used to develop a model of the process of decision-making support, and this model was explained in Chapter 4 and exemplified in Chapter 5 of the thesis.

The process of decision-making support identified by this research was not a linear, static process. It was multifaceted, dynamic and recursive. The process was characterised by the dynamic interaction between expressions of the person's will and preferences in relation to a decision opportunity and their supporter's responses. This interaction was shaped by five influencing factors: the experiences and attributes the person and their supporter brought to the process; the quality of their relationship; the environment in which decision making occurred and the nature and consequences of the decision. When the process of decision-making support occurred specific elements and influencing factors were always involved, however because the nature of each and the way in which they interacted differed for each decision, the type of support provided and the outcomes observed varied significantly. Therefore, the process of decision-making support was highly individualised and contextually dependent.

Support strategies.

The range of experiences explored in this research reflected the diversity of personalities, relationships, circumstances and decisions encountered. People with intellectual disabilities were supported using a wide range of strategies and practices, which were constantly changing in response to changes in the five influencing factors. There were occasions when support was brief and involved the provision of minimal assistance. At other times, support was provided over many months and involved a variety of forms of support.

Support involved a wide range of activities such as planning and breaking things down, enabling and clarifying understanding of information, minimising stress and anxiety, choosing when and how to discuss things, providing advice, helping problem solve, monitoring the person's safety, explaining risks and creating opportunities to try new things. The provision of support also involved interpreting non-verbal communication, learning the person's unique language, making choices based on the best interpretation of the person's will and preferences and clarifying whether the choices were acceptable by observing the person's reactions.

The provision of the same type of support could be enabling in one situation and restrictive in another depending on the context. For example, it was clear in the findings withholding information was a support strategy that could be used to present information at an appropriate time enabling the person to make an informed choice. In these situations, delaying access to information allowed the person's will and preferences to be clarified. However, withholding information was also used as a means of denying the person relevant information about a decision opportunity to try and control the decision-making process and achieve a specific outcome. The same support strategy provided in a different relational, decisional and environmental context, could lead to very different outcomes for the person receiving support.

Diversity in the needs of central participants, and their circumstances, meant that how a person with intellectual disability was supported with their decision making could only be evaluated in light of each person's unique situation. The findings of this research suggest that any attempt to evaluate the effectiveness of decision-support strategies must take into consideration the broader context in which they are provided.

Range of factors.

The literature has demonstrated a range of factors shape supported decision-making for people with disability. In 2017, Shogren and her colleagues conducted an extensive review of the conceptual and empirical literature relating to intellectual disability, mental health and ageing populations and identified a wide range of contextual and environmental factors that had been found to shape decision making (Shogren et al., 2017a). The factors identified included decision-making experience, emotional factors, disability characteristics, the accessibility of information, the complexity of the decision, relationships with providers, opportunities for decision making and family attitudes about decision making (Shogren et al., 2017a). The range of factors identified in the literature aligns very strongly with the elements and factors identified in the model of the process of decision-making support developed from this research. Therefore, this research makes a unique contribution to the body of knowledge on decision-making support by providing a conceptual framework for understanding how a range of individual, relational, decisional and environmental factors worked together to influence the process of decision-making support.

Relational quality.

The importance of relationships as the context for providing decision-making support has been identified in existing research (Björnsdóttir et al., 2015; Fetherstonhaugh et al., 2016; Knox et al., 2016a; Watson, 2016a). Watson (2016a) found decision supporters of people with severe or profound intellectual disability were more likely to be responsive to the person's will and preferences if they were relationally close. Similarly, Knox (2016d) found effective decision support for people after severe traumatic brain injury required "an in-depth knowledge of who the person is and the impact of the brain injury on their behaviour" (Knox, 2016d, p.228). Knox (2016d) characterised a positive support relationship as including "…trust, closeness, honest and effective communication, mutual respect and a commitment to the long term nature of the relationship" (p.211). When supporting people with severe traumatic brain injury having a "deep understanding of the person" was necessary to be able to provide person centred support (p.211).

The findings of this research add further to our understanding of the importance of relational quality as a factor shaping how people with intellectual disability are supported with decision making. It reinforces the importance of relational closeness as identified by Watson (2016a) and clarifies further four characteristics of quality support relationships: equality, respect, knowledge and trust. These characteristics mirror many of those identified by Knox (2016d) as constituting positive support relationships for people after severe traumatic brain injury.

Equality and respect were values that the person and supporter brought with them to the support relationship that shaped how they perceived one another. Knowledge and trust were characteristics developed within the relationship over time. When the support relationship was characterised by equality the person and their supporter identified with one another as human beings, sharing the same fundamental needs, rights and opportunities. They spoke about the importance of reciprocity in their relationships and recognised the similarities in their hopes and dreams. Equal relationships were identified by a sense of 'sameness' rather than 'otherness'.

While research participants in quality support relationships celebrated their 'sameness' they also respected individuality. When support relationships were characterised by respect the people in the relationship acknowledged and appreciated the values, beliefs, goals and priorities that defined each person and made them unique. Respect was demonstrated in how the person and their supporter listened to and accepted what was important to each other. Quality support relationships were characterised by respect for each person's right to live their own life.

The values of equality and respect shaped how people with intellectual disabilities were supported with their decision making. When the support relationship was characterised by inequality and a lack of respect supporters perceived their own will and preferences to be superior to those of the person. Supporters became experts who not only knew more than the person but also what was best for them. This perspective relied on a perception that the person's preferences were less informed than their own. In these contexts, when the person attempted to create a decision opportunity their attempts were often ignored or shut down. Similarly, when the person expressed their will and preferences they were often disregarded or changed.

Quality support relationships were also characterised by a deep sense of knowing between the person and their supporter. This type of knowledge meant understanding the other person's essential self and feeling known in the same way. Knowing the person meant knowing what they wanted in life, understanding their needs, preferences and unique way of communicating. This type of knowledge accumulated over time, by living and experiencing things together. Knowledge allowed the person to trust their supporter and gave them confidence their supporters knew what was important to them. Knowledge also gave supporters confidence they understood the broader context of the person's will and preferences.

Finally, quality support relationships were characterised by trust. Trust grew out of respect and was built over time through mutual knowledge and shared experiences. Trust was the key to influencing one another in the process of decision-making support. Trust opened the person to receiving information and guidance from their supporter. Trust also assisted the supporter to acknowledge and respect the person's will and preferences and change their own perspective in response.

The extent to which the person and their supporter shared knowledge and trust of one another contributed to shaping how the person was supported in the process of decision-making support. If the person did not know or trust their supporter, they were often not open to receiving support and guidance with their decision making. Sometimes the person chose not to express their will and preferences and resisted listening to their supporter because they did not trust their advice. Without meaningful knowledge, supporters were unable to contextualise the will and preferences of the person and their subjective conceptualisation of a good life. When the supporter did not know the person well they often attempted to change their will and preferences to align with what they perceived to be in the person's best interest.

The complexity of informal caring relationships (Penning & Wu, 2016; Thompson, Kerr, Glynn & Linehan, 2014), and how relationships make the provision of decision-making support complicated, is acknowledged in the conceptual literature (Clough, 2014). Supporters can represent and facilitate the voices of their adult family members with intellectual disabilities in ways “that reflect intimate knowledge and skill at avoiding stress and anxiety” (Lashewicz et al., 2014, p.19). However, families can also have “entrenched roles” for both the person and supporter that can “obscure” or “diminish” the person's voice (p.21-22). Arstein-Kerslake (2014) suggests that the product of the support relationship “is always an expression of the individual's will and preference and not that of the supporter” (p.12). The research findings revealed this was not always the case. Even when relationship quality was high, there were other important factors which shaped the extent to which supporters accepted the person's will and preferences. For example, the consequences of the decision and risks associated with it were sometimes serious enough for supporters to disregard the person's will and preferences.

Therefore, these findings have added to the current body of knowledge by affirming the importance of relational quality as one of five factors that shaped how people with intellectual disabilities were supported with decision making and clarified further the characteristics of quality support relationships in this context: equality, respect, knowledge and trust.

Dependency and shared interests.

Many people with disabilities are dependent on the support of others to identify and express their conception of the good (Francis & Silvers, 2007), and more specifically their individual will and preferences (Series, 2015; Watson, 2016a). In the context of relationships of dependency, support with decision making has been characterised as "assistive thinking", whereby decision support acts as a cognitive "prosthesis" (Silvers & Francis, 2007, p.487). Support in this sense involves decision supporters co-constructing the person's will and preferences (Bach & Kerzner, 2010; Watson, 2016a). In the existing literature, questions have been raised about whether it is possible for supporters to strip the process of their personality and interests (Silvers & Francis, 2009, p.493). For example, when supporting people with severe to profound intellectual disabilities there is a risk of supporters assigning meanings that reflect their own hopes, fears and desires (Johnson et al., 2012).

This research has demonstrated supporters bring a range of personal experiences and attributes to the process of decision-making support which can include expectations for the person and the outcome of the process. For example, the support Lisa provided to Cecily during the process of decision-making support was shaped by the beliefs she had, about her role as a decision supporter to help guide Cecily to make the best possible decision, and that swimming was necessary to help in the management of her heart condition.

The interests of the supporter were often intertwined with the interests of the person. This was the case in both familial and professional support relationships. For example, when Sarah spoke about her son Reuben and the importance of the Hindu religion in his life (I: Sarah 2, p.2) it was difficult to separate his interest from the broader context of her strong expectation he would respect and practice "Indian ways" while living in her home (I: Sarah 1, p.18).

These insights echo the findings of Bigby et al. (2017a) who conducted research exploring the perspectives of decision supporters of people with intellectual disabilities in Australia. Their research suggested it is very difficult for supporters to "remain neutral in decision support relationships" (Bigby et al., 2017a, p.10) and to provide "prosthetic rationality" without substituting their own ideas (Silvers & Francis, 2009, p.485). The model of the process of decision-making support developed from this research suggests the dynamic interaction of elements and individual, relational, environmental and decisional factors are constantly shaping how decision supporters respond in the process of decision-making support. Often decision supporters are unconscious of these influencing factors, and asking decision supporters to remain neutral, and separate their personality and interests from the process in this context, seems unrealistic.

Agency.

The model of the process of decision-making support developed from this research has identified the complex and dynamic interaction of elements and factors that increased or decreased the person's agency during the process of decision-making support.

In the research findings there were instances when the interaction of elements and factors led the supporter to respond by accepting or trying to clarify the person's will and preferences which increased the person's agency during the process. When the person was supported in a way that increased their agency it resulted in the outcome (the decision) closely aligning with their will and preferences. In other situations, the interaction of elements and factors led the supporter to respond by trying to change or disregard the person's will and preferences which decreased the person's agency, and resulted in the outcome (the decision) deviating from their will and preferences.

The model of decision-making support developed from this research strongly aligns with feminist conceptualisations of autonomy and agency as relational and contextually embedded (Mackenzie & Stoljar, 2000). Relational autonomy is an umbrella term that describes seeing people as socially embedded and that their identities are formed within the context of,

> …intersecting social determinants, such as race, class, gender, and ethnicity. Thus the focus of relational approaches is to analyse the implications of the

> intersubjective and social dimensions of selfhood and identity for conceptions of individual autonomy and moral and political agency. (Mackenzie & Stoljar, 2000, p.4)

In this context, agency (that is being an agent) is understood “not as a matter of individual will” but the result of “complex and shifting configurations of power” (Mackenzie & Stoljar, 2000, p.10-11). The findings of this research may suggest the dynamic interaction between the person’s will and preferences and supporter’s responses are mediated by a negotiation of power. It would be interesting for future research to reflect on the nature of power both within the support relationship and more broadly in the dynamic interaction at the heart of the process of decision-making support.

An attribute supporters brought to the process of decision-making support that contributed to shaping the person’s agency was the extent to which the supporter saw the person as an agent capable of decision making. When supporters did not see the person as capable of expressing their will and preferences, or of understanding the decision and did not trust that they could engage in the decision-making process, they were more likely to try to change or disregard their will and preferences. Whereas when the supporter saw the person as capable of expressing their will and preferences and engaging in the process of decision-making support, they were more likely to respect the person’s decision-making agency by accepting their will and preferences.

These findings are supported by existing empirical research exploring the experiences of people with traumatic brain injury and dementia. The existing research suggests the perception decision supporters have of the person they are supporting, such as whether they are seen “in a positive light” (Knox et al., 2015, p.11) or as an “adult” capable of decision making (Björnsdóttir et al., 2015, p.18), influences the relational space in which decision making occurs. It is in this relational space that “the supporter recognises the person being supported as a reason-giver and a reason-taker; and in doing so, authorises them as an agent capable of engaging with these considerations” (Craigie, 2014, p.403).

This research suggests how people with intellectual disability were supported with their decision making reflects relational conceptualisations of autonomy and that the complex and dynamic interaction of elements and factors could increase or decrease the person's agency during the process of decision-making support.

Undue influence.

An important question raised in the literature on supported decision-making is "when does 'influence' threaten authentic agency" (Series, 2015, p.86)? For Series, and others, the answer lies in developing a better understanding of the concept of 'undue influence' (Series, 2015, p.86; Gooding, 2015, p.56). The literature on supporting people with psychosocial disability has conceptualised undue influence and coercion along a continuum (Largent et al., 2012) that includes formal and informal forms of leverage (Rathner, 1998). Undue influence has been referred to as a "milder form" of influence than coercion which is often associated with more formal threats of harm (Largent et al., 2012). Even so, informal coercion can include "request[s], reasoning, persuasion, barter, bargaining, gentle prodding, enticement, selective information, manipulation, deceiving, blackmail, threat and even various forms of physical force" (Rathner, 1998, p.186).

A number of decision-making processes explored in this research involved undue influence, and informal coercion as defined by Rathner (1998). When supporters sought to change the person's will and preferences, and would not accept them until they aligned with their own, the support used to achieve this outcome often involved undue influence and informal coercion. While it is accepted that social influence shapes human agency to some degree (Carney et al., 2008; Gooding, 2015), when influence is coercive it diminishes agency to a larger extent as it "dramatically closes down the size of the remaining decisional 'space' within which a person still retains the power of choice..." (Carney et al., 2008, p.9).

At times, the type of support the supporter used to align the person's will and preferences with their own preferences could seem benign such as verbal encouragement, presenting an idea as if it came from the person, bargaining and offering rewards. At other times, the support seemed more concerning when supporters used anger and intentionally shaped, framed and withheld information from the person. However, the impact of all of these types of support was that it diminished the agency of the person during the process of decision-making support.

According to Lehman and Phelps (2005) undue influence is any act of persuasion that overcomes the freewill and judgement of another. When engaging in the process of decision-making support if the supporter lacked respect for the person's will and preferences and sought to change them by any means they used strategies that exerted undue influence. The General Comment on Article 12 defines undue influence as occurring where "the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation" (Committee on the Rights of Persons with Disabilities, 2014, Para 22, p.5). These research findings suggest that there were occasions when fear and anger were observed during the dynamic interaction between the person's will and preferences and the supporter's responses. However, this was rare. Deception and manipulation did occur but were difficult to identify because the same strategy could be supportive or deceptive depending on the supporter's intention and the broader context (e.g., withholding information).

Arstein-Kerslake (2014) suggests undue influence can occur when the support relationship is not an "empowering dependency" (p.85) but rather dominating and characterised by a "power imbalance" (p.86). This research suggests it may be problematic to attempt to identify undue influence by associating it with a particular characterisation of the support relationship. The findings show support relationships were not easily categorised. At times they were empowering and at other times paternalistic. Sometimes supporters exerted more control over the person's decision making than at other times (depending on the five influencing factors). The *quality* of the support relationship was only one important factor (among five) shaping the extent to which supporters tried to influence the person's will and preferences during the process of decision-making support.

Sometimes supporters wanted to change the person's will and preferences because they believed they would have negative long-term consequences on their health and quality of life. Sometimes it was because they believed the person had limited life experience and needed to be pushed to try new things. Sometimes supporters sought to change the person's will and preferences because they were at risk of losing money or other important resources. There were a range of individual, decisional and environmental factors that also contributed to the desire of supporters to change the person's will and preferences, reducing their agency in the process of decision-making support.

Therefore, the findings of this research suggest decision-making support in the context of representation agreements and microboards sometimes involved undue influence, and informal coercion. While the literature has tended to focus on certain characterisations of the support relationship as an indicator of undue influence (Arstein-Kerslake, 2014), relational quality was only one of a number of individual, decisional and environmental factors that also played an important role shaping supporter influence. This research suggests undue influence and informal coercion are likely to be involved when decision supporters refuse to accept the person's will and preferences until they align with their preferred outcome (which was often their own will and preferences).

Understanding the concept of supported decision-making.

The perspectives supporters had about the concept of supported decision-making influenced how they perceived their role as a decision supporter and subsequently how they responded to the person's expressions of will and preference during the process of decision-making support. Research participants had a broad range of perspectives regarding the nature of supported decision-making including supporting a person to make their own decisions (I: Jason, p.5), shared decision-making (I: Ailsa, p.1) and making decisions in a person's best interest (I: Ruby, p.7). Only one of the seven central participants had an understanding of what supported decision-making was and how it related to their life and the lives of other people (I: Betty 2, p.9).

Existing research conducted into the practice of supported decision-making in Canada has concluded decision supporters need to understand what supported decision-making is and how it is different to substituted decision-making to ensure its aims are achieved (James & Watts, 2014). The findings of the research reported in this thesis suggest without knowledge of the concept of supported decision-making, the values, beliefs, goals and priorities the person and their supporter brought to the process of decision-making support were not shaped by the aims and principles of supported decision-making.

Adhering to the principles of supported decision-making.

The literature on supported decision-making suggests achieving the aims of supported decision-making requires the process of decision-making support to be guided by a set of supported decision-making principles (Bach, 1998). In Canada, there is not one agreed set of supported decision-making principles (Nunnelley, 2015) as there are a number of documents which reference similar but slightly different principles depending on their focus, for example, law reform or practice guidelines (Bodnar & Coflin, 2003; CACL Taskforce, 1992; Gordon, 2012; Nunnelley, 2015; Coalition on Alternatives to Guardianship, 2014). From these five documents, the key supported decision-making principles recognised in Canada can be summarised as follows:

- All people have a right to autonomy and self-determination.
- All people are entitled to the presumption that they are capable of making decisions and, where necessary, to support and assistance in order to understand and make informed decisions on their own behalf.
- The person is at the centre of the decision-making process and their will and preferences direct the process.
- Support should be entered into freely, and must be free from abuse and undue influence.
- Supported decision-making is about the process not outcomes.

Many of the decision-making processes observed and discussed, in the context of representation agreements and microboards that allow for supported decision-making, did not appear to be guided by these principles. The will and preferences of the person did not always direct the process of decision-making support. The person was not always presumed to be capable of making the decision, and at times supporters were more focused on achieving a specific outcome than engaging in a process free from undue influence. Neither central participants nor their decision supporters clearly identified or discussed specific supported decision-making principles when reflecting on how they went about providing decision-making support. Emerging research in to the provision of decision-making support suggests poor practice is often the result of a lack of information and appropriate guidance (James & Watts, 2014; Knox, 2016d; Watson, 2016a). These research findings support the contention of James and Watts (2014) that education and training about supported decision-making and its principles, are important and necessary for those engaging in practice.

Realising the aims of supported decision-making.

