

Exploring Article 12 of the Convention on the Rights of Persons with Disabilities.

An Integrative Literature Review



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Exploring Article 12 of the United Nations Convention on the Rights of Persons with Disabilities: An Integrative Literature Review

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Executive Summary

Disabled people continue to face barriers to exercising legal capacity, often as a consequence of being denied equal recognition before the law.

The purpose of this report is to provide information and direction based on recent research literature and evidence of actions taken by other states parties about the ways in which New Zealand may give effect Article 12, the right of disabled people to equal recognition before the law, of the United Nations Convention on the Rights of Persons with Disabilities. As a state party to the Convention, New Zealand has recognised that it has an obligation to give effect to the right in Article 12. The report was guided by questions provided by the Office for Disability Issues that have been utilised as an organising framework for this report.

Setting the scene

The report begins with an overview of states parties' obligations set out in the Convention and Article 12, including obligations to adjust legislation, policy, and practice so to:

- Replace substituted decision-making with supported decision-making as both a process and a legal paradigm.
- Adjust and modify systemic factors and environments (both within states parties' jurisdictions and private sectors) in order to improve opportunities for disabled people to exercise legal agency and capacity on an equal basis with others. This obligation is underpinned by an expectation that member states will approach disability from a social model rather than medical model perspective.
- Abolish capacity tests, such as the status, outcome, and functional approaches and replace them with disability-neutral practices and safeguards regarding disabled people's exercise of legal capacity.
- Discard notions of legal incapacity, which involves the conceptual separation of *mental* and *legal* capacity. As a consequence, legal capacity is recognised as a non-derogable right while mental capacity, and subsequently the level of support a person requires, may fluctuate. This involves conceiving of capacity as a human right.

- Replace 'best interests' with 'will and preference' as part of a paradigm shift towards conceptualising legal capacity, whereby 'will and preference' becomes the determining and central factor in decision-making.

These principles signal an obligation for states parties to radically depart from current prevailing practice, norms, and models upon which disabled people are engaged with often on an involuntary basis. In traditional and current practice in various jurisdictions, disabled persons have been denied equal legal agency and capacity before the law on the basis of a minimum threshold of evidence of cognitive ability or solely on the basis of their status of having a disability (Bartlett, 2012; Keeling, 2016; and Kohn & Blumenthal, 2014), often for the purposes of risk-avoidant interventions (McDaid & Delaney, 2010). It is expected that this radical departure ought to occur as an immediate and wide-scale revision. The Convention has been the catalyst for a paradigm shift in conceptualising legal capacity as independent of mental capacity and as non-derogable. However, the obligations that have emerged as a result of this re-conceptualisation remain hotly contested.

Remaining tensions concerning Article 12

Although there is general consensus with the spirit of the Convention, issues of tension remain due to dramatically different interpretations being posited about the nature and extent of states parties' obligations. While the General Comment No. 1 (2014) was intended to clarify the intent of Article 12 and to provide states parties with direction on how to give expression to it, interrogation of the literature enabled a number of key issues and debates related to the implementation of supported decision-making at a systemic and practice level to be highlighted. These included debates about: how to theorise supported decision-making for individuals with severe cognitive impairment; how to determine when a disabled person requires assistance with decision-making; how to identify and manage situations whereby a person's will and preferences conflict; how to determine and how to respond when disabled people and their supporters have conflicting will and preferences; and the nature and extent of safeguards required for disabled people, and in some cases their supporters, in the Convention era.

Particularly, disagreement remains in the literature regarding the extent to which disabled persons can be engaged with on purely voluntary bases and whether substituted decision-making is a necessary last resort option or whether it can be replaced in its entirety by different forms of supported decision-making (such as facilitated decision-making). One side of the debate argues that there will always be cases where a person is too dangerous, lacks a sufficient understanding of the decision, or is completely unable to communicate their will and preference (see Dawson, 2015; Ciavano, 2014; Gooding, 2015). On the other side of the debate, it is argued that it is critical to optimise people's true will and preferences as much as possible and violating the equal rights and dignity of people through proxy (substituted decision-making) is not permissible (see Byrnes et al., 2007; Kohn & Blumenthal, 2014). It is also argued from this body of literature, that people's will and

preferences can always be ascertained, even if it means proceeding on the basis of information known about them, which enables that person to exercise their agency through a third party (see Arstein-Kerslake & Flynn, 2015; Devi, 2013; Flynn & Arstein-Kerslake, 2014). It is also argued that disability-neutral options are available to states parties to protect disabled people and others from danger (see Richardson, 2012; WNUSP, 2008).

Who are we talking about?

The significance of the obligations in Article 12, and the subsequent radical departures from traditional understandings of legal and mental capacity they require, pertain to *all* disabled persons but pertain significantly to groups most who have frequently been obstructed from exercising their legal capacity. The groups most significantly affected, as identified through the literature, are people with: developmental and learning disabilities; dementia; acquired brain injuries; and mental distress.

Giving effect to Article 12 in law, policy, and practice

This report identifies and explores specific approaches and mechanisms for supported decision-making that have been signalled in the literature, or have been implemented by states parties committed to embedding Article 12 of the Convention in the daily lives of disabled people. While a dominant way of theorising the implementation of supported decision-making is still to emerge, there is quite a high degree of consensus relating to the elements of effective supported decision-making. The most extensive body of research relating to Article 12 of the Convention articulates the critical elements required to ensure that will and preference remains central in all situations involving disabled people who require assistance with decision-making.

Implementation strategies by states parties, non-governmental organisations, and disabled persons' organisations have ranged from:

- Legislative change to discard notions of legal incapacity (as in the case of Sweden) or adjust notions of incapacity (Denmark).
- Legislative change or review to embed Article 12 in jurisdictionally-binding rights frameworks (Charter of Human Rights and Responsibilities, Australia).
- Legislative change to embed the reasonable accommodation of disabled people in jurisdictionally-binding rights frameworks (Charter of Human Rights and Responsibilities, Australia).
- Legislative change to make provisions for supported decision-making practices, including:

- Legislative change to grant rights to access supported decision-making (as in the case of Scotland).
- Legislative change to provide formal supported decision-making options, including microboards (British Columbia, Canada), co-decision-making arrangements (Saskatchewan, Canada), personal mentors or administrators (Sweden), or other recognised supporter roles (Delaware, USA; Texas, USA).
- Legislative change to provide formal monitoring options for safeguarding supported decision-making arrangements (British Columbia, Canada).
- Legislative change to make provisions for formal support agreements (for example Representation Agreements in British Columbia, Canada).
- Provisions for support in practice or pilot programs, including:
 - Enabling advance support decisions made in statements (pilot program, South Australia, Australia).
 - Making supporters in the form of advocates available for individual and/or decision-specific assistance (Scotland; Victoria, Australia).
 - Making supporters in the form of advocates available for taking initiatives towards addressing structural obstacles that impact on the exercise of legal capacity (Scotland; Victoria, Australia).
 - Providing information for supporters and supported people on making decisions, factors to consider, and organising formal supported decision-making arrangements (Nidus Personal Planning Resource Centre, Canada; Scotland; Victoria, Australia).
- Practice restrictions on the use and frequency of involuntary treatment and detention (Victoria, Australia).

However, it is important to note that no states parties have fully given effect to Article 12, in line with the interpretation proffered by the Committee on the Rights of Persons with Disabilities, as a result of their efforts to comply with the United Nations Convention on the Rights of Persons with Disabilities.

Challenges to giving effect to Article 12 in law, policy, and practice

A number of challenges have been identified in the literature as having the potential to derail states parties efforts to give effect to Article 12 and embed supported decision-making within their particular jurisdictions. These challenges include: outdated understandings and perceptions of disability and their subsequent impact on the treatment of disabled people; ensuring supporters are trained to provide effective support, given the limited resources available; the complex and subjective process of obtaining people's will and preferences; system and service issues that frustrate the realisation of disabled persons' will and preference; the tendency to favour risk-avoidance and paternalistic intervention; implementing robust and appropriate safeguards; and disabled people often having limited or absent close support networks who could provide support with decision-making.

Gaps in the literature

Discourse in the literature about the process of giving effect to Article 12 highlights a number of issues of contention. Debates remain about how to identify and manage situations whereby a person's will and preferences conflict internally. There are differing opinions about how to determine and how to respond when disabled people and their supporters have conflicting will and preference. More significantly, there are gaps in empirical research to guide and inform legislative change and guide policy, and practice related to supported decision-making. There is also a critical need for well-considered and substantial safeguards that are designed to protect both disabled people and their supporters.

With regard to resources, and beyond the signalled need that could be used to provide better resources to best facilitate decision-making, the literature is unclear about the specific ways in which resources should be provided and distributed for supported decision-making.

The review also identified an acute lack of evidence to guide legislative change related to Article 12, to underpin and inform policy, and practice related to supported decision-making. Of particular note is an absence of the experiences and perceptions of disabled people within the body of information available. It is also apparent that there is a lack of robust evidence about the level of resourcing required to embed supported decision-making in the lives of *all* disabled people, including who should provide, and who should receive such resourcing.

Future challenges

Available literature has evidenced that states parties have often taken a conservative position on the implementation of Article 12; that is they perceive substituted decision-making (and thus involuntary treatment or detention) as sometimes being necessary in last resort and extreme cases, and consequently have developed supported decision-making initiatives alongside the traditional paradigm of substituted decision-making. In considering the literature in relation to the questions upon which this review is based it is apparent that considerable tension exists in relation to how to interpret the wider intent of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities, and consequently, how states parties should proceed to implement it in legislation, policy, and practice. While there are robust and well-considered arguments emerging from both sides of the debate, to date, no states parties have implemented the required level of legislative, policy, and practice change for their efforts to be recognised as giving full expression to Article 12, according to the Committee on the Rights of Persons with Disabilities's interpretation of Article 12. As the ultimate arbiter of the Convention, it is clear that to achieve this goal states parties would need to accept the Committee's interpretation, be prepared to undertake significant change to legislation, policy, and practice, and expend time and effort to identify, develop and embed supported decision-making processes and the necessary safeguards for both disabled people and their supporters.

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Introduction

As a state party to the Convention, New Zealand has recognised its obligations to give effect to the 50 articles and preamble of the Convention, including Article 12, the right to equal recognition before the law. This integrative literature review was undertaken to provide New Zealand with guidance on how to implement Article 12, as signalled by the literature and initiatives taken by other jurisdictions. This report presents the findings of a literature review commissioned by the Office for Disability Issues to facilitate understanding of the ways in which Article 12 of the United Nations Convention on the Rights of Persons with Disabilities may inform the New Zealand Disability Action Plan 2014-2018, Action 7A. Action 7A commits to 'ensuring disabled people can exercise their legal capacity, including through recognition of supported decision making.' The Office for Disability Issues (ODI) is responsible for leading work on this action.

To ensure that the findings of the research have practical utility as New Zealand considers how to give expression to Article 12, the review prioritises current practice and innovative examples of how other signatory nations have attempted to ensure that disabled people can exercise legal capacity, and be supported with decision-making. In this context, a rights-based approach is taken, consistent with the UN Convention on the Rights of Persons with Disabilities, as well as an acknowledgement that the ability to exercise rights requires adequate structural provisions and support to meet particular needs. This review is intended to furnish information and direction about the ways in which supported decision-making can be established as a guiding principle within the daily lives of disabled people in New Zealand.

The review was underpinned by a series of questions. These questions were provided by the ODI and comprised of two primary questions and 19 supplementary questions. The primary questions form the basis for the literature review, by guiding the literature searches and providing an organising framework. The two key questions pursued were:

1. What can be learned from literature that has been published since 1 January 2010 that examines, discusses, provides case studies/individual stories, or reviews/ evaluates the practice of disabled people exercising their legal capacity. Particularly, what has been done to enable or better support disabled people's exercise of legal capacity?
2. What are the trends in the evolution and development of thinking and practice over time of support for disabled people's exercise of legal capacity, where relevant?

The literature review responds broadly to the primary questions, and where specific sections answer particular secondary questions it is clearly stated within signposts or footnotes. This system was adopted

because some sections relate to more than one question, and some questions are answered in more than one section of the report. The full and original list of questions can be seen in Appendix A. The review was conducted using an integrative literature review methodology, so that a diverse range of literature could be included (Wittemore & Knaft, 2005). This approach was appropriate in this case as useful discussions of Article 12 and supported decision-making have been delivered through a range of different mediums, and these diverse examples were relevant to include in the review. A more detailed account of the literature review methodology is contained in Appendix B.

The report has been organised into two sections. Part One provides necessary background in order to contextualise the focus of the review and includes: an overview of the Convention; an explanation of who Article 12 relates to; information relating to the paradigm shift in the conceptualisation of legal and mental capacity; an articulation of the paradigm shift from best interests to will and preference; and the realisation of legal capacity through supported decision making. Article 12 establishes that disabled people have an absolute, non-derogable right to legal capacity; that is a right to be both a person and an agent whose decisions are valid by law. As a consequence, to give effect to the Convention states parties have been informed that they have an obligation to replace substituted decision-making with supported decision-making, abolish capacity tests, and replace notions of incapacity, and 'best interests' with the recognition and centrality of will and preference. The Convention has been the catalyst for a paradigm shift in conceptualising legal capacity as independent of mental capacity, so that a person can retain their legal capacity even when their mental capacity and need for support may fluctuate. As is described in Part One, the literature recognises the consequences of Article 12 for all disabled people but emphasises that it most significantly impacts on people with developmental and learning disabilities, dementia, acquired brain injuries, and mental illness.

Although there is general consensus with the spirit of the Convention, issues of tension remain with the dramatically different interpretations being made about states parties' obligations (Kerzner, 2011). The General Comment No. 1 was intended to clarify the intent of Article 12 and to provide states parties with direction on how to give expression to it. Although the General Comment is not binding, it is intended to be utilised by states parties as an interpretative aid to assist their efforts in meeting their obligations under the Convention (see authors who have used it in this way, such as Arstein-Kerslake & Flynn, 2015; Gooding, 2015; Minkowitz, 2014; Minkowitz, 2013). Debate has continued and is typically centred on: the abolishment of substituted decision-making and capacity testing; the extent to which will and preference can be realised through supported decision-making; the distinction between rights to legal standing and rights to legal agency under the broad notion of legal capacity; how to achieve equal treatment in the context of criminal law; and the factors that obstruct a person's ability to realise their legal capacity and how to remove them.

Part Two of the report is concerned with articulating the specific actions that states parties have undertaken with the purpose of giving expression to Article 12. It identifies and explores specific approaches and mechanisms for supported decision-making that have been signalled in the literature, or have been

implemented by states parties committed to embedding Article 12 of the Convention in the daily lives of disabled people. It includes sections on: legislation and policy; approaches to supported decision-making signalled in the literature; supported decision-making in practice; reasonable accommodation and will and preference; realising will and preference adequately and safely. This section of the review highlighted that while a dominant way of theorising the implementation of supported decision-making is still to emerge, there is quite a high degree of consensus relating to the elements of effective supported decision-making. The most extensive body of research relating to Article 12 of the Convention articulates the critical elements required to ensure will and preference remains central in all situations that involve disabled people who require assistance with decision-making.

Interrogation of the literature enabled a number of key issues and debates related to the implementation of supported decision-making at a systemic and practice level to be highlighted. These included debates about: how to theorise supported decision-making for individuals with severe cognitive impairment; how to determine when a disabled person requires assistance with decision-making; how to identify and manage situations whereby a person's will and preferences conflict; how to determine and how to respond when disabled people and their supporters have conflicting will and preferences; and the type and extent of safeguards required for disabled people, and in some cases their supporters, in the Convention era.

The review also identified an acute lack of evidence to guide legislative change related to Article 12, and to underpin and inform policy and practice related to supported decision-making. Of particular note is an absence of the experiences and perceptions of disabled people within the body of information available. It is also apparent that there is a lack of robust evidence about the level of resourcing required to embed supported decision-making in the lives of *all* disabled people, including who should provide and receive such resourcing.

The report concludes with a discussion of key themes and future challenges and a list of relevant resources on Article 12 and supported decision-making actions and activities being undertaken by other states parties. Relevant examples of activity related to Article 12 are highlighted through the use of coloured text boxes throughout the report.

Part One: The Convention on the Rights of Persons with Disabilities – An overview

The United Nations Convention on the Rights of Persons with Disabilities (hereafter “Convention”) is an international human rights treaty promulgated by the United Nations to clarify, enshrine and enact the rights of persons with disabilities in its member states (see Kerzner, 2011). It consists of 50 articles and a preamble setting out states parties’ obligations. The Committee on the Rights of Persons with Disabilities was set up as a mechanism for monitoring the Convention (Series et al., 2014). New Zealand became a signatory to the Convention in 2007 alongside 81 other states and later ratified the convention on the 26th September 2008 (Milner & Mirfin-Veitch, 2012; “United Nations Convention,” 2016).¹ Since then, the Convention has achieved 166 ratifications and 90 ratifications to the Optional Protocol (“Up to today,” 2016). In ratifying the Convention, New Zealand accepted that it has an obligation to give effect to the fundamental rights and freedoms of persons with disabilities within the duties set out by the Convention (see Series et al., 2014). This includes the obligation to give effect to disabled people’s equal recognition before the law under Article 12. In ratifying the Convention, New Zealand has a duty to ensure strong and timely steps are made toward implementation. The imperative to meet these obligations is underpinned by an acknowledgement that disabled people, both historically and currently, have not always received equal recognition before the law due to attitudinal and legislative contexts that obstruct them from exercising legal capacity.

Amongst the Convention’s 50 Articles, Article 1 sets out the purpose of the Convention 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.

Articles 2 and 3 set out definitions and communication of the Convention, whilst Articles 4 to 32 set out the responsibilities of states to persons with disabilities.

Article 12, the focus of the current report, specifies the concept of legal capacity as an absolute, non-derogable right for all persons irrespective of disability, and introduces the notion that states are responsible for ensuring that persons with diminished or impeded mental capacity receive adequate support to exercise

¹ New Zealand has also recently acceded to the Optional Protocol to the Convention and it is due to come into force from 4 November 2016 (“United Nations Convention, 2016).

their legal capacity through decision-making. Firstly, this requires the abolition of capacity tests and notions of legal incapacity (Flynn & Arstein-Kerslake, 2014). Secondly, the General Comment to the Convention (General Comment No. 1, 2014) further clarifies that supported decision-making is intended to replace substitute decision-making in all its forms, including guardianship and other proxy decision-making mechanisms, irrespective of a person's disability (also see Arstein-Kerslake, 2014; WNUSP, 2008²). On the basis of the intent and purpose underpinning the Convention, it is perceived that substituted decision-making models are inconsistent with the Convention on the basis of the following characteristics (see Arstein-Kerslake & Flynn, 2015; Gooding, 2015; Stavert, 2015; Series et al., 2014):

- It involves the removal of a person's capacity (even if only for a single decision).
- It can involve the appointment of a substitute decision-maker, who is someone other than the person concerned, even against the will of the person with a disability.
- It involves an objective 'best interests' judgement behind the decision made by the substitute decision-maker (in other words, the rights, will and preference of the person are not *central* to any decisions).

While the key elements of this position will be explored in greater depth later in this report, it is important to articulate here that there is an expectation that states move from a consideration of best interests to facilitating the will and preference of the decision-maker (also see Dickey, 2016; Watson, 2016a). This constitutes a departure from the widespread practice of making proxy decisions based on an assessment of what is in the best interests of a person deemed to lack mental capacity. Consequentially, it also requires abolition of treatment without consent, civil detention, and certain criminal defences based on disability (Bartlett, 2012).

