

## Supported Decision Making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice

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This article aims to help readers to understand the conceptual link between supported decision making and legal capacity and how this is influencing the development of practice. It examines how the concept has been defined as: a process of supporting a person with decision making; a system that affords legal status; and a means of bringing a person's will and preference to the centre of any substituted decision-making process. The conceptual link between supported decision making and legal capacity is explored by outlining three conceptualisations that are influencing the development of practice. It is important to understand the difference between supported decision making and support *with* decision making. Both involve offering support to a person who is unable to navigate decision making independently. However, the key difference is whether or not the process results in greater legal capacity for the individual. Additionally, supported decision making requires the development of legal mechanisms that legitimise the interdependent nature of decision making and the concept of shared capacity. By having a greater understanding of the conceptual foundations of supported decision making, practitioners can engage in more focused evaluation of proposed new law reform and practice. Research will be vital in understanding how supported and substituted decision making could coexist and how mental capacity could be assessed in this new decision-making paradigm. If a more substantial theory of practice can be developed, supported decision making has the potential to empower and enrich the lives of people with cognitive disabilities, both in Australia and all over the world.

**Keywords:** supported decision making; legal capacity; support with decision making and practice

This article explores the development of supported decision making, firstly in Canada and then internationally in human rights law, as an idealistic and enigmatic concept. It delves into how the concept of supported decision making has been defined in Australia and evaluates the conceptual link between supported decision making and legal capacity.<sup>1</sup> The article highlights the important distinction between support *with* decision making and supported decision making. Understanding the difference between these two concepts will assist in the design and evaluation of supported decision making practice. If a more substantial theory of practice, informed by evidence, can be developed, supported decision making may have the potential to empower and enrich the lives of people with cognitive disabilities both in Australia and all over the world.

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Supported decision making has been introduced in Australia as an alternative to traditional adult guardianship (Carney, 2012) within the context of growing recognition that guardianship legislation has become outdated (Chesterman, 2010; NSW Legislative Council Standing Committee on Social Issues, 2010; Victorian Law Reform Commission, 2012). Legislation such as the Victorian Guardianship and Administration Act (1986) has been criticised as having “an air of paternalism that sits uneasily with modern-day conceptions of the rights of people with disabilities” (Chesterman, 2010, p. 61). Supported decision making has also been discussed as a “conceptual and practical bridge” (p. 432) to better realising the rights of people with disabilities in the context of mental health legislative and policy reform (Gooding, 2012). Alongside these reflections, supported decision making has been discussed in the context of the National Disability Insurance Scheme, as the means by which people with cognitive impairment can be supported to remain in control of their own financial packages and individualised support (ACT Disability, Aged and Carer Advocacy Service, 2013). Linked to these significant issues, it would be difficult to dispute the future importance of supported decision making in Australia. Therefore, it is important for practitioners to become familiar with the concept and its origins in Canada more than 20 years ago.

### **Idealistic Vision**

Supported decision making has its origins in Canada, stemming from a movement that was driven by a specific purpose and idealistic principles. In the early 1990s, disability organisations in Canada conceived of supported decision making as a way to overcome the barriers that prevented people with intellectual disabilities from being self-determining citizens. It was seen to be a way to remove legal barriers created by issues of competency, which prevented people with intellectual disabilities receiving individualised funding (Bach, 1998). In particular, these organisations objected to the removal of an individual’s legal right to make decisions (legal standing) through the appointment of guardians and financial administrators (Gordon, 2000). The aim of supported decision making was to provide people with intellectual disabilities with the necessary support to make decisions and communicate their choices (Bodnar & Coffin, 2003).

The first clearly articulated principles of supported decision making were written by the Canadian Association for Community Living Taskforce in their report on Alternatives to Guardianship in August 1992. The taskforce proposed supported decision making as an alternative conceptual framework for decision making that challenged the belief that personal autonomy could only be expressed independently.