The broad aim of supported decision-making is to enable people with cognitive disabilities to exercise their legal capacity (Salzman, 2010) and determine their own lives (Bodnar & Coflin, 2003), through the provision of quality support and legal recognition of the interdependent nature of decision making (Browning et al., 2014, p.42). The findings of this research demonstrate many of the perspectives held by supporters on supported decision-making did not strongly align with the aims of supported decision-making articulated in the literature. It also seemed central participants involved in this research had very limited understanding of the aims of supported decision-making.

Self-determination.

An important goal of supported decision-making is enabling people with intellectual disability to be self-determining (Bodnar & Coflin, 2003; Shogren et al., 2017a). In the literature, self-determination has been defined as “a quality or characteristic within a person who determines his or her own fate or course of action” (Shogren et al., 2015, p.252). The range of practice encountered in this research suggests not all decision-making support provided in the context of legal mechanisms that allow for supported decision-making offered people with intellectual disabilities control and self-determination in their lives.

When providing decision-making support some forms of assistance helped the person to communicate and act on their will and preferences. For example, when supporters developed communication systems, provided accessible information, and explored the pros and cons of options. In these situations, support enabled the person with intellectual disability to clarify their will and preferences and allowed them to influence the process of decision-making support. This finding is supported by existing research that has shown the accessibility and presentation of information can have a significant impact on the extent to which people with intellectual disabilities engage in decision-making processes (Bailey et al., 2011; Dukes & McGuire, 2009; Wehmeyer et al., 2007).

In contrast, other forms of support observed in this research led to the will and preferences of the person being changed, ignored or disregarded. For example, when supporters withheld information, offered the person rewards and ignored their communication it reduced the extent to which the person's will and preferences shaped and directed the process of decision-making support. These findings align with existing empirical research that has identified supporters usurping decision-making control, obstructing or coercing the implementation of decisions diminishes the self-determination of people with intellectual disability (Nonnemacher & Bambara, 2011).

The research findings suggest the actions decision supporters took when providing decision-making support played an important role in shaping the extent to which the person was able to control and direct the decisions affecting their lives.

Enabling the exercise of legal capacity: legal recognition.

The literature on supported decision-making often focuses on the important, conceptual link between the process of decision-making support and enabling people with disability to exercise their legal capacity (Browning et al, 2014). The literature describes the exercise of legal capacity as both having legal recognition and legal agency (McSherry, 2012). In the context of this research the presence of representation agreements and microboards, which recognised central participants as legal decision makers, provided them with legal recognition (the first aspect of legal capacity).

When supporters discussed why they had created and established representation agreements and microboards, they spoke about the role the legal mechanisms played in resolving practical problems and assisting them to ensure the person's welfare now and in the future. Representation agreements and microboards enabled supporters to be able to access information and be included in relevant meetings regarding the person (F: Jenny, p.8-9). For some supporters recognition as a representative allowed them to feel they had a sense of power when interacting with service organisations (I: Shirley, p.14-15). Legal mechanisms gave parents comfort there were systems in place to manage individualised funding and make decisions for their child after they die (I: Sarah 1, p.8; F: Natalie, p.2). Legal mechanisms also offered supporters a way to avoid guardianship and government bureaucrats becoming involved in the life of the person with intellectual disability (I: Peta 1, p.8). These reasons for creating and using representation agreements and microboards are evidenced in other exploratory studies examining their implementation in Canada (James & Watts, 2014; Nunnelley, 2015).

In the data generated, there was little evidence that demonstrated legal mechanisms were an environmental factor, which shaped how central participants and their supporters went about making decisions together. Generally, supporters did not discuss the presence of legal mechanisms when explaining how they went about providing decision support. The only exceptions were Betty's representatives Jason, Terry and Michaela. In most cases, the presence of legal mechanisms was not observed to be a factor that contributed to shaping the dynamic interaction between the person's will and preferences and the supporters responses during the process of decision-making support. Therefore, the findings of this research support academic literature that has suggested the success of supported decision-making relies on much more than just the presence of legal mechanisms (Carney, 2012; Stainton, 2016). While the presence of legal mechanisms offered legal recognition for the person, and resolved some important practical issues for supporters, this research suggests how people with intellectual disability were provided with decision-making support was not substantially shaped by central participants having legal recognition.

Enabling the exercise of legal capacity: supporting legal agency.

Legal agency in the context of the right to legal capacity has been defined as "an action or inaction that the individual intended and which has legal consequences; or creates, modifies or extinguishes a legal relationship" (Arstein-Kerslake & Flynn, 2017, p.25). In this research, the vast majority of decisions observed and discussed were not about matters that had legal consequences such as providing medical consent, opening a bank account or creating a new legal relationship through signing a contract. There were only a handful of decision-making examples in the data generated that created an opportunity for central participants to exercise their legal agency. Two such examples were Betty asking to open a bank account and Jack deciding he wanted Jenny to purchase half of his home. In both of these examples, the potential existed for the central participant to be supported to be "an actor in the law" (Committee on the Rights of Persons with Disabilities, 2014, para 12) and yet the potential was never realised. For Betty, her trustee refused to discuss her suggestion and shut down the decision opportunity. For Jenny, Jack's limited beliefs about her decision-making ability led him to exclude her from the decision-making process entirely.

While the literature on supported decision-making acknowledges not every form of support with decision-making amounts to an exercise of legal capacity (Arstein-Kerslake & Flynn, 2017), there has been a tendency "to overemphasise supported decision-making in specific instances or environments such as health care or financial decisions" (Stainton, 2016, p.6). The findings of this research support the assertion that focusing too heavily on the exercise of legal capacity may not reflect the reality that supported decision-making is an "organic process" which is embedded in people's everyday lives (Stainton, 2016, p.6). The decision making which made up the largest part of participants lives was not necessarily that which had significant legal consequences and required an exercise of legal capacity. How people with intellectual disability were supported with their decision making in the context of two mechanisms which create opportunities for supported decision-making often had little to do with enabling them to exercise their legal agency. Therefore, these research findings suggest it may not helpful for proponents of supported decision-making to be overly focused on the ability of supported decision-making to enable people with disability to exercise their legal capacity. There is a risk that adopting a narrow focus for supported decision-making, as a mechanism to enable the exercise of legal capacity, may lead practitioners to disregard the important role it can have in shaping the self-determination of people with intellectual disabilities.

Decision-making capacity.

Historically, decision making has been withheld from people with intellectual disabilities on the grounds that they lack competence, have poor judgement and fail to meet a rational ideal of decision making (Jenkinson, 1993). Traditional views about decision-making competence, or mental capacity, have required people with intellectual disability to demonstrate their autonomous, rational capacity to understand and appreciate the consequences of decisions. And on the basis of these types of capacity assessments, people with intellectual disabilities have been declared incompetent and had their legal right to make decisions removed and a guardian and financial administrator appointed (Glen, 2015; Lord et al., 2010; Rasmussen & Lewis, 2006). More recently, changes in thinking about intellectual disability, which acknowledge the impact of social and environmental factors on the person (Gallagher et al., 2014) have resulted in recognition of the importance of supports and accommodations to assist people with cognitive disability to exercise their decision-making capacity (United Nations, 2006).

The research findings support this change in thinking about decision-making capacity. The data generated demonstrates there were a range of factors, which shaped the person's decision-making ability and that these same factors also shaped the supporter's perception of their decision-making ability. There were individual factors relating to the person (e.g., limited life experience, cognitive ability) and factors relating to their supporter (e.g., low expectations/negative beliefs). There were relational factors (e.g., poor knowledge and understanding of each other), decisional factors (e.g., complexity of the decision, risk to person and others) and environmental factors (e.g., time pressure, organisational expectations). The model developed from this research suggests conceptualisations of decision-making capacity that have tended to focus predominantly on the person's cognitive capacities may underplay the significant impact of relational, decisional and environmental factors in shaping the person's decision-making ability.

Decision-making capability.

In the supported decision-making literature, a conceptual alternative to decision-making capacity has been proposed. Scholars that reject seeing a person's decision-making capacity as solely rational and autonomous (Flynn & Arstein-Kerslake, 2014), have suggested embracing the concept of decision-making capability instead (Bach & Kerzner, 2010).

The concept of "decision-making capability" (Bach & Kerzner, 2010, p.67) recognises the person's unique decision-making abilities and the supports and accommodations available to them in the decision-making process rather than relying on "the limitations of a 'mental capacity' test" (Bach & Kerzner, 2010, p.68). Bach and Kerzner (2010) suggest,

> A broader account of human agency and personhood, or of persons who exercise legal capacity, and of the ways in which they exercise it, expands our understanding of how the right to legal capacity can be exercised. The notion of 'decision-making capability' – as a combination of unique decision-making

> abilities combined with supports and accommodations – provides a key conceptual tool with which to fashion a legal paradigm for recognizing the right to legal capacity that is consistent with the provisions of the CRPD and its social model approach to disability. (p.72)

The model of the process of decision-making support developed from this research offers a framework to better understand the theoretical proposition of ‘decision-making capability’ (Bach & Kerzner, 2010) and the multitude of factors which shaped the decision-making capability of the person at the centre of the process of decision-making support. These research findings also support the proposition of reconceptualising capacity in the context of supported decision-making legislation and practice. Decision-making capability better reflects the reality that a person’s decision-making ability is multifactorial and depends on a wide range of factors, which include the supports and accommodations available to the person in the decision-making process.

Conclusion

The discussion outlined the unique contribution this research makes to current thinking about the process of decision-making support by comparing the research findings to the existing empirical and conceptual literature on supported decision-making and more generally decision-making support. This chapter concludes by exploring the implications of these findings for supported decision-making legislation, policy and practice.

Implications for legislation, policy and practice.

Legislation.

While the presence of legal mechanisms offered legal recognition for the person, and resolved some important practical issues for supporters, this research suggests the presence of legal mechanisms did not substantially shape how central participants were supported with their decision making. Rather a range of individual, relational, decisional and environmental factors, were found to influence the process of decision-making support and ultimately the extent to which the outcome was directed by the person's will and preferences. Even though these findings are not able to be generalised they raise some important questions regarding how much focus creating legal mechanisms and legislative frameworks has had in the discourse about realising the aims of supported decision-making internationally.

While some authors have acknowledged the success of supported decision-making relies on much more than the presence of legal mechanisms (Carney, 2012; Stainton, 2016), there has been a strong focus on legislative reform as necessary to meet the aims of supported decision-making (Carney & Beaupart, 2013; Carney, 2015b; Dinerstein, 2012; Flynn & Arstein-Kerslake, 2014; Glen, 2015; Gooding 2013; Richardson, 2012). The strong conceptual link made between supported decision-making and the exercise of legal capacity at the CRPD (Browning et al., 2014) may have distracted legislators, scholars and practitioners from practical and ethical questions regarding the provision of decision-making support (Carney, 2017; Kohn, Blumenthal & Campbell, 2013). The narrow focus on legal capacity may also have taken attention away from supported decision-making as a mechanism to realise the self-determination of people with cognitive and psychosocial disabilities (Bodnar & Coflin, 2003; Shogren et. al., 2017a). It is only in more recent times that scholars are beginning to explore the exercise of legal agency, as the second element of legal capacity, in the context of legal mechanisms of supported decision-making (Arstein-Kerslake & Flynn, 2017).

Therefore, it will be important for legislators wanting to embrace the support paradigm and realise the aims of supported decision-making to understand, that creating legal recognition for people with intellectual disability (and their supporters) is not enough to ensure they are able to exercise their legal capacity. The quality of the decision-making support that people with intellectual disability receive will also influence their ability to exercise their legal agency. Education and training for people who intend to use the legal mechanisms consistent with supported decision-making must sit alongside the introduction of new legislation. Education would need to explore the aims and principles of supported decision-making, explain the process of decision-making support and develop the capacity of supporters to reflect on how their support influences the person's agency as well as the outcome of the process.

Adoption of the term decision-making capability.

In Australia over the last five years, legislation has been enacted that allows for supported decision-making in specific contexts (e.g., the support person role in the *Medical Treatment Planning and Decisions Act 2016*; and the supportive attorney provisions in the *Powers of Attorney Act 2014* in Victoria). While these pieces of legislation allow people with cognitive disabilities to appoint decision supporters, a requirement of making an appointment is that the person has decision-making capacity. While both pieces of legislation use criteria for assessing capacity, which reflect traditional cognitive based capacity tests (understand and appreciate), they also contain the following statement. "A person has decision-making capacity to make a decision if it is possible for the person to make a decision with practicable and appropriate support" (*Medical Treatment, Planning and Decisions Act* 2016, section 4(d)). While still predominantly focusing on the person's cognitive capacities the new legislation recognises that certain supports and accommodations, for example giving the person more time, can result in a change in their decision-making capacity.

The findings of this research support taking this approach further in the drafting of future supported decision-making legislation. This research discovered the capacity of central participants to engage in decision making was multifactorial and dependent on wide range of individual, relational, decisional and environmental factors. The model developed from this research suggests conceptualisations of decision-making capacity in supported decision-making legislation, which focus predominantly on the person's cognitive capacities, may underplay the substantial impact of relational, decisional and environmental factors in shaping the person's decision-making ability.

Given the research findings, it is recommended future supported decision-making legislation adopt the concept decision-making capability which "combines an individual's particular decision-making abilities with the supports and accommodations needed to exercise legal capacity" (Bach & Kerzner, 2010, p.72). The determination of a person's decision-making capacity should include the supports and accommodations available to them in the process of decision-making support. Adopting a change in terminology may assist legislators, policy makers and practitioners to recognise the importance of including the supports and accommodations available to the person in the process of decision-making support as central to rather than secondary to the person's decision-making ability.

Policy.

In Australia, supported decision-making has been identified as key to the National Disability Insurance Agency fully realising its aims to enable people with disability in Australia to determine their own lives (Bonahady, 2016). Supported decision-making is believed to offer NDIS participants with cognitive disabilities a practical means of being supported to choose and control their financial packages and service delivery (ADACAS, 2013).

The findings of this research support an emerging body of research, which suggests overriding the preferences of people with intellectual disability, and acquired brain injury is a common part of decision-making support (Bigby et al., 2017a; Knox et al., 2016c). A number of central participants had their will and preferences changed through the use of informal coercion and undue influence and others experienced having their will and preferences disregarded entirely. Therefore, it is important that policy makers and practitioners supporting people with cognitive disability develop a greater understanding of the conditions that create undue influence and informal coercion and work to minimise these practices. Policy and practice guidance is needed to ensure people with cognitive disabilities, receiving decision-making support, are not subjected to informal substituted decision-making. As discussed already legislation on its own is not enough.

The model of the process of decision-making support developed from this research, together with other emerging research, may give policy makers a clearer framework to understand the roles the person being supported and their supporter have when engaging in supported decision-making. They may also start to clarify a range of factors, which shape the influence supporters seek to exert during the process.

This research found undue influence and informal coercion were likely to be involved when decision supporters refused to accept the person's will and preferences until they aligned with their preferred outcome (which was often their own will and preferences). Therefore, agencies wanting to minimise the incidence of undue influence and informal coercion could play an important role in:

- changing cultural beliefs and assumptions about the decision-making capability of people with intellectual disability;
- supporting people with intellectual disability to know their rights and become empowered to express their will and preferences;
- assisting supporters to understand their role is to be responsive to the will and preferences of the person;
- helping people with intellectual disability and their supporters to understand the aims and principles of supported decision-making;
- helping supporters to understand the process of decision-making support and reflect on whether their responses are aligned with the aims and principles of supported decision-making;
- recognising the importance of relational quality and fostering relationships that are characterised by relational closeness, equality, respect, trust and mutual knowledge;
- assisting supporters to develop skills in self-reflection that will allow them to better understand the values, beliefs, goals and priorities they bring to the process of decision-making support;

- assisting supporters to identify the individual, relational, decisional and environmental factors shaping the process of decision-making support;
- assisting supporters to develop the ability to review the outcomes of the process of decision-making support (including the extent to which it was directed by the person's will and preferences); and
- mitigating the negative influence of environmental factors on the process of decision-making support such as organisational expectations, time constraints, limited staffing and risk averse organisational cultures.

Having a clearer conceptual model of the process of decision-making support offers agencies the potential to foster and develop good supported decision-making practice. By developing a greater understanding of the factors that shape supporter influence in the process of decision-making support, agencies may be able to adopt a range of strategies to reduce the incidence of undue influence and informal coercion.

Practice.

Developing frameworks for practice.

When considering building frameworks for supported decision-making, Shogren et al. (2017b) suggest it is important to clearly define the steps involved in a decision-making process "to allow for assessment of a person's support needs related to each of the steps… (Shogren et al, 2017b, p.149). In Australia, attempts have begun to develop practice frameworks such as the model of support for decision making developed by Bigby and Douglas (2015) which includes three elements: steps in support for decision making; principles of support for decision making and strategies for practice.

While practitioners may seek concrete direction when providing decision-making support this research challenges conceptualisations of decision making as a series of steps that imply a linear progression. The recursive nature of the dynamic interaction between the person and their supporter(s) is at odds with characterising decision-making support in such a segmented way. When explaining their model Bigby and Douglas (2015) acknowledge the "real world is less ordered" than their model may appear and have attempted to frame the steps as "iterative" where they "often occur simultaneously" (Bigby & Douglas, 2015, p.10). However, there is a risk this type of conceptualisation may lead practitioners to underestimate the complexity and interactional nature of decision-making support uncovered in this research.

Reflecting the complex, dynamic and recursive nature of the process of decision-making support in frameworks and conceptual diagrams is very difficult. The research findings suggest frameworks of supported decision-making that present the process of decision-making support in interactional terms may resonate more strongly with the lived experiences of people engaging in practice than stepped, progressive characterisations.

Decision-making capability and generalised assessments of support need.

The model developed from this research embeds the decision-making ability of central participants in the individual, relational, decisional and environmental context of each decision-making process. As such, the findings of this research support the recommendation that supported decision-making legislation, policy and practice adopts the concept of decision-making capability. Even though some supported decision-making practitioners have embraced a "social-ecological model of disability" (Shogren et al., 2015, p.18) the frameworks of supported decision-making they are developing tend to see the person's decision-making ability as a factor which exists separately to the environmental demands and supports the person needs for decision making (Shogren et al., 2015).

If new and emerging models of supported decision-making do not adopt the concept of decision-making capability (which understands decision-making ability includes the supports and accommodations available to the person), there is a risk practitioners will become overly focused on assessment of the individual and the development of skills and supports needed to increase their decision-making ability (capacity). It seems this may already be occurring in the work of Shogren et al., (2015; 2017a; 2017b) who developed a framework for considering the design of assessments and interventions to promote supported decision-making (Shogren et al., 2015) and later proposed an assessment process called the "Supported Decision Making Inventory System (SDMIS)" (Shogren et al., 2017b, p.434).

The SDMIS is designed to be completed by a person with intellectual disability in partnership with a trusted person to determine "areas of support needs to enhance decision-making abilities and competencies as well as to identify environmental and personal factors that would need to be accounted for in designing supports" (Shogren et al., 2017b, p.435). The individualised assessment asks the person with intellectual disability the degree to which specific statements are true for them such as "I generally feel free to express my opinions" (p.436) and "to what degree do you know the potential impacts of your decisions on others" (p.436).

The findings of this research raise some concerns regarding the development of generalised assessments of the support needs of people with intellectual disability like the SDMIS. First, this research has demonstrated the supports and accommodations each person needs when making decisions will differ significantly from one decision-making context to the next. Therefore, assessments that attempt to identify a person's generalised need for supports, and develop systems of supports and accommodations on the basis of generalised needs, fail to recognise the nuanced and contextually dependent nature of decision-making capability.