Supported decision-making is the proposed model to achieve this significant change and states parties are required to fully implement the provisions of Article 12 immediately following ratification, unlike the Convention's other articles, which permit a period of transition to full implementation. New Zealand, along with other states parties must engage with this model, and explore ways to embed it within the public structures of our society and the private lives of disabled people. The implementation of Article 12 can be seen, therefore, as a fluid and developing process which requires states parties to grapple with the implications of existing legislation (and policy and practice) that, in many cases, will need wide-scale revision to align with the Convention. Many member states appear to be taking an iterative process, allowing for a full consideration of the need for, and implications of, legislative reform alongside operational considerations.

² WNUSP (World Network of Users and Survivors of Psychiatry) is an organisation that had a significant role in the crafting of the Convention and has published a manual to guide states parties on the obligations and implementation of the Convention (WNUSP, 2008).

This literature review has attempted to capture the emerging thinking and action in order to assist New Zealand in considering how it might think and act with regard to the implementation of Article 12.

Who does Article 12 relate to?

This section provides information to address the question: “What does the population of affected disabled people look like (for example, number of people, proportion of the population, other relevant demographic information)?” (Question 2, Appendix A). The Convention is inclusive of all disabled people. It employs a partial definition of ‘persons with disabilities’ so to not inadvertently exclude groups and so to specifically include persons with mental disabilities and cognitive impairment (Bartlett, 2012). The definition refers to ‘persons with disabilities’ as (Article 1):

“... those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

In the New Zealand context, the Human Rights Commission defines disability as any long-term limitation in a person’s ability to carry out daily activities, with its governing legislation (Human Rights Act 1993) specifying a wide range of physical, cognitive and psychological bases for disability. In keeping with this approach, Statistics New Zealand uses a similarly broad conceptualisation of disability that broadly permits self-identification as a person with (or without) a disability for census and other survey purposes. In the New Zealand context, the term ‘disability’ refers to “long-term limitation (resulting from impairment) in a person’s ability to carry out daily activities” (Statistics NZ, 2014).

Aligning the classifications of the Household Disability Survey (HDS) (MacPherson, 2014) with those in the capacity and Convention literature is difficult. Persons with disabilities comprise a significant proportion of New Zealand’s population. Also in New Zealand, the HDS identifies five key areas of disability: sensory, physical (including motor and agility), intellectual, psychological/psychiatric, and ‘other.’ According to Statistics NZ, 64% of adults with disabilities identified themselves as having a physical disability (representing 18% of the total adult population over 15); whilst 59% of children with disabilities were identified as having a learning disability (6% of the total child population of New Zealand). The most common cause of adult disability was disease, illness or injury, with ageing a prominent factor, whilst childhood disability most commonly related to conditions present from birth. Additionally, the statistics and literature also recognise that disabled people often have more than one disability (Statistics NZ, 2014, Werner, 2013). According to the National Disability Survey 2013, 24% of New Zealanders identify as having a disability, with a pronounced skew towards older adults (aged 65+), and Māori and Pacific peoples (Statistics NZ, 2014).

With reference to Article 12 and supported decision-making however, the emerging literature focuses on four key groups of disabled people (Carney, 2015a). These include: people with developmental and learning

disabilities; people with dementia; people with acquired brain injuries (such as traumatic brain injuries); and people who experience mental distress. These groups have been identified as significant in the context of the Convention and Article 12 because they are most affected by the obligations set out due to the fact that they are citizens who often confront barriers to exercising legal capacity and other rights. The Convention recognises that the extent to which legal capacity may be exercised is frequently limited on the grounds of disability, both directly and indirectly (Bartlett, 2012; Flynn and Arstein-Kerslake, 2014; Keeling, 2016; Kohn & Blumental, 2014). As a result, literature is often concerned with Article 12 and supported decision-making in the context of groups most significantly affected by the use of evidence of cognitive ability.

Attempts to identify what percentage or proportion of the total number of disabled people who could be affected by the provisions of the Convention may not be necessary. Given that the intention of the Convention is to achieve change for *all* disabled people; potential benefits are to be felt in the structural reconceptualisation of legal personhood and the eradication of unequal treatment for disabled people generally. Further, it seems clear that the Convention recognises that the extent to which legal capacity may be exercised is frequently limited on the grounds of disability alone (Flynn and Arstein-Kerslake, 2014; Keeling, 2016). In this regard, then, any explicit legislative requirement that disability *cannot* compromise legal capacity, and *must not* be used as grounds to limit the exercise of that legal capacity, has the potential to directly and indirectly benefit all disabled people.

A paradigm shift in the conceptualisation of legal and mental capacity

The provisions of the Convention signal a substantive change in the ways in which disabled people are considered in terms of their ability to exercise legal capacity. At the heart of Article 12 is a clarification, and rearticulation, of the definition of capacity.³

The Convention and General Comment challenge traditional notions of legal capacity and mental capacity and propose a new way of conceptualising the relationship between them and therefore some definitional context is required to introduce and contextualise this alternative approach. *Legal capacity* is concerned with legal recognition and the granting of legal personhood (Arstein-Kerslake & Flynn, 2015; Browning et al., 2014; Flynn & Arstein-Kerslake, 2014). As is explained by Douglass (2016),⁴ Minkowitz (2013) and Parker (2016), people are recognised to have legal capacity when their decisions are recognised as valid before the law. As is recognised in the literature on the Convention (see for example Arstein-Kerslake & Flynn, 2015; Martin et al, 2014; Parker, 2016; Richardson, 2012; Series, 2015), it is crucial to distinguish between the two concepts of legal capacity and mental capacity in the context of the Convention because, as Parker explains, “You cannot have your decision- making capacity taken away, but you can have your capacity to make decisions taken away, if we understand ‘capacity to make decisions’ here to mean the right to make them” (p. 384). The distinction is important as it highlights that mental capacity is an ability held by the person but that external recognition of that decision is validated by law. That is, the person *may (or may not) be permitted* to act on their will and preference. Under this traditional approach to legal capacity, legal capacity – and therefore expressions of will and preference – can be denied, i.e. a person is considered to be incapacitated as an agent under the law (Craigie, 2015; Douglass, 2016; Minkowitz, 2013; Willner, 2011; Wong et al., 1999). This approach, in the view of some commentators, assumes that it is permissible to perceive some groups as ‘less

³ Question 4 asks, “Have there been any changes in the treatment, by society, of disabled people exercising their legal capacity?”. The literature clearly highlights the paradigm shift created by the Convention at this stage, but there is little empirical evidence yet that identifies explicitly changes in treatment of disabled people by society.

⁴ Douglass (2016) has recently published on mental capacity as it pertains to the New Zealand context.

deserving' of equal rights to legal capacity (Flynn & Arstein-Kerslake, 2014, p. 85).⁵ This traditional capacity-incapacity divide has been referred to as 'the binary approach' (Allen & Tulich, 2015). The notion of *mental capacity* is connected to the binary approach on the basis that mental capacity has historically been the basis for granting legal capacity or incapacity (see Willner, 2011). Richardson (2013) notes the connection that conventionally has been made, that is: the exercise of *legal capacity* depends upon the possession of *mental capacity*, a functional ability to process information and deliberate in order to reach an autonomous choice (also see Douglass, 2016; Willner, 2011). In other words, mental capacity based on a person's cognitive functioning and decision-making ability has typically been used as the basis on which legal capacity has been granted (Martin et al., 2012). In this context, 'decision-making ability' refers to a person's set of abilities that can be assessed and which comprise an idea of what it means to be able to make decisions relatively independently (Martin et al., 2012). Decision-making ability encompasses cognitive or mental ability and also considers the processes a person uses to consider and weigh risks and benefits (Keeling, 2016) and their ability to communicate a decision (Pathare & Shields, 2012). In this sense, *legal capacity* has been conceived of as referring to the process where law recognises a person's ability to make decisions for themselves (Devi, 2013). As previously noted, under traditional approaches to legal capacity, one would have legal capacity recognised under law upon meeting thresholds (tests) for mental capacity (Ciavano, 2014; Devi et al., 2011). Where a person does not meet this threshold they are regarded as lacking mental capacity and as a consequence the person is denied legal capacity meaning their decisions are not valid under law (see Kerzner, 2011; Minkowitz, 2013; Nilsson, 2012). This approach has provided the ethical basis for third party intervention and substituted decision-making (Series, 2015).

On the basis of traditional notions of legal and mental capacity, disabled persons have historically been denied equal recognition under law (Darvell, 2016; WNUSP, 2008; Watson, 2016a; Watson, 2016b; Weller, 2014; Woudzia, 2016).⁶ Bartlett (2012) describes how people who experience mental distress have historically been denied capacity on a very low threshold of evidence regarding cognitive ability on the basis of *parens patriae* and have been excluded from decision-making processes completely or without their knowledge.

⁵ This section details the ways in which medical model constructions of incapacity have impacted on the extent to which disabled people have had the opportunity to exercise legal capacity. This pertains to Question 7: "Has there been any discussion or change to transition or move from consideration of a person's 'best interests' to a person's 'rights, will and preference' in the context of disabled people exercising their legal capacity?". However, information relating to this question is also communicated in other sections.

⁶ This issue of cultural tendencies that favour paternalistic intervention pertains to Question 1, "What evidence exists that there is a problem with disabled people exercising their legal capacity, and what is the impact on those disabled people and others?".

New Zealand law reflects the traditional connection made between legal and mental capacity, and the thresholds involved in this process. In this country, the PPPRA defines capacity and specifies thresholds that need to be met for the purposes of determining a person's legal capacity. These require a that a person can:

understand the nature, and to foresee the consequences, of decisions in respect of matters relating to his or her personal care and welfare; and

communicate decisions in respect of those matters. (Protection of Personal and Property Rights 1988, Pt 1 S5)

Whilst definitions of capacity differ in the detail across jurisdictions where the concept is in use, meeting the criteria to exercise legal capacity generally requires that a person has the ability to understand circumstance-relevant information, to be able to apply reason to that information in order to reach a decision, and to communicate that decision via any practical means (see, e.g. Ashton, 2006; Douglass, 2016).

Legal and mental capacity in the context of the Convention

As outlined in the previous section, Article 12 challenges the traditional notions described above that obstruct disabled people from making decisions and realising their will and preference. In the context of the Convention, there is a distinction between and separation of legal and mental capacity, where legal capacity is recognised as a non-derogable and universal right that every person can exercise irrespective of mental capacity or disability (General Comment No. 1, 2014; Devi, 2013; Mental Disability Advocacy Center, n.d.; Parker, 2016; Perlin, 2013; Stavert, 2015). Specifically, the Convention recognises that all persons have legal capacity by virtue of being human as a human right (Browning et al., 2014; Devi et al., 2011; Flynn & Arstein-Kerslake, 2014). This is entitled the 'rights-based model' for capacity (as is described in Dickey, 2016; General Comment No. 1, 2014; Keeling, 2016; Lang et al., 2011; Werner, 2012). Additionally, because it applies to all human persons, it is also referred to as the *universal* approach to capacity (Stavert, 2016). In this sense, the Convention firmly rejects the idea that some people meet standards for legal capacity and others do not in an 'all or nothing' sense (Browning et al., 2014). Instead the Convention perceives legal capacity to be held by all people all of the time, and consequently, that the notion of 'incapacity' should be discarded, no matter the extent to which a person requires support in relation to their exercise of legal capacity (Devi et al., 2011; Weller, 2014). Further, by virtue of the right to legal capacity, a person's will and preferences should be at the centre of and be the determining factor within any decision-making process (Keeling, 2016; Series, 2015; Watson, 2016a). Because the Convention separates cognitive function from legal capacity it is acknowledged that a person's decision-making ability can fluctuate while legal capacity remains static (Browning et al., 2014). In short, the Convention perceives *all* people as having legal capacity but also recognises that some

people require assistance to demonstrate or exercise mental capacity. This position sits in stark contrast with traditional interpretations of legal capacity and relationships with mental capacity. It also remains an issue of contention in the literature, as is explored by Douglass (2016), and is identified by some as being an unrealistic obligation.

Sweden has completely discarded notions of 'legal incapacity' (Åkerberg, 2011; Committee on the Rights of Persons with Disabilities, 2014c). However, decisions can be recognised as legally invalid, for example, when a person would not have made a choice had they been in a more optimal state to make decisions (Åkerberg, 2011). Sweden is regarded as having instituted one of the most progressive law reforms in response to the Convention (Watson, 2016a). The Committee recognises that Sweden has abolished notions of 'incapacity' (see Committee on the Rights of Persons with Disabilities, 2014c), however, authors such as Watson (2016a) take the position that Sweden implies incapacity by means of its substitute-like support mechanisms.

Whilst much of the capacity literature focuses on the significance of disconnecting notions of legal and mental capacity in the context of health care, many authors note that it is important to recognise the significance of the absolute right to legal capacity in many other contexts. These include but are not limited to: education (Whitlatch, 2016; Werner, 2016), employment (Werner, 2012), criminal and contract law (Craigie, 2015; Davidson et al., 2016; Slobogin, 2015), residential choices (Chan, 2016; Darvell, 2016; Watson, 2016a; Werner, 2012), and sexual and reproductive choices (Werner, 2012). The literature also argues for full expression of supported decision-making in all facets of the daily lives of disabled people (Stainton, 2015; Tracy, 2015).

The role of capacity assessment in the age of the Convention

In challenging legal capacity, the Convention seeks to also challenge capacity assessments (as described earlier in this section). The test employed in New Zealand's Protection of Personal and Property Rights Act (1988) ("PPPPRA") and commonly employed in other jurisdictions has been entitled the 'functional test' for capacity. This test, along with other tests in which disability and cognitive ability are deciding factors, is challenged by the Convention and considered discriminatory. These tests include the:

- Functional approach: where a person is found to not have capacity on the basis that a person's decision-making skills are considered to be deficient.
- Status approach: where a person is found to not have capacity on the basis of the diagnosis of an impairment.

- Outcome approach: where a person is found to not have capacity on the basis that a person is making a choice that is estimated will have negative or harmful consequences to the person themselves or others (see Ciavano, 2014; Devi et al., 2011; Nilsson, 2012).

The functional approach has traditionally been considered to be a value-neutral test (Richardson, 2012; Series 2015). However, this interpretation is challenged by the Convention, which sees this test as being value-laden and discriminatory towards disabled people (Arstein-Kerslake, 2014; Byrnes, 2007; Carney, 2015b; Flynn & Arstein-Kerslake, 2014; General Comment No. 1, 2014; Richardson, 2012; Series et al., 2014). Notable commentators and researchers on the Convention (see for example Arstein-Kerslake, 2014; Flynn & Arstein-Kerslake, 2014) explain that disability acts as the threshold factor within all the aforementioned tests. With regard to the functional test, the process involves using any medical evidence of an impairment to infer that a person does not have the ability to make a particular decision. This test ultimately applies disability as a threshold factor – even if it does so indirectly (Flynn & Arstein-Kerslake, 2014). Additionally, groups of people, particularly disabled people, are disproportionately more likely to be perceived as lacking capacity to make a decision, and therefore much more likely to have their expressions of agency obstructed (Carney, 2015b). In addition, being found to lack capacity is made on the basis of interactions with people in positions of power and social and political contexts, which Stavert (2015; n.d.) and Stefan (quoted in Series, 2016) argue compromises the value-neutral status of capacity assessment. Therefore, maintaining notions of ‘incapacity’ is perceived to be a violation of the principle of equality underlying Article 12 and consequently is inconsistent with the Convention (see Carney, 2015b; General Comment No. 1, 2014; WNUSP, 2008). This is what has led to calls for the construct of incapacity to be discarded (Browning et al., 2014; General Comment No. 1, 2014; WNUSP, 2008). Consistent with the Convention, the literature generally supports the separation of mental capacity and cognitive functioning from the process of recognising legal capacity under law (Flynn & Arstein-Kerslake, 2014; Gooding, 2013; Richardson, 2012). It is recognised that every person, with or without a disability, has different cognitive functioning and decision-making ability to an extent that ‘all or nothing’ approaches cannot reflect (Flynn & Arstein-Kerslake, 2014).

Rights to legal standing versus rights to legal agency

Historically, legal capacity has been concerned with legal recognition and the granting of full legal personhood, that is, the granting of legal agency and status (Arstein-Kerslake & Flynn, 2014; Arstein-Kerslake & Flynn, 2015; Browning et al., 2014; Kerzner, 2011; Series et al., 2014). However, as previously alluded to, there is debate in the literature concerning the appropriateness of granting legal capacity to all persons regardless of mental capacity, as well as debate as to whether or not the Convention intended to grant rights to legal capacity in the full sense, including standing and agency. *Legal standing* (or status) reflects the situation whereby a person is a holder of rights and the state has an obligation to protect and enforce those rights (Flynn & Arstein-Kerslake, 2014; Series, 2015; Werner & Chabany, 2015). *Legal agency* is concerned with

a right to exercise legal capacity and take action under law (Åkerberg, 2011; Browning et al., 2014; Flynn & Arstein-Kerslake, 2014; Stainton, 2015; Werner & Chabany, 2015). For example, if disabled people are granted *legal agency* under the Convention, they are able to make a full range of decisions, even those that are dangerous or compromise their welfare, and even if they do not fully understand the implications of their choices (as discussed in Chan, 2016; Dawson, 2015; Dunn et al., 2008; Gooding, 2015; Gooding, 2013; Kapp, 2007). Conversely, if disabled people are granted only *legal status* under the Convention, then they do not have the same ability to make dangerous decisions and the state still has obligations to protect them from abuse.

On one side of the debate, authors argue that the Convention and General Comment do not recognise a right to legal agency under 'legal capacity' because it would be unreasonable to do so and does not protect the welfare and integrity of disabled persons who may need to be protected from their own decisions (see for example Bach & Kerzner, 2010⁷; Batchelor et al., 2012; Dawson, 2015). In other words, it is argued that there is an ethical obligation to protect vulnerable persons (*parens patriae*), which is sufficient to deny a person legal agency under the law. In this sense, it is argued that not all persons reach a threshold of understanding to warrant granting them recognition of legal agency under the umbrella of 'legal capacity'.

Denmark utilises an idea entitled 'legal disqualification' whereby a person can be disqualified from being a legal agent under law, for example in cases where they are putting their interests at risk or making themselves vulnerable to exploitation (Alzheimer Europe, 2011). This approach implies that legal agency can be disqualified but all persons have a non-derogable right to legal capacity in the partial sense and that 'partial sense' encompasses legal standing.⁸

On the other side of the debate, authors explore how the recognition of both legal standing and agency under the umbrella concept of legal capacity is consistent with the purpose and spirit of the Convention and the General Comment (Gooding, 2013). Those who object to the continuation of disqualifications and caveats in

⁷ Bach & Kerzner promoted facilitated decision-making in hard cases but argued that last resort substituted decision-making will sometimes be necessary. As examined in later sections, other authors extend on the idea of facilitated decision-making and promote the idea that substituted decision-making can always be replaced by facilitated decision-making.

⁸ Denmark's approach is an example of how an initiative has tried to balance disabled persons' autonomy with their protection. Therefore, this is in relation to Question 5, "How are the rights for promoting a disabled person's autonomy versus safeguards for their protection and safety being balanced?". However, the approach remains problematic given that some of the literature takes the position that denial of legal agency is inconsistent with the Convention, as is discussed in this section.

the Convention era perceive that requiring a threshold to be met for *legal agency* is equivalent to requiring a threshold to be met for *legal capacity*. It is argued that continuing to deny groups recognition under law, whether it be for legal capacity or legal agency, constitutes discrimination on the premise that some groups are less deserving of legal recognition (Flynn & Arstein-Kerslake, 2014). Therefore, affording legal status but not agency to disabled people is inconsistent with the intention of the Convention.

What can obstruct the realisation of a person's legal capacity?

This section examines how disabled people can experience problems exercising their legal capacity under current jurisdictional and practical frameworks (which pertains to Question 1, Appendix A) and how these problems are based on a favouring intervention and best interests considerations. The literature indicates that states parties have taken a number of steps to reinforce the notion of rights-based legal capacity, and a presumption of mental capacity (Arstein-Kerslake & Flynn, 2015; Government of Australia, 2012; Government of Canada, 2015; Government of Sweden, 2012; Morrissey, 2012; Pathare and Shields, 2012). However, social perceptions of disability remain a clear obstacle to wide-scale recognition of the right to exercise legal capacity (Werner, 2012; Chan, 2016; Watson, 2016a). Such social perceptions apply with negative consequences for many disabled people.