The proposed supported decision-making model was based on a number of assumptions and principles including: (a) all adults have a right to self-determination and the right to make decisions affecting their lives with the support, affection, and assistance of family and friends of their choosing; everyone has a will and is capable of making choices; (b) a cornerstone of supported decision making is the existence of a trusting relationship between a person giving support and a person receiving support; and (c) the law must not discriminate on the basis of perceptions of a person’s capacity or competence. These principles challenged traditional views about autonomy and capacity by seeking recognition of the interdependent nature of decision making. They rejected the assessment of an individual’s competence (mental capacity) and recommended instead a move toward assessing whether the decision making process had been competent.

These original principles proposed by the Canadian Association for Community Living were refined over time and in 1993, 1996, 2000, 2003, and 2008 supported decision making was incorporated into legislation in the Canadian provinces of Manitoba,

British Columbia, Saskatchewan, Yukon, and Alberta respectively.<sup>2</sup> Supported decision making gained international attention when it was discussed at the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

### **Influencing Human Rights Law**

The UNCRPD (2006) was the first human rights treaty of the twenty-first century. Its purpose, as expressed in Article 1, was 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. It has been hailed as “a great landmark in the struggle to reframe the needs and concerns of persons with disability in terms of human rights” (Kayess & French, 2008, p. 2). The UNCRPD has 50 Articles, some of which are of particular interest when considering supported decision making. It was during the drafting of Article 12 (Equal Recognition before the Law) that supported decision making entered into discussions between delegates at the United Nations. Supported decision making was introduced as the legal mechanism or framework through which governments could provide people with disabilities with the support they may require to be able to exercise their legal capacity as required in Article 12.3. Another important section of the UNCRPD that has heavily influenced the promotion of supported decision making was Article 5 (Equality and Non-discrimination), which set out the need for governments to ensure they take steps to reasonably accommodate people with disabilities, to promote equality, and eliminate discrimination.

Integrating the ideas within Articles 12 and 5, it can be said that just as people with physical disabilities need a ramp to ensure that they are reasonably accommodated to access a building, supported decision making is seen as the vehicle to reasonably accommodate people with cognitive disabilities to exercise their legal capacity (Salzman, 2010). Therefore, governments who are signatories to the UNCRPD, such as Australia, have a human rights obligation to ensure that people with disabilities are provided with the support they need to exercise their legal capacity on an equal basis with others. As a result, governments have been encouraged to replace regimes of substituted decision making such as guardianship, which take away legal capacity, with regimes of supported decision making. In seeking to implement the UNCRPD, many countries have begun to grapple with the practice of supported decision making and are finding it to be an enigmatic concept.

### **Defining Supported Decision Making**

Australia is yet to adopt a clear definition of supported decision making, and in the absence of research internationally (Kohn, Blumenthal, & Campbell, 2013) its practice remains ill-defined and subject to multiple interpretations. The term “supported decision making” is used in many different contexts, and it is often unclear exactly what people mean when they refer to it. Supported decision making is referred to as a process, a mechanism, a system, and a framework. The literature suggests it is a process of supporting people with their decision making, a system that affords legal status, and a means of bringing a person’s will and preference to the centre of any substituted decision-making process (ACT Disability, Aged and Carer Advocacy Service, 2013).

In one sense, supported decision making is something that happens as a decision is being made (Quinn, 2010). That is, it is a process of support directed by an individual (Kerzner, 2011) whose supporter explains issues and interprets the individual’s signs and preferences (UN Enable, 2006). In this sense, supported decision making is a process that enables some people to exercise their legal capacity, and thus greater autonomy and self-determination.

In another sense, supported decision making is defined as an end that legally recognises the process of supporting a person with their decision making. That is, it is an alternative legal regime to substituted decision making (UN Enable, 2006) and a system intended to replace guardianship (Dinerstein, 2012; Inclusion Europe, 2008). In this sense, supported decision making is part of a new legal paradigm for protecting autonomy, the right to legal capacity (Bach & Kerzner, 2010), and a model that accommodates deficits in decision-making capabilities (Advocacy for Inclusion, 2012; Kämpf, 2010). Therefore, supported decision making is both a process and an end, which legally recognises the process of supporting decision making and the legal standing of decisions reached as part of this process.