Second, these research findings suggest the person in need of assistance may be completely unaware of a range of factors that substantially influence their ability to participate in the process of decision-making support. Decision making is a complex cognitive process (Harris, 2003) and most of the central participants in this research had significant difficulty identifying and discussing the factors, which shaped their participation in the process of decision-making support. Given this was the case, it is possible this type of generalised assessment of the person's support needs would miss identifying important influencing factors. Examples may include, the skills and abilities their decision supporter(s) brings to the process, the quality of their relationship, the complexity of the decision and environmental factors such as resource constraints (time, staff funding) and limiting community attitudes.

Third, only one central participant, of the seven who participated in this research, would be able to complete this type of assessment with a trusted supporter. During this research, it was through extended periods of participant observation that the researcher was able to understand the complex interaction of factors that shaped the person's decision-making participation. These research findings suggest spending time getting to know people with intellectual disability and observing their decision-making experiences over time is a helpful and rich way of understanding the personal and environmental factors that shape their decision-making participation. A written assessment is likely to exclude the perspectives of many people with intellectual disability especially people with severe to profound intellectual disability who communicate non-verbally and do not read.

Fourth, the assessment of the support needs of people with intellectual disability may unnecessarily formalise an organic, every day process. Shogren et al. (2017b) acknowledge, “most people make decisions in consultation and partnership with others” (Shogren et al., 2017b, p.438), and yet few people have an inventory taken of the personal and environmental demands that may be shaping their decision making. Formalising the provision of decision supports creates the need for “assessment and intervention frameworks” (Shogren et al., 2017a, p.153) and in doing so risks “treating supported decision-making as an option required because of disability” (James & Watts, 2014, p.20). Practitioners need to ask whether the assessments and interventions they are creating are “pathologising” the decision-making processes of people with intellectual disability unnecessarily and in doing so perpetuating “an inherently discriminatory perspective on decision making” (James & Watts, 2014, p.20).

Self-reflection and review.

Self-reflection and review have been identified as essential components of effective decision-making support for people with severe traumatic brain injury (Knox, 2016d). Emerging research into the experiences of decision supporters for people with intellectual disabilities suggest self-reflection about practice “should form the basis for resources developed to train or mentor decision-making supporters about their practice” (Bigby et al., 2017b, p.20). The findings of this research point to the benefit of supporters engaging in three types of reflection: self-reflection prior to decision making, reflection during the process of decision-making support, and a reflective review of the outcomes of the process.

Self-reflection prior to engaging in the process of decision-making support may benefit the supporter’s involvement in the process in two ways. First, self-reflection may assist supporters to develop an awareness of the values, beliefs, goals and priorities they bring to the process of decision-making support. This reflection may help supporters identify the assumptions they bring about the person’s decision-making capability, the expectations they have in regard to their role as a supporter and their understanding about what constitutes a good life from their perspective. The more aware a supporter becomes of the experiences and attributes they bring to the process the more it will assist them to identify how these experiences and attributes have the potential to influence the process. For example, a supporter may be very risk averse because of difficult experiences in her past. By becoming aware of her tendency to avoid risk, she can attempt to mitigate the influence this would likely have when supporting someone else in a decision-making process involving risk. Second, self-reflection prior to decision making may help supporters consider how the values, beliefs, goals and priorities they have relate to those of the person they are supporting. These attributes might align or be quite different. Knowing how the person conceptualises a good life, and reflecting on any similarities or differences, will give the supporter the ability to acknowledge and account for these differences in the way they go about providing support.

Reflection during the process of decision-making support may improve the ability of the supporter to identify the range of factors shaping the process. The more skilled supporters can become at identifying the elements and individual, relational, decisional and environmental factors shaping their support the more likely they would be able to respond more consciously during the process of decision-making support. Given the considerable impact of how the supporter responds during the process on the agency of the person, greater awareness of the factors influencing the process may help the supporter to explore and challenge their actions before responding. For example, at the beginning of the process the supporter may become aware that she is allowing the judgement of other family members to influence her feelings about a decision opportunity for the person. By stepping back from the situation and reflecting on the insight, the supporter may decide the judgement of family members are not founded on legitimate concerns and that she does not want them to negatively influence her exploration of the decision opportunity with the person.

Finally, reflection may also be beneficial after the process of decision-making support has ended to review the outcome of the process for the person and others. Review of the process as a whole may allow the supporter to identify the extent to which the process increased or decreased the agency of the person and was directed by their will and preferences. Decisions are not made in isolation and often lead to other decisions

(Bigby et al., 2015). Reviewing the process might assist with the exploration of the impact of the decision on the person's life and whether changes or other decisions may be required in the future. It could also help the person and supporter determine whether the process facilitated the development of decision-making skills for the person and how the process might be improved in the future.

The practice of supported decision-making would likely benefit from decision supporters developing the ability to: engage in self-reflection (leading to greater self-awareness), identify the elements and factors shaping the process of decision-making support, understand how the elements and factors are shaping their responses during the process and conduct a reflective review of the outcomes of process.

A tension for decision supporters.

A tension exists for decision supporters between having relational closeness and adopting a neutral, non-judgemental approach to engaging in the process of decision-making support. These research findings suggest different types of support relationships may have different challenges managing this tension.

Relational closeness has been identified in this research, and other Australian studies, as foundational to the provision of good decision-making support (Fetherstonhaugh et al., 2016; Knox et al., 2015; Knox et al., 2016d; Watson, 2016a). This is because there is a complex interplay between supporter responsiveness, relational closeness and the attitudes and perceptions supporters have of the person's decision-making capability (Watson, 2016a). As evidenced in the literature, this research found relational closeness was not necessarily linked to the length of time supporters had known the person they were supporting (Watson, 2016a) or the type of relationship for example, paid or unpaid (Watson, 2016a) but rather the quality of the support relationship (Knox et al., 2015). Even though relationship type did not necessarily prevent the development of relational closeness for some paid staff, when acting as decision supporters, the ability of employees to develop relational closeness can be constrained by time limitations and organisational expectations of professional distance (Watson, 2016a).

Interestingly, while relational closeness was not necessarily linked to relationship type, this research supports emerging empirical evidence that the ability of supporters to adopt a neutral, non-judgemental approach when providing support may be more challenging for family members who have a clear “vision” for their family member’s life (Bigby et al., 2017a, p.6). There is always a “plurality of interests” in family life that can make it difficult for decision supporters who are family members “to divorce themselves from their own emotional ties and interests and view the interests of their relative in an objective and unbiased manner” (Clough, 2014, p.140). This may not present the same challenge for paid staff who try to mitigate their influence over the person’s decision making by adopting a non-judgemental approach and “being neutral” (Bigby et al., 2017, p.6).

Therefore, these research findings suggest the type of support relationship the supporter has in the person’s life may raise different challenges in managing the tension between relational closeness and adopting a neutral, non-judgemental approach when engaging in the process of decision-making support. It seems paid staff, such as support workers, may find it more challenging to develop relational closeness because of time constraints and professional expectations of distance but are less likely to have difficulty adopting a neutral, non-judgemental approach to providing decision-making support. This may be because they have less vested interest in the outcome of the decision-making process.

On the contrary, family members may find it easier to develop high levels of relational closeness, from years of shared life history, but experience greater challenges trying to separate their own goals and priorities from those of the person. When family members have a clear vision for the person’s life (including goals and priorities), it may make adopting a neutral, non-judgemental approach to providing decision-making support challenging.

Understanding this tension has implications for the development of training and education for decision supporters engaging in practice. Those facilitating training may find acknowledging the different challenges experienced by different types of support relationships assists with problem solving and overcoming these challenges. Greater insight into how different supporters experience tensions when providing decision-making support may help resolve conflict between their different perspectives.

Research strengths and limitations.

This research set out to understand how people with intellectual disabilities were supported with decision making in the context of two legal mechanisms which create opportunities for supported decision-making in Canada, representation agreements and microboards. The aims of the research were met by identifying a common process of decision-making support, describing the factors that shaped the process, and exploring the highly individualised and contextually dependent way in which the elements and factors interacted. This research has a number of strengths and limitations, which must be considered when assessing the findings.

The experiences of central participants and their supporters, as described in the research findings, were unique to those individuals and the circumstances in which they made decisions. The complex interaction of individual, relational and environmental factors shaping the process of decision-making support were unique to this research context. Therefore, it is not appropriate to suggest that the findings can be generalised to other groups of people with intellectual disability being supported with decision making in other contexts such as Australia.

However, although it is not possible to generalise the findings some of the concepts explored are supported by emerging research in Australia and Canada. These small, exploratory studies, collectively raise a number of similar issues to those identified in this research for example, the centrality of quality support relationships to good supported decision-making practice (Knox et al., 2016d; Watson, 2016a). Therefore, to develop a more formal theory of supported decision-making practice, comparative analysis of findings across a broader range of participants and contexts is needed.

This research was the first investigation in Canada of decision-making support in the context of legal mechanisms which allow for supported decision-making, which utilised both participant observation and interviewing as methods of data generation. Method triangulation is a strength of this qualitative research because it allowed the checking of inferences drawn from interviewing with data generated from participant observation (Hammersley & Atkinson, 2007). The addition of participant observation as a method created a richness in understanding how people with intellectual disabilities, who had limited verbal ability, were supported with their decision making. It also allowed the researcher to develop a deeper understanding of the specific context of decision making and the participants involved in the research (Taylor & Brogdan, 1998).

There was a tension for the researcher identifying as a critical realist (whose epistemology is constructivist and ontology more closely aligned with realism than relativism), using constructivist grounded theory methods. The struggle in trying to ensure paradigmatic consistency throughout the research process was time consuming and difficult. However, there were important reasons the researcher made the decision to use constructivist grounded theory, which included the exploratory nature of the subject matter, decision making being such a relational, co-constructed concept and the previous success of constructivist grounded theory exploring decision-making support in other contexts. The additional reflexivity required to ensure paradigmatic consistently assisted the researcher to identify the highly nuanced and individualised nature of the process of decision-making support. To have been able to characterise the incredible variability in the process could have only come about using constructivist grounded theory and is a strength of these research findings.

One challenge the researcher experienced engaging in participant observation, as a research method to explore decision-making support, was that participants often did not know when they would be making decisions. Decision opportunities emerged unexpectedly throughout the day, which resulted in the researcher spending extended time with participants engaging in their everyday lives hoping decision opportunities would emerge. Further research into the process of decision-making support should expect participant observation to take significant time, because of the irregularity and unpredictability of decision-making opportunities.

The process of decision-making support developed from this research uniquely reflects the experiences of a range of central participants with mild, moderate and severe to profound intellectual disability. The inclusion of central participants with a range of intellectual disabilities is another strength of this research investigation. However, the scope of participant recruitment in this research was limited in other ways. The data generation period was constrained by time and the financial resources available to the researcher living away from home. These constraints meant data was generated to a point of theoretical “sufficiency” (Dey, 1999, p.117) rather than saturation (Morse, 2007). Resource constraints meant limiting the number of participants recruited, and the locations where they lived (only two provinces in Canada). While different types of relationships were explored (for example, familial, professional and friendship), these research findings would be expanded by an increased understanding of supported decision-making in the context of a more diverse range of support relationships in terms of relationship quality (the extent to relationships are characterised by equality, respect, trust, knowledge).

Only one of the seven central participants, and their decision supporters, in this research were from a non-English speaking background. Research has shown that cultural context shapes the expression of preference in choice making (Savani et al., 2008) and how people understand the outcomes of decision making (Weber & Hsee, 2000). Therefore, it will be important to expand the findings of this research to include the experiences of people from other cultures who engage in supported decision-making.

Directions for future research.

Future research needs to examine and extend the theoretical factors characterising the process of decision-making support that have emerged from this research. These factors need to be explored in a range of different contexts. This could be achieved by seeking to understand the experiences of people with intellectual disability in different geographic locations, in relationships of different quality and engaging in different types of decisions. It could also be achieved by exploring the experiences of people with different forms of cognitive disability, people of different ages and who live in different cultures.

While this study offers some important insights into relational quality in the context of the support relationship, these research findings would be expanded by an increased understanding of supported decision-making in the context of a more diverse range of support relationships. Relationships could be explored in terms of what type of cognitive disability the person at the centre of the decision-making process has (such as dementia or psychosocial disability); and the ages of central participants (for example, teenagers learning to assert their independence) and supporters (for example, children supporting their parents with dementia).

Future research on supported decision-making would benefit from exploring in greater detail decision making where the nature of the decision has legal consequences. This will be necessary to better understand how the process of decision-making support can assist people exercising their legal capacity. The experience of this research suggests decision making with legal consequences is a fairly infrequent experience in life. Therefore, future research will need to target people about to make significant legal contracts such as marry, purchase property or vote and explore the environmental, relational and individual factors which shape their decision-making processes.

Although this research provides some insight into the factors that shape supporter responses, further research is needed to understand whether it is possible for supporters to become more conscious of these factors when engaging in the process of decision-making support. It would also be interesting to explore whether developing greater self-awareness improves the ability of supporters to change their responses and align their practice more closely with the principles of supported decision-making. Additionally, mixed method research using a pre/post intervention design could evaluate whether education (provided in the form of a resource or training program on reflective practice) had any impact on supporter awareness of how their responses during the process of decision-making support shape the agency of the person.

Current research being conducted under an Australian Research Council (ARC) Linkage Grant (2015-2019) entitled ‘Effective Decision Making Support for People with Cognitive Disability’ will begin to explore the impact of education on the decision-making support provided to people with acquired brain injuries and intellectual disabilities. The mixed methods study across three states in Australia will assess the impact of a capacity building education program for participants, using two parallel randomised trials (Carney, 2017). The evaluation will measure the effectiveness of capacity building education in key domains such as orchestration, commitment, strategy development and support principles for people being supported and their supporters (Carney, 2017).

These research findings were limited by the time and financial constraints of generating data in another country. Future research into the practice of supported decision-making would benefit from exploring the experiences of receiving and providing decision-making support over a longer period of time. Future research could recruit young adults transitioning from childhood to adulthood and in the early stages of making significant life decisions to participate in a longitudinal study. This type of study would use both quantitative and qualitative research methods to explore the range of factors, including environmental, relational and individual, that shape and change supported decision-making practice over the lifetime.

Over the last ten years a number of jurisdictions have introduced legislation which recognises the practice of supported decision-making. For example, the *Adult Guardianship and Trusteeship Act 2008* (Alberta); *Assisted Decision-Making (Capacity) Act 2015* (Ireland); and the *Powers of Attorney Act 2014* (Vic). Research is needed to explore how the process of decision-making support differs in different cultures. Future research exploring supported decision-making in these jurisdictions would allow comparative analysis of research findings across groups and contexts creating the possibility of developing a formal theory of supported decision-making practice.

Concluding Statement

The aim of this research was to explore how people with intellectual disabilities were supported with their decision making in the context of two legal mechanisms which create opportunities for supported decision-making in Canada, representation agreements and microboards. The process of decision-making support discovered in the research was complex, dynamic and multifactorial involving a person with intellectual disability expressing their will and preferences in relation to a decision opportunity and their supporters responding by providing a range of support. The range of practice encountered in this research suggests not all decision-making support provided in the context of legal mechanisms that allow for supported decision-making offered people with intellectual disability control and self-determination in their lives. How supporters responded in the dynamic interaction shaped whether the agency of the person increased or decreased during the process and the extent to which the outcome was directed by their will and preferences.

While the presence of legal mechanisms offered legal recognition for central participants, and resolved some important practical issues for supporters, representation agreements and microboards did not substantially shape how decision-making support was provided to central participants. This research proposes a conceptual model for understanding the range of individual, relational, decisional and environmental factors that did influence the process of decision-making support for people with intellectual disability.

The model developed from this research challenges frameworks of supported decision-making (or support for decision making) that conceptualise decision making as a linear process characterised by progressive steps. It also challenges conceptualisations of decision-making capacity that underplay the substantial impact relational, decisional and environmental factors have in shaping a person's decision-making ability. If supported decision-making practitioners do not adopt the concept of decision-making capability there is a risk, they will become overly focused on the assessment of the person and the development of skills and supports needed to increase the person's decision-making capacity. These research findings suggest education may be helpful for legislators, policy makers and practitioners wanting to improve supported decision-making practice. Education could explore the aims and principles of supported decision-making, understanding the process of decision-making support and facilitate reflection on how the actions supporters take during the process of decision-making support shape the extent to which the outcome is directed by the person's will and preferences.

There is still much to be learned about the process of decision-making support in a range of contexts and this research has made a small contribution to an important, emerging body of research on supported decision-making practice.

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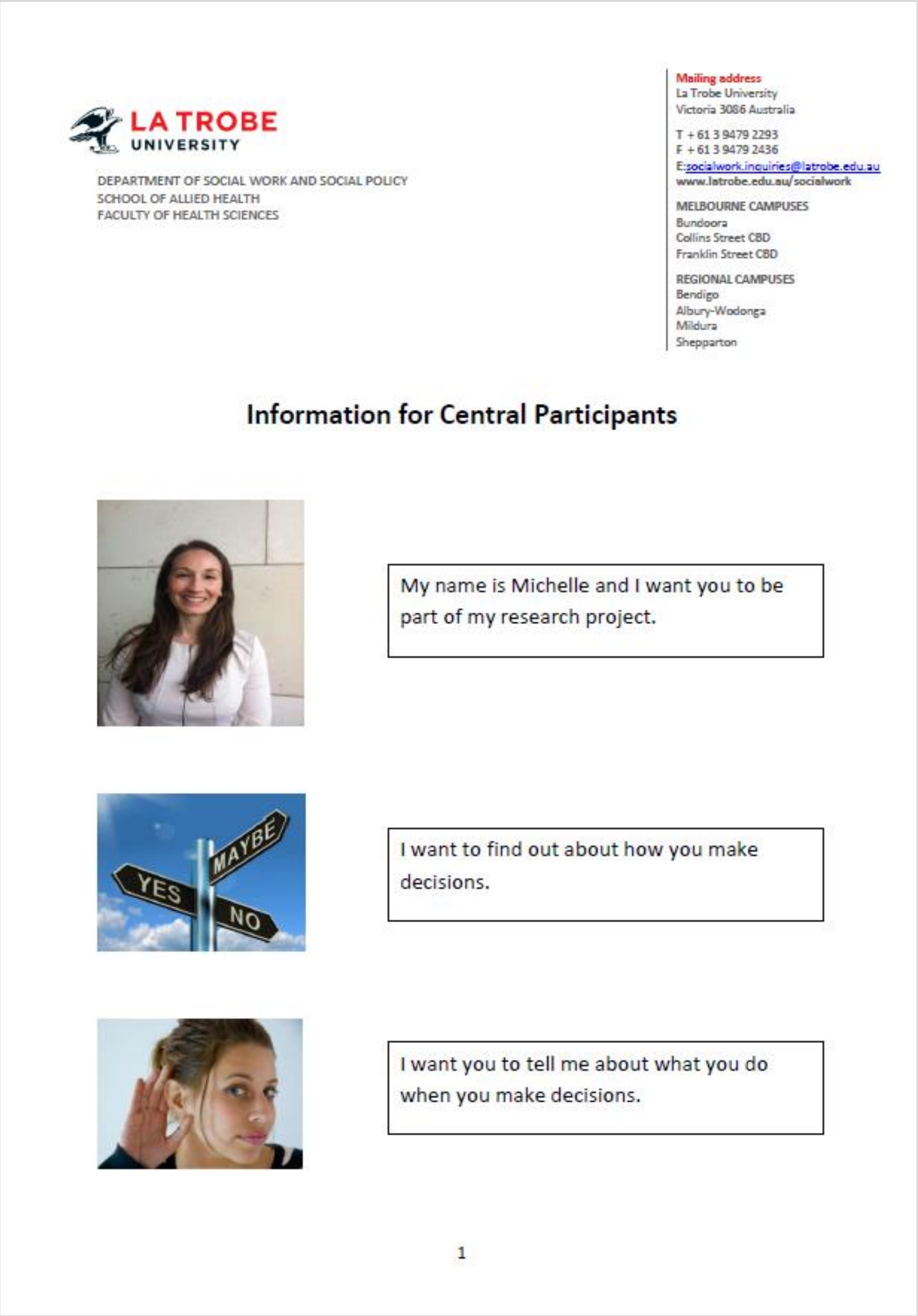
Appendices

Appendix A: Information sheets and consent forms for research participants



LA TROBE
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REGIONAL CAMPUSES
Bendigo
Albury-Wodonga
Mildura
Shepparton

Information for Central Participants

My name is Michelle and I want you to be part of my research project.