Another confounding factor relates to the diverse ways in which states have attempted to interpret the provisions of the Convention to fit pre-existing understandings of supported and substitute decision-making, a move that has been roundly criticised by the Committee on the Rights of Persons with Disabilities (see Committee on the Rights of Persons with Disabilities, 2013; Committee on the Rights of Persons with Disabilities, 2014a; Committee on the Rights of Persons with Disabilities, 2014b; Committee on the Rights of Persons with Disabilities, 2014c; Minkowitz, 2013). For example, Australia and Canada are states parties that have explicitly retained the possibility of substitute decision-making in difficult exceptional cases despite implementing significant legislative and policy changes⁹ in an attempt to align with the Convention (Carney, 2010; Davidson et al., 2016; Devi et al., 2011; "Australia's Initial Report under the Convention", 2010; Government of Canada, 2015; Watson, 2016a). At the more extreme end of the scale, other states parties have interpreted the Convention as permitting obviously coercive and discriminative substituted decision-

⁹ These are examples of how only some progress has been made with regard to changing the practice and mandate of substituted decision-making and illustrate that states parties are (incrementally) moving towards limiting its utilisation. Therefore, these examples pertain to Question 13, "Has there been any change in the practice and mandate for substitute decision- making?".

making mechanisms. Tunisia, for example, noted an intention to retain guardianship laws in cases of 'insanity, mental impairment or profligacy' (cited in Dinerstein, 2012), whilst Spain asserted compliance with supported decision-making because provisions for guardianship were found on its statute (Dinerstein, 2012). Whilst these two examples are inconsistent with the spirit of the Convention, they reflect the positions held by some Convention commentators who perceive that the duty of care owed to vulnerable persons justifies the retention of substitute decision-making mechanisms within legislation (see for example Dawson, 2015).

As previously noted, the best interests concept has long been used as the basis for substitute decision-making, and other interventions that can obstruct the realisation of legal capacity. The Convention and the associated General Comment, signals that such considerations are no longer acceptable, emphasising instead the imperative that person's will and preference is prioritised. Nevertheless, it seems that many states (and commentators) remain wedded to the best interests concept, if only in difficult cases. In a recent report for the New Zealand Law Foundation, Douglass argued that best interests, as articulated in the Mental Capacity Act 2005 of England and Wales, should be a standard for decision-making in the New Zealand context (Douglass, 2016). Kelly (2015) also noted the general value of best interests considerations, with particular regard to the ways in which the concept helps to inform the practice of those caring for persons with disabilities, particularly parents caring for profoundly disabled children. Kohn et al. (2014) take a more absolutist position against best interests justifications on the basis that such approaches always undermine the human dignity of the person and the rationale is vulnerable to abuse (where disabled people become at risk of being denied legal agency on the basis of lower evidence thresholds). The paradigm shift from the best interests concept to that of will and preferences is discussed in more depth below.

Paradigm shift from best interests to will and preference

This section explores the discussion in the literature that pertains to the paradigm shift from best interests considerations to the centrality of will and preference and specifically addresses Question 7 of Appendix A: “Has there been any discussion or change to transition or move from consideration of a person’s ‘best interests’ to a person’s ‘rights, will and preference’ in the context of disabled people exercising their legal capacity?”. In implementing a shift in framework from substitute to supported decision-making, it is seen as critical that the ‘will and preferences’ paradigm should replace the ‘best interests’ principle (see General Comment No. 1 and, for example, Ciavano, 2015; Dickey, 2016; Keeling, 2016; Martin et al., 2014; Stavert, 2015; Series, 2015; Watson, 2016a), and be applied in all decision-making contexts, including criminal and contract law, residential choices, and other areas of life (Davidson et al., 2016), as mentioned earlier. A significant body of literature argues that will and preference should be the *central* and determining factor of any decision-making process that is seeking to be consistent with Article 12 and the Convention (see Keeling, 2016; Series, 2015; Watson, 2016a). Although third parties involved in substituted decision-making contexts may take a disabled person’s will and preferences into consideration, a disabled person’s will and preferences are not central to the process as the *determining* factor as is required by the Convention (Ciavano, 2014; Martin et al., 2014; Stavert, 2015). According to this interpretation of the obligations and spirit of the Convention, frameworks that rely on best interests models do not give effect to the Convention, by virtue of their reliance on best interests, regardless of their secondary consideration of will and preference. Despite this, there have been efforts made by states parties to adjust existing best interests models (as has been done in England and Wales with the implementation of the best interests checklist, Mental Capacity Act 2005) and proposals to implement new best interest decision-making measures (as forwarded by Douglass et al., 2016).

As previously noted, a commitment to the will and preference paradigm places all persons on an equal footing in terms of their right to make self-determined choices irrespective of the perceived wisdom of those choices, or whether they accord with previously held interests and values. In response, some states have taken steps to review their legislative provisions to replace best interests models with the centrality of will and preference. Some of these states parties, as illustrated below, have done so in only a limited way.

Ireland has begun the process of reforming its Mental Health Act 2001 to exclude considerations of best practice, which due to the requirement to ensure legal parity between Northern Ireland and Eire, will also

require a change in the Mental Capacity legislation in the North. In particular, the Irish Bill rejects the idea that will and preference is only one factor to consider in identifying 'best interests', specifying that those 'intervening' in respect of a person shall "give effect, in so far as is practicable, to the past and present will and preferences of the relevant person, in so far as that will and those preferences are reasonably ascertainable" (MHA [Ire], s.8(7)(b)).

England and Wales had earlier signalled intent to remove the best interests provisions at Pt 4 of its Mental Capacity Act 2005 following recommendations in 2013 from the House of Lords Select Committee on the Mental Health Act (Kelly, 2015). Very recently, case law has signalled a redefinition of best interests to emphasise the particularity of the interests, will and preference of the person concerned. In *Wye Valley NHS Trust v Mr B* [2015] EWCOP 60, Peter Jackson J ruled that a person's express wishes must not be excluded from consideration simply on the basis that others did not think they were in their best interest. In particular, he insisted that 'best interests' were those that related to that particular person; they were not, and must not, be the subject of determination by third parties. The practice implications, set out by prominent chambers 39 Essex Lane, are worth repeating in full:

Peter Jackson J has made clear just how far along we have come on the journey to recognising the dangers of treating capacity as a cliff-edge off which one falls into the clinging embrace of paternalism. The approach endorsed by Peter Jackson J to the construction of best interests decisions on behalf of those lacking capacity is one that is light years removed from the paternalistic model that still remains prevalent in so many settings. He sought to recognise Mr. B as an "individual human being", echoing Lady Hale's phrase from *Aintree*, and emphasised that "the wishes and feelings, beliefs and values of people with a mental disability are as important to them as they are to anyone else, and may even be more important."

These are interesting departures from the standard interpretation of best interests as the justification for substitute decision-making. It seems possible, therefore, that England and Wales will retain a best interests clause within their legislation but that future interpretations may place more emphasis on the will and preference of the individual.

Equal versus differential treatment under criminal law

The paradigm shift in understanding capacity to a rights-based approach also impacts on criminal defences that are premised on recognising incapacity. Historically, persons have been permitted to be exempt from

criminal responsibility on the basis of legal incapacity, such as the criminal defence of insanity (see Government of Norway, 2015). However, the literature argues that such defences are on the basis of cognitive impairment as a determining factor and therefore do not give effect to states parties' obligations under the Convention (see WNUSP, 2008). It is argued that these defences should be abolished and replaced with disability-neutral defences or standards for determining responsibility (Richardson, 2012; WNUSP, 2008). Instead, disabled people, particularly those with cognitive impairment or mental distress, would have access to all the defences available to non-disabled persons, including intent and circumstance (WNUSP, 2008). In contrast, Slobogin (2015) argues for the continuation of functional capacity tests in the criminal justice system so that interventions can be permitted under *parens patriae* (protecting the vulnerable), including incapacity as a defence and involuntary hospitalisation as a legal option (as is the case with the IDCCR legislation in the New Zealand context). However, the literature is relatively unequivocal that in order to align with clarifications in the General Comment, that the continuation of such tests would not give effect to the Convention or meet the obligations of states parties (Flynn & Arstein-Kerslake, 2014; O'Mahony, 2012).

Decision-making in the absence of mental capacity tests

The literature highlights that recognising disabled people within the framework of rights-based capacity does not mean that the Convention proceeds on an assumption that people can make decisions completely independently (see for example, Watson, 2016a). Convention researchers and commentators recognise that most people, with or without disability, require feedback from formal and informal support networks to assist with decision-making (Gooding, 2013; Mental Disability Advocacy Center, n.d.; Series, 2015; Stavert, 2015). The recognition of this interdependence challenges the idea that decisions are necessarily independent and made in a vacuum (Martin et al., 2012; Series, 2015), rather it conceives of decision-making as collaborative, interdependent and *relational* (Carney & Beaupert, 2013; Dickey, 2016; Gooding, 2015; Harding, 2013; Martin et al., 2012; Series, 2015; Watson, 2016a). In this conceptualisation of decision-making, third parties assist a person to realise their will and preferences in decision-making processes (Series, 2015).

Obligations to protect vulnerable people

This section explores approaches signalled in the literature about how to balance promoting disabled persons' autonomy with safeguarding their protection (Question 5, Appendix A). On the basis of *parens patriae* (obligation to protect the vulnerable) arguments are made for the need to employ substituted decision-making, capacity tests and notions of 'incapacity' in difficult cases, especially in health care contexts (see Allen & Tulich, 2015; Chan, 2016; Dawson, 2015; Dunn et al., 2008; Gooding, 2015; Gooding, 2013; Kapp, 2007). The notion of *parens patriae* (lit. "parent of the nation") allows a state to act as a de facto parent for a vulnerable individual (Jameson et al., 2015). The concept has been used to legally justify the duty of care principle, and it is this principle that has been used to balance any risks that potentially arise as a result of a

person exercising his or her legal capacity (Dawson, 2015; Chan, 2016; Gooding, 2013). A 'duty of care', entails an obligation to "exercise a level of care towards an individual, as is reasonable in all circumstances to avoid injury to that individual or his/her property" (Watson, 2016a, p. 140; also see Baxter & Carr, 2007). There is an assumed tension between the provisions of the Convention and the duty of care principle that has led some commentators to criticise Article 12. These commentators see a move away from 'best interests' as having the potential to expose vulnerable individuals to harmful consequences; particularly if it is replaced with the notion of will and preference, and if there is no mechanism for substituted decision-making (see for example Dawson, 2015; Douglass, 2016).

The body of literature in favour of 'last resort' substituted decision-making (see for example, Dawson, 2015; Douglass, 2016; Ciavano, 2014; O'Mahony, 2012; and Perlin, 2013) shows little engagement with the concept of 'facilitated decision-making' as an option in difficult or exceptional cases. Therefore, there is a lack of robust criticism *against* facilitated decision-making as a potentially viable alternative of supported decision-making in these exceptional cases. This alternative is explored later in the section concerning options for support that have been signalled or that are currently emerging.

In summary, there is a perception within some quarters that the more liberal interpretation of the Convention subjects those less able to exercise their legal capacity in accordance with their will and preference to unacceptable levels of negligence. While the General Comment No. 1 (2014) explicitly excludes the possibility of substitute decision-making (at paragraph 28), it equally emphasises the 'development of supported decision-making alternatives.' Flynn and Arstein-Kerslake (2014) suggest that an insistence on exceptions to the disestablishment of substitute decision-making undermine the ethos of the Convention, inasmuch as the 'exceptions' invariably apply to persons with disabilities. Other authors also stand in opposition to the notion of 'last resort' substituted decision-making (see Minkowitz, 2014; Minkowitz, 2013; Callaghan & Ryan, 2014). Arstein-Kerslake and Flynn (2015) contend that, rather than protecting disabled people by means of denying them legal rights to capacity, they can instead be protected through empowerment, the recognition of their decision-making ability, and support through trust and connection (also see similar arguments in Arstein-Kerslake and Flynn, 2014; Bartlett, 2012; Dickey, 2016; O'Mahony, 2012; Morrissey, 2012; Series, 2016; Stainton, 2015).

In the context of finances for example, Smetanka (2015) proposes an idea of what protecting persons through empowerment would look like, including checking for signs of abuse and taking pro-active measures towards inter-dependent decision-making (planning, reviewing, managing, and understanding the disabled person's finances as a team). It can also involve encouraging self-advocacy by providing them with suggestions and ways to refuse requests for money.

Similarly, with regard to decisions under extreme distress and/or disruption in their authentic self and 'true' will and preference, close attention can be paid to what is known about the person. Arstein-Keirslake (2014), Callaghan & Ryan (2014), and Series (2015) propose a justification for interventions whereby facilitators

(based on the facilitator's knowledge of the person and their states of thinking) proceed on the premise that there are disturbances in a person's authentic agency and 'true' will and preference – but where authentic will and preference and supporting the realisation of agency remain central to decisions. McMillan, Hope & Walker (2014) also argue for a similar approach in the context of persons with severe dementia showing radical changes in their expressed interests and preferences. Although fulfilling a duty of care frequently entails recourse to that person's previous characteristic preferences, it is important to revisit one of the key characteristics of models that are inconsistent with the Convention, that is: models in which the rights, will and preference of the respective person are not central to any decisions made. Real connection with the obligations set out in the Convention is lost when the person's will and preference is no longer the determining and central factor (as is highlighted in Arstein-Kerslake, 2016; Arstein-Kerslake & Flynn, 2015; Douglas et al. 2015; Flynn & Arstein-Kerslake, 2014; Knox et al., 2016; Series et al., 2014; Stavert, 2016; Tracy, 2015; Watson, 2016a).¹⁰

What to do when it is not possible to obtain the will and preferences of a person has been highlighted as another significant difficulty within the debates relating to Article 12. Some commentators argue that it is always possible to determine a person's will and preference or at least come to a best interpretation; that is, that every human person has the ability to express their will and preferences (Watson, 2016a). When a person is unable to express their will and preferences (in a manner that others can easily interpret), a third party must gather these expressions and other available information (including values and beliefs or previous expressions of agency) and imagine the will and preferences of the person based on these factors (Arstein-Kerslake & Flynn, 2015; Devi, 2013; Flynn & Arstein-Kerslake, 2014). Using this approach, it is argued, a third party can assist the disabled person to execute agency, instead of making a substituted decision about their best interests (Series, 2016). In order to execute the person's agency, the supporter must commit to discovering the person's core values and preferences even when doing so requires great effort (see Allen & Tulich, 2015; Flynn & Arstein-Kerslake, 2014). In this way the person's will and preferences remain at the centre of the decision as the determining factor, rather than having the will of another imposed on them (Arstein-Kerslake & Flynn, 2015; Flynn & Arstein-Kerslake, 2014). Gooding (2015) and Allen & Tulich (2015) describe this process as: proceeding on the 'best interpretation' of the person's will and preference so as to give expression to a person's agency. These types of approaches are explored again later in this report, but have been raised here as a way of answering common critiques of supported decision-making. Additionally, some evidence suggests that advances in assistive technology better enable third parties to establish communication with persons in minimally conscious states so as to obtain their will and preferences in the present (Gooding et al., 2015).

¹⁰ This relates to Question 18, "How far can supported decision-making be applied before it loses real or practical connection with a disabled person's will and preference, and in practice what is happening is very nearly or already substitute decision-making in their best interests?".

Considerations of the expression of will and preference have highlighted that disabled people must be permitted to both ask for, and refuse, support (Flynn & Arstein-Kerslake, 2014). In other words, disabled people should have their will and preferences respected, even when their choices are perceived as unorthodox or when it means that they may put themselves at risk (Richardson, 2012; Series, 2015; Series et al., 2014). Callaghan & Ryan (2014) and Flynn & Arstein-Kerslake (2014) refer to this as 'dignity of risk': a significant part of human experience that should not be denied on the basis of disability.

Related to the above point, evidence also suggests that employing substituted decision-making in exceptionally difficult cases can have negative consequences (see for example Chan, 2016; Callaghan & Ryan, 2014). In cases where individuals exhibit behaviours of concern (are dangerous to themselves or others), evidence highlights that they are often accommodated in closed environments under current practice, including residential institutions and detention centres (Chan, 2016). Chan (2016) highlights that involuntary detention and treatment can exacerbate concerning behaviour and mental distress in these 'extremely difficult cases' rather than improving it by means of other courses of action. Callaghan & Ryan (2014) also raise concern with involuntary hospitalisation, including: persons being subjected to violence in psychiatric wards and that it may lead to increases in suicidal feelings. With regard to mental health, evidence suggests that supported decision-making and support with decision-making has positive effects on treatment outcomes and the relationship disabled people have with practitioners (Mahone et al., 2011; Morrissey, 2012).

Can substituted decision-making continue in the age of the Convention?

As already established, Article 12 has proved contentious and problematic mostly due to diverse and strongly held views about its implementation and application (see Dawson, 2015; Douglass, 2016; Martin et al., 2014 compared to Arstein-Kerslake and Flynn, 2015; WNUSP, 2008; Minkowitz, 2014). Most significantly, member states generally have statutory provisions for substitute decision-making in cases where people are found to lack the capacity to make decisions for themselves. States parties have struggled to understand what full implementation entails, and have typically resorted to interpretative approaches to legislation that allow existing substituted decision-making legislation and statutory provisions to remain in situ alongside the implementation of models of supported decision-making.¹¹ In most states – including New Zealand – there has been a legislative assumption that there will always be cases of persons for whom substitute decision-

¹¹ This shift towards practicing substituted decision-making alongside supported decision-making is another change relevant to Question 13, "Has there been any change in the practice and mandate for substitute decision-making?"

making must be undertaken (see Government of Australia, 2012; Government of Canada, 2015; New Zealand Government, 2015). Similar approaches are held by authors such as Dawson (2015), Martin et al. (2014), Douglass (2016) and Douglass et al. (2016), who advocate for adjustments to current frameworks. Dawson (2015) and Martin et al. (2014) argue that, despite the attempt to clarify both the intent and practice of Article 12 and supported decision-making, states parties' obligations remain ambiguous and inconsistent. They specifically argue that states parties are required to interpret whether the Convention prohibits substituted decision-making. Dawson (2015), for example, proposes a less 'radical' interpretation of States parties' obligation and argues that the Convention can be interpreted as permitting substitute decision-making in exceptional circumstances. Other authors, such as Douglass (2016), Douglass et al. (2016), and Parker (2016) proceed on the basis that current substituted decision-making mechanisms need to be adjusted, rather than radically departed from. These interpretative approaches allow for the continuation of substituted decision-making and best interests frameworks that many states parties execute in law, policy, and practice. If these positions were adhered to, for example, the continuation of legal capacity tests, involuntary treatment, and involuntary detention would all be permitted in exceptional circumstances.

However, if implemented according to the interpretation contained in General Comment No. 1 and Article 12, the Convention eliminates that possibility. As discussed earlier, a large body of literature (especially the literature of authors who had insight or involvement in constructing the Convention) strongly contrasts with these interpretations and poses that radical departure from the current prevailing norms and paradigms is critical to giving effect to the Convention (see the manual provided by WNUSP and the Handbook for Parliamentarians, Byrnes et al., 2007, and Arstein-Kerslake & Flynn, 2015; Bach & Kerzner, 2010; Minkowitz, 2013; Watson, 2016a). The retention of substituted decision-making provisions, in the view of the United Nations, the Committee on the Rights of Persons with Disabilities, and many other commentators, does not meet the intention of Article 12 and subsequently makes it difficult to achieve other Articles and obligations contained within the Convention (Minkowitz, 2014; Pathare & Shields; 2012; Quinn, 2010). In this sense, there is a significant gap between contributors to the literature who support a radical interpretation of the Convention and states parties' more conservative interpretations.