In a third sense, supported decision making is the means by which substituted decision making, whether formal or informal, can be grounded in the will and preferences of the person (ACT Disability, Aged and Carer Advocacy Service, 2013). In this sense, supported decision making increases the participation of people with disabilities who are unable to be supported to make their own decisions, to be central to decision making in their own lives. Microboards used in the Canadian province of British Columbia exemplify this conceptualisation of supported decision making. While they are legal structures that allow others to manage individualised funding on behalf of the person, they do so in a manner that places the individual at the centre of every decision and action taken by the board (Vela Microboard Association, 1997).

In Australia, there has been a lack of clarity in the way supported decision making is being defined. In the absence of legal frameworks that recognise supported decision making, some agencies have focused on the development of the process of support with decision making (Victorian Government Department of Human Services, 2012). Offering people with disabilities more involvement in their own lives through preference and choice making is vitally important to their quality of life (Jenkinson, 1993) and should be pursued. However, it will be important for stakeholders involved in this area to clarify whether the support they are providing to people in decision making will lead to greater exercise of their legal capacity. Determining when and how the term “supported decision making” should be used, as opposed to “support with decision making”, will have a significant influence on the successful implementation of this new paradigm in legislation, policy, and practice.

### **Linking Supported Decision Making and Legal Capacity**

In Australia, it is yet to be determined what supported decision making can achieve. The UNCRPD promoted supported decision making as the means to assist people with disabilities to exercise their legal capacity to the greatest extent possible (UN Enable, 2006). However, no research has explored the impact of supported decision making on the ability of people with disabilities to exercise their legal capacity. There is an urgent need to investigate the link between the two concepts, but in order to conduct this research greater clarity is required about the way legal capacity is being defined in the context of supported decision making.

McSherry (2012) suggested that legal capacity has two constitutive elements: legal standing and legal agency. Legal standing refers to being recognised as a person before the law, while legal agency refers to the ability to act within the framework of the legal system. The literature on supported decision making appears to have three conceptualisations of legal capacity that are shaping thinking about supported decision making, each of which brings a different aspect to the fore. A summary of how supported decision making has been conceptualised according to the continuum and universal approaches can be seen in [Table 1](#).

*All or Nothing Approach*

The first conceptualisation of legal capacity is the “all or nothing” approach. A traditional status approach to mental capacity makes the assumption that because a person has a disability, he or she lacks legal capacity. Gerard Quinn (2010) argued that status-based assumptions rest on a binary view of mental capacity – “you either had it *in toto* or you lacked it *in toto*” (p. 12). He suggested that mental capacity is not a binary concept and that people can have varying levels of mental capacity to make different kinds of decisions. This approach to legal capacity, which is characterised as “all or nothing”, is seen as largely outdated. Supported decision making challenges the notion of mental capacity being a binary concept and resists the way this model views decision making as autonomous. From an all or nothing approach, providing support to people will do nothing to change their disability status, which is assumed to render them incapable. Supported decision making is incompatible with this conceptualisation of legal capacity.

*Universal Approach*

The second conceptualisation of legal capacity is the universal approach. This view forms when people focus on legal standing more than on legal agency when defining legal capacity. From this perspective, legal capacity is seen as a universal human attribute (Dhanda, 2007), which is possessed by all people (Bach, 1998; Bodnar & Coflin, 2003; Dhanda, 2007). It is a social and legal status that exists independently of a person’s particular mental capacities or capabilities and “does not reflect an individual’s ability to make decisions. Rather it reflects an individual’s right to make decisions and have those respected” (Bach & Kerzner, 2010, p. 18). Legal capacity is seen as a form of legal recognition (Mental Disability Advocacy Centre, n.d.) and a tool that people use to assert themselves in the world (Quinn, 2011). From this perspective, legal capacity is about more than just decision making; it represents what it means to be human (Commissioner for Human Rights, 2012).