I want to find out about how you make decisions.

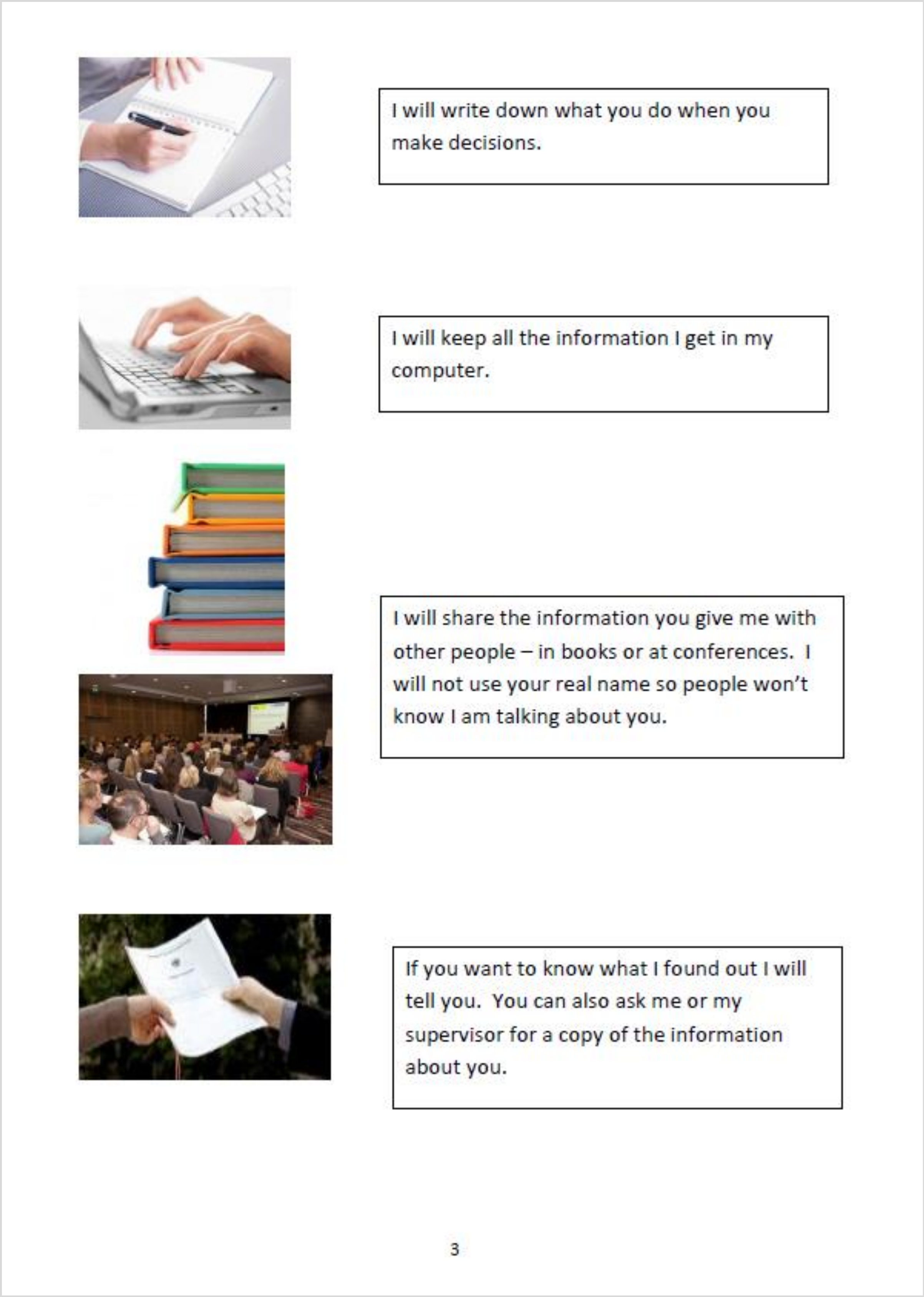
I want you to tell me about what you do when you make decisions.

I also want to talk to the people that help you make decisions.

I will record the talks I have with you and other people so I can listen to them again later. I will ask you if you are happy to have your voice recorded.

I want to spend time with you and watch you making decisions with your representative or microboard.

2

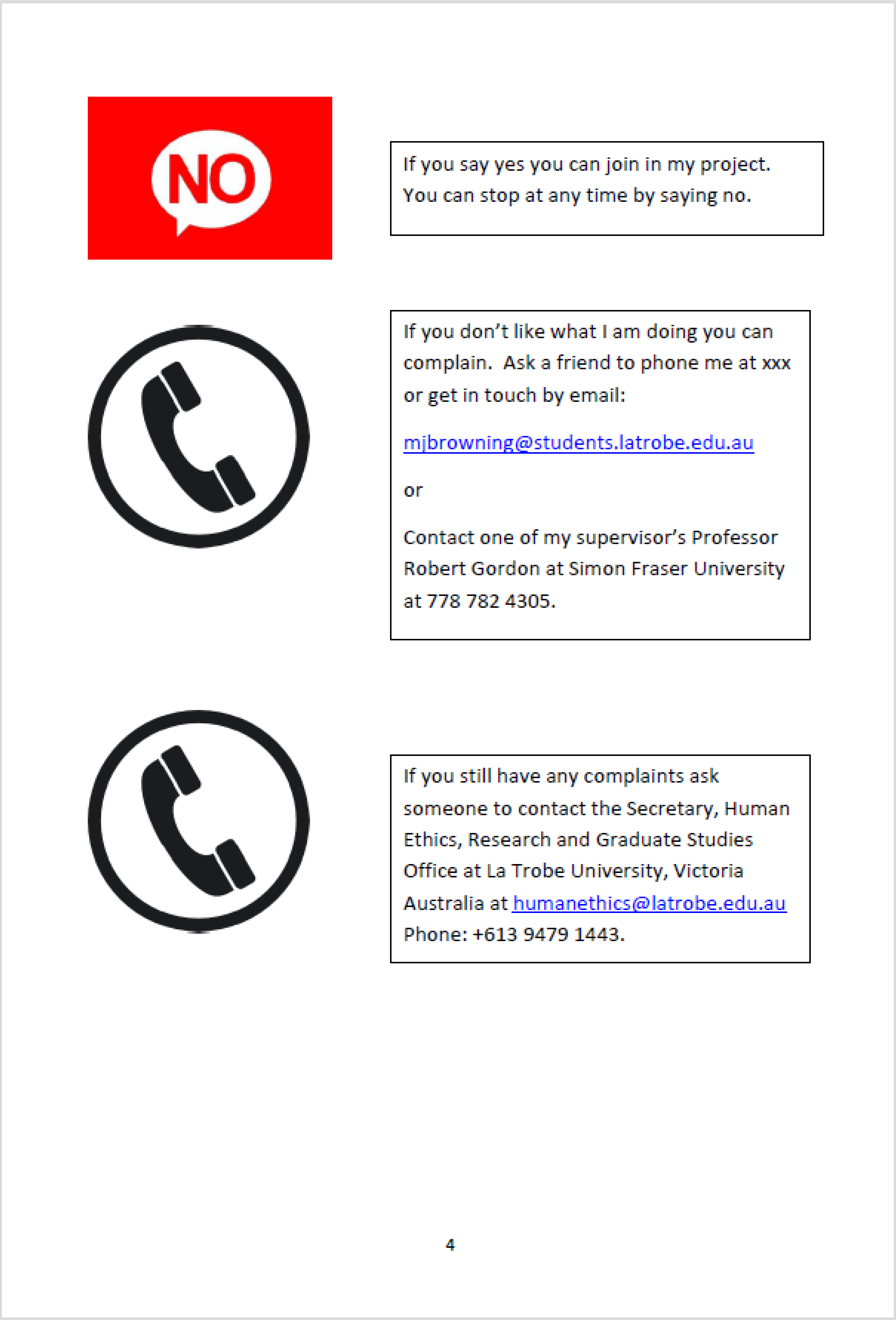


I will write down what you do when you make decisions.

I will keep all the information I get in my computer.

I will share the information you give me with other people – in books or at conferences. I will not use your real name so people won't know I am talking about you.

If you want to know what I found out I will tell you. You can also ask me or my supervisor for a copy of the information about you.



If you say yes you can join in my project. You can stop at any time by saying no.

If you don’t like what I am doing you can complain. Ask a friend to phone me at xxx or get in touch by email:

mjbrowning@students.latrobe.edu.au

or

Contact one of my supervisor’s Professor Robert Gordon at Simon Fraser University at 778 782 4305.

If you still have any complaints ask someone to contact the Secretary, Human Ethics, Research and Graduate Studies Office at La Trobe University, Victoria Australia at humanethics@latrobe.edu.au Phone: +613 9479 1443.

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Information Sheet for Decision Supporters

Project Title

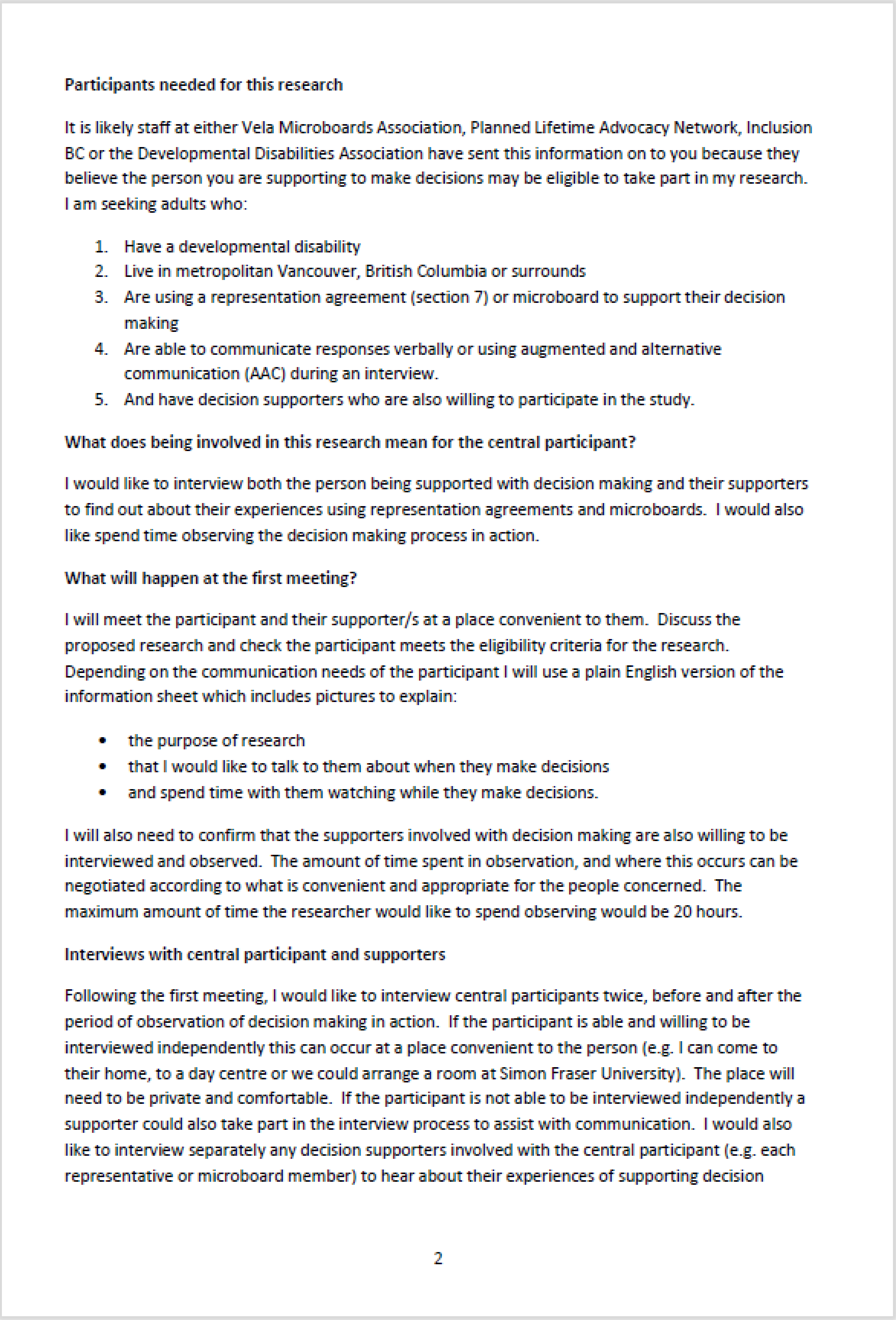
How is supported decision making realised in practice? An exploration of two examples of supported decision making in British Columbia, Canada: representation agreements and microboards.

Introduction

My name is Michelle Browning and I am a PhD student at La Trobe University, Australia. My supervisors are Professor Christine Bigby, primary supervisor, in the school of Social Work and Social Policy and Dr Jacinta Douglas, secondary supervisor, in the school of Human Communication Sciences. I also have an external supervisor Professor Robert Gordon, from Simon Fraser University, in Vancouver Canada. The following information is provided for you to decide whether you would like to participate in my research. The aim of this research is to understand how people with cognitive disabilities can be supported to make decisions. I am seeking information from people using both representation agreements and microboards in British Columbia to develop a theory explaining the practice of supported decision making. I want to interview research participants to talk about their decision making and observe them in the process of making decisions together.

Reason for doing this research

Supported decision making developed in Canada and has been discussed as a way of enabling people with cognitive impairment to have greater control over their lives. Models of supported decision making, such as representation agreements and microboards, allow people with disabilities to make significant decisions in their life with support and have those decisions legally recognised. Australia is interested in implementing models of supported decision making and this research is about trying to understand how the process actually works in practice.



Participants needed for this research

It is likely staff at either Vela Microboards Association, Planned Lifetime Advocacy Network, Inclusion BC or the Developmental Disabilities Association have sent this information on to you because they believe the person you are supporting to make decisions may be eligible to take part in my research. I am seeking adults who:

1. Have a developmental disability
2. Live in metropolitan Vancouver, British Columbia or surrounds
3. Are using a representation agreement (section 7) or microboard to support their decision making
4. Are able to communicate responses verbally or using augmented and alternative communication (AAC) during an interview.
5. And have decision supporters who are also willing to participate in the study.

What does being involved in this research mean for the central participant?

I would like to interview both the person being supported with decision making and their supporters to find out about their experiences using representation agreements and microboards. I would also like spend time observing the decision making process in action.

What will happen at the first meeting?

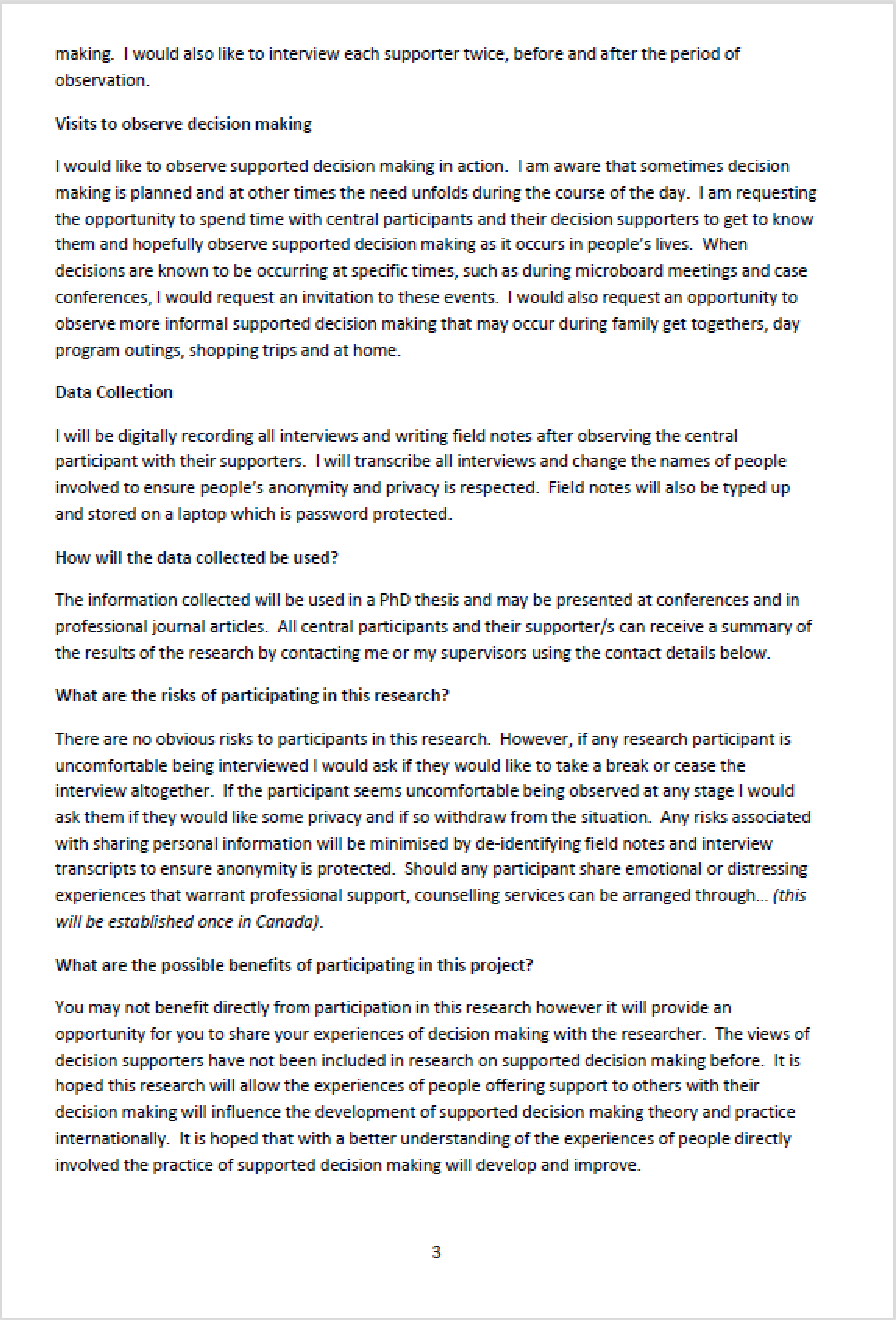
I will meet the participant and their supporter/s at a place convenient to them. Discuss the proposed research and check the participant meets the eligibility criteria for the research. Depending on the communication needs of the participant I will use a plain English version of the information sheet which includes pictures to explain:

- the purpose of research
- that I would like to talk to them about when they make decisions
- and spend time with them watching while they make decisions.