As is stated by the General comment:

States parties' obligation to replace substitute decision-making regimes by supported decision-making requires both the abolition of substitute decision-making regimes and the development of supported decision-making alternatives. (para. 28)

At all times, including in crisis situations, the individual autonomy and capacity of persons with disabilities to make decisions must be respected. (para. 18)

[support] should never amount to substitute decision-making. (para. 17)

Despite this strong articulation, and as previously mentioned in this report, there is debate as to the extent that this obligation under the Convention is an appropriate obligation at all (as is highlighted by Devi, 2013).

Those on one side of the debate (which aligns with the actions already taken by a number of member states) argue that substituted decision-making is necessary in exceptional circumstances and that it is unreasonable to abolish measures within the framework (see for example Dawson, 2015). Those on the other side of the debate argue that all circumstances, including exceptional circumstances, can be addressed through strategies of supported decision-making and a commitment to the empowerment of disabled people, and is therefore a reasonable obligation that respects the dignity of disabled people (see for example Arstein-Kerslake & Flynn, 2015; Kohn et al., 2014). This issue of contention is raised in the following sections.

The research literature identifies a number of circumstances where the exercise of legal capacity, in accordance with will and preference, may be problematic. The first of these is where a person does not understand a decision, its related factors, or their relationship to the decision (Werner, 2012). Concern has been raised about circumstances where persons may not be able to understand the gravity of the decision they are making or the danger that may be involved with it (Gooding, 2015). Research has indicated that it can be particularly difficult for disabled people to make decisions based on a sense of magnitude (such as an amount of money) or delay (consequences that are not immediate) (Werner, 2012). Relatedly, Smetanka (2015) notes that disabled persons, along with older people, are a group targeted at higher rates for financial abuse because of these gaps in understanding. The notion of 'executive functioning', involving more complex cognitive processes such as time and task prioritisation and management has also been raised due to a recognition that some people experience difficulty in these areas (Werner, 2012). Werner (2012) also notes that people with more complex and significant intellectual disabilities may not be aware of their role in the decision-making process.

Considerations of risk

Some commentators also argue that persons who are dangerous to themselves and/or others ought not to be able to realise choices that are harmful to their personal welfare or integrity, or harmful to the personal welfare or integrity of others (see Chan, 2016; Gooding, 2013; Callaghan & Ryan, 2014). One of these circumstances is where a person may make decisions that are so palpably unwise that to allow them to continue with the exercise of such choice abdicates the duty of care that has traditionally been owed to them (see Dawson, 2015; Richardson, 2012; Series, 2015; Callaghan & Ryan, 2014). Another related circumstance is where allowing the autonomous exercise of will and preference would risk harm to others; in this regard, the curtailment of autonomy is usually applied to persons with mental illness, subject to compulsion under the Mental Health (Compulsory Assessment and Treatment) Act 1992 (or similar legislation) or the provisions of criminal justice legislation, for example the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 in the New Zealand context. Certainly, in New Zealand, human rights legislation permits exceptions to the exercise of human rights where there is a risk of harm (whether to self or others) (Human Rights Act 1993, Part 2, various sections) because abandoning considerations of risk (to others) entirely may jeopardise the autonomy of others.

A key area where risk of harm to self and harm to others fuses in a potentially problematic way is the compulsory confinement of those with learning disabilities, whether as a prisoner, special patient, or former prisoner or special patient. In New Zealand, such cases are governed by the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003. In common with compulsory treatment orders under the Mental Health Act, a 'care' recipient is required to accept care (Pt. 5, s.47), and there are clear tensions here between the domestic legislation and the provisions of the Convention. Whilst the provisions of the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 are articulated in terms of 'care' and 'need', the practicalities require that a care manager specify the terms under which care recipient conduct their lives. The limitations, therefore, of such a care recipient's ability to exercise their legal capacity seem evident, even when decisions on their behalf are ostensibly taken in a person's best interests.

The realisation of legal capacity through supported decision-making

Some of the literature makes a distinction about the scope of states parties' obligations to give effect to the realisation of legal capacity, will and preference. This work is ultimately concerned with the distinction being made between the obligation to provide 'support for' decision-making versus the obligation to provide supported decision-making, that is, the scope of states parties' obligations.

Defining supported decision-making

'Support for decision-making' and 'supported decision-making' seem to be conceptually equivalent because both involve the process of supporting a person to make decisions (Watson, 2016a). Watson (2016a) argues that supported decision-making is also referred to as 'support with decision-making', 'supportive decision-making', and 'decision-making support'. Applying a different interpretation, Browning et al. (2014) argue that there is a subtle difference between the two concepts of 'support with decision-making' and 'supported decision-making'.¹² In the view of Browning et al., 'support with decision-making' refers to the mechanisms by which a person can be directly supported to make decisions, while 'supported decision-making' refers to the realisation of the exercise of agency and decision-making ability of the supported person, which includes taking steps to indirectly (such as by law, policy, and practice) and directly do so (Gooding, 2015). That is, they argue that the supported decision-making framework goes beyond support with decision-making to encompass revisions to states parties legislative positions on capacity. Gooding (2015) adds that supported decision-making also includes upholding other rights of the disabled person, for example, rights to legal capacity, rights to life, rights to dignity, and rights to choose where to live. Consequently, some commentators argue for the distinction on the basis that full realisation of the supported decision-making

¹² This discussion pertains to Question 14, "How is support for disabled people's exercise of legal capacity being distinguished from supported decision-making?".

model, including legislative change, is the only way to give full effect to the Convention (Browning et al., 2014).¹³

¹³ This argument is in direct conversation with Question 17, “Does recognition of supported decision-making need legislation to ensure supported decisions are implemented and protection assured for the disabled decision-maker and their supporters?”, which is discussed in more depth in later sections.

Summarising the key points and issues of contention

As is evidenced by many states parties' reports to the Committee on the Convention (see for example, Australia, Canada, New Zealand, Norway, Denmark), and a significant body of literature that surrounds the Convention (see for example Ciavano, 2014; Dawson, 2015; Martin et al., 2014), there has been uncertainty about the obligations of states parties and, especially, how jurisdictions can give effect to Article 12. While most people agree about the broad intention of the Convention in principle, the most significant tension lies with Article 12. While the General Comment was intended to clarify the ambiguity related to Article 12, debate remains and focuses on:

- The abolishment of substituted decision-making in its entirety, including mental capacity tests.
- The nature by which states parties can give effect to Article 12 through supporting disabled people's decision-making and the realisation of will and preference.

Furthermore, in the shift from conceiving of mental and legal capacity as intrinsically linked to the non-derogable and rights-based recognition of legal capacity regardless of mental capacity, the following tensions can also be seen in the discourse relating to the Convention:

- Distinctions between rights to legal standing and rights to legal agency under the umbrella notion of 'right to legal capacity'.
- Debate concerning equal and differential treatment under criminal law.
- Obstructions to the realisation of person's legal capacity in practice, including negative perceptions of disability, as well as states parties' misinterpretations of their obligations.

Part Two: Implementing supported decision-making in legislation, policy, and practice

Part Two of this report considers the specific approaches and mechanisms for supported decision-making that have been signalled in the research literature, or implemented by states parties, as a way of informing New Zealand's pathway to giving expression to Article 12 in the future.¹⁴

As outlined in Part One of this report, supported decision-making has been defined as, "[...] a process of supporting people with their decision making, a system that affords legal status, and a means of bringing a person's will and preference to the centre [of the process]" (Browning et al., 2014). In other words, it is a framework in which disabled people are supported to make decisions that exercise their legal capacity and promote self-determination, will and preference (Arstein-Kerslake & Flynn, 2015; Browning et al, 2014; Kohn & Blumenthal, 2014; Werner & Chabany, 2015). When required, it is intended that third parties take the position of 'supporters' to assist disabled people to make, express, and execute their will and preferences (see Ciavano, 2014; Nilsson, 2012). This may involve support mechanisms or supporters that help in the provision of information and relevant issues to a decision, increase understanding, and help to communicate decisions made (Carney & Beaupert, 2013; Ciavano, 2014; Devi et al. 2011; Tracy, 2015). The means of support will depend on the needs of the disabled person and the social and systemic factors that influence their ability to realise their legal capacity (Pathare & Shields, 2012).

Legislation and policy

The literature has a general focus on law reform as an essential component of realising the Convention (see Burgen, 2016; Carney, 2013; Kerzner, 2011). Burgen (2016) proposes that supported decision-making should

¹⁴ Primarily, this section is concerned with Question 6, "What forms of better support for disabled people's exercise of legal capacity have been implemented or signalled?"

be conceived of as both a process (in which support is provided and efforts are made to accommodate for and assist disabled people) and a legal paradigm.¹⁵ Authors such as Browning et al. (2014) argue that the supported decision-making model requires legislative change to “legitimise the interdependent nature of decision-making and the concept of shared capacity” (p. 34; also see Carney, 2013), and thus requires legislative change to both recognise the status of supports to provide assistance and to provide a range of support options (Kerzner, 2011) but also indicate a range of legally binding duties for supporters (Bach & Kerzner, 2010). As is highlighted in Parker (2016), legislative change is perceived to be crucial to courts and tribunals having the ability to grant access to supported decision-making. In proposing a list of recommendations for giving effect to supported decision-making in the New Zealand context, Douglass (2016) signals that legislative recognition is necessary to the process of implementation. McSherry & Wilson (2011), who specifically examine New Zealand and Australia, also perceive the Convention as (potentially) having a huge impact on policy and legislation. Minkowitz (2013), however, argues that jurisdictions are going to have to proceed with a level of uncertainty about how to effectively implement the supported decision-making framework. This uncertainty is linked to the fact that, as yet, law reform would be (and is) occurring in the absence of robust evidence about what actually works with regard to embedding supported decision-making through legislative change (Carney & Beaupert, 2013; Carney, 2015b; Kohn & Blumenthal, 2014; Watson, 2016a).

Despite the acknowledgement that a clear pathway is yet to be determined, it is simultaneously argued that legislators need to know the ethos underlying the Convention in order to be guided to make appropriate legislative changes (Disabled Person’s Organisations, 2014).

As previously noted, within the context of legislative amendment and change, it has been contended that disabled people must be permitted to refuse support (Arstein-Kerslake & Flynn, 2015; Flynn & Arstein-Kerslake, 2014) and to have their will and preferences respected, even when their choices are unorthodox or risky (Richardson, 2012; Series, 2015). For this reason, civil and criminal legal protection have been recognised as needing to be extended to third parties for when the will and preferences of disabled people are respected, and when their will and preferences have potential negative consequences (Arstein-Kerslake & Flynn, 2015). This is to avoid a supporter being implicated if upholding the will and preferences of a person to the greatest extent possible exposes them to civil or criminal liability, such as negligence (Arstein-Kerslake & Flynn, 2015). It is argued, therefore that civil and criminal liability must be adjusted to enable supporters to fulfil their role

¹⁵ This section examines the discussion around whether legislative change is necessary to give effect to Article 12 and what has been signalled by the literature with regard to this. Specifically, this pertains to Question 17, “Does recognition of supported decision-making need legislation to ensure supported decisions are implemented and protection assured for the disabled decision-maker and their supporters?”

adequately. The following examples outline legislative reform implemented by states parties in recognition of their obligations to Article 12 of the Convention.

According to the Handbook for Parliamentarians¹⁶ (Byrnes et al., 2007, also see Kerzner, 2011; Parker, 2016), reasonable accommodation is a necessary component of legislative change and providing legal protection against discrimination of disabled people.

Sweden has made legislative provisions to replace formal guardianship with two means of support: the appointment of a mentor ('god man') to facilitate a disabled person's agency and will and preferences, and the appointment of a third party to manage financial decisions and interests (Watson, 2016a). However, the Disability Committee is concerned that the appointment of the mentor is a form of substituted decision-making (Committee on the Rights of Persons with Disabilities, 2014c).

Sweden has completely discarded notions of 'legal incapacity' (Åkerberg, 2011; Committee on the Rights of Persons with Disabilities, 2014c). However, decisions can be recognised as legally invalid, for example, when a person would not have made a choice had they been in a more optimal state to make decisions (Åkerberg, 2011). The Committee recognises that Sweden has abolished notions of 'incapacity' (see Committee on the Rights of Persons with Disabilities, 2014c) but authors such as Watson (2016a) take the position that Sweden implies incapacity through how people give effect to the second supported decision-making role of 'Forvaltare'.

Like New Zealand, **Ontario, Canada**, has a presumption of capacity whereby all persons are assumed to have legal capacity under law (there is a 'presumption of capacity'). However, inconsistent with the Convention, it provides exception to cases where a person is significantly incapacitated or where the person is a risk to others or themselves (Davidson et al., 2016).

Canada has implemented a legislative change in the form of the Canadian Guardianship Law. This new legislation makes provisions for support networks, primarily informal supporters such as friends or family to support disabled people with decision-making (Gooding, 2013).

Alberta, Canada made legislative provisions for courts to legally recognise and authorise supporters to

¹⁶ Byrnes et al.'s (2007) Handbook for Parliamentarians, published by the United Nations, seeks to assist and advise parliamentarians in changes the Convention expects in practice and also explains the Convention itself and its concerns.

take on a particular scope of duties (co-decision-making duties) for a disabled person (Kerzner, 2011).

In **Australia**, the Charter of Human Rights and Responsibilities has been reviewed for the purpose of potentially adjusting to the obligations under the Convention. One subsection now added to the Charter includes:

All persons have the right to enjoy legal capacity on an equal basis with others in all aspects of life. This includes, but is not limited to, persons with disabilities, children, women, older persons and Aboriginal persons.

In addition, at the state level, Victoria has presented a draft Mental Health Bill (2014) which includes: statutory provisions for the presumption of capacity; a nominated persons scheme for people to act as representatives on a disabled person's behalf; access to advocacy decision-making assistance, and safeguards (Davidson, 2016; Department of Health, 2014).¹⁷

Scotland has made statutory provisions for disabled persons to access funded support services (advocacy) for people who meet particular criteria (Carlin, 2016; SIAA, 2016).¹⁸ The criteria for the right to advocacy services is set out in the Mental Health (Care and Treatment) (Scotland) Act 2003, which reserves this right for people with a mental disorder (also see The Scottish Government, 2013). For the purposes of the Act it includes people with a mental illness, personality disorder, or learning disability.

Ireland explored revising the legal duties within guardianship roles to replace the centrality of best interests with the centrality of 'will and preference'. This was explored in the context of the Assisted Decision-Making (Capacity) Bill 2013 (Series et al., 2014). However, the Bill still permits the continuation of the substituted decision-making framework in legislation.

Delaware, USA, has implemented legislative change that recognises supported decision-making arrangements ("ASAN Praises Supported Decision-Making," 2016). Under law, the supporter is permitted to support decision-making, for example by means of assisting to organise or understand the components

¹⁷ This example specifically pertains to measures to provide access, that is, Question 11, "Has there been any recognition in law or policy by a government regarding the obligation in Article 12(2) that: 'States parties shall take appropriate measures to provide access to persons with disabilities to the support they may require in exercising their legal capacity.'?"

¹⁸ This is also an example that pertains to Question 11.

involved in a particular decision. The legislation makes provisions for these arrangements to extend to major life decisions.

Texas, USA, has implemented legislative provisions for supported decision-making as an alternative to guardianship (Hiser, 2015). Supporters are granted legal recognition to support decision-making processes proceeding on the consent of the supported person ("Supported Decision-Making Alternatives to Guardianship," n.d.).

England and Wales have made legislative changes by introducing the English and Welsh Mental Capacity Act 2005 (MCA), which serves to regulate substituted decision-making (Watson, 2016a). The notion of best interests is central to the framework (Williamson, 2007). Recent changes make provisions for a 'best interests checklist' so to establish procedural means of making best interests judgements (Watson, 2016a). However, this legislative change has been seen as problematic due to its conflation of legal capacity and mental capacity, and because it is not compliant with the Convention (The Centre for Disability Law and Policy in Galway, quoted in Watson, 2016a) due to the fact it centres around best interests, employs the functional test for legal capacity, and utilises notions of incapacity (Baxter & Carr, 2007; Watson, 2016a).

As can be seen above, no state party or jurisdiction, including Canada and Australia, has fully replaced substituted decision-making (Arstein-Kerslake & Flynn, 2015). Jurisdictions continue to employ substituted decision-making in exceptional cases (Davidson et al. 2016; Government of Canada, 2016; Government of Australia, 2012). Davidson et al. (2016) argue that no jurisdiction will fully replace supported decision-making, and thus fully comply with Article 12, in the near future (as do Doyle & Flynn, 2013 in the case of Ireland). Even Victoria, Australia and British Columbia, Canada, which both are jurisdictions widely recognised as being progressive in their quest to embed Article 12 and supported decision-making (Carney, 2015b; Carney, 2015a; Carney & Beaupert, 2013; Kohn & Blumenthal, 2014; Knox et al., 2016; Lang, 2011; Watson, 2016a) have not reached full compliance with the intent of Article 12.

At a federal level, Canada has recognised supported decision-making as the framework that should be dominant in the country (Ciavano, 2014). Although Canada has been described as a leading example (Devi et al., 2011), the Canadian provinces have reached different stages of the process towards supported decision-making. British Columbia has been praised for its progress on a Representation Agreement (RA) initiative, which extends its scope to support for personal, health, and financial matters. Victoria has also been commended in the literature on being the first jurisdiction in the world to implement legislative changes towards reforming their substituted decision-making model (Carney, 2015b; Carney, 2015a).

Approaches to supported decision-making signalled in the literature

Potential theoretical models

Several theoretical models of supported decision-making have been posed. A well-known conception of supported decision-making is the Bach and Kerzner model (as cited in Bach & Kerzner, 2010; Devi, 2013; Doyle & Flynn, 2013; Gooding, 2013; Parker, 2016; Watson, 2016a; Werner & Chabany, 2015). This model consists of a continuum of support but is grounded on the notion that legal capacity is a static status (Devi, 2013). There are three areas on the continuum, all of which involve different levels of support depending on the person's circumstances but none make statements or judgements about the mental or legal capacity of the individual (Bach & Kerzner, 2010). These include:

1. *Legally independent.* This level refers to persons who need little support and make decisions relatively independently (Devi, 2013; Keeling, 2016). Like all people who make decisions, it is accepted that disabled people may refer to their family or close friends to help them examine an issue in depth or may need information to be provided to them in a more accessible (understandable) manner (Devi, 2013).
2. *Supported decision-making.* In this level of the continuum, there is recognition that more assistance is required. For example, a third party may become involved in order to assist a disabled person to exercise their capacity to the greatest extent possible by means of explanation, representation, decision-making or communicative aids, and/or other assistance (Devi, 2013; Keeling, 2016). The literature for supported decision-making typically regards all persons to have will and preferences, and it is argued that attempts must be made to ascertain the will and preferences of persons as much as possible, even when it requires great effort (Allen & Tulich, 2015; Flynn & Arstein-Kerslake, 2014).
3. *Facilitated decision-making.* Facilitated decision-making is intended for more difficult (exceptional) cases where a disabled person's will and preferences are not able to be communicated by the person themselves, the person has significant disabilities, and/or does not have a network of people to provide support (Bach & Kerzner, 2010; Devi, 2013; Keeling, 2016). This level of support involves a representative executing the disabled person's legal agency on their behalf; consistent with that person's will and preferences and on the basis of the understanding and knowledge of the person (Arstein-Kerslake & Flynn, 2015; Bach & Kerzner, 2010; Flynn & Arstein-Kerslake, 2014). The literature regards this level of support to be consistent with the Convention (Devi et al. 2011). Under a supported decision-making model, 'facilitated decision-making' would be employed in cases that

are exceptionally difficult rather than the traditional substitute decision-making model (Arstein-Kerslake & Flynn, 2015; Flynn & Arstein-Kerslake, 2014; O'Mahony, 2012; Morrissey, 2012; Series, 2016;). The involved third party must execute the *agency* of the disabled person, which is in contrast with substituted decision-making (Series, 2016). Critically, the person's will and preferences remain at the centre of the decision as the determining factor, and care is taken to not impose the will of another (best interests) on the disabled person (Arstein-Kerslake & Flynn, 2015; Flynn & Arstein-Kerslake, 2014).

