



## Future direction in supported decision making

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## **Future Directions in Supported Decision-Making**

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### **Abstract**

*Supported decision-making is at the forefront of modern disability research. This is due to Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD), which creates a state obligation to provide support for the exercise of legal capacity. This turned the practice of supported decision-making into a human rights imperative. Government and funding agencies are increasingly focusing their attention on the area. Researchers are similarly increasing their interest in the field. The impending danger is that the rush of interest in the area will overshadow the original intention of supported decision-making: to ensure that people with cognitive disability are provided with the freedom and the tools to participate as equal citizens and for every individual to be free to direct their own life. This article explores the theoretical foundations of supported decision-making and the evolution of supported decision-making research. It explains the research that is emerging in leading jurisdictions, the United States and Australia, and*

*its potential to transform disability services and laws related to decision-making. Finally, it identifies areas of concern in the direction of such research and provides recommendations for ensuring that supported decision-making remains protective of the rights, will and preferences of people with cognitive disability.*

## Introduction

This article was inspired by our experiences during a one-day symposium held by the Hallmark Disability Research Initiative at the University of Melbourne in July 2015. The symposium brought together academics, practitioners, people with disability and service provider organizations to discuss future directions in supported decision-making research. Dr Anna Arstein-Kerslake hosted the symposium and Professors Peter Blanck and Gerard Quinn delivered the keynote lectures. The symposium included focus groups, a panel discussion, and presentations.

After hearing the call from symposium participants for using caution in going forward with supported decision-making research and practice, we have endeavoured to write this article as a precursor to future empirical work, research, and practice in supported decision-making. In this article, we will provide the background of the right to legal capacity – including the theoretical foundations of the right as well as a description and interpretation of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Article 12 provides the first articulation of the right to legal capacity in an international human rights instrument and also details the state obligation to provide support for the exercise of legal capacity. We will discuss how the practice of supported decision-making has evolved and how Article 12 has fuelled that evolution as well as the popularity of the concept. Finally, we will discuss some of the current research and practices in supported decision-making that are underway in Australia and the United States. We conclude the article with a specific warning of where we see supported decision-making may be at risk of losing its core purpose: to protect the autonomy rights of people with cognitive disability.

We use the term 'supported decision-making' in this article, because it is the term most commonly used in conjunction with the right to legal capacity in Article 12 of the CRPD. It is also the term that is increasingly being seen in legislative, policy, and practice documents. This term is intended to encompass active decision-making and other forms of support for decision-making.

Supported decision-making is one of the newest buzzwords in the disability field. The core of supported decision-making is that people with cognitive disability have access to assistance for decision-making to enable participation in society on an equal basis. Support for the exercise of legal capacity, in particular, is essential for such participation. Many people require such support to be able to enter into contracts, get married, vote, and engage in other legal exchanges and relationships. People with cognitive disability may particularly need such support –

including people with intellectual or developmental disability, psycho-social disability, dementia, Alzheimer's, acquired brain injury, and other disabilities potentially affecting cognition. It is our belief and the belief of many of the symposium's participants that such support is at risk of being co-opted by service providers and others in positions of disproportionate power. As with any other practices by such actors (e.g. person centred practice), if it is not constructed, led, and continually guided by those using the support, there is a high risk that it will become a practice that fulfils the needs and goals of the service providers as opposed to those being served.

## **Theoretical Foundations**

### **Support For Legal Decision-Making**

Support for decision-making is not new. It is something that we all use, on a daily basis. We all use people around us, available information, and other forms of support to make big and small decisions. Some people use a significant amount of support and others use less, based on the needs and preferences of each individual. It is such an ingrained part of human relationships and interactions, that we often don't think about how we use support in our decision-making.

Support for legal decision-making is particularly overlooked. Traditional legal theory was dominated by masculine concepts that accentuated the individual as an isolated being that exercises autonomy on his own, without assistance from others (Mackenzie & Stoljar, 2000; Silvers & Pickering Francis, 2007). Our legal systems have emerged from such theories and vestiges of such concepts of autonomy continue to exist. For example, much legislation still only allows individuals to make legal decisions if the individual can demonstrate that she or he can exercise such agency independently. This overlooks the reality that all people exercise decision-making and legal agency within the context of the social environment in which they live (Arstein-Kerslake, 2014).