I will also need to confirm that the supporters involved with decision making are also willing to be interviewed and observed. The amount of time spent in observation, and where this occurs can be negotiated according to what is convenient and appropriate for the people concerned. The maximum amount of time the researcher would like to spend observing would be 20 hours.

Interviews with central participant and supporters

Following the first meeting, I would like to interview central participants twice, before and after the period of observation of decision making in action. If the participant is able and willing to be interviewed independently this can occur at a place convenient to the person (e.g. I can come to their home, to a day centre or we could arrange a room at Simon Fraser University). The place will need to be private and comfortable. If the participant is not able to be interviewed independently a supporter could also take part in the interview process to assist with communication. I would also like to interview separately any decision supporters involved with the central participant (e.g. each representative or microboard member) to hear about their experiences of supporting decision



making. I would also like to interview each supporter twice, before and after the period of observation.

Visits to observe decision making

I would like to observe supported decision making in action. I am aware that sometimes decision making is planned and at other times the need unfolds during the course of the day. I am requesting the opportunity to spend time with central participants and their decision supporters to get to know them and hopefully observe supported decision making as it occurs in people's lives. When decisions are known to be occurring at specific times, such as during microboard meetings and case conferences, I would request an invitation to these events. I would also request an opportunity to observe more informal supported decision making that may occur during family get togethers, day program outings, shopping trips and at home.

Data Collection

I will be digitally recording all interviews and writing field notes after observing the central participant with their supporters. I will transcribe all interviews and change the names of people involved to ensure people's anonymity and privacy is respected. Field notes will also be typed up and stored on a laptop which is password protected.

How will the data collected be used?

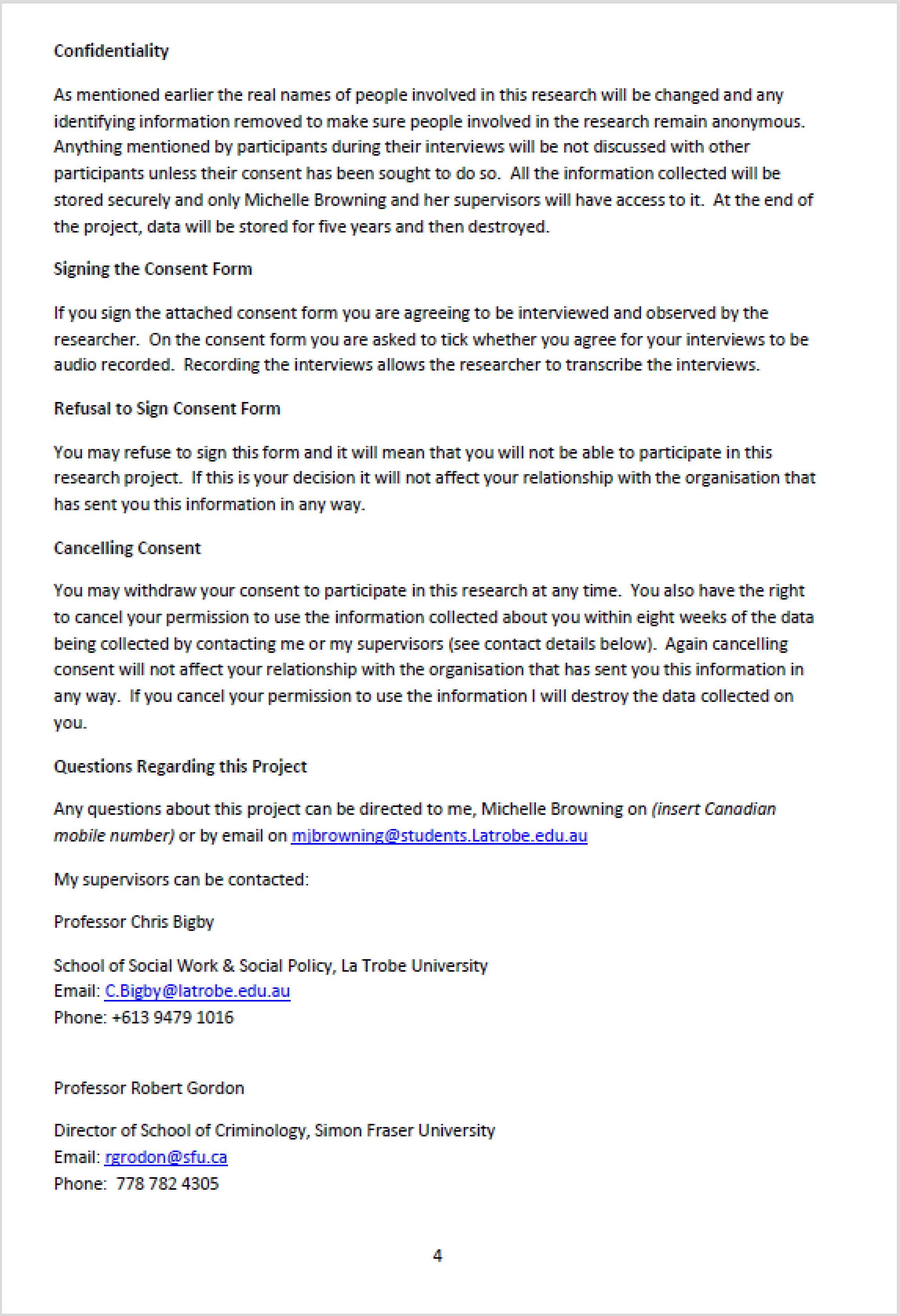
The information collected will be used in a PhD thesis and may be presented at conferences and in professional journal articles. All central participants and their supporter/s can receive a summary of the results of the research by contacting me or my supervisors using the contact details below.

What are the risks of participating in this research?

There are no obvious risks to participants in this research. However, if any research participant is uncomfortable being interviewed I would ask if they would like to take a break or cease the interview altogether. If the participant seems uncomfortable being observed at any stage I would ask them if they would like some privacy and if so withdraw from the situation. Any risks associated with sharing personal information will be minimised by de-identifying field notes and interview transcripts to ensure anonymity is protected. Should any participant share emotional or distressing experiences that warrant professional support, counselling services can be arranged through… *(this will be established once in Canada)*.

What are the possible benefits of participating in this project?

You may not benefit directly from participation in this research however it will provide an opportunity for you to share your experiences of decision making with the researcher. The views of decision supporters have not been included in research on supported decision making before. It is hoped this research will allow the experiences of people offering support to others with their decision making will influence the development of supported decision making theory and practice internationally. It is hoped that with a better understanding of the experiences of people directly involved the practice of supported decision making will develop and improve.



Confidentiality

As mentioned earlier the real names of people involved in this research will be changed and any identifying information removed to make sure people involved in the research remain anonymous. Anything mentioned by participants during their interviews will be not discussed with other participants unless their consent has been sought to do so. All the information collected will be stored securely and only Michelle Browning and her supervisors will have access to it. At the end of the project, data will be stored for five years and then destroyed.

Signing the Consent Form

If you sign the attached consent form you are agreeing to be interviewed and observed by the researcher. On the consent form you are asked to tick whether you agree for your interviews to be audio recorded. Recording the interviews allows the researcher to transcribe the interviews.

Refusal to Sign Consent Form

You may refuse to sign this form and it will mean that you will not be able to participate in this research project. If this is your decision it will not affect your relationship with the organisation that has sent you this information in any way.

Cancelling Consent

You may withdraw your consent to participate in this research at any time. You also have the right to cancel your permission to use the information collected about you within eight weeks of the data being collected by contacting me or my supervisors (see contact details below). Again cancelling consent will not affect your relationship with the organisation that has sent you this information in any way. If you cancel your permission to use the information I will destroy the data collected on you.

Questions Regarding this Project

Any questions about this project can be directed to me, Michelle Browning on *(insert Canadian mobile number)* or by email on mjbrowning@students.Latrobe.edu.au

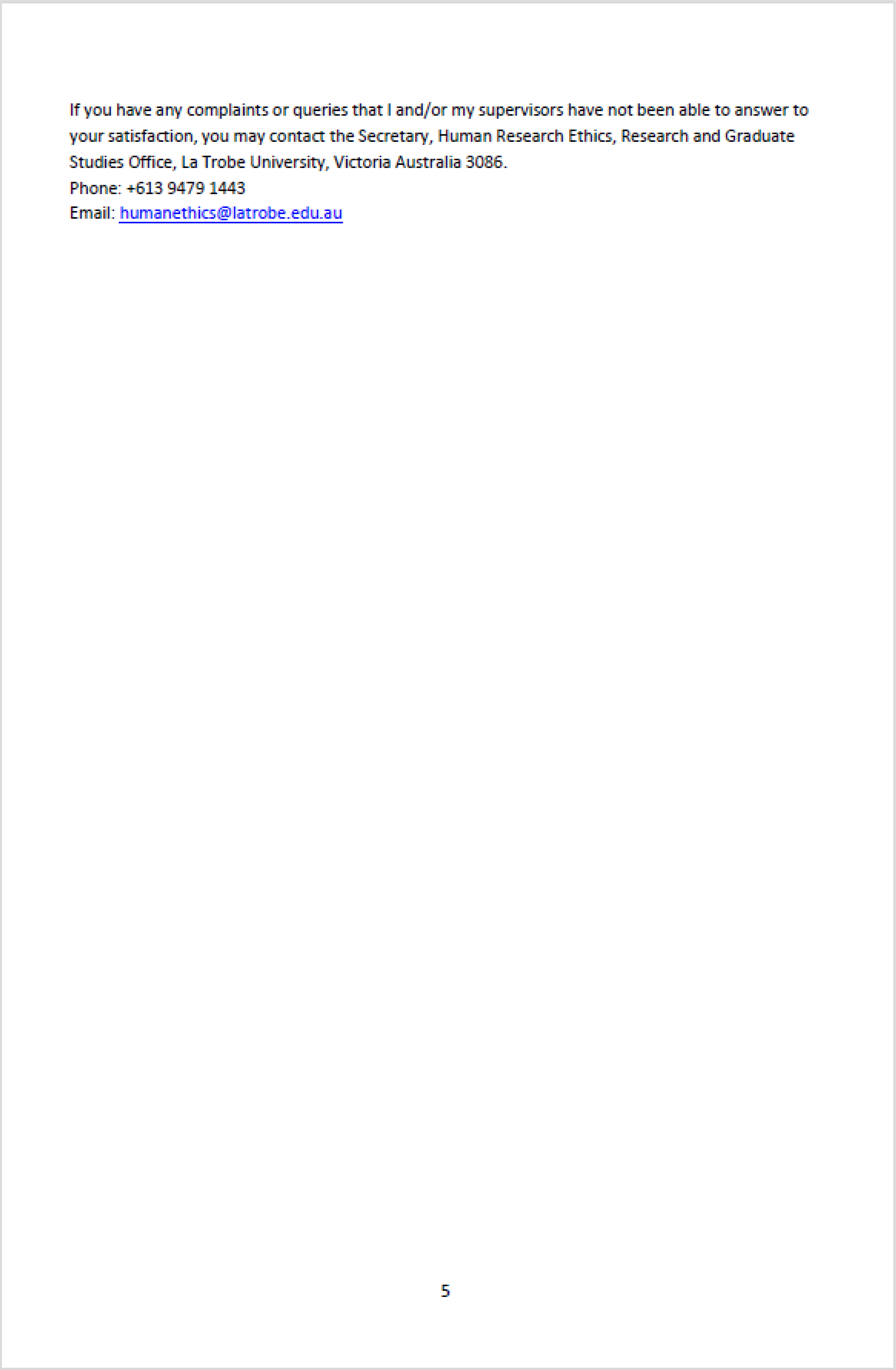
My supervisors can be contacted:

Professor Chris Bigby

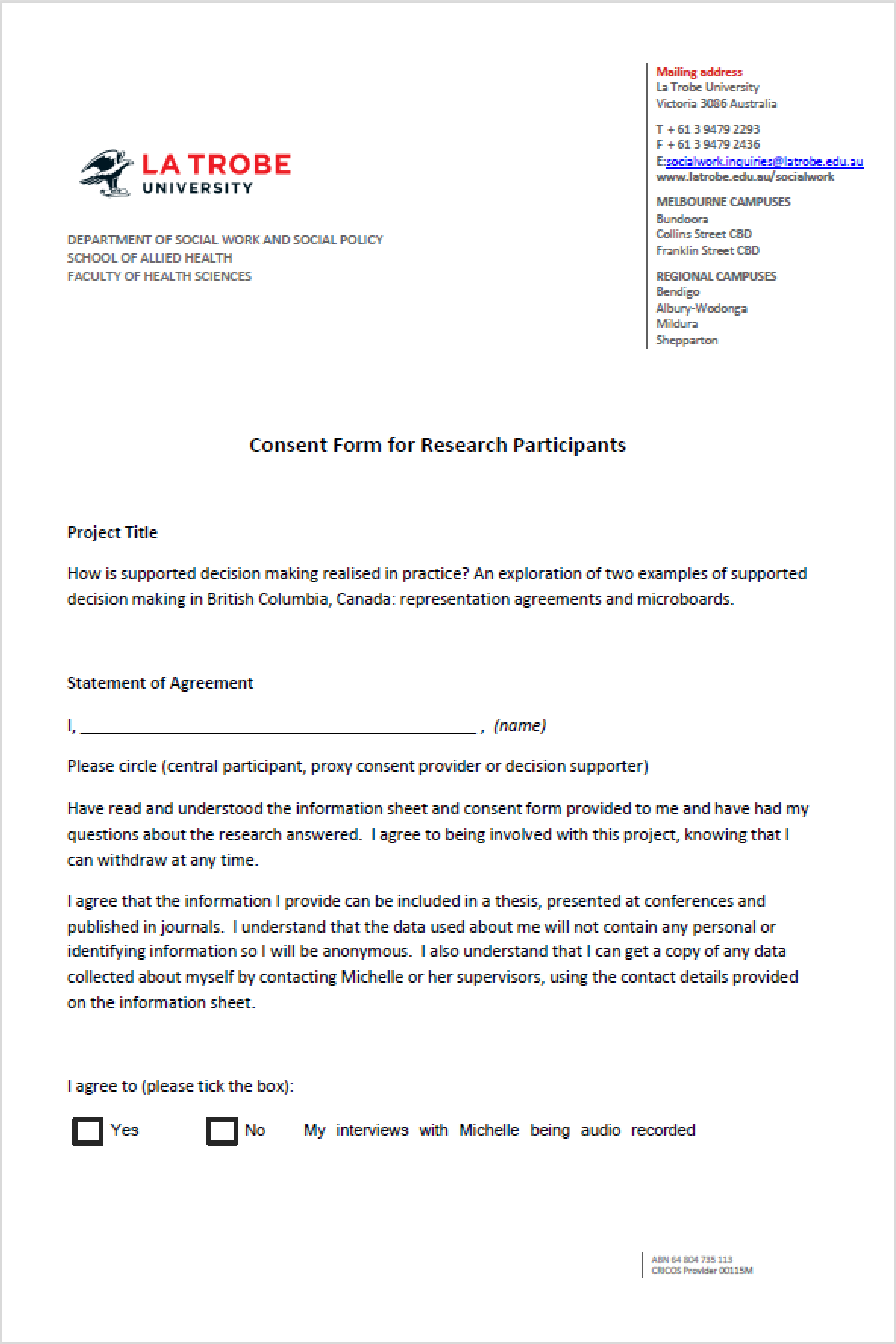
School of Social Work & Social Policy, La Trobe University
Email: C.Bigby@latrobe.edu.au
Phone: +613 9479 1016

Professor Robert Gordon

Director of School of Criminology, Simon Fraser University
Email: rgrodon@sfu.ca
Phone: 778 782 4305



If you have any complaints or queries that I and/or my supervisors have not been able to answer to your satisfaction, you may contact the Secretary, Human Research Ethics, Research and Graduate Studies Office, La Trobe University, Victoria Australia 3086.
Phone: +613 9479 1443
Email: humanethics@latrobe.edu.au



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FACULTY OF HEALTH SCIENCES

Consent Form for Research Participants

Project Title

How is supported decision making realised in practice? An exploration of two examples of supported decision making in British Columbia, Canada: representation agreements and microboards.

Statement of Agreement

I, ____ , *(name)*

Please circle (central participant, proxy consent provider or decision supporter)

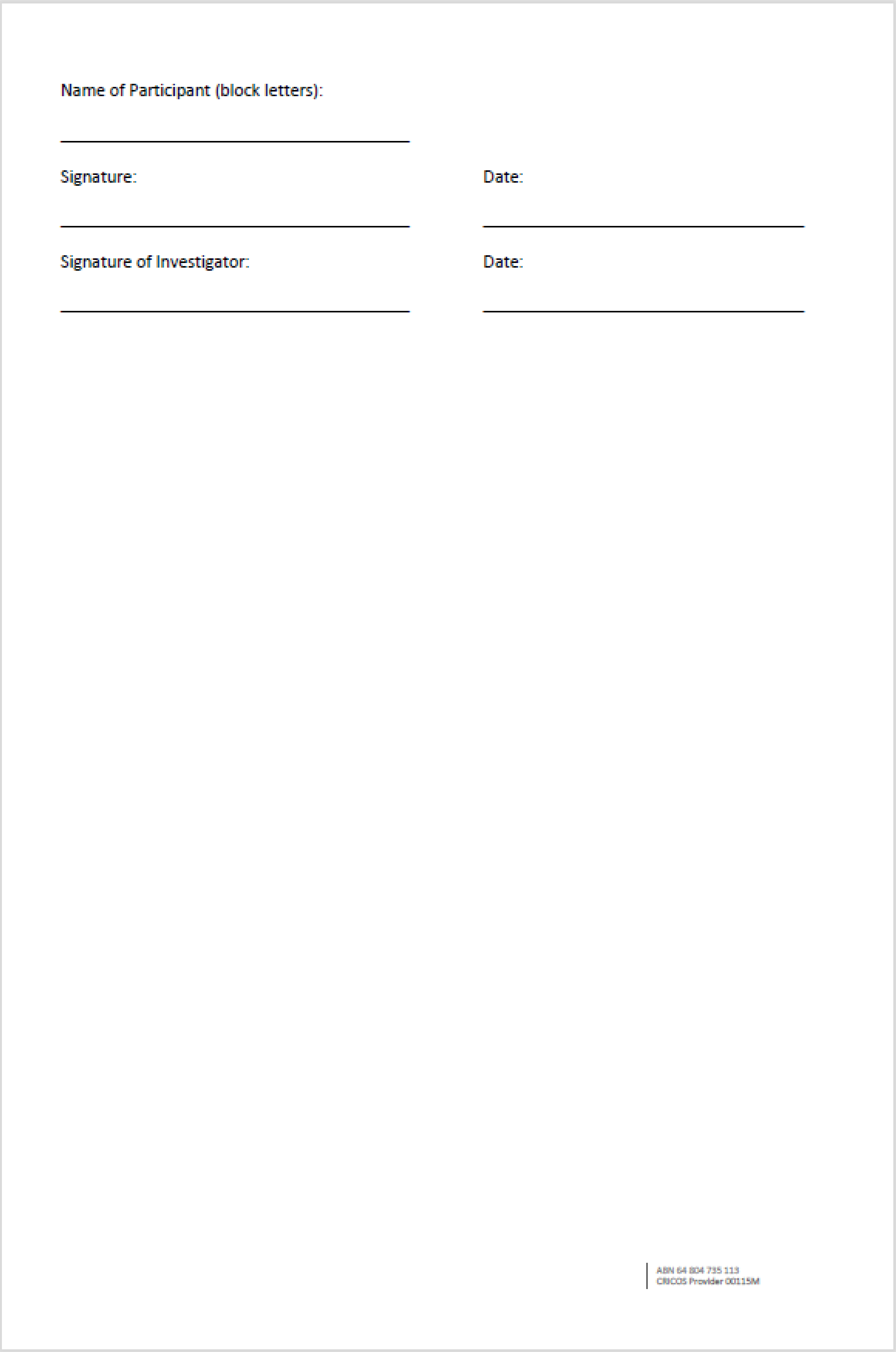
Have read and understood the information sheet and consent form provided to me and have had my questions about the research answered. I agree to being involved with this project, knowing that I can withdraw at any time.

I agree that the information I provide can be included in a thesis, presented at conferences and published in journals. I understand that the data used about me will not contain any personal or identifying information so I will be anonymous. I also understand that I can get a copy of any data collected about myself by contacting Michelle or her supervisors, using the contact details provided on the information sheet.

I agree to (please tick the box):

☐ Yes ☐ No My interviews with Michelle being audio recorded

ABN 64 804 735 113
CRICOS Provider 00115M



Name of Participant (block letters):

Signature:

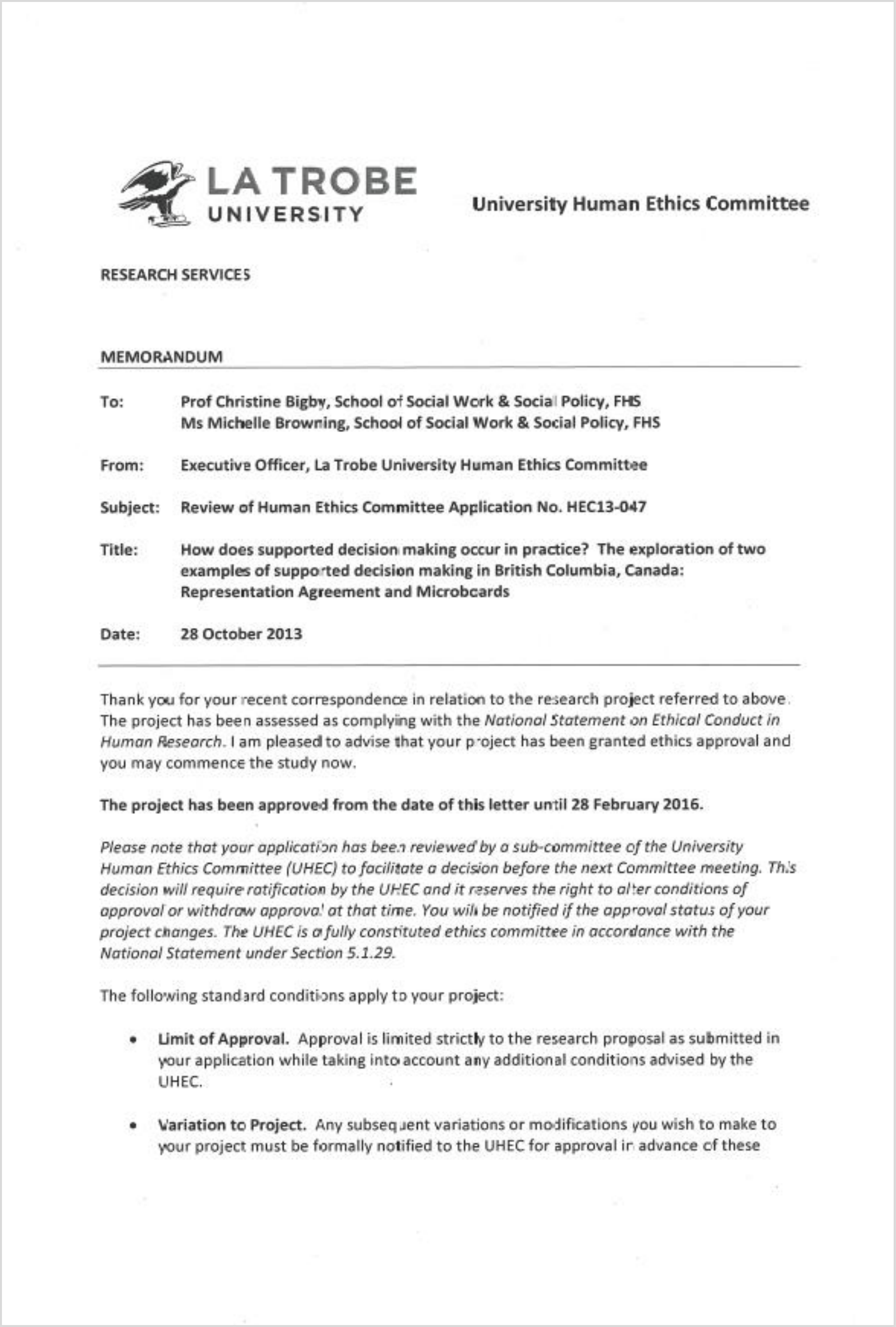
Date:

Signature of Investigator:

Date:

ABN 64 804 735 113
CRICOS Provider 00115M

Appendix B: Ethical approval



LA TROBE UNIVERSITY

University Human Ethics Committee

RESEARCH SERVICES

MEMORANDUM

To: Prof Christine Bigby, School of Social Work & Social Policy, FHS
Ms Michelle Browning, School of Social Work & Social Policy, FHS

From: Executive Officer, La Trobe University Human Ethics Committee

Subject: Review of Human Ethics Committee Application No. HEC13-047

Title: How does supported decision making occur in practice? The exploration of two examples of supported decision making in British Columbia, Canada: Representation Agreement and Microboards

Date: 28 October 2013

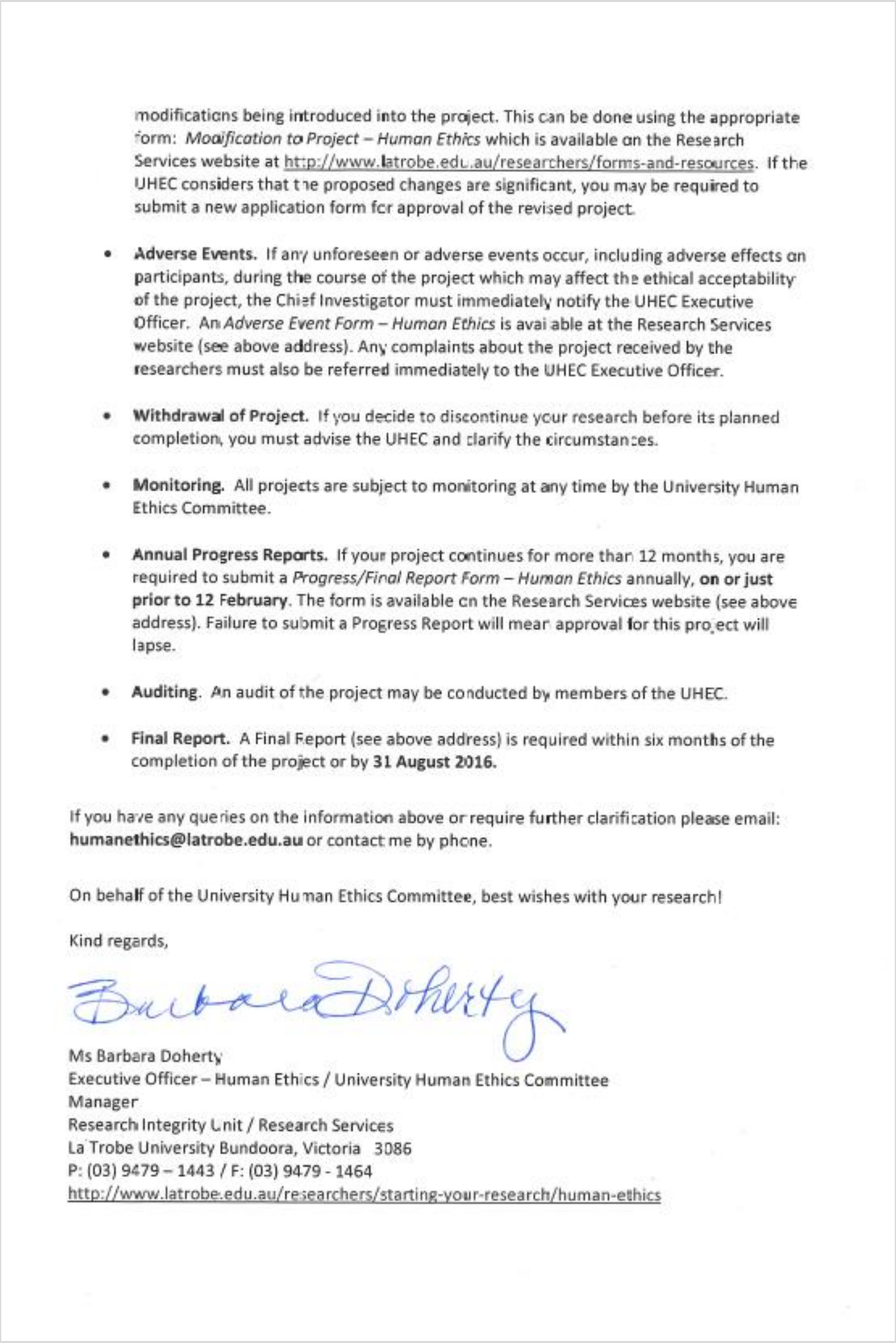
Thank you for your recent correspondence in relation to the research project referred to above. The project has been assessed as complying with the *National Statement on Ethical Conduct in Human Research*. I am pleased to advise that your project has been granted ethics approval and you may commence the study now.

The project has been approved from the date of this letter until 28 February 2016.

Please note that your application has been reviewed by a sub-committee of the University Human Ethics Committee (UHEC) to facilitate a decision before the next Committee meeting. This decision will require ratification by the UHEC and it reserves the right to alter conditions of approval or withdraw approval at that time. You will be notified if the approval status of your project changes. The UHEC is a fully constituted ethics committee in accordance with the National Statement under Section 5.1.29.

The following standard conditions apply to your project:

- **Limit of Approval.** Approval is limited strictly to the research proposal as submitted in your application while taking into account any additional conditions advised by the UHEC.
- **Variation to Project.** Any subsequent variations or modifications you wish to make to your project must be formally notified to the UHEC for approval in advance of these



modifications being introduced into the project. This can be done using the appropriate form: *Modification to Project – Human Ethics* which is available on the Research Services website at http://www.latrobe.edu.au/researchers/forms-and-resources. If the UHEC considers that the proposed changes are significant, you may be required to submit a new application form for approval of the revised project.

- **Adverse Events.** If any unforeseen or adverse events occur, including adverse effects on participants, during the course of the project which may affect the ethical acceptability of the project, the Chief Investigator must immediately notify the UHEC Executive Officer. An *Adverse Event Form – Human Ethics* is available at the Research Services website (see above address). Any complaints about the project received by the researchers must also be referred immediately to the UHEC Executive Officer.

- **Withdrawal of Project.** If you decide to discontinue your research before its planned completion, you must advise the UHEC and clarify the circumstances.

- **Monitoring.** All projects are subject to monitoring at any time by the University Human Ethics Committee.

- **Annual Progress Reports.** If your project continues for more than 12 months, you are required to submit a *Progress/Final Report Form – Human Ethics* annually, **on or just prior to 12 February**. The form is available on the Research Services website (see above address). Failure to submit a Progress Report will mean approval for this project will lapse.

- **Auditing.** An audit of the project may be conducted by members of the UHEC.

- **Final Report.** A Final Report (see above address) is required within six months of the completion of the project or by **31 August 2016.**

If you have any queries on the information above or require further clarification please email: **humanethics@latrobe.edu.au** or contact me by phone.

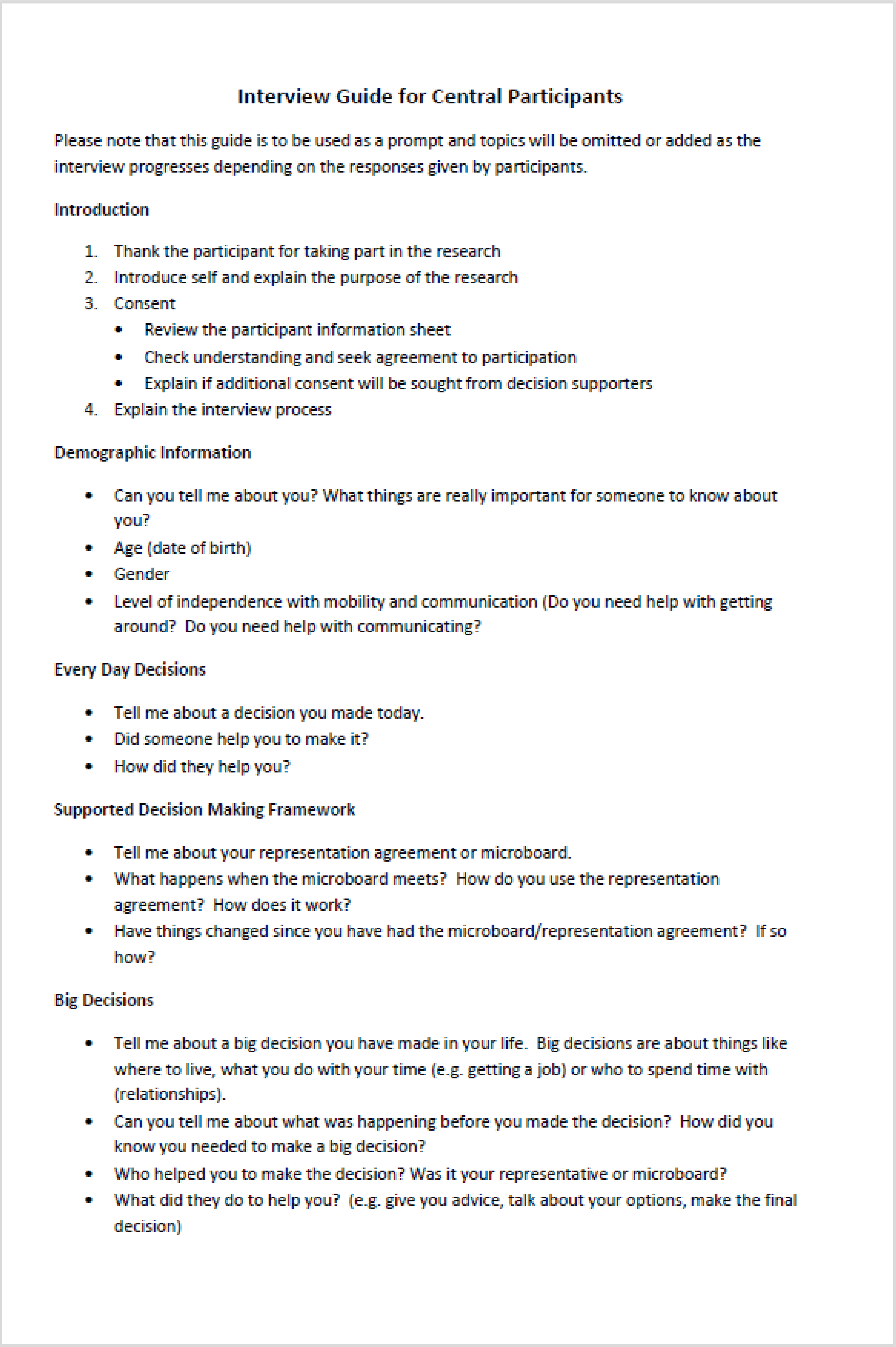
On behalf of the University Human Ethics Committee, best wishes with your research!

Kind regards,

Barbara Doherty

Ms Barbara Doherty
Executive Officer – Human Ethics / University Human Ethics Committee
Manager
Research Integrity Unit / Research Services
La Trobe University Bundoora, Victoria 3086
P: (03) 9479 – 1443 / F: (03) 9479 - 1464
http://www.latrobe.edu.au/researchers/starting-your-research/human-ethics

Appendix C: Interview guides



Interview Guide for Central Participants

Please note that this guide is to be used as a prompt and topics will be omitted or added as the interview progresses depending on the responses given by participants.

Introduction

1. Thank the participant for taking part in the research
2. Introduce self and explain the purpose of the research
3. Consent
   - Review the participant information sheet
   - Check understanding and seek agreement to participation
   - Explain if additional consent will be sought from decision supporters
4. Explain the interview process

Demographic Information

- Can you tell me about you? What things are really important for someone to know about you?
- Age (date of birth)
- Gender
- Level of independence with mobility and communication (Do you need help with getting around? Do you need help with communicating?

Every Day Decisions

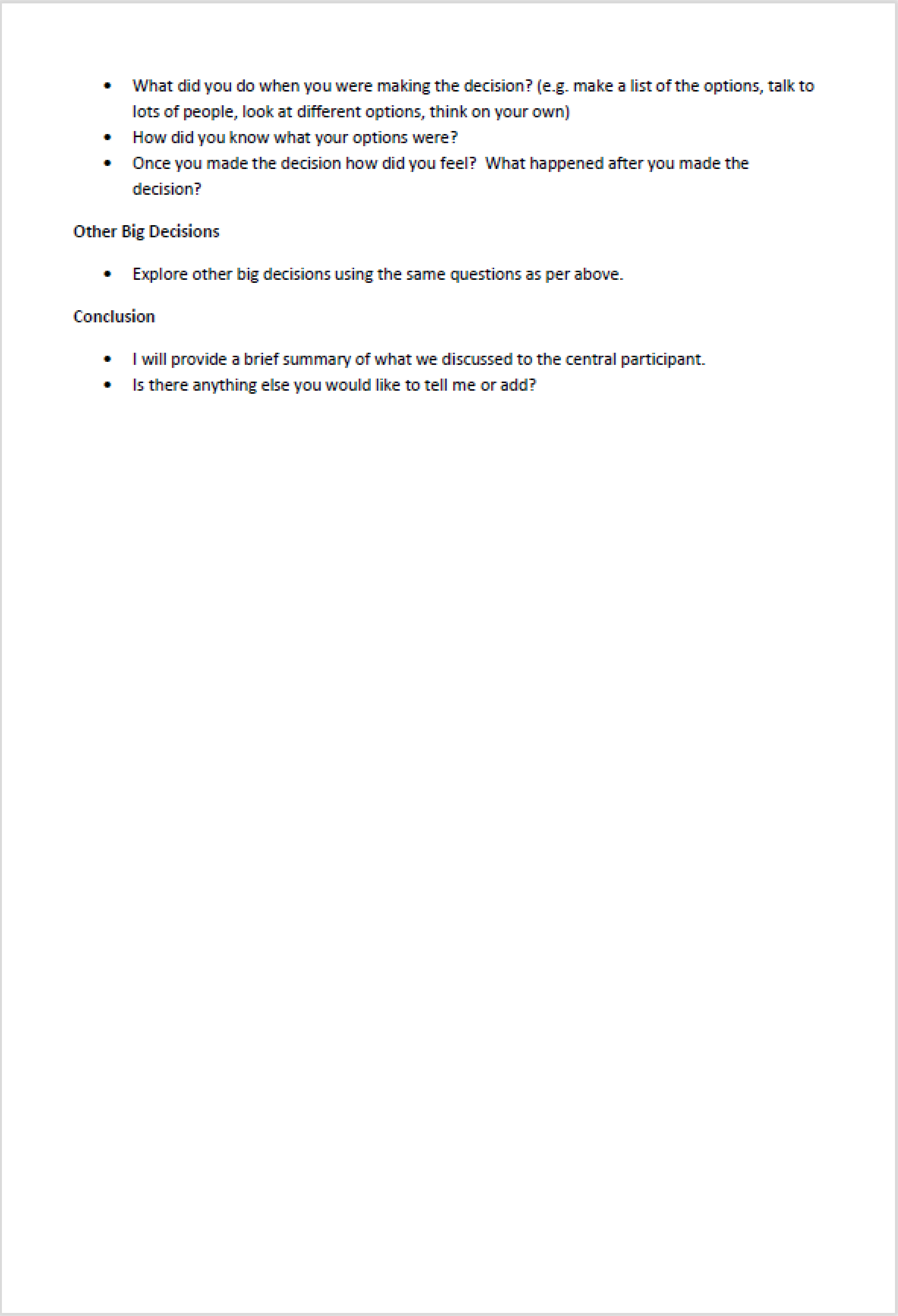
- Tell me about a decision you made today.
- Did someone help you to make it?
- How did they help you?

Supported Decision Making Framework

- Tell me about your representation agreement or microboard.
- What happens when the microboard meets? How do you use the representation agreement? How does it work?
- Have things changed since you have had the microboard/representation agreement? If so how?

Big Decisions

- Tell me about a big decision you have made in your life. Big decisions are about things like where to live, what you do with your time (e.g. getting a job) or who to spend time with (relationships).
- Can you tell me about what was happening before you made the decision? How did you know you needed to make a big decision?
- Who helped you to make the decision? Was it your representative or microboard?
- What did they do to help you? (e.g. give you advice, talk about your options, make the final decision)



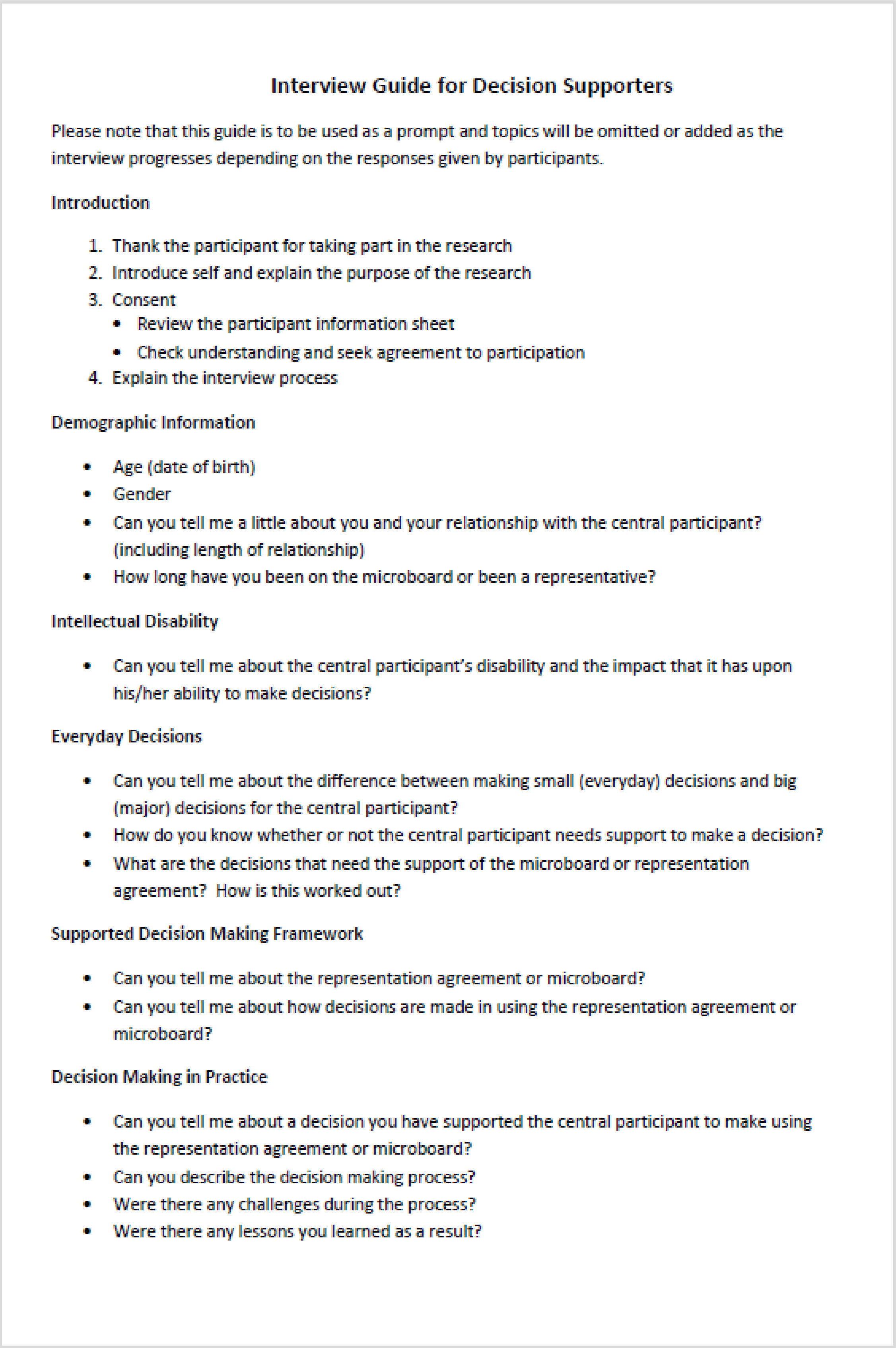
- What did you do when you were making the decision? (e.g. make a list of the options, talk to lots of people, look at different options, think on your own)
- How did you know what your options were?
- Once you made the decision how did you feel? What happened after you made the decision?

Other Big Decisions

- Explore other big decisions using the same questions as per above.

Conclusion

- I will provide a brief summary of what we discussed to the central participant.
- Is there anything else you would like to tell me or add?



Interview Guide for Decision Supporters

Please note that this guide is to be used as a prompt and topics will be omitted or added as the interview progresses depending on the responses given by participants.

Introduction

1. Thank the participant for taking part in the research
2. Introduce self and explain the purpose of the research
3. Consent
   - Review the participant information sheet
   - Check understanding and seek agreement to participation
4. Explain the interview process

Demographic Information

- Age (date of birth)
- Gender
- Can you tell me a little about you and your relationship with the central participant? (including length of relationship)
- How long have you been on the microboard or been a representative?

Intellectual Disability

- Can you tell me about the central participant's disability and the impact that it has upon his/her ability to make decisions?

Everyday Decisions

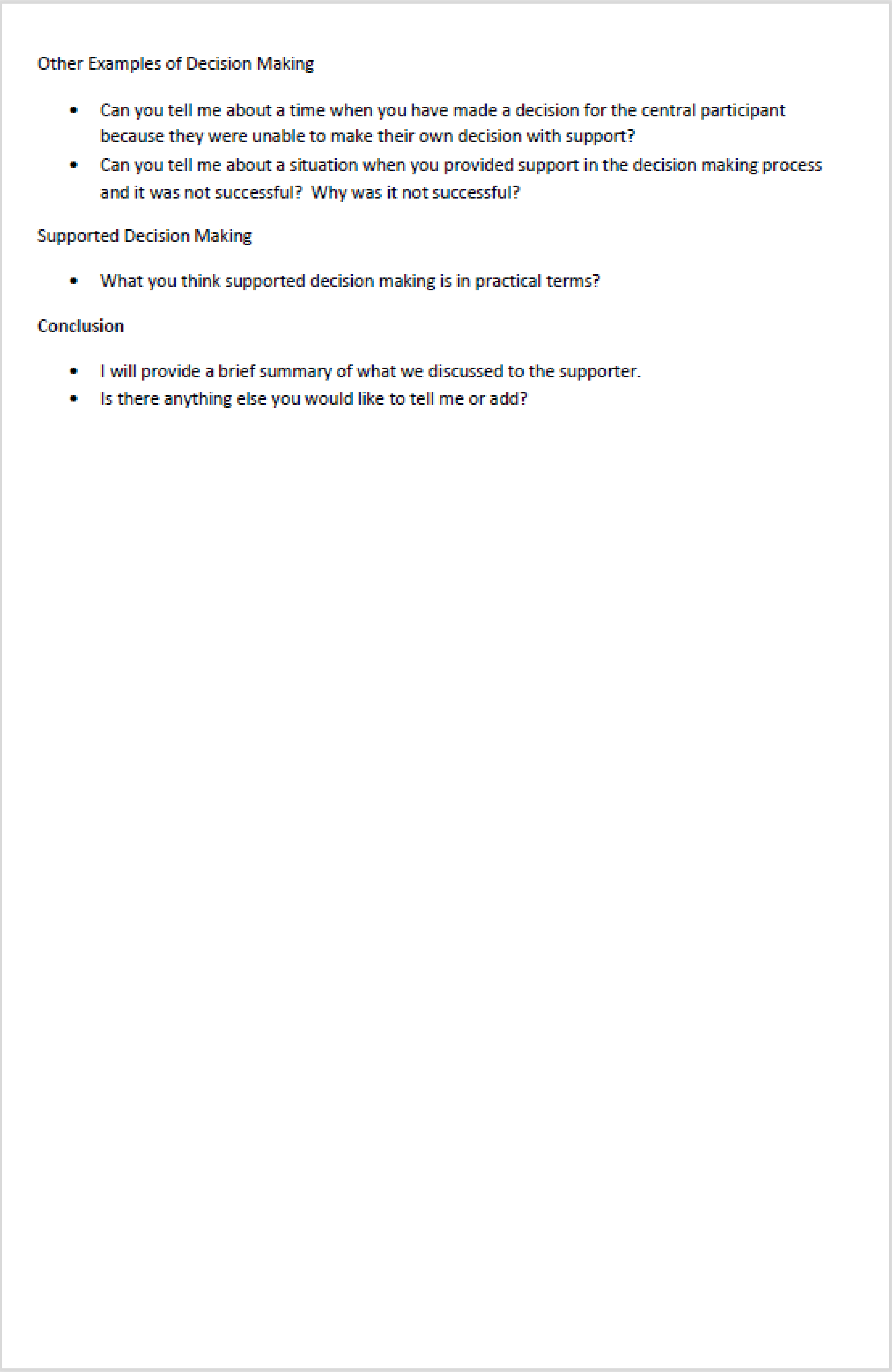
- Can you tell me about the difference between making small (everyday) decisions and big (major) decisions for the central participant?
- How do you know whether or not the central participant needs support to make a decision?
- What are the decisions that need the support of the microboard or representation agreement? How is this worked out?

Supported Decision Making Framework

- Can you tell me about the representation agreement or microboard?
- Can you tell me about how decisions are made in using the representation agreement or microboard?

Decision Making in Practice

- Can you tell me about a decision you have supported the central participant to make using the representation agreement or microboard?
- Can you describe the decision making process?
- Were there any challenges during the process?
- Were there any lessons you learned as a result?



Other Examples of Decision Making

- Can you tell me about a time when you have made a decision for the central participant because they were unable to make their own decision with support?
- Can you tell me about a situation when you provided support in the decision making process and it was not successful? Why was it not successful?

Supported Decision Making

- What you think supported decision making is in practical terms?

Conclusion

- I will provide a brief summary of what we discussed to the supporter.
- Is there anything else you would like to tell me or add?

Appendix D: Examples of in vivo coding

Eg of knowing what the person is capable of.

part of her life. So when we would swim I would push her to her limit swimming because I know she could do it. I had done it before with her, she's had really good results swimming laps and I know she could do well. So some days she would not want to swim any laps at all. And some days for whatever reason she was having a really good swimming day and she could just keep going. So in that kind of situation I knew what Emily was capable of because I had been there before so at one point I think she was doing, one day she was doing fifty laps, which is a pretty high amount.	Pushing I know her and that she could do it well. Knowing the person Knowing what they are capable of.
MB: Yes! Laughs. For me for anybody.	
S: If we got to say 12 and she decides I've had enough there are certain things she would say to express to me I'm done. It would not be I'm finished I want to get out of the pool it would be it's time to go. Or time to go see mum. Or I want to go have lunch. Or things that are part of her routine that she would start talking about. So I knew we are almost getting done. So I could push her to 'we are just going to do this many more' and I would swim with her of course so I am there and then I could stop her. So in that case I am making a decision for her but I am also aware of the things that she is saying, the way that she looks and the way she feels in the moment and I have also been there in the past. So I know her capabilities, I know what she can manage. But if you didn't know those things and she said I'm done perhaps you would stop and that would be it.	Push HER More laps INFLUENCE
Pushing & Testing (go together) going	Power struggle
MB: Why does it feel important to push her that little bit?	
S: Well part of it is just because she says something it doesn't mean that the activity is over. Cause I know that exercise wasn't her favourite thing. She would rather go for coffee or watch tv or go see her friends but I know that exercise is important for her and for her family that she does. So I would try my best always to maximise those activities with her as much as we were able to for that day. Who knows, maybe she is just testing me too. Because she is very smart that way. Who will allow her to stop when she says stop and who will push her a little bit more. She can sense that with people. In that way she is perhaps a little childlike. When children know may be which parents gives in a little quicker than the other. Kids pick up those things from people also. So with swimming and exercise, like going for a walk sometimes she really kind of put her foot down and will not get out of the car. But then sometimes you have to dangle the carrot and say 'we have to go for a walk and then we will go for coffee.' Because you know that is a preferred activity. And even if you went once, there is a lake near her house, we walk one time around the lake, that's good for today. Sometimes she would walk five times around it.	Pushing because exercise is important for her and for her family. Testing me E.g. Framing **Carrot** **Linking the necessary activity with a preferred activity** Jenny also Jessica & Carly talk about this too
MB: When you talk about dangling the carrot, is that part of supporting her with decision making is finding ways to motivate?	
S: Yes I would say so. I'm not sure if this was due to having a developmental disability or just what Emily is familiar with and her own personality. I don't know if she is intrinsically motivated by things. She is very comfortable sitting on the couch watching tv and she would be happy to do that for a long part of the day. Or staying in bed. It would be, she would stay in bed for a long part of the day if nobody said Emily it's time to get up. And I think the supports and the future hopes that many of us have for Emily is that she would never be in a care home because her needs are low because she would be happy to sit on a couch all day and watch tv. Bu the quality of living for Emily then would be very low and not what any of us want for her. Because her motivation is not there to do her own independent activities because we don't know what she can't express her motivation so you have to find things that allows her to be motivated to live life to the fullest rather than sitting on a couch and watching tv and just being in bed.	**Not Intrinsically motivated** **Part of the support is providing external motivation.** **Motivation/Interest as an aspect of capability.** ↑
MB: That's so interesting because that's really shifting for me what the boundaries are	

about improving capability

Advocacy
Self-interest
Promoting/Managing

Knowledge
Understanding Consequences
Experience
Emotional wellbeing health

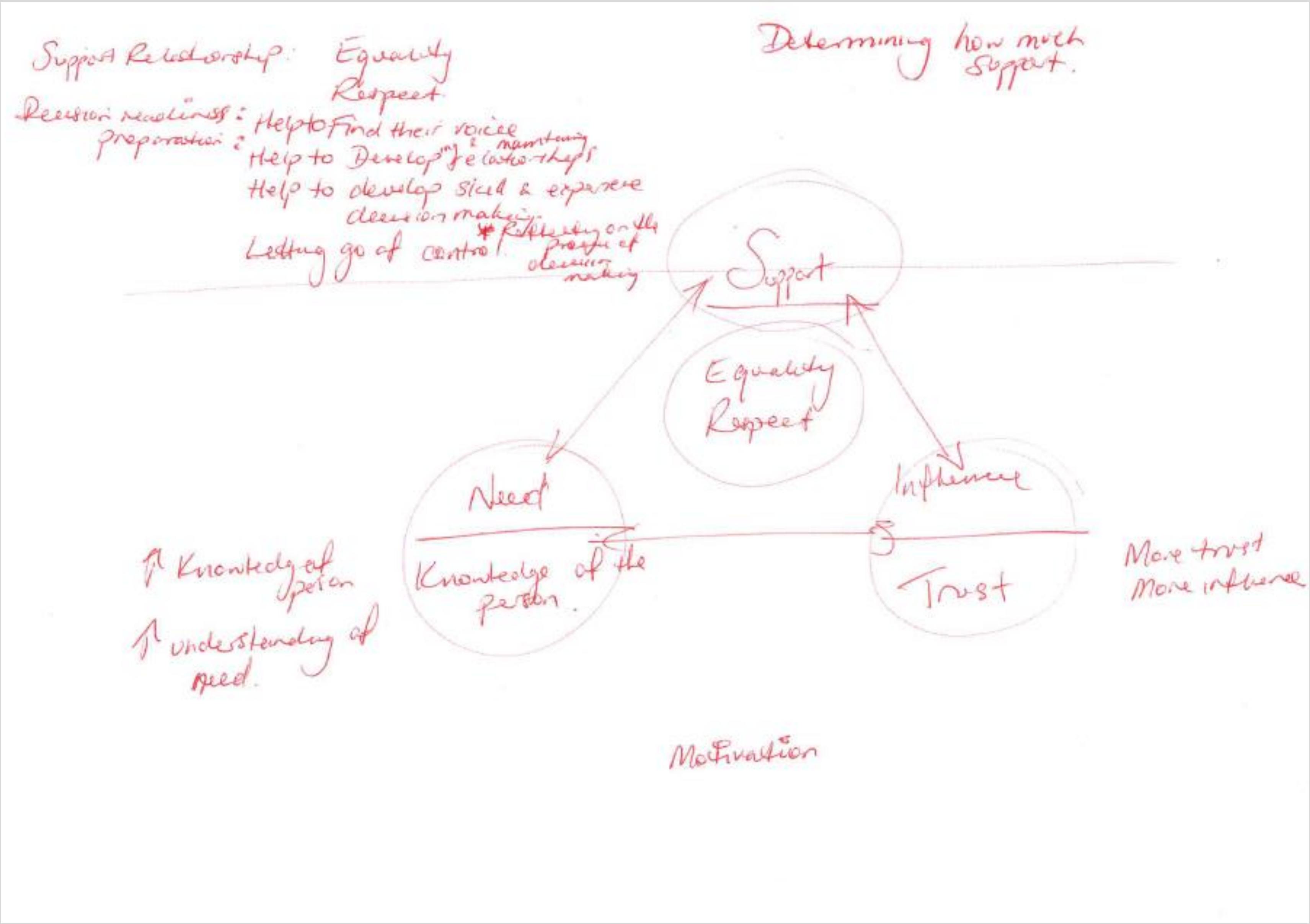
* Support to **improve** capability links to all the different aspects of the concept.

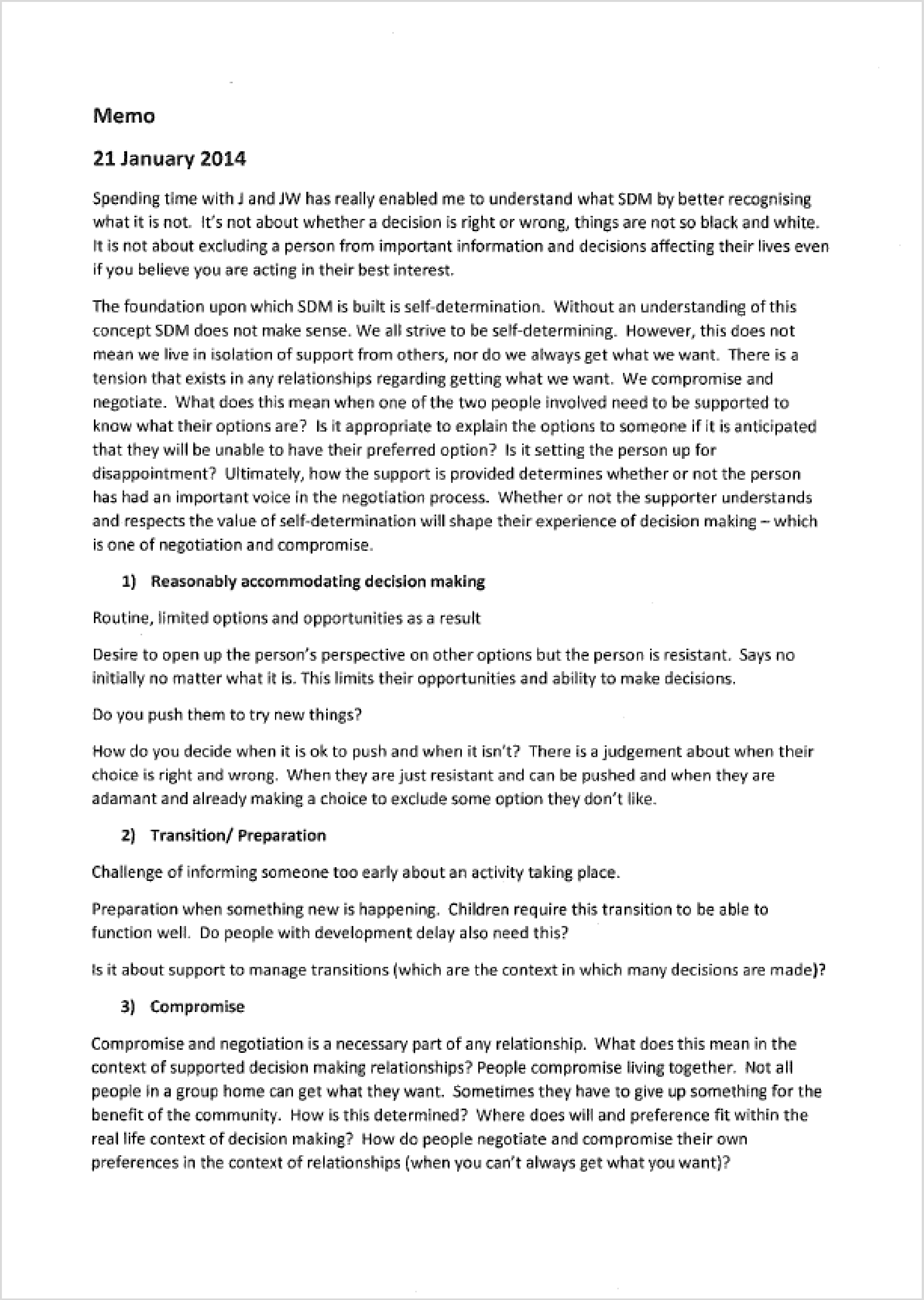
that.	
MB: Interesting. Sorry were you going to say something else?	
C: I was going to back to your original question I don't think she has any say in any of those changes that were made. But you know what, to be fair I don't know that I don't know how to say this without sounding super harsh but regardless of whether she wanted to stay in the house she can't, if she wanted to stay in the program she can't. Those are just not logical things to even get her and try to maybe get her hopes up or something that's just not realistic. You know you are going to have to make these changes so I don't even know how much input was even requested of her. I don't think anybody asked her. I am sure her program spoke with her.	No control over her situation No real choices No inclusion in the process
J: Dad lies to her about everything.	
C: What does that mean?	
J: You can't hear a conversation with Dad without him whispering, that would be a disaster.	
MB: How do you think Jenny responds or feels about that? That information is being kept from her?	
J: She is one sneaky little devil. She is always listening even if you don't think she is listening. How many things has she picked up when you think she is out of earshot and you're talking about something and then she'll come up to you and you're like (inaudible). So my Dad only does it keep her like	
C: Not that we stand around and talk about her all the time	Respect
J: No but like her sister coming, **or we had to get rid of the cats for allergy reasons and my Dad was worried about that so he wanted to lie to her to protect so that she wouldn't be so upset about it. So we had to make up a different reason.**	Lying to Jenny
C: I wonder how much of that is just him thinking a little bit of my grandma's mentality thinking that she can't handle it instead of being real with her.	Thinking she couldn't handle the truth instead of being real.
J: When he did get rid of the cats she was totally fine with it and never cared about it.	
C: Right.	
J: Or when grandpa died and everyone thought, the people that worked with her at the workshop, they all thought she was going to take it really badly because my grandpa and her were really close. But there was no emotion there what so ever. They got her Mr Butchy as a therapy cat but she didn't really have any. Even with grandma whow as her life for fifty years she really walked away from that without anything. She doesn't talk about her.	
C: I really really wonder, it's hard to think now she is fifty I have always, we've always wondered I bet you, I bet you she could have been on her own. Maybe in a somewhat assisted, semiassisted I bet she could have been on her own. She is very capable. She just has been so restricted for so long that now it's hard to think that she could be but she could be. She could've been. She could've been.	She could have been on her own.
MB: Can I ask that approach that your Dad has taken with lying or withholding information	

Appendix E: Examples of mind mapping, diagramming and reflective memos

Capacity is decision specific
When a person has capacity they can do the following
- Understand the facts involved
- understand the main choices
- weigh up the consequences of the choices
- understand how the consequences affect them.
- communicate their decision

22/10/14


Support Relationship: Equality
Respect
Decision readiness: Help to Find their voice
preparation: Help to Developing & maintaining relationships
Help to develop skill & experience
decision making
Letting go of control!
* Reflecting on the process of decision making
Determining how much Support.
Support
Equality
Respect
Need
Knowledge of the person.
Influence
Trust
↑ Knowledge of person
↑ understanding of need.
More trust
More influence
Motivation



Memo

21 January 2014

Spending time with J and JW has really enabled me to understand what SDM by better recognising what it is not. It's not about whether a decision is right or wrong, things are not so black and white. It is not about excluding a person from important information and decisions affecting their lives even if you believe you are acting in their best interest.

The foundation upon which SDM is built is self-determination. Without an understanding of this concept SDM does not make sense. We all strive to be self-determining. However, this does not mean we live in isolation of support from others, nor do we always get what we want. There is a tension that exists in any relationships regarding getting what we want. We compromise and negotiate. What does this mean when one of the two people involved need to be supported to know what their options are? Is it appropriate to explain the options to someone if it is anticipated that they will be unable to have their preferred option? Is it setting the person up for disappointment? Ultimately, how the support is provided determines whether or not the person has had an important voice in the negotiation process. Whether or not the supporter understands and respects the value of self-determination will shape their experience of decision making – which is one of negotiation and compromise.

1) Reasonably accommodating decision making

Routine, limited options and opportunities as a result

Desire to open up the person's perspective on other options but the person is resistant. Says no initially no matter what it is. This limits their opportunities and ability to make decisions.

Do you push them to try new things?

How do you decide when it is ok to push and when it isn't? There is a judgement about when their choice is right and wrong. When they are just resistant and can be pushed and when they are adamant and already making a choice to exclude some option they don't like.

2) Transition/ Preparation

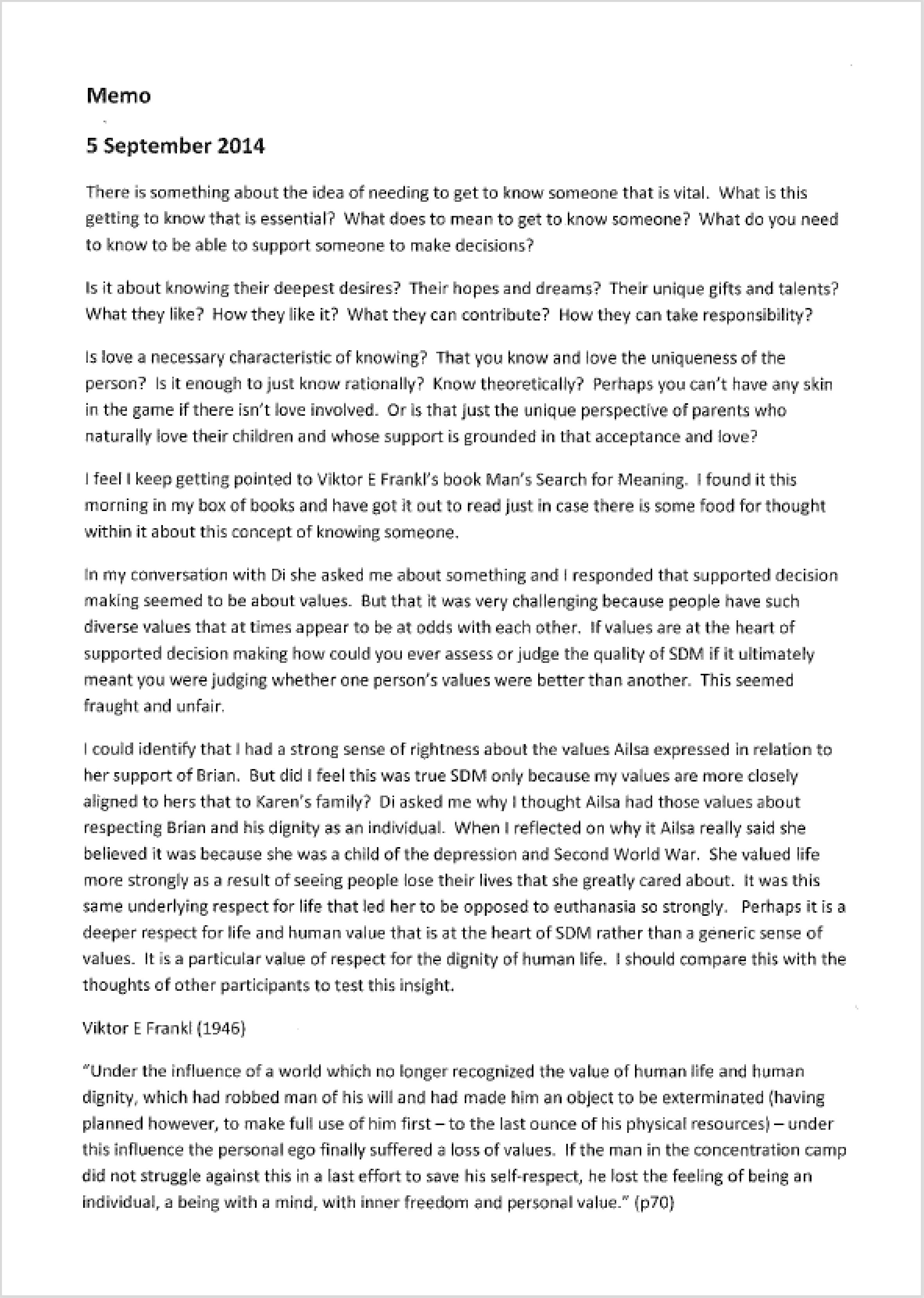
Challenge of informing someone too early about an activity taking place.

Preparation when something new is happening. Children require this transition to be able to function well. Do people with development delay also need this?

Is it about support to manage transitions (which are the context in which many decisions are made)?

3) Compromise

Compromise and negotiation is a necessary part of any relationship. What does this mean in the context of supported decision making relationships? People compromise living together. Not all people in a group home can get what they want. Sometimes they have to give up something for the benefit of the community. How is this determined? Where does will and preference fit within the real life context of decision making? How do people negotiate and compromise their own preferences in the context of relationships (when you can't always get what you want)?



Memo

5 September 2014

There is something about the idea of needing to get to know someone that is vital. What is this getting to know that is essential? What does to mean to get to know someone? What do you need to know to be able to support someone to make decisions?

Is it about knowing their deepest desires? Their hopes and dreams? Their unique gifts and talents? What they like? How they like it? What they can contribute? How they can take responsibility?

Is love a necessary characteristic of knowing? That you know and love the uniqueness of the person? Is it enough to just know rationally? Know theoretically? Perhaps you can't have any skin in the game if there isn't love involved. Or is that just the unique perspective of parents who naturally love their children and whose support is grounded in that acceptance and love?

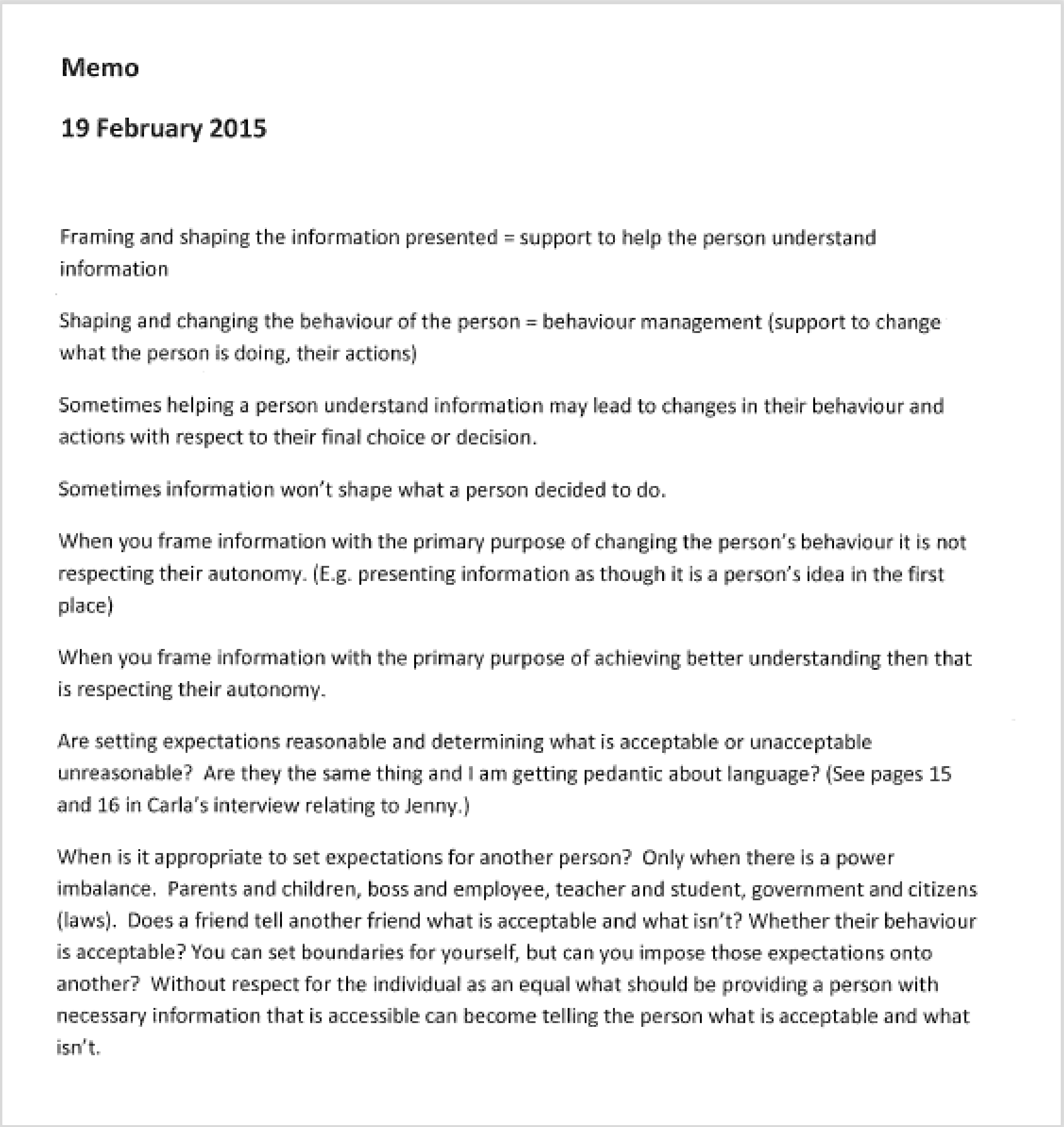
I feel I keep getting pointed to Viktor E Frankl's book Man's Search for Meaning. I found it this morning in my box of books and have got it out to read just in case there is some food for thought within it about this concept of knowing someone.

In my conversation with Di she asked me about something and I responded that supported decision making seemed to be about values. But that it was very challenging because people have such diverse values that at times appear to be at odds with each other. If values are at the heart of supported decision making how could you ever assess or judge the quality of SDM if it ultimately meant you were judging whether one person's values were better than another. This seemed fraught and unfair.

I could identify that I had a strong sense of rightness about the values Ailsa expressed in relation to her support of Brian. But did I feel this was true SDM only because my values are more closely aligned to hers that to Karen's family? Di asked me why I thought Ailsa had those values about respecting Brian and his dignity as an individual. When I reflected on why it Ailsa really said she believed it was because she was a child of the depression and Second World War. She valued life more strongly as a result of seeing people lose their lives that she greatly cared about. It was this same underlying respect for life that led her to be opposed to euthanasia so strongly. Perhaps it is a deeper respect for life and human value that is at the heart of SDM rather than a generic sense of values. It is a particular value of respect for the dignity of human life. I should compare this with the thoughts of other participants to test this insight.

Viktor E Frankl (1946)

"Under the influence of a world which no longer recognized the value of human life and human dignity, which had robbed man of his will and had made him an object to be exterminated (having planned however, to make full use of him first – to the last ounce of his physical resources) – under this influence the personal ego finally suffered a loss of values. If the man in the concentration camp did not struggle against this in a last effort to save his self-respect, he lost the feeling of being an individual, a being with a mind, with inner freedom and personal value." (p70)



Memo

19 February 2015

Framing and shaping the information presented = support to help the person understand information

Shaping and changing the behaviour of the person = behaviour management (support to change what the person is doing, their actions)

Sometimes helping a person understand information may lead to changes in their behaviour and actions with respect to their final choice or decision.

Sometimes information won't shape what a person decided to do.

When you frame information with the primary purpose of changing the person's behaviour it is not respecting their autonomy. (E.g. presenting information as though it is a person's idea in the first place)

When you frame information with the primary purpose of achieving better understanding then that is respecting their autonomy.

Are setting expectations reasonable and determining what is acceptable or unacceptable unreasonable? Are they the same thing and I am getting pedantic about language? (See pages 15 and 16 in Carla's interview relating to Jenny.)

When is it appropriate to set expectations for another person? Only when there is a power imbalance. Parents and children, boss and employee, teacher and student, government and citizens (laws). Does a friend tell another friend what is acceptable and what isn't? Whether their behaviour is acceptable? You can set boundaries for yourself, but can you impose those expectations onto another? Without respect for the individual as an equal what should be providing a person with necessary information that is accessible can become telling the person what is acceptable and what isn't.