Currently, there is no legislation or policy framework that adopts an approach to legal capacity that focuses primarily on legal standing. This is because it is a philosophically driven position, embedded in human rights principles that are yet to be realised in practice. There will be a number of implications for the development of supported decision making if a universal approach to legal capacity is adopted. From this perspective, a person’s mental capacity is not defined in terms of his or her disability, but rather the focus is primarily the social and contextual factors that impact upon his or her ability to make decisions (Shakespeare, 2006). Therefore, the development of supported decision making would concentrate on the need to change the cultural context of decision making for people with disabilities. By focusing on the legal standing of every person, this approach would hope to counter “the frequent underestimation of the abilities of persons with intellectual, psychosocial and other conditions affecting mental functioning. Accordingly, supported decision making enables each individual to realize his or her fullest capabilities” (Salzman, 2010, p. 181). This focus on socio-contextual change is seen as the antidote to a system that has been too focused on the failings of individuals and their disability. This approach tends to align with the perspective that sees supported decision making as an alternative legal regime. However, legal capacity is about more than just legal standing; it also about legal agency, the person’s ability to act within the framework of the legal system, which is the focus of the third conceptualisation.

Table 1. Conceptualisations of supported decision making according to the Universal and Continuum Approaches to Legal Capacity.

Supported decision making	Offers people with disability	Universal approach to legal capacity	Continuum approach to legal capacity	Implementation	Challenges
As a process	Support to make decisions and exercise legal capacity	The support process enables the person to exercise his or her legal capacity.	The support process enables the person to exercise his or her legal capacity to the greatest extent possible. Some people with profound disability will not be able to be supported to make their own decisions.	Support with decision making can occur within informal and formal networks. The process should aim to enhance the person's legal capacity. Increased confidence and skill development may avert substituted decision making.	Changing negative attitudes towards people with disability determining their own lives; Developing processes of support, recruiting and monitoring supporters; Evaluating how support changes the decision-making process.
As a legal framework	Legally recognised support to make decisions	A new legal framework would recognise the interdependence of decision making and redefine capacity as shared.	A new legal framework would include the need for a continuum of support options.	Alternative legal mechanisms must be developed alongside improvements in support processes, e.g., Representation Agreements, and Microboards.	Defining the ability to make legally binding decisions; Setting standards as benchmarks; and Assessing capacity on a decision-by-decision basis.
As a means to improve substituted decision making	Confidence that the person's preferences will be the basis of substituted decisions made on his or her behalf	Supporters can ascribe agency to the actions of the person. In doing so, will and preference becomes the basis of decisions made together.	If a person is assessed as unable to make a decision with support the will and preference of the person becomes central to the substituted decision-making process.	If it is accepted that substituted decision making will sometimes be necessary, it is important to explore how substituted and supported decision making can coexist on the continuum.	Conducting research and evaluation into the new models of capacity assessment, which would enable the overuse of formal and information substituted decision making to be challenged.

*Continuum Approach*

The third conceptualisation of legal capacity found in the literature is referred to here as the continuum approach. This approach focuses on legal agency more than legal standing when thinking about legal capacity. It recognises that a person's agency or his or her ability to act within the framework of the legal system is not static but can change over time and in accordance with environmental factors and personal experience. It is possible to represent this approach by conceptualising legal capacity along a continuum (Adult Guardianship and Trusteeship Act, 2008; Advocacy for Inclusion, 2012; Brayley, 2009; Carter & Chesterman, 2009).

The continuum approach to legal capacity needs to define a person's ability to make binding legal arrangements (Victorian Department of Human Services, 2012) and set standards that allow a person to engage in legal relationships (Victorian Law Reform Commission, 2012). In Australian legislation, legal capacity usually means that "a person has sufficient knowledge and understanding to reach the threshold of capacity necessary to commit to a legal contract or take legal action on his or her own behalf" (Carter & Chesterman, 2009, p. 4). Thus, from this perspective, not all human beings possess legal capacity and a person can be declared incompetent (Dhanda, 2007). This outcome is possible because although people have the right to legal capacity, a distinction has been made between the capacity to have rights and the capacity to exercise those rights (Commissioner for Human Rights, 2012).