Although Bach & Kerzner also promoted last resort substituted-decision-making in addition to this model, a body of literature has taken their proposed continuum-based framework further to conceive of a model in which substituted decision-making is not necessary at all. Instead facilitated decision-making and full support are sufficient provisions in hard cases where substituted decision-making would usually be utilised (see for example Arstein-Kerslake & Flynn, 2015; Allen & Tulich, 2015; Flynn & Arstein-Kerslake, 2014). These independent, supported, and facilitated aspects of the Bach and Kerzner continuum are considered to be consistent with the Convention because all of its levels involve supported, rather than substituted, decision-making, the centrality of will and preference, disability-neutral assessments, and the discarding of all notions of 'legal incapacity' (as was discussed in the earlier section on legal capacity) (see for example Flynn & Arstein-Kerslake, 2014; Gooding et al., 2013; Richardson, 2012).

Douglass (2016) has proposed an alternative model for the New Zealand context, which proceeds on the premise that substituted decision-making is necessary in difficult cases. In Douglass' model practical support for decision-making is offered and provided, as much as is reasonable, on a continuum personalised to the disabled person. The model allows for substituted decision-making to be utilised as a last resort.

Flynn & Arstein-Kerslake (2014) have posed yet another alternative, the 'cognitive prosthesis model'. In this model, the support person is conceived of as a cognitive prosthesis; a mechanical tool for decision-making, which better enables disabled people to be full participants and express their interests (Flynn & Arstein-Kerslake, 2014). Authors argue that thinking of supported decision-making in this way is a means of understanding and promoting the supporter as an empowering and neutral party (Arstein-Kerslake, 2016).

Supported decision-making in practice

Despite the dearth of empirical research, that which is available has been very consistent in terms of its identification of the key elements of supported decision-making. These key elements include:

- *Positive relationships:* The importance of the supporter-supported relationship being based on trust, positive regard, and honest interaction has been universally highlighted (Browning et al, 2014; Devi, 2013; Glen, 2013; Keeling, 2016; Morrissey, 2012; McDaid & Delaney, 2010; Nunnolley, 2015; Pathare & Shields, 2012; Series, 2015; Stainton, 2015; Enabling Good Lives, n.d.; Gooding, 2015; Government of Alberta, 2010; Victorian Law Reform Commission, 2012; Watson, 2016a; Woudzia, 2016). Furthermore, decision-making relationships have been identified as optimal when they are ongoing, long-term, and stable (Carney, 2015b; Devi, 2013). For example, for persons with acquired disabilities, having knowledge of the person's previous life history assists supporters to transition into the supporter role and ensures that support is orientated toward the person's will and preference (Knox et al., 2016). Additionally, encouraging disabled people to make both small and large decisions, and showing interest in their choices has been identified as critical to facilitating and developing confidence and learning (Tracy, 2015). Some research has highlighted that disabled people's participation depends on the decision-making opportunities they have been presented with (Werner, 2012) and evidence also suggests that a person's decision-making ability and participation can improve when they are able to experience support with decision-making (Carney, 2015a).
- *Engagement:* Effective support involves the efficient engagement of the third parties around the supported person (Douglas et al., 2015). Collaboration between the disabled person and their supporters and between the supporters themselves is also important (Knox et al., 2016). Burgen (2016) provides evidence that this is not always easy in practice, which is discussed later.
- *Commitment:* The importance of the supporter(s) being committed to acquiring knowledge about the supported person, their disability, and the complexity of their will and preferences or decision-making processes and communication methods, even when it takes great effort has been recognised as being fundamental to supported decision-making (Burgen, 2016; Douglas et al. 2015; Stavert, 2015; Tracy, 2015; also see IHC Advocacy Toolkit). Commitment to both learning about the person and commitment to building a personal relationship are recognised as being of particular importance (Devi, 2013). It has also been suggested that persistence and commitment are significant to the process of realising the will and preferences of disabled people given that there can be many external and systemic challenges at play (Burgen, 2016).

- *Support principles*: The fundamental elements of individual and general practice in the process of assisting decision-making, that is, what makes assistance 'good', have been referred to as 'support principles' (Douglas et al. 2015). For example, it is proposed that self-awareness is important; supporters must be aware of values and biases they may bring to the process (Arstein-Kerslake, 2016; Douglas et al. 2015; Stainton, 2015; Tracy, 2015; Werner, 2012) in order that they are able to be responsive to and focused on the autonomy, identity, and will and preferences of the supported person (Arstein-Kerslake, 2016; Douglas et al. 2015; Knox et al., 2016; Tracy, 2015; Watson, 2016a; Woudzia, 2016). The latter involves being centred on the person, respecting their choices, recognising their rights to make decisions, and recognising that their ability to participate in specific decisions may vary (Tracy, 2015).
- *Strategy and Communication*: Supporters have been identified as needing a range of strategies on-hand that are appropriate to the needs of the disabled person in order to adapt to different circumstances and personalise their support quickly and effectively (Douglas et al. 2015; Knox et al., 2016; IHC, 2016). It is acknowledged that, 'good' support involves supporters listening well to various communication strategies (Arstein-Kerslake, 2014; Carney & Beaupert, 2013; Tracy, 2015; also see Watson, 2016a) and involves employing strategies to effectively communicate information and issues relevant to the decision-making to the person involved (Carney & Beaupert, 2013).
- *Consent*: Consent is recognised as being important to support and realising the will and preferences of disabled people (Flynn & Arstein-Kerslake, 2014; Morrissey, 2012; Nilsson, 2012). Some people do not want support and support mechanisms because, even when well-intentioned, they can conflict with a disabled person's will and preference (Carney & Beaupert, 2013; Carney 2014b).

Specifically, in providing direct support to exercise legal capacity, notable scholars Flynn & Arstein-Kerslake (2014) propose that supported decision-making should:

- Work on the strengths of the individual.
- Approach the supported person with an attitude of identifying what supports are necessary to enable a person to exercise capacity rather than approaching them to assess whether they *have* legal capacity.

The literature also points to the ways in which both support persons (both professionals and family and friends) can assist a person to execute their legal agency. Key elements include:

- Providing sufficient, accessible information (also noted in Carney & Beaupert, 2013; Devi, 2013; Keeling, 2016; McDaid & Delaney, 2010; Watson, 2016a).
- Reminding the person of the information and reiterating previous information when required (Devi, 2013).

- Helping the person understand the consequences and risks of a decision (Devi, 2013).
- Using methods of communication that are appropriate to the person (Carney & Beaupert, 2013; Keeling, 2016; Auckland Disability Law, n.d.).
- Making the person feel at ease (Keeling, 2016). Further, McDaid & Delaney (2010) highlight the specific need to show empathy to people in emotional distress.
- Communicating the person's will and preference to others (Keeling, 2016) and recognising their personal communication styles and strategies (Tracy, 2015; Wade, 2016; Watson, 2016a).
- Utilising the skills of others to aid the process of communication and understanding. For example, engaging family or sign language interpreters or others who can assist with communication (Keeling, 2016; Wade, 2016).
- Recognising and respecting people's different decision-making processes. Including allowing sufficient time (Carney & Beaupert, 2013; Devi, 2013; Keeling, 2016; McDaid & Delaney, 2010; Auckland Disability Law, n.d.) and recognising and supporting the value of close, trusting relationships and their potential role in decision-making (also see Auckland Disability Law, n.d.; Keeling, 2016).

Where is supported decision-making practiced and by whom?

Formal supported decision-making initiatives

Formal support with decision-making could be provided through private appointment according to the needs of the individual or by means of a tribunal, court, or centre that specialises in providing support (Bach & Kerzner, 2010; Carney & Beaupert, 2013; Carney, 2013; Devi, 2013).⁴⁹ In British Columbia, for example, courts can formally appoint someone already close to the disabled person by means of an administrative tribunal upon an application, including an application from the disabled person themselves (Devi, 2013). In Scotland, formal and funded support can be provided by means of independent advocates who can visit on request (Stavert, 2016; The Scottish Government, 2013). Some evidence suggests that independent advocates can have an advantage in roles intended to support decision-making due to the fact that they do not come to the supporter role with ingrained assumptions about the person and they do not have a personal stake in the choices a person might have (Burgen, 2016).

⁴⁹ This section on formal supported decision-making initiatives also discusses how people access support, which is in relation to Question 3, "How do disabled people access support for exercising their legal capacity?"

Sweden's PO Skåne programme has been a frequently recommended model in the literature and by the European Commissioner for Human Rights (Gooding, 2013; Gooding, 2015; Mental Disability Advocacy Center, n.d.). In Sweden, a mentor (who can be someone close to the disabled person) is appointed through the court system with the consent of the person to assist their legal capacity (Devi et al., 2011; Morrissey, 2012). This is described as an advocacy arrangement (Gooding, 2015). Requesting these services is informal, fast and free (Devi et al., 2011). Services are flexible so that they can be available 24/7 if required (Mental Disability Advocacy Center, n.d.). The disabled person retains full legal capacity when employing this assistance and the disabled person can withdraw consent to the relationship according to their will and preference (Devi et al., 2011). The programme is run by an independent NGO (Mental Disability Advocacy Center, n.d.).

The program has contributed to meaningful positive results for decision-making and reductions in psychiatric symptoms, including a reduced need for crisis interventions (Series, 2015).

The Representation Agreement Act in [British Columbia, Canada](#), is an example of a formal, statutorily recognised supported decision-making initiative (Devi et al., 2011; Series et al., 2014; Watson, 2016a). Under the Representation Agreement (RA) process, a disabled person can enter into a contractual agreement with a trusted person who is appointed to represent them, their will, and preferences and to help them exercise their legal capacity (Devi et al., 2011; Series, 2015; Series et al., 2014; Watson, 2016a). This may be by means of explaining information or expressing the person's interests to others or making decisions for the disabled person at their direction (Devi et al. 2011; Gooding, 2013; Morrissey, 2012). Legal capacity is assumed (Pathare & Shields, 2012; Morrissey, 2012).

To date, supported decision-making under the Representation Agreement initiative can be implemented for decisions regarding healthcare, personal care, legal matters, and financial matters (Pathare & Shields, 2012; Stainton, 2015). A disabled person can have multiple representatives for different areas of their lives (Pathare & Shields, 2012; Stainton, 2015). There is no test for capacity unless the decision is restricted from a representative's scope under the Act, for example ECT and abortion decisions and refusals of treatment require a level of capacity from the supported person so that a representative can make decisions with regard to those (Stainton, 2015). Although the process is formal, it is inexpensive and relatively straightforward to establish (Stainton, 2015). This initiative has not been evaluated (Watson, 2016a).

The parliament of [Victoria, Australia](#), has made provisions for a publicly-funded support scheme in their legislative change, The Mental Health Bill 2014 (Department of Health, 2014). Currently, the 'Advocates' support scheme is only for persons already receiving public mental health service. Therefore is not available to all disabled people who may need support with decision-making.

In [Saskatchewan, Canada](#), a co-decision-making initiative has been implemented for financial decision-making (Victorian Law Reform Commission, 2012). However, co-decision-making arrangements are established by the court rather than by personal appointment and the consent of the disabled person is not required.

Another option for formally supporting disabled persons is through advocacy initiatives, as has been implemented in Scotland (see Flynn, 2010; SIAA, n.d.). Advocacy can take the form of representative advocacy (issue-based, citizen, peer and collective), systemic advocacy, and self-advocacy. Issue-based, citizen, and peer advocacy are person-to-person approaches (SIAA, n.d.). For example: issue-based advocacy can be paid or unpaid and short-term or long-term support undertaken by a professional; citizen advocacy is where a citizen supports a person (unpaid); and peer advocacy is where someone advocates for a disabled person on the basis of their having a shared interest (SIAA, n.d.). In comparison, collective advocacy is where a group of people come together on the basis of having a shared interest and work to represent that interest collectively. Systemic advocacy involves a process whereby persons advocate for systemic reform to lessen societal-level issues that have adverse impacts on disabled persons and their rights, and to promote positive reform (Flynn, 2010); it seeks to empower disabled people. Generally, advocacy is a means of better enabling disabled peoples' access to support services (Flynn, 2010). Therefore, all forms of advocacy serve to empower and encourage self-advocacy (Flynn, 2010; SIAA, n.d.). All advocacy has the purpose of helping disabled people have their will and preferences heard (SIAA, n.d.) or decision-making supported (Stavert, 2015).

The state of [Victoria, Australia](#) has recently started a support scheme whereby advocates are able to provide decision-making support over the telephone or in person. The scope of their support entails providing advice, providing information, and aiding disabled persons' understanding about their rights (Department of Health, 2014).

In [Australia](#), Disabled Persons' Organisations (DPOs) engage in systemic advocacy and mostly rely on government funding for their activities (Kayess et al. 2014). However, tensions can arise when DPOs target government policies and initiatives while receiving government funding.

In [British Columbia, Canada](#), a resource centre has been established to provide people with resources and training freely or inexpensively, entitled The Nidus Personal Planning Resource Centre and Registry (Stainton, 2016; refer to Additional Resources section). The resources have a focus on assisting disabled people to get information about and gain access to support.

In [Quebec, Canada](#), committees serve to assist people to engage in self-advocacy but also address systemic issues with service providers (Carney, 2013).

Informal support networks

Supported decision-making is often discussed in the literature as primarily being utilised in formal healthcare and finance settings but supported decision-making is also significant to all people and all aspects of life (see Allen & Tulich, 2015; Chan et al., 2012; Flynn, 2010; Smaill, 2016; Darvell, 2016). The literature argues that informal and everyday support is significant and meaningful for disabled people in their expressions of agency throughout their lives (see Burgen, 2016; Carney, 2013; Stainton, 2015; Tracy, 2015). Similar to the formal initiatives outlined above, the literature suggests that family, peer groups, support networks, and others who are close to the disabled person can provide informal support by explaining information to the person and by assisting the disabled person express their interests to others, especially to those in positions of authority (Carney & Beaupert, 2013; Devi et al., 2011; Gooding, 2015).

Watson (2013a) emphasised that informal supporters must be:

- Able to see things from the perspective of the disabled person, and;
- Familiar with the disabled person's expressions of agency and communicative method.

For example, family and close friends can support a disabled person's financial decision-making by helping with more technical aspects of navigating money and banking, such as setting up automatic payments and pin numbers (Enabling Good Lives, n.d.). Gooding (2015), however, makes an important note that family and peers should not replace states parties' efforts to provide support to disabled people.

Circles of support is a longstanding approach to supporting disabled people, which has regained currency in the new era of the Convention and particularly in relation to Article 12. A 'circle of support' refers to an arrangement whereby multiple people work together to form a circle of support in which they work collaboratively to optimise the decision-making process of a disabled person (Devi, 2013; Watson, 2016a; Werner & Chabany, 2015). Those who are close to the disabled person (family and friends) can form a circle of support (Carney, 2013; Watson 2013; Watson, 2016a; refer to Additional Resources for guides and manuals relating to circles of support). A formal form of this type of support is where it is a legally recognised organisation of people, such as a microboard (Watson, 2016a). Circles of support have been developed in Canada and Australia to support disabled people to make decisions (see Werner & Chabany, 2015).

Circles Network, [UK](#), has been implementing circles of support, where people meet on a regular basis to

provide support to a disabled person (Mental Disability Advocacy Center, n.d.). There is a 'focus person' directing the support provided and facilitating the provision of support. The Circles Network is a voluntary organisation.

British Columbia, Canada, has been implementing the Microboard model since the 1990s (Stainton, 2015). In this initiative a small group of at least five people (who are close to the disabled person) set up a Board that supports decision-making, advocates, and connects the disabled person to their community (Stainton, 2015). It is very similar to a circle of support but is a formally and legally recognised organisation (Watson, 2016a). The disabled person retains their capacity (Stainton, 2015). This particular model has been criticised for focusing too much on funding and managing and not enough on providing advice to support the disabled person (Nunnelley, 2015).

Alberta, Canada, has implemented a co-decision-making scheme, in which the disabled person and their supporter collaborate to arrive at decisions but the disabled person retains legal capacity and participation in decision-making (Pathare & Shields, 2012). Co-decision-making arrangements are available through the court, proceeding on the consent of the supported person (Victorian Law Reform Commission, 2012). A co-decision-maker cannot make decisions on behalf of the patient but the scheme formally recognises the authority of a person to help make decisions with a disabled person. Usually a family member or close friend occupies the role of co-decision-maker. Currently, the co-decision-making scope does not include financial decisions (Government of Alberta, 2010).

Systemic and organisation level support for decision-making

Organisations and state services have been identified as being able to support decision-making by providing resources in accessible formats about planning (advanced care planning and financial planning), decision-making, mechanisms through which disabled persons can communicate, such as templates for communication passports (see Carney & Beaupert, 2013; Keeling, 2016). To ensure that content is accessible, resources need to be presented in diverse ways using for example, pictures, signs, braille, and Makaton symbols (Keeling, 2016). Organisations and state services are required to respect disabled persons' personal communicative methods and offer the support they may require for full participation, including for example when they give evidence in legal settings (Wade, 2016). The necessity of these systemic and organisational changes in practice and policy will be further examined in the later section on reasonable accommodation.

The Convention promotes an increase in the resources and capacity available to disabled persons' organisations so that they can progress more advanced advocacy initiatives and monitoring processes (Gooding, 2015). As is argued in Lang et al. (2011) and highlighted by DPOs in Scotland (SIAA, 2016), disabled

persons' organisations are over-worked and under-resourced in addition to often being excluded from key policy decision-making processes.

Self-advocacy

Some supported decision-making researchers have recommended providing training to disabled people so that they can more effectively and confidently pursue their will and preferences (Werner, 2016). For example Morris (2015) explored how disabled people could be assisted to develop financial literacy. Kayess et al. (2014) highlighted the importance of self-advocacy in empowering disabled people to have their views and opinions heard. In doing so, Kayess et al. (2014) contend that the way in which systems contribute to the complex marginalisation of disabled people can be exposed. As Burgen (2016) discusses, disabled people are often not familiar with being granted agency, which reinforces preconceived ideas about their abilities, and also reinforces their own fears about decision-making processes, and exacerbates learned behaviours of dependency. Learned behaviours of dependency encourage disabled persons to take passive roles in decision-making (McDaid & Delaney, 2011). Support that encourages self-advocacy has been shown to challenge these (Burgen, 2016).

It is suggested that self-advocacy can be encouraged by increasing the frequency of disabled people's involvement in new experiences or decisions so as to gain familiarity with such processes (Burgen, 2016; Tracy, 2015). Additionally, person-centred planning and care planning are proposed as mechanisms by which support can be provided (Browning et al., 2014; Devi, 2013). However, as noted in the previous section on structural support and following section on reasonable accommodation, changing the barriers, obstacles, and discrimination disabled persons experience ultimately lies in changing society itself and changing how third parties shift from occupying the role of substitute decision-maker to supporter (as discussed in conceptualising the 'social model' in O'Mahony, 2012; Mental Disability Advocacy Center, n.d.; Richardson, 2012; Umeasiegbu, 2013).

An example of decision-making training for disabled people can be seen in a mental health initiative, which utilises advocates, in [Victoria, Australia](#). Advocates serve to assist disabled people generally but also provide and explain disabled peoples' rights to decision-making participation (Department of Health, 2014). Overall, advocates are purposed to offer advice but also empower disabled persons and help them develop self-advocacy skills (also see Flynn 2010 for more on advocacy).