The historical prevalence of the medical model of disability has also contributed to the construction and maintenance of legal systems and practices that only recognise independently exercised autonomy and decision-making. The medical model perceives a person with disability as a person with deficits that need to be corrected (Shakespeare, 2013, p. 216). It places the burden of social inclusion on the individual to correct. This is in contrast with a social model perspective that identifies the social environment as the creator of barriers that, in interaction with an individual's impairment, disable that individual and prevent social inclusion (Shakespeare and Watson, 1997; Oliver, 2013). This places the burden of social inclusion on society to correct – society must remove the barriers that it creates in order to allow participation of all, regardless of impairment. The way most legal decision-making structures currently operate, the burden is on the individual with cognitive disability to prove that she or he can independently engage in decision-

making. This is a reflection of the medical model of disability. The social model would instead require the legal system to ensure that appropriate social and other supports were in place to allow an individual with cognitive disability to engage in decision-making, either independently or with assistance from others. This is also the essence of what Article 12 of the CRPD requires and it should be the goal of any law, policy, or practice related to support for legal or other decision-making.

## **Legal Capacity**

Legal personhood is the law's recognition of an individual or entity as a subject with rights and responsibilities (Berg, 2007). Legal capacity is the mechanism by which those rights and responsibilities are granted or denied to the individual. It has always been, and will likely continue to be, a challenge to draw the line to determine who and what should be recognized as a legal person with full legal capacity. Women, slaves, immigrants, and other marginalized groups have been denied full personhood throughout history, some of which continues to this day (Flynn & Arstein-Kerslake, 2014, p. 81-82). Conversely, non-human entities such as animals, corporations, and natural objects are increasingly recognized as legal entities and granted both legal personality and legal agency (Archer, 2014; Green, 1946; Hogue Werhane, 1985; Stone, 2010).

People with cognitive disability are being denied legal capacity on the basis of purported measures of cognition. This is a denial of legal personhood on the basis of perceived cognition. This is dangerous because of the difficulty with the accuracy of assessing cognition and the questionable role that rationality plays in decision-making (Damasio, 2010; Lehrer, 2009). It is also concerning because of the gravity of denying an individual legal personhood. There are practical implications, such as the loss of the right to enter into contracts, marry, vote, or found a family. There are also psychological implications both for the individual and for society. A label of non-person and a denial of decision-making rights can have a significant impact on the psyche of the individual. The existence of such law may also serve to further stigmatize and create prejudice against people with cognitive disability – reaffirming the discriminatory notion that people with cognitive disability cannot be full and valuable members of society. For these reasons, it is imperative that we re-examine such law.

Refraining from denying legal capacity or legal personhood on the basis of cognitive disability may allow us to step closer to formal equality, meaning the elimination of barriers to equality in the recognition of an individual's decision-making. However, it will likely be a far cry from substantive equality; substantive equality would include both recognition of individuals with cognitive disability as decision-makers on an equal basis with others and the creation of appropriate supports to ensure that there is adequate assistance to make such recognition of decision-making meaningful and empowering for people with cognitive disability (Arstein-Kerslake, 2014a). This would require the law to

recognize the interdependence of all individuals by creating a legal recognition of the role of support in decision-making. It would require a move towards recognizing that autonomy is exercised in relation to our social environment. In order to achieve this, much work remains to be done both on how the law must change and how to best support people in the exercise of their legal capacity and decision-making. The remainder of this article provides a snapshot of the development of supported decision-making and some of the leading research in the area. It also explores what direction that research should take in the future, to ensure that substantive equality is achieved.

## **The Evolution of Supported Decision-Making Research**

An increasing awareness of the rights of people with disability led to the development of the CRPD, which was the first human rights treaty of the 21st Century. It came about through the persuasive lobbying of non-governmental organisations, disability organisations and governments who believed there was a need to clarify the rights of persons with disability under international law (Mackay, 2007). The CRPD and Optional Protocol entered into force on 3 May 2008, and has more