Therefore, in this approach there is a point along the continuum where a person is determined to be unable to make a decision, even with support. This approach means that some form of mental capacity assessment remains relevant and necessary. However, in contrast to the all or nothing approach, mental capacity is no longer linked solely to disability status and also needs to consider social and contextual factors. As a result, people adopting a continuum approach to legal capacity will move towards the assessment of mental capacity on a decision-by-decision basis. In Australia, the most clearly articulated example of the continuum approach is Brayley's (2009) stepped model of supported and substituted decision making. The model is an attempt to develop a continuum of decision-making options, real and potential, which would reflect changes in the ability of a person to act autonomously and his or her need for decision-making intervention by the state. This approach recognises the contribution and value of the different perspectives of supported decision making.

From the continuum approach, new legal tools are being explored that will enable legal recognition of people's decision making. However, Carney (2012) has argued that even if new legal tools are adopted that allow for supported decision making as it is understood in this approach, they will only be as good as the service system and social environment available to the person needing support. Legal options are meaningless unless the resources exist to realise the choices and decisions made by the person.

*Understanding the Link has Practical Implications*

How people think about legal capacity is important because it will inevitably influence the development of supported decision-making practice in Australia. Some practitioners have focused on the universal "right to decide" (ACT Disability, Aged and Carer Advocacy Service, 2013, p. 10) and the cultural changes that are necessary to enable people with disabilities in Australia to be supported to exercise this right. Although necessary and critically important, environmental change alone is unlikely to be enough. Similarly,



changing the legal system to incorporate supported decision making without changing cultural attitudes and perspectives is unlikely to be effective. There has been a tendency for those who focus on legal standing to ignore the necessary questions of whether the support provided to a person has been effective in enabling decision making or whether it is just informal substituted decision making. While carried out in an effort to move away from stigmatising labels of incompetence, discussions that avoid the reality of informal, substituted decision making will ultimately undermine the credibility of supported decision making. Although everyone has a right to legal capacity, the reality is that for some people, primarily those with profound or multiple disabilities, support will not be sufficient to enable them to make their own decisions.

If it is accepted that substituted decision making will sometimes be necessary, it is important to explore how these two concepts, substituted and supported decision making, can coexist on the continuum. One way of doing this is to evaluate overseas models of supported decision making that allow for both supported and substituted decision making. These models may provide useful information about how decision supporters move between acting as a supporter and a substituted decision maker. They may also offer insights into how mental capacity can be assessed when it includes support offered in the decision-making process. Significant questions remain about assessment of mental capacity in the context of this new decision-making paradigm. Rather than ignoring this area, future trials and research into supported decision making may need to explore new ways of conceptualising capacity as something that is shared, and evaluate the success of implementing new forms of assessment. Increased understanding in this area would enable the overuse of formal and informal substituted decision making to be challenged effectively.

### More Than Support *With* Decision Making

It is important to understand the difference between supported decision making and support *with* decision making. Both involve offering support to a person who is unable to navigate decision making independently. However, the critical difference is whether or not the process results in greater legal capacity for the individual.

Gunn, Wong, Clare, and Holland (1999) demonstrated that an individual's capacity to make decisions can be improved if the individual is provided with information that is accessible, in size and form. During their experiments, which sought to obtain consent from people with various cognitive disabilities (including intellectual disability, brain injury, and mental illness) for a blood test, they found that providing simple information was enough for some people to improve from being assessed as incapable to being assessed as capable of making the decision. While there is a body of knowledge on the impact of support on choice making (Cannella, O'Reilly, & Lancioni, 2005; Parsons, Harper, Jensen, & Reid, 1997; Wehmeyer et al., 2007; Willner, Bailey, Parry, & Dymond, 2010), further research is needed to determine how reasonable accommodation in the decision-making process improves a person's ability to act within the framework of the law. However, if supported decision making is limited solely to support with decision making, the full potential of the concept will not be realised. Supported decision making also requires the establishment of alternative legal frameworks or the reinterpretation of existing frameworks to allow mental capacity (or the person's decision-making skills) to be seen as broader than just the assessment of an individual's capacity. Therefore, supported decision making redefines decision making as interdependent and must change the way mental capacity is interpreted. If decision making is a shared process then the