[Scotland](#) has set up a free and independent advocacy initiative that serves to support people in expressing their will and preference and to participate in decision-making (Pathare & Shields, 2012; Scotland et al., 2013). The initiative is entitled "the Scottish Independent Advocacy Alliance (SIAA)". Advocates are purposed to ensure that persons are treated fairly by others, encourage empowerment and self-advocacy, and to increase

the decision-making abilities of disabled people (Scotland et al., 2013). Support is not provided according to a template; all support is personalised according to what the person wants and needs. SIAA works to provide advocacy support to anyone in Scotland.

England & Wales made provisions for supported decision-making within the Mental Capacity Act (2005), referred to as 'independent mental capacity advocates' (IMCA) service. IMCAs advocate on behalf of a disabled person to support the expression of their will and preference and assist in the decision-making process.

Key elements of the supporter role

Understanding will and preference

As Watson (2016a) argues, understanding a person's will and preferences can be a complex process. More technical means of support may need to be employed to ascertain will and preferences, to relay information related to a decision, and to support their decision-making. This section examines what support could look like with regard to decision-making processes or expressive and receptive communication. There are many means by which communication and decision-making can be aided.

Some key means and mechanisms suggested in the literature for the supporting role includes:

- Information in accessible formats.
- Assistive technology.
- Other means, such as Talking Mats and Communication Passports.
- Advance care planning.

Communicative support

Earlier in this section, broad and well-understood strategies to support communication within decision-making were identified and included pictures, signs, or Makaton symbols (Keeling, 2016), braille, and large font (Auckland Disability Law, n.d.). At a more sophisticated level, it has also been noted that assistive technology is an important – but often neglected – means of providing support (Gooding et al., 2015). Technology-based communication supplements can include augmentative systems, which add to or assist existing speech or communication, and alternative systems, which provide another means of communicating (Smail, 2016). They include: voice recognition programs, screen readers, screen enlargement, online portals, text-to-speech/speech generating devices, apps, and cognitive assistance that facilitates communication (see

Gooding et al., 2015; Smaill, 2015). Even functional magnetic resonance imaging is an option for persons in minimally conscious states (see Gooding et al., 2015).

Other low-tech means of support can be utilised for the purpose of facilitating communication, including: communication boards, visual schedule boards, and rating scales (see Smaill, 2016). This also includes utilising a diverse range of non-conventional communication methods as is suitable for the person (Keeling, 2016).

Assistive technology can be useful for conveying messages in contexts where people are not familiar with a disabled person's personal communicative method (Gooding et al., 2015).

Communication Passports

Watson (2016) and Smaill (2016) both discuss communication passports as an explanatory and interpretative aid for supporters who do not know the disabled person closely enough to understand their expressions of agency. Communication passports are a documentation of a person's communicative behaviours that provide others with an understanding of how a person conveys their individual likes and dislikes (Watson, 2016a). People close to the disabled person document the information in a communication passport by observing and analysing a disabled person's behavioural and communicative cues and then translate that information into a physical or digital format for other people (Watson, 2016a). It is particularly useful for disabled people who do not communicate conventionally or intentionally, such as people with 'severe and profound' disabilities (Smaill, 2016; Watson, 2016a). A barrier to the widespread adoption of communication passports has been identified as the demand on the resources and time required to gain the level of information about a person that makes the passport meaningful in a communicative and decision-making context (see Watson, 2016a).

Direct preference assessments

For people with severe and profound disabilities, evidence suggests that direct preference assessments can improve the expressions of agency of disabled people to reliably express likes and dislikes (Watson, 2016a). Another technique that is increasingly being employed in the context of the United Kingdom and the Netherlands is Multisensory Story Telling (Watson, 2016a). This approach involves the creation of, a personalised story which is read to the disabled person to assess any reactionary patterns the person has in response to the story. These reactionary patterns are taken to indicate interests, likes, and dislikes.

Advance directives

Advance directives or advance statements are also means for a person to express will and preference and act as a legal agent in advance of circumstances where they are not able to do so (see Moorhead et al., 2016; Pathare & Shields, 2012; Stavert, 2015). Specifically, non-binding advance directives are a good option for people to express their will and preferences (see Carney, 2015b; Keeling, 2016). Non-binding advance directives enable a person to record their interests and values while allowing flexibility according to emerging changes in circumstance. Support for advanced planning is explicitly encouraged as an important form of

support in the literature and the General Comment (General Comment No. 1, 2014; Stavert, 2015). However, advance directives have been noted as having some challenges to overcome in practice; specifically about the potential for others to override them, and the fact that not many people are provided with the opportunity to develop one (Stavert, 2015).

In a pilot project in [South Australia](#), disabled people made written support agreements to describe areas where support would be wanted and what types of support would be needed (Office of the Public Advocate, 2011; Series et al., 2014). This is particularly useful for people with intellectual disabilities, acquired brain injuries, and neurological diseases (as noted in Series, 2015).

Decision-making support

Decision-making support can be employed to assist many different stages of a person's decision-making process. First, it can be useful to identify the components of the decision-making process that can be aided. Some of these stages include: "1) framing of the situation; 2) generating possible alternative solutions; 3) evaluating potential consequences associated with each alternative; and 4) selecting a decision response" (Werner, 2012, p. 17-18). Werner (2012) notes that visual aids can improve decision-making ability and weighing processes, including in everyday settings. Visual aids can also be digitised.

Talking mats have been discussed in the literature as being both a communicative and decision-making aid (see Smail, 2016; Watson, 2016a; Werner, 2012). It has been proposed that Talking Mats enable the expression of choice (Smail, 2016; Werner, 2012) but also that they enable disabled people to understand the different factors related to a decision (Smail, 2016).

This section of Part Two examined that which has been signalled in the literature and implemented in other jurisdictions with regard to where, how, and by whom supported decision-making can be realised. The following sections explore other aspects of supported decision-making: reasonable accommodation as a necessary practice within the framework, impacts on disabled people, and safeguards and issues for the framework.

Reasonable accommodation and will and preference

This section explores the discourse on reasonable accommodation and support for disabled people's exercise of legal capacity and in doing so is intended to address Question 10. *Reasonable accommodation* is any modification, change or alteration at the system-level intended to specifically address a disabled person's needs (New Zealand Human Rights Commission et al., 2015; Bach & Kerzner, 2010; Browning et al., 2014; Byrnes et al., 2007). Accommodations serve to create an 'enabling environment' (Perlin, 2013), that is, it serves to optimise the disabled person's decision-making process and participation in decision-making (Kerzner, 2011). The provision is set out under Article 2 of the Convention, defining a 'reasonable accommodation' as:

- necessary and appropriate modification and adjustments;
- not imposing a disproportionate or undue burden;
- where needed in a particular case;
- ensuring to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

Kerzner (2011) argues that communication and decision-making assistance also falls under the purview of accommodating for disabled people. It means that states parties such as New Zealand, and the private sector, must facilitate access to support and make provisions for a wide range of supports to suit people's diverse needs (see Arstein-Kerslake, 2014; Bach & Kerzner, 2010; Byrnes et al., 2007; Kerzner, 2011). According to the Handbook for Parliamentarians (Byrnes et al., 2007), reasonable accommodation is seen as a necessary step towards giving effect to protecting the rights of disabled people, including the right to equal recognition under law in Article 12, and safeguarding against mistreatment and abuse (also see Nilsson, 2012). Lang et al. (2011) and WNUSP (2008) argue that disabled people and DPOs need to be included in implementing the supported decision-making framework and initiatives for reasonable accommodation.

Spain made provisions to recognise reasonable accommodation within its legal framework. In The Equal Opportunities Law 51/2003 defines it as "the necessary measures in order to adapt the physical and social environment and the behaviour patterns to the special needs of the persons with disability, which, effectively and practically and not implying a disproportionate burden, facilitate the accessibility and participation of the persons with disability upon equal conditions as the other citizens"

Impacts of supported decision-making in practice

Pilot programs and empirical research into support and supported decision-making are currently lacking (Gooding, 2015) and more research is needed to assess how supported decision-making measures can meet their objectives (Douglass, 2016). As at 2014, Browning et al. (2014) and Kohn & Blumenthal (2014) reported finding no evidence of the impact supported decision-making could have on disabled persons exercising legal agency. Yet, Jameson et al. (2015) claimed that there was an 'extensive' amount of literature on the positive effects of supported decision-making. However, this issue is not solely isolated to the supported decision-making model; few studies have interrogated the impact of substituted decision-making, including guardianship and provisions for best interest measures (Gooding, 2015; Kohn et al., 2013). As the literature notes, the lack of strong, empirical evidence continues to remain a challenge to the implementation of robust policy and law reforms (Gooding, 2015).

There is, however, a substantial amount of evidence that highlights the positive effect that greater self-determination has on disabled persons (Watson, 2016a; Jameson et al., 2015). On the basis that supported decision-making seeks to better enable disabled persons to execute their self-determination, it is inferred that supported decision-making should generate these positive results (see Jameson et al., 2015).

Studies or pilot programmes have been recently implemented in Australia to gather more data on support and supported decision-making. The Victorian Office of the Public Advocate conducted one of these studies, particularly focusing on people who were socially isolated (Burgen, 2016). The study found that support and advocacy volunteers had a positive impact in assisting disabled persons to become more confident in decision-making, more engaged with participating in decision-making processes, and more engaged in self-advocacy. Durand et al. (2014), explored the impact of shared decision-making (collaborative decision-making to promote participation in processes) amongst disadvantaged groups generally, and found that there were significant positive outcomes, including increased self-advocacy and engagement in decision-making.

South Australia has implemented a pilot programme based on a non-statutory model (De Mestre, 2014). The programme focused on a single support-person approach based on a support agreement. Although the Victorian Office of the Public Advocate found that the agreements were often not needed (Burgen, 2016), this pilot in South Australia found that the agreement gave disabled people a sense of formal approval for their

participation in decision-making (De Mestre, 2014). In this sense, it was identified as empowering for disabled people.

Pathare & Shields (2012) also found that professionals were able to facilitate greater participation of disabled persons in decision-making processes as a result of supporting decision-making. Additionally, disabled persons themselves engaged in greater self-advocacy.

However, as noted elsewhere in this report, further research needs to be undertaken to provide insight into supported decision-making and its process and results (Douglass, 2016; Kohn & Blumenthal, 2014; IHC, 2016; Jameson et al., 2015). This includes exploring the extent to which supported decision-making provisions achieve their intended goals in relation to Article 12 of the Convention.

Therapeutic evidence

This section examines the available evidence on the impact of increased support on decision-making (Question 12) and of initiatives on supported decision-making (Question 16) and how the literature answers these questions.

Positive results have been reported for [Finland's](#) Open Dialogues model, which is employed generally as a means of support and employed in cases of extreme distress (Gooding, 2013). The model involves a process whereby the disabled person, their family and other people in their close social network provide a forum in which discussion takes place about options and concerns (Morrissey, 2012). The evidence with regard to persons with psychosis shows that they spent fewer days hospitalised, experienced fewer symptoms of psychosis, and lessened their use of neuroleptic medication as a result of their involvement in the open dialogues model (Gooding, 2013). Morrissey (2012) also looks at other evidence that suggests personal support (rather than solely medical support) best improves a person's medical decision-making.

Further evidence suggests that employing substituted decision-making in extremely difficult cases can have negative consequences for disabled people (see for example Chan, 2016; Callaghan & Ryan, 2014). As previously discussed, in cases where individuals exhibit behaviours of concern (are dangerous to themselves or others), evidence shows that they are often accommodated in closed environments under current practice (Chan, 2016). This includes being placed in residential institutions and detention centres. Chan (2016) suggests that this can exacerbate mental distress and concerning behaviours, and promote and entrench the factors that cause them. In short, Chan suggests that involuntary detention and treatment can sustain the challenges posed within these 'extremely difficult cases' rather than improve or alleviate them. Callaghan & Ryan (2014) raised concern with hospitalisation, including persons being subjected to violence in psychiatric wards and the potential for suicidal feelings to be increased. This supports the argument made by Arstein-

Kerslake and Flynn (2015): that, rather than protecting disabled persons by means of denying them legal agency, persons can be protected through empowerment.²⁰ Evidence that substituted decision-making can be a more harmful option provides another reason for the shift away from substituted decision-making for those in the literature that were not convinced of the viability of the rights-based approach.

²⁰ This argument also relates to Question 5, "How are the rights for promoting a disabled person's autonomy versus safeguards for their protection and safety being balanced?"

Realising will and preference adequately and safely

Real connection with will and preference

This section pertains to discussion in the literature around how far supported decision-making can be applied before it loses real or practical connection with a disabled person's will and preference (Question 18, Appendix A). On one side of the discussion it is argued that, regardless of the implementation of a supported decision-making framework, there will be cases where a disabled person's will and preferences cannot be obtained (Gooding, 2015). Furthermore, it is also argued by some that we can never know the mind of another person and accurately read communicative styles and behavioural cues (as examined by Carney, 2015b). In this sense, these questions give rise to the perception that supported decision-making loses real connection with a person's will and preferences when extensive interpretation is required and/or when a person has not explicitly provided their will and preferences in advance or cannot do so in their current state (for example, when they are in a minimally conscious state). However, the General Comment takes the position that a person's legal capacity and will and preferences must be respected even in times of crisis (Gooding, 2015).

On the other side of this argument, commentators have contended that supported decision-making loses real connection with a disabled person's will and preference when will and preference is no longer the determining and central factor (as is highlighted in Arstein-Kerslake, 2016; Arstein-Kerslake & Flynn, 2015; Douglas et al. 2015; Flynn & Arstein-Kerslake, 2014; Knox et al., 2016; Stavert, 2016; Tracy, 2015; Watson, 2016a). With regard to this opinion, it is argued that every human person has the ability to express their will and preferences (Watson, 2016a), and therefore supporters must make effort to discover these even when doing so requires great effort (see Allen & Tulich, 2015; Flynn & Arstein-Kerslake, 2014). Allen & Tulich (2015), Gooding (2015) and Series et al. (2014) describe this process as proceeding on the 'best interpretation' of the person's will and preference had they been able to exercise their legal agency. Recognising that all people communicate in some way involves adopting an inclusive view of communication, which recognises the diverse range of communicative means people may use (Watson, 2016a). It also involves recognition that communication is an interdependent process. This includes body language facial expression and gesture (Watson, 2016a). The position held by this literature argues that 'real connection' with a person's will and

preference is not lost if *real* effort is made to ascertain them. For example, supporters can gather information from the person themselves by being responsive to a person's complex communicative means or by referring to those who know the person well (Flynn & Arstein-Kerslake, 2014). In the practice of substitute decision-making, a disabled person's will and preference is not the determining and central factor, even if they are taken into consideration. In the Convention era, safeguards need to be implemented in a manner that prioritises real connection with the will and preferences of disabled persons.

Recognition and /or safeguards for the disabled person

This section is concerned with Question 8, specifically the safeguards required for disabled people exercising their legal capacity. Further and more in-depth research is required in order to identify and understand the challenges that disabled people still face in the context of supported decision-making (Gooding, 2015; Lang et al., 2011). As noted above, the challenge presented to states parties to the Convention is implementing safeguards that find the right balance between freedom for and protection of disabled people but also serve to realise the will and preferences of those same individuals (Arstein-Kerslake and Flynn, 2015; Gooding, 2015).

It has been suggested that safeguards could take the form of: robust means of addressing exploitation of disabled persons; dispute-resolving procedures in circumstances where 'best interpretations' of a disabled person's will and preference conflict (Gooding, 2015); monitoring of human rights abuses; availability of financial resources; and evaluations of supported decision-making policies and programmes (Lang et al., 2011). In discarding the notion of incapacity, as is required under a radical interpretation of the Convention, a person can never be denied legal agency under law as a means to safeguarding their welfare (Bartlett, 2012). Ultimately, safeguards must serve to protect and ensure respect for disabled persons rights to legal capacity (General Comment No. 1).

Perceptions of disability

Most frequently noted is that perceptions of disability held by supporters, professionals, and/or society are significant to the participation of disabled people and the realisation of Article 12 (Chan, 2016; Smaill 2016; Watson, 2016a; Watson, 2016b).²¹ Upon the status of having an intellectual disability, for example, people are

²¹ This section highlights that perceptions of disabled people by society have yet to change in a significant way, and therefore most authors agree that little change in treatment has occurred to date. This relates to

often assumed to be incapable of decision-making, along with other negative perceptions (Dorozenko et al., 2016). Negative perceptions of disability affect how disabled persons are treated, and thus supporters' perceptions can negatively impact support (Chan, 2016; Watson, 2016a). Perceptions of disability remain an obstacle to disabled persons' opportunities for and participation in decision-making (Chan, 2016; Dorozenko et al., 2016; Watson, 2016a; Watson, 2016b). For example, social perceptions about whether disabled people should be exerting sexual agency impacts a person's ability and opportunity to make sexual and reproductive choices (Werner, 2012). Related to this issue is the common perception that disabled people occupy a state of permanent non-adulthood, and thus their interests and behaviours should be childish or non-adult accordingly (Dorozenko et al., 2016). There is also a tendency for people to be more interventionist on the basis of assumptions and low expectations of disabled people's decision-making ability (Jameson et al., 2015). In addition, perceptions of a disabled person's decision-making ability affect the *opportunities* offered for decision-making, and thus the choices made (Watson, 2016a). Further, supporters and others are more likely to have more significant negative perceptions of disabled persons with severe or profound disability, which in turn more significantly effects how they are treated and supported (Watson, 2016a).

Werner et al. (2013) for example, provide evidence of psychiatrists holding negative attitudes and perceptions of disabled people, including a reluctance to be involved in their care. Similarly, McSherry & Wilson (2011) provide evidence that professionals in New Zealand and Australia have the perception that human rights approaches were a waste of resources and too demanding on professional time. Pathare & Shields (2012) found that psychiatrists can find supported decision-making processes stressful and perceive disabled persons as difficult to treat. IHC (n.d.) describes some of the negative perceptions encountered in the New Zealand context, including seeing disabled people as an 'other' and/or a burden. Werner (2012) explores the evidence that perceptions impact on disabled people's participation in the job market and how their employment choices are impacted by societal bias rather than their will and preference. Subsequently, Werner et al. (2013) argue that provisions need to be made for improving the perceptions of professionals so to better enable the participation of disabled people in decision-making, as is in the spirit of the Convention. It is argued that perceptions need to shift at the level of practice to perceiving disability through the social model and having an increased awareness of the obstacles and forms of discrimination disabled people face (Umeasiegbu, 2013). Further, Chan (2016) and Stein & Lord (2008) caution that negative perceptions are particularly reinforced in language and the media. If states parties have an obligation to optimise the participation of disabled people in decision-making and society, then this caution could serve as a suggestion for jurisdictions to address the perceptions reproduced in the media and encourage society to employ the use of more respectful language.

Question 4, "Have there been any changes in the treatment, by society, of disabled people exercising their legal capacity?"

When these perceptions are not addressed, there is potential for the lack of willingness to participate in the implementation of supported decision-making initiatives and instead continue exercising paternalistic measures (Lang et al., 2011; Watson, 2016a; Werner, 2012). It is signalled that the perceptions of the disabled person themselves are important too; it is important that the person feels supported and encouraged and confident in decision-making (Pathare & Shields, 2012; Tracy, 2015).

In its support initiative, [Scotland](#) promotes the idea that disabled persons are not an 'other' but are just like everyone else (Scotland et al., 2013). Scotland recognises decision-making as being relational and common practice in all persons' lives, thus normalising the idea of support for decision-making. There is little information on how initiatives promote these ideas in the practice and training of supported decision-making.

Unresponsiveness, resources, and support

Allowing time for decision-making and communication was frequently mentioned as an important part of how third parties can contribute to supported decision-making (Carney & Beaupert, 2013; Carney, 2013; Keeling, 2016; Smaill, 2016; Tracy, 2015; Watson, 2016a). However, as noted by Watson (2016a), those who provide direct support may find the resources required to provide substantial support too demanding for the skill and time they have available. It is implied that, due to resource, situational and/or time constraints, the most effective means of support may have to be compromised for a more practical and workable option based on supporters' abilities to commit (as mentioned in Tracy, 2015 and implied in Watson, 2016a).

Generally, it is signalled that individuals who deal with disabled people in formal settings need greater skill in communicating with disabled persons, developing a sense of trust, and in responding to the needs of disabled persons (Pathare & Shields, 2012). However, place and time can compromise professionals' abilities to use these skills (Pathare & Shields, 2012; also see Tracy, 2015), as is discussed in the later section on support for supporters.

In [Scotland](#), an independent advocate serves both as a supporter who commits their time and resources to the disabled person and as a safeguard; advocates are purposed to ensure disabled persons are being heard by others and are not being excluded from participating in decision-making processes (Scotland et al., 2013).

Obtaining will and preference

As noted earlier, interpreting disabled persons and obtaining their will and preferences can be a very complex process (Watson, 2016a). In supported decision-making processes, including facilitated decision-making, a person's expressions of agency and will and preferences can be misinterpreted (Series, 2015). First of all, expressions of preference can go unnoticed, for example they may be misinterpreted as meaningless expressions rather than meaningful expressions (Watson, 2016a). Secondly, there is the process of

interpreting those expressions and then, thirdly, interpreting as to how the disabled person's agency can be executed in practice (Watson, 2016a). The process is extremely subjective and can require a lot of intuition to understand the disabled person. Evidence suggests that paid supporters can be better at distinguishing between different expressions of agency (Watson, 2016a). As Watson (2016a) notes, the issues in obtaining will and preference can be more of an obstacle for people with severe and profound disability because they are not able to contradict a wrong interpretation of their will and preference.

As is argued by Gooding (2015), disabled persons can be limited in their participation in decision-making which are 'natural' or socially engineered in nature. He argues that this distinction is important because it recognises that disabled persons' opportunities to participate in decision-making can be compromised by low expectations (previous section) or a lack of accommodation in systems (next section) or by people (this section). In taking a more inclusive view of capacity, it is possible to involve people in decision-making who would traditionally be considered to be unable to communicate and therefore to make decisions, such as people who are minimally conscious or those who have significant cognitive impairment (Gooding, 2015).

System and service issues

A study in Victoria, Australia with support and advocacy volunteers found that there were challenges when it came to interacting and collaborating with service providers (Burgin, 2016). The issues included: the dismissals (by staff and other professionals) of complaints and recommendations about accommodating for disabled people; the failure of staff and other professionals to follow through on responsibilities that were significant to the realisation of disabled peoples' will and preferences; the lack of engagement by staff and other professionals in decision-making processes; staff obstructing the realisation of disabled people in disagreement; a lack of willingness to participate in things that were beyond the 'routine' (Burgin, 2016). Additionally, Beadle-Brown (2015) notes how there is a cultural tendency to doubt disabled peoples' abilities to make decisions and thus a tendency to not provide support for disabled people. These system and cultural issues within service provision can be very difficult for a supporter or advocate to mitigate and highlights that the task of implementing good support can be a lot more complex than anticipated (Burgin, 2016). Additionally, disabled people can experience barriers in accessing the support or services they need, which can include issues with cost, transportation, and lack of time for appointments (Pathare & Shields, 2012).

Paternalism and Abuse

There is concern raised in the literature about whether support persons (who are often family members) can be fully trusted to help make decisions that are consistent with the will and preferences of the disabled person rather than conflating their own opinions and interests in the process (Arstein-Kerslake, 2016; Knox et al., 2016; Scotland et al., 2013; Stainton, 2015). Evidence shows that it is not uncommon for supporters to conflate their interests or value their own opinions and judgements above the supported person (see Tracy,

2015 and Werner 2012). Gooding (2015) argues that where decisions reflect the interests of the third party instead of the disabled person themselves, then decisions of this nature are a form of *de facto* substituted decision-making. It can be difficult for those who are not as close to the disabled person to distinguish between the interests and voice of the disabled person and the interests and voice of the supporter (Woudzia, 2016). Additionally, caregivers experience a professional and ethical responsibility to make the 'right' choice, which can compromise the extent to which they realise a person's will and preferences and support their participation (Watson, 2016a; Werner, 2012). For example, caregivers and support workers may have a 'duty of care' but, at the same time and under the Convention, supporters are encouraged to support the will and preferences and decision-making capacity of the disabled person (Dickey, 2016; Keeling, 2016; Series, 2015; Watson, 2016a). Thus, persons who support disabled people to make decisions find themselves having to negotiate between different obligations, which are sometimes in conflict with each other. As Watson (2016a) argues, this is an example of the support environment being set up in such a way that the exercise of legal capacity is compromised and paternalism is encouraged. There is some evidence that there is a tendency among supporters to comply with their duty of care over the supported person's will and preference (Watson, 2016a).

Furthermore, disabled people are often in high-dependency relationships which can subsequently result in an increased risk of control and coercion (Arstein-Kerslake, 2016). In addition, a support person is an individual with their own personality, interests, biases, and opinions (Knox et al., 2016; Series et al., 2014), not a mechanical tool as the 'cognitive prosthesis model' earlier might suggest (Arstein-Kerslake, 2016). Evidence suggests that, given these relationships of dependency, family can obstruct disabled people from accessing support (for example, by means of controlling the disabled person's finances) based on their own values and views about what the disabled person should be doing (Burgin, 2016). The role of supporter can place a large demand on a person because it requires that they: divorce their identity from the support they provide; be insightful into their own biases to avoid conflation; and be perceptive to the person's will and preferences and perceptive about the means to best facilitate the decision-making process (Arstein-Kerslake, 2016). It is proposed that it can be ensured that the relationship does not become abusive through:

- a. Supported decision-making training and providing both parties with adequate access to resources, training, and assistance so that parties are aware of how to engage in a relationship which does not involve abuse and domination.
- b. The disabled person being present or participating in all decision-making processes for the purposes of checking-in with them and providing the disabled person opportunities to respond to the support provided (Arstein-Kerslake, 2016; also see Flynn, 2010).

McSherry & Wilson (2011) argue that generally there has been little attention given by professionals to human rights and human rights instruments in mental health. This indicates that there is a practical issue to realising

the shift from paternalistic intervention to supported decision-making and the Convention that needs to be addressed.

Chan (2016) explores how accommodating for disabled persons in closed environments, such as detention centres, can heighten the vulnerability and risk of abuse for disabled persons. He implies that accommodating disabled persons in this manner needs to be avoided for the purposes of safeguarding patients from abuse and exploitation and for the purposes of complying with the 'will and preference' focus of the Convention.

IHC (2016) notes that abuse and neglect tend to be underreported and under-recognised, and thus that safeguards will have to be implemented to address this. Lang et al. (2015) similarly advocate for human rights abuses reporting mechanisms. Kohn & Blumenthal (2014) argue that there is a concerning lack of evidence about intrusion and coercion and their potential and prevalence.

Douglas et al. (2015) discuss issues in the context of [Australia](#) with regard to how supporters can consciously or unconsciously dominate the decisions being made in the support process. It is also noted that these supporters receive little guidance on how to most effectively provide support that is consistent with the will and preferences of the supported person, and further it is implied that this is related to the prevalence of supporter bias and domination (Douglas et al., 2015).

Similarly, [Sweden](#) has also made operational moves to strengthen and widen the availability and type of support (Watson, 2016a), including the implementation of a mentoring service. Such actions are important precursors to legislative change.

[British Columbia, Canada](#), has established a monitoring role which serves as a safeguard in a Representation Agreement (Nidus Personal Planning Resource Centre, 2012). A monitor can be appointed by the supported person to oversee the powers and duties of the representative, review information and records related to the disabled person's representation, co-ordinate multiple representatives, and review the continuation of the agreement itself by ensuring the RA complies with the disabled person's interests. They are independent from the representative. A monitor is usually necessary with regard to financial matters so to protect a supported person's financial dignity from potential abuse (Nidus Personal Planning Resource Centre, 2012). However, persons are encouraged to name a monitor wherever possible because doing so ensures an extra safeguard is in place to protect the disabled person from abuse (Pathare & Shields, 2012).

Similarly, it is important that safeguards are in place to avoid the over-regulation of the life of the disabled person (Arstein-Kerslake, 2016). Although the functional approach to testing capacity is employed in England and Wales, Byrnes et al. (2007), Keeling (2016), Kohn & Blumenthal (2014), and Picton & Elsmore (2009) raise concern about cases where paternalism is used to override a person's decisions on the basis of disability (i.e.

status) and deny them legal agency illegally. Similarly, some evidence suggests a culture that favours risk-avoidance and defensive practice over pursuing the will and preferences of a person (McDaid & Delaney, 2010), which compromises particular groups (such as disabled people) and their opportunities to exercise legal capacity (Watson, 2016a). Further, support for decision-making is not as strongly endorsed in health care in comparison to other environments in which disabled persons make decisions; paternalistic intervention is often favoured (Werner, 2012). It also appears that disabled people are not always involved in decision-making processes, often on the status approach (Keeling, 2016). It is argued that these policy-practice gaps serve to continue the stigmatisation of disabled persons and violation of their human dignity (Kohn & Blumenthal, 2014). There is a need to address these challenges in the policy-practice gap and to address the tendency for processes involving disabled people to be paternalistic in nature. Kohn & Blumenthal (2014) argue that the potential for paternalistic abuse likely increases with informal means of supported decision-making but also notes that there is a lack of empirical data on how abuse acts as a problem in supported decision-making processes. Carney & Beaupert (2013) take a similar position and argue that informal decision-making support ought to be prevented. However, the General Comment (General Comment No. 1, 2014) explicitly clarifies that the Convention promotes provisions of support in both informal and formal arrangements.

Overall, in all means of support, informal and formal, safeguards are needed to avoid the expansion of paternalistic intervention and powers of guardianship under the guise of 'supported decision-making'. As discussed, options available may include changing perceptions of disability so that perceptions change about their decision-making abilities and better supporting supporters so that they know more about supported decision-making as a viable alternative.

With regard to mental health initiatives, [Victoria, Australia](#), is setting up Independent Mental Health Tribunals to execute oversight into more restrictive interventions. The jurisdiction has also restricted the powers professionals and support persons have available to them under law in an effort to reduce the duration of restraint and seclusion interventions (Department of Health, 2014).

Lack of support network

Sometimes disabled people do not have a network or people close to them who can provide support (Stainton, 2015; Scotland et al., 2013). Some groups of disabled people tend to have smaller social networks and a limited amount of relationships (Watson, 2016a). Some people may be disconnected from their family or other social and support networks, as can be the case for people with acquired brain injuries (Knox et al., 2016). Persons with severe and profound intellectual disabilities also tend to have limited unpaid support (Watson, 2016a). Dickey (2016) describes an occurring trend where people are becoming more individualised or isolated in their social spheres or communities. Ultimately, reduced support networks present a challenge

to protecting and preserving people's decision-making ability. Relationship-building support may be needed for such people (Devi, 2012). Additionally, in addition to the literature's emphasis on the importance of close relationships (discussed earlier), evidence suggests that the presence of close relationships in a disabled person's support network are very valuable for the purposes of supporters being able to be appropriately responsive and better able to interpret a disabled person and their will and preference (see Watson, 2016a). However, paid support remains an option in cases where a disabled person lacks a support network. With regard to people with severe or profound intellectual disability, there is evidence that paid supporters may have more of a positive impact (Watson, 2016a). As Watson (2016a) notes, like unpaid family and friend support, paid support can also involve a relationship that is positive and close.

In [Canada](#), the Planned Lifetime Advocacy Network works to reduce the occurrence of circumstances where people are without support networks. They work to establish and build resources for ongoing support networks and they also provide resources to aid decision-making, including resources on wills, estate planning, and financial security (Stainton, 2015).

[Sweden's](#) PO Skåne program most often involves developing a trusting, stable, and positive relationship between the PO and supported person over a number of years (Morrissey, 2012).

It is also noted in the literature that the presence of understanding, trust, and closeness as a part of those relationships is a significant part of providing support for decision-making (see Burgen, 2016).

Recognition of the need for safeguards for supporters

The last section examined safeguards for the disabled person themselves and this section is concerned with the supporters in Question 9, "What recognition and/or protection has been put in place for those *people supporting* a disabled person to exercise their legal capacity?". The Committee on the Rights of Persons with Disabilities explicitly recommends training initiatives be developed (also see Inclusion Europe, 2007) in close consultation with disability organisations and disabled people (Bartlett, 2012; Committee on the Rights of Persons with Disabilities, 2013; Lang et al., 2011). Evidence suggests that the training and support provided to supporters, including professionals (such as medical practitioners and psychiatrists) and caregivers, have a significant affect on the support provided to disabled people (Werner, 2012). Studies have shown that misunderstandings and a lack of knowledge about supporter responsibilities for professionals remain (Werner, 2012) including: a lack of awareness that autonomy does not involve entirely independent decision-making (Watson, 2016a); and lack of understanding about 'supported decision-making' versus 'substituted decision-making' and 'interests' versus 'best interests' (Gooding, 2014). Additionally, Gooding (2014) found

that psychiatrists were unlikely to perceive mental illness as being under the umbrella of 'disability' as it is conceived of in the Convention.

Better training and support for professionals needs to be provided so that clear lines are drawn about what is in compliance with the Convention, including: the 'will and preference', social model, and rights-based philosophies underlying the Convention; the persons under the scope of the Convention; and professionals' and families' roles in the supported decision-making processes. Professionals can provide more than just emotional support for disabled people; it is important that they realise the range of support they can offer, including providing information, helping weigh relevant factors, and respecting close relationships with others (see Gooding, 2014; Keeling, 2016). Professionals also had the tendency to not regard supported decision-making as a viable alternative to substituted decision-making (Gooding, 2014), however it is inferred that this could be addressed through training and the better dissemination of information (Arstein-Kerslake, 2016; Flynn, 2010; Gooding, 2014; Werner, 2012). Lastly, a supporter's understanding of unconventional forms of communication and collaborative decision-making seem to affect support, which suggests improvement in this knowledge could lead to improved support (Watson, 2013b). It is signalled that individuals in a person's support network need to be provided with training, knowledge, and skills for purposes of communicating with disabled people (Jameson et al, 2015; Werner, 2012) and for improving supporters' ability to discuss topics that they may find uncomfortable (Werner, 2012). An option discussed in Knox et al. (2016) is the benefit of having supporters collaborate with each other, support each other, and bounce ideas off each other for the purposes of arriving at more effective support.

Similar to the issues discussed in previous sections, Werner (2012) also notes that workload, availability of aids, staffing shortages, and other organisational factors can compromise a professional's ability and resources to provide effective support and utilise support mechanisms. Gooding (2015) also notes that sufficient resources, particularly financial resources, remain a general problem to providing support for exercising legal capacity. He describes how funding schemes are being developed and utilised so to improve resources for implementing support. Evidence from Sweden's PO Skåne programme suggests that funding schemes work to reduce cost in the long-term because funding effective support reduces the use of crisis mental health services and reduces system weaknesses in service provision (Gooding, 2015). Supporting supporters extends to developing the strength of support networks that exist or have been created. Strong support networks are crucial to developing their capacity to most effectively facilitate a person's participation in decision-making (Carney & Beaupert, 2013).

Need for data

As has been signalled throughout this report, there is a critical need for increased research relating to Article 12 and supported decision-making in particular. A major concern in designing and implementing supported

decision-making models, arrangements and initiatives is the paucity in empirical research available that can be used for evidence-based approaches in this area (Gooding, 2015).

There is a need for data on what works for the purposes of supported decision-making and addressing obstacles for disabled persons to decision-making (IHC, n.d.; Kohn & Blumenthal, 2014; Lang et al., 2011). This lack of data also leads to a lack of understanding of how and when supported decision-making is utilised (Kohn & Blumenthal, 2014; Kohn et al., 2013). This challenge needs to be overcome because only with adequate knowledge can jurisdictions, providers, and people implement the most appropriate methods to support disabled persons in decision-making and subsequently create supported decision-making initiatives (Kohn & Blumenthal, 2014). It is argued that data collection is an obligation at the government level (Lang et al. 2011).

The Swedish National Council for Crime Prevention (BRÅ), [Sweden](#), is set up to document violence against disabled people, gaps in knowledge, avenues for further research, and as a means of addressing violence against disabled people. Their 2007 report highlighted issues with invisibility, vulnerability, and dependence. They argue that this knowledge is crucial to understanding the needs and obstacles for persons with disabilities (Government of Sweden, 2012).

Pilot studies have been implemented in [Australia](#) to gather data on supported decision-making in the jurisdictions of: South Australia, Victoria, and the Australian Capital Territory.

Monitoring has also been identified as problematic, in particular, policy-practice gaps can occur where inadequate state-based arrangements exist (Lang et al., 2011). States parties need to monitor their processes more effectively and collect statistical data to identify any policy-practice gaps that are inconsistent with the Convention (Kohn & Blumenthal, 2014; Lang et al., 2011; O'Mahony, 2012; Umeasiegbu, 2013). There is a need for increased research into safeguards (Dickey, 2016).

Summarising key points and issues of contention

The review of the literature relating to the theory, policy, and practice of supported decision-making has thrown up a number of key points and issues of contention. In particular, there are:

- Differing opinions about how to theorise supported decision-making for individuals with severe cognitive impairment.
- Debates about how to determine when a disabled person requires assistance with decision-making.
- Shared understandings about the importance of communication strategies in support, responsiveness to varying methods of communication, and the resulting implications for support resources that need to be made available.
- Gaps concerning the level of resourcing required in practice to embed supported decision-making in the lives of *all* disabled people, including who should provide and receive such resourcing.
- Difficulties identified about managing situations whereby a person's will and preferences conflict internally. For example, where a person with anorexia holds both a will to live but a preference to not eat (as discussed in Arstein-Kerslake & Flynn, 2015; Series et al., 2014). This can also be difficult in cases of phobia, addiction, and psychosis (Callaghan & Ryan, 2014).
- Differing opinions about how to determine and how to respond when disabled people and their supporters have conflicting will and preference.
- Gaps in empirical research to guide and inform legislative change and guide policy, and practice related to supported decision-making.
- A need for well-considered safeguards for disabled people, and in some cases those individuals who are acting as supporters.

Key Themes & Future Challenges

This review has been developed around the overarching questions:

1. What can be learned from literature that has been published since 1 January 2010 that examines, discusses and provides cases studies and individual's stories, or reviews/evaluates the practice of disabled people exercising their legal capacity?
2. What are the trends in the evolution and development of thinking and practice over time of support for disabled people's exercise of legal capacity, where relevant?

It is clear from this review that most Convention commentators agree that the interpretation and implementation of Article 12 is critical to the achievement of the broad intent of the Convention, and expression of all other rights-based articles contained within it. It is this acknowledgement that underpins the imperative for states parties to commence activity designed to embed Article 12 in legislation, policy, and practice immediately. Progress has been impeded however, due to polarised and strongly held views about the extent to which the paradigm shift advocated by the Convention and its proponents should be applied in practice. In particular, the proposed move away from substituted decision-making, notions of incapacity (and related diagnostic tests) and the concept of best interests have been hotly contested. While the Committee on the Rights of Persons with Disabilities (the Committee) has attempted to provide clarity on the interpretation of Article 12 through General Comment No. 1, some Convention commentators continue to promote divergent understandings, and indeed many states parties have proceeded with implementation strategies that only go part of the way toward giving expression to Article 12. It has been common for traditional practices of substituted decision-making, and capacity and best interests tests to retain a place alongside Convention-inspired revisions to legislation and nomenclature. In short, to date, no states parties have succeeded in giving full expression to Article 12 of the Convention, according to the Committee's interpretation.

In considering the literature in relation to the foundation questions upon which this review was based, it is reasonable to state that while there is considerable difference in views about how to interpret Article 12 and theorise the implementation of supported decision-making, there is a reasonable level of consensus about the critical elements of effective supported decision-making. What is less evident is empirical research that has robustly evaluated supported decision-making initiatives over time. It is also evident that disabled people themselves have not yet had adequate opportunity to be significantly involved in research and evaluation in a manner that has enabled them to reflect on the impact of Article 12 in general, and their experiences of supported decision-making in particular. For this reason, the voices of disabled people themselves are largely

absent from this review. Similarly, embedding Article 12 and supported decision-making in the context of current disability support structures and services is yet to comprehensively be explored in the literature.

The issues that have been identified throughout this review have highlighted a need for strong consideration of appropriate safeguards for disabled people and those who support them in the context of Article 12 and supported decision-making. The paradigm shift to disabled people having a non-derogable right to legal capacity, and the associated prioritisation of will and preference, has been argued as exposing them (and others) to undue risk in some situations. Legislation, policy, and practice will all have to be amended to mitigate these concerns and potential risks. It is important to note, however, that the traditional paradigm underpinned by notions of incapacity, substituted decision-making, and best interests has also failed to consistently safeguard disabled people in a range of situations and contexts.

In summary, while this review has provided valuable insight into theoretical and practical aspects related to legal capacity and supported decision-making, it has equally highlighted the difficulties that states parties have experienced with regard to interpreting, and subsequently implementing Article 12 of the Convention. It appears that states parties will continue to be assessed as failing to give expression to the intent of the Convention and to meet their obligations related to Article 12 if they persist in pursuing alternative interpretations to those conveyed by the Committee on the Rights of Persons with Disabilities and the General Comment.

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Additional resources

Pilot Projects

New South Wales, Australia

OPA Supported Decision Making Pilot Project [Automatic download]

Burgen

https://www.google.co.nz/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&cad=rja&uact=8&ved=oahUKEwiTpLqvmJHPAhUHomMKHWFFDKcQFgglMAE&url=https%3A%2F%2Fwww.asid.asn.au%2Ffiles%2F653_65_b_burgen.pdf&usq=AFQjCNGP8ivCikwiMtYGTDqrOH87YEovlg&sig2=e1nVUmxzDRXAQXjvCGgy-w&bvm=bv.133053837,bs.2,d.dGo

Supported Decision Making projects

Ageing, Disability and Home Care (ADHC)

http://www.adhc.nsw.gov.au/individuals/inclusion_and_participation/supported-decision-making/sdm-projects

Supported decision making framework 2013

Ageing, Disability and Home Care (ADHC)

http://www.adhc.nsw.gov.au/__data/assets/file/0008/346193/SDM_Policy_Framework.pdf

My life, my decision. An independent evaluation of the Supported Decision Making Pilot

Ageing, Disability and Home Care (ADHC)

http://www.adhc.nsw.gov.au/__data/assets/file/0009/346194/sdm_pilot_project_evaluation_report.pdf

Victoria, Australia

Supported decision-making

Office of the Public Advocate

<http://www.publicadvocate.vic.gov.au/advocacy-research/supported-decision-making>

Supported Decision Making Project

Monash University

<http://artsonline.monash.edu.au/supported-decision-making/>

South Australia, Australia

South Australian Supported Decision Making Project Report of Preliminary "Phase I" [Automatic download]

Office of the Public Advocate

<https://www.google.co.nz/url?sa=t&rct=j&q=&esrc=s&source=web&cd=25&cad=rja&uact=8&ved=0ahUKEwi1sv->

[FmpHPAhUiS2MKHXRhDUA4FBAWCDMwBA&url=http%3A%2F%2Fwww.opa.sa.gov.au%2Ffiles%2Fbatch1376447055_phase_1_supported_decision_making_project_evaluation.pdf&usq=AFQjCNGoExEcj9OlxCjgGP7QeRha7A4mdg&sig2=GoF5886ZYCBDPS_e836ibg&bvm=bv.133053837,bs.2,d.dGo](https://www.google.co.nz/url?sa=t&rct=j&q=&esrc=s&source=web&cd=25&cad=rja&uact=8&ved=0ahUKEwi1sv-FmpHPAhUiS2MKHXRhDUA4FBAWCDMwBA&url=http%3A%2F%2Fwww.opa.sa.gov.au%2Ffiles%2Fbatch1376447055_phase_1_supported_decision_making_project_evaluation.pdf&usq=AFQjCNGoExEcj9OlxCjgGP7QeRha7A4mdg&sig2=GoF5886ZYCBDPS_e836ibg&bvm=bv.133053837,bs.2,d.dGo)

RC Zelda Project, Latvia

RC ZELDA has completed the Pilot Project on Implementation of the Supported Decision Making in Latvia

<http://zelda.org.lv/en/news/rc-zelda-has-completed-the-pilot-project-on-implementation-of-the-supported-decision-making-in-latvia-2467>

Handbook: First Steps in Implementation of Supported Decision-Making in Latvia

http://zelda.org.lv/wp-content/uploads/ZELDAS_bro%C5%A1%C5%ABra_EN_WEB.pdf

Supported Decision-Making Pilot Project, USA

Pilot project

Center for Public Representation and Nonotuck Resource Associates, Inc.

<http://supporteddecisions.org/pilot-project/>

Supported Decision Making Pilot: A Collaborative Approach

Center for Public Representation and Nonotuck Resource Associates, Inc.

<https://www.courts.wa.gov/content/publicUpload/Guardian%20WINGS%20II/Supported%20Decision%20Making%20Pilot.pdf>

10 Steps to Independence: Promoting Self-Determination in the Home

Michael L. Wehmeyer, Sharon Davis, and Susan B. Palmer

http://ngsd.org/sites/default/files/10_steps_to_independence.pdf

Volunteer-Supported Decision-Making for People with Cognitive Impairments

Texas Department of Aging and Disability Services

http://www.tcdd.texas.gov/wp-content/uploads/2013/01/2013_Feb_handout_05_Guard.pdf

Examples of Practice

Making Healthcare Choices: Perspectives of People with Disabilities [Video]

American Civil Liberties Union

<https://youtu.be/QTyZrSC2l6U>

Safeguarding Human Dignity: Sweden's Personal Ombudsmen System

FuturePolicy.org

<http://www.futurepolicy.org/rights-and-responsibilities/swedens-personal-ombudsmen-system/>

Resources

Ted Inspired Talk given at Financial Counselling Australia Conference 2016 [Video]

Jo Watson

<https://youtu.be/qMerG7CULJE>

Listening to those rarely heard

Jo Watson and Rhonda Joseph, Scope Victoria

<https://vimeo.com/21176882>

What is Self-Determination and Why is It Important to People with Developmental Disabilities? [Video lectures]

Michael Wehmeyer

<http://www.ngsd.org/everyone/what-self-determination>

Active citizenship for persons with disabilities, UN CRPD, and DISCIT project (Multiple captions) [Video]

European Disability Forum

https://www.youtube.com/watch?v=sBoo5_os6yU

At Open Society: Michael Bach [Video]

Open Society

<https://www.opensocietyfoundations.org/videos/open-society-michael-bach>

Building the Evidence Base on Supported Decision Making [Slideshow]

Christine Bigby

<http://www.slideshare.net/ChristineBigby/building-the-evidence-base-on-supported-decision-making>

Understanding the Lived Experiences of Supported Decision-Making In Canada

Krista James & Laura Watts

<http://www.lco-cdo.org/capacity-guardianship-commissioned-paper-ccel.pdf>

Draft General Comment on Article 12 of the Convention - Equal Recognition before the Law & Draft General Comment on Article 9 of the Convention – Accessibility. Call for Comments

Submissions made towards the drafting of the General Comments to the Convention

<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx>

Supported decision-making guides and manuals

Supporting decision making guide

Department of Human Services

<http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/policies,-guidelines-and-legislation/supporting-decision-making-guide>

CRPD Manual [Automatic download]

World Network of Users and Survivors of Psychiatry

<https://www.google.co.nz/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&cad=rja&uact=8&ved=oahUKEwjrrMO9xZLPAhWBGZQKHTbODOUQFgggMAE&url=http%3A%2F%2Fwww.un.org%2Fdisabilities%2Fdocuments%2FCOP%2FWNUSP%2520CRPD%2520Manual.doc&usq=AFQjCNHUoG8Rc7beulpQGVodeOOCWwoNtg&bvm=bv.133053837,bs.1,d.dGo>

Handbook for Parliamentarians

United Nations

<http://www.un.org/disabilities/documents/toolaction/ipuhb.pdf>

The Convention on the Rights of Persons with Disabilities Training Guide Professional Training Series No. 19

United Nations

http://www.ohchr.org/Documents/Publications/CRPD_TrainingGuide_PTS19_EN%20Accessible.pdf

Supporting Decision-Making. A Guide for Supporters of People with an Intellectual Disability

IHC

https://www.ihc.org.nz/sites/default/files/documents/10007_1511_SupportedDecisionMaking_Resource_V4.3_PRINT.pdf

My life, my decision A handbook for decision makers

Ageing, Disability and Home Care (ADHC)

http://www.adhc.nsw.gov.au/__data/assets/file/0004/346198/Handbook_for_decision_makers.pdf

Supported Decision Making. A Handbook for Supporters

Ageing, Disability and Home Care (ADHC)

http://www.adhc.nsw.gov.au/__data/assets/file/0011/346196/Handbook_for_supporters.pdf

Supported Decision Making. A Handbook for Facilitators

Ageing, Disability and Home Care (ADHC)

http://www.adhc.nsw.gov.au/__data/assets/file/0003/346197/Handbook_for_facilitators.pdf

Supporting Decision-Making A Guide for Supporters of People with an Intellectual Disability

IHC

https://www.ihc.org.nz/sites/default/files/documents/10007_1511_SupportedDecisionMaking_Resource_V4.3_PRINT.pdf

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

Professor Christine Bigby, Dr Mary Whiteside and Professor Jacinta Douglas

http://apo.org.au/files/Resource/final_full_report_for_support_for_decision_making_dilemmas_and_challenges_6_june_2015_o.pdf

Circles of support guides and manuals

Creating a Circle of Support

Kim Davis

<https://www.iidc.indiana.edu/pages/creating-a-circle-of-support>

Circles of Support. A manual for getting started

Resourcing Families

http://www.resourcingfamilies.org.au/uploads/70239/ufiles/Circles_of_Support_Manual_2015.pdf

Organisations & Resource Centres

Advocacy Denver

<http://www.advocacydenver.org/>

Centre for Disability Law and Policy National University of Ireland, Galway

www.nuigalway.ie/research/centre_disability_law_policy

National Resource Center for Supported Decision-Making

<http://supporteddecisionmaking.org/>

Nidus Personal Planning Resource Centre

<http://www.nidus.ca/>

World Network of Users and Survivors of Psychiatry

<http://wnusp.rafus.dk/>

Auckland Disability law

The Conversation: Supported Decision Making Hui Film [Video]

Auckland Disability Law

<https://www.youtube.com/watch?v=78j8of1hGRc&feature=youtu.be>

Auckland Disability Law Videos

<http://aucklanddisabilitylaw.org.nz/supported-decision-making-home/supported-decision-making-videos/>

Let's talk about Supported Decision Making

[http://aucklanddisabilitylaw.org.nz/wp-](http://aucklanddisabilitylaw.org.nz/wp-content/uploads/resources/Lets+Talk+about+Supported+Decision+Making+Leaflet.pdf)

[content/uploads/resources/Lets+Talk+about+Supported+Decision+Making+Leaflet.pdf](http://aucklanddisabilitylaw.org.nz/wp-content/uploads/resources/Lets+Talk+about+Supported+Decision+Making+Leaflet.pdf)

Easy Read version:

<http://aucklanddisabilitylaw.org.nz/wp-content/uploads/2016/07/Supported-Decision-Making-Easy-Read.pdf>

Supported Decision Making: A Roadmap to Success

[http://aucklanddisabilitylaw.org.nz/wp-](http://aucklanddisabilitylaw.org.nz/wp-content/uploads/resources/Supported+Decision+Making+Roadmap+Poster.pdf)

[content/uploads/resources/Supported+Decision+Making+Roadmap+Poster.pdf](http://aucklanddisabilitylaw.org.nz/wp-content/uploads/resources/Supported+Decision+Making+Roadmap+Poster.pdf)

Promoting Supported Decision Making and the Protection of Personal and Property Rights Pamphlet

[http://aucklanddisabilitylaw.org.nz/wp-](http://aucklanddisabilitylaw.org.nz/wp-content/uploads/resources/Promoting+Supported+Decision+Making+and+the+PPPR+Act+Pamphlet.pdf)

[content/uploads/resources/Promoting+Supported+Decision+Making+and+the+PPPR+Act+Pamphlet.pdf](http://aucklanddisabilitylaw.org.nz/wp-content/uploads/resources/Promoting+Supported+Decision+Making+and+the+PPPR+Act+Pamphlet.pdf)

Healthtalk Australia

Supported decision-making (SDM) and challenges to SDM: How to increase participation in decision making

<http://research.healthtalkaustralia.org/supported-decision-making/support-in-treatment-decisions>

Supported decision-making (SDM) and challenges to SDM: Support in Treatment Decisions

<http://research.healthtalkaustralia.org/supported-decision-making/how-to-increase-participation-in-decision-making>

Relationships, support and challenges: Family and friends

<http://research.healthtalkaustralia.org/supported-decision-making/family-and-friends>

Appendix A

Review Questions

As noted in the introduction to this review, the Office for Disability Issues identified the questions that underpinned this review. They specifically posed a two-phased primary question, and 19 additional secondary questions, which fell broadly into two groupings: legal capacity, and supported decision-making.

Primary Questions

What can be learned from literature that has been published since 1 January 2010 that examines, discusses, provides case studies/individual stories, or reviews/evaluates the practice of disabled people exercising their legal capacity. Particularly, what has been done to enable or better support disabled people's exercise of legal capacity? and

What are the trends in the evolution and development of thinking and practice over time of support for disabled people's exercise of legal capacity, where relevant?

Secondary Questions

Exercise of legal capacity

1. What evidence exists that there is a problem with disabled people exercising their legal capacity, and what is the impact on those disabled people and others?
2. What does the population of affected disabled people look like (for example, number of people, proportion of the population, other relevant demographic information)?
3. How do disabled people access support for exercising their legal capacity?
4. Have there been any changes in the treatment, by society, of disabled people exercising their legal capacity?

5. How are the rights for promoting a disabled person's autonomy versus safeguards for their protection and safety being balanced?
6. What forms of better support for disabled people's exercise of legal capacity have been implemented or signalled?
7. Has there been any discussion or change to transition or move from consideration of a person's 'best interests' to a person's 'rights, will and preference' in the context of disabled people exercising their legal capacity?
8. What safeguards have been developed and put in practice alongside any moves to support disabled people's exercise of legal capacity?
9. What recognition and/or protection has been put in place for those people supporting a disabled person to exercise their legal capacity?
10. Is there any discourse on the intersection between reasonable accommodation and support for disabled people's exercise of legal capacity?
11. Has there been any recognition in law or policy by a government regarding the obligation in Article 12(2) that: 'States parties shall take appropriate measures to provide access to persons with disabilities to the support they may require in exercising their legal capacity.'?
12. Is there any evidence measuring the impact from increased support for disabled people's exercise of legal capacity?
13. Has there been any change in the practice and mandate for substitute decision-making?

Supported decision-making

14. How is support for disabled people's exercise of legal capacity being distinguished from supported decision-making?
15. What forms of supported decision-making have been implemented?
16. Is there any evidence measuring the impact from recognition/practice of supported decision-making?
17. Does recognition of supported decision-making need legislation to ensure supported decisions are implemented and protection assured for the disabled decision-maker and their supporters?

18. How far can supported decision-making be applied before it loses real or practical connection with a disabled person's will and preference, and in practice what is happening is very nearly or already substitute decision-making in their best interests?
19. Is there any discourse on the impact on a disabled person's right to privacy or informed consent in the context of support to exercise legal capacity?

Appendix B

Because this literature review was intended to provide an evidence base for policy decisions, it was conducted using an integrative review methodology (Whittemore & Knafl, 2005). Integrative reviews permit the inclusion of a wide range of studies, including academic articles that detail quantitative and qualitative studies, and 'grey' literature such as reports, policy, and opinion pieces. It was considered that such an approach would provide richer and more diverse evidence with potential to be utilised by those considering Article 12 of the United Nations Convention on the Rights of Persons with Disabilities and its implementation. In particular, an integrative review methodology was seen as generating appropriate evidence at different levels to inform research, practice and policy, and was therefore preferred as the means of addressing the broad range of questions upon which the Office of Disability Issues (ODI) posed (Refer Appendix A).

An integrative review methodology combines data from both theoretical and empirical literature, and permits the development and synthesis of theory in the service of practical solutions. Such a synthesis offers several advantages over alternative review methodologies, such as meta-analyses (which require data to be of similar nature) or systems analysis (which risks excluding particular qualitative data and, therefore, limits the possibilities for considering the views of key stakeholders, particularly in the disability sector). An integrative review methodology is appropriate for the analysis of complex concepts or issues, allowing all possible interests and considerations to be included. This was considered critical in the present context, given the imbrication of legislation, case law, interests of the disabilities sector and its stakeholders, phenomenologies of decision-making, and the international context of legislative and conventional compliance.

Typically there are six stages to an integrative review. These include the preparation of the guiding question(s), preparing and conducting the literature search; collecting data; undergoing critical analysis of the included studies/sources; a discursive consideration of the results and the appropriate presentation of the review sufficient to furnish evidence for policy-making and legislative review and/or reform. These steps were applied in the context of developing the current review.

Definitions of disability

The review considered the potential impacts of Article 12, and more particularly the implementation of supported decision-making on disabled people of all ages, impairment types, genders, ethnicities and geographic locations. Those particularly affected by Article 12(2) were taken to be people with experience of dementia; people with learning/intellectual disabilities; people experiencing mental distress; and other people with diverse or impaired cognitive functioning and/or communication. The review considered how impacts

differ for people in these groups, but did not seek to offer a comparative review insofar as that sets a hierarchy of experience that is not particularly helpful in this context.

Limitations of scope

In keeping with the requirements of the ODI, the literature review was broadly limited to the period 2010-2016. However, because much of the salient literature on legal capacity, decision-making and, in particular, the New Zealand legislative framework for those issues, pre-date 2010, key sources outside the specified timeframe were included on occasion.

Sources

The primary source for this review was the University of Otago's Library Ketu database. Ketu is an aggregate database, which facilitates access to a wide range of specific databases. In addition, Google Scholar was individually searched as a way of checking all relevant references were identified. The United Nations Convention on the Rights of Persons with Disabilities online database was also extensively utilised in this review, particularly to gain insight into Article 12, and to access states parties reports and concluding comments. Approximately 25 different search terms were utilised to identify relevant references. These terms were:

- United Nations Convention on the Rights of Persons with Disabilities
- Convention on the Rights of Persons with Disabilities
- Convention on the Rights of Persons with Disabilities Article 12
- General Comment Article 12
- GC Article 12
- Convention
- Article 12 Convention
- Legal capacity
- Mental capacity
- Decision-making capacity
- Decisional capacity

- Right to legal capacity
- Supported decision making
- Decision making medical treatment
- Medical refusal
- Treatment refusal
- Legal capacity disabilities
- Supported decision making
- Supported decisions
- Capacity supported decisions
- Substitute decision making
- Substitute decisions
- Compulsory treatment
- Compulsory treatment disabilities
- Compulsory treatment mental health/MHA

The application of these search terms resulted in approximately over 300 potentially relevant references being identified. Approximately 130 of these were included in the final report as having particular relevance, however all provided important insights and information that have informed the development of the review. Some of those that were not used in the body of the review are included as additional resources following the reference section of the report.



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Disability issues

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Administered by the Ministry of Social Development