assessment of the person's ability to make the decision must include the support provided to the process. It logically follows that our traditional definition of mental capacity, which focuses on assessing an individual's ability to understand and appreciate the consequences of a legal decision, must be reconceived in this new framework (Bach & Kerzner, 2010).

### **Not *Just* Reasonably Accommodating Decision Making**

Reasonable accommodation is defined in Article 2 of the UNCRPD as “necessary and appropriate modifications and adjustments . . . to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms”.<sup>3</sup> Such positive measures are needed as a result of ongoing systemic discrimination against people with disabilities (Power, Lord, & de Franco, 2013). Forms of reasonable accommodation such as building a ramp to accommodate a person in a wheelchair, or providing information in plain language for a person with an intellectual disability, are familiar to current practitioners. Similarly, reasonably accommodating the decision making of people with cognitive impairment, while important and necessary, should already be embedded in the practice of disability services in Australia. Supported decision making moves beyond reasonably accommodating decision making and is about determining how to reasonably accommodate people with cognitive impairment in the exercise of their legal capacity. As such, supported decision making explores the use of legal mechanisms that legitimise the interdependent nature of decision making and the concept of shared capacity. Co-decision making is one such legal mechanism that has been developed and legislated in Alberta, Canada, as part of the Adult Guardianship and Trusteeship Act (2008).

A full appreciation of the conceptual links between supported decision making and legal capacity will ensure that supported decision making is not limited to the exploration of support with decision making. While the development of forms of support such as accessible information, improved communication, and recognition of the influence of environmental factors (e.g., location and timing) are important (Mental Capacity Act Code of Practice, 2005), practitioners should not lose sight of the fact that the broader goal of supported decision making is to help people to exercise their legal capacity. This will entail the exploration and introduction of alternative legal mechanisms that give people legal standing and recognise their need for support to act within the framework of the law. Supported decision making is about providing the structures that will enable people with disabilities to determine their own lives.

### **Conclusions**

This article has explored the idealistic vision of the original ideas about supported decision making developed in Canada and has shown it to be an enigmatic and ill-defined concept. It has suggested there is a strong conceptual link between supported decision making and legal capacity that is important to understand. Supported decision making requires more than reasonably accommodating the decision-making process. It must also explore legal mechanisms that legitimise the interdependent nature of decision making and the concept of shared capacity. With a greater understanding of the conceptual foundations underpinning supported decision making, it is hoped that its practice can be evaluated more rigorously. Research will be important in understanding how supported and substituted decision making could coexist and how mental capacity could be assessed in this

new supported decision-making paradigm. If a more substantial theory of practice can be developed through the process of research and evaluation, supported decision making has the potential to empower and enrich the lives of people with cognitive disabilities, both in Australia and all over the world.

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### Notes

1. Legal capacity as defined by the Commissioner for Human Rights (2012) is “a person’s power or possibility to act within the framework of the legal system” (p. 7).
2. The Vulnerable Persons Living with a Mental Disability Act, CCSM c.V90 1993 (Manitoba); Representation Agreement Act, RSBC 1996 c.405 (British Columbia); Adult Guardianship and Co-decision Making Act, SS 2000 (Saskatchewan); Decision Making, Support and Protection to Adults Act, 2003 (Yukon); Adult Guardianship and Trusteeship Act, SA 2008 (Alberta).
3. Definition retrieved 3 February 2014, from <http://www.un.org/disabilities/default.asp?id=262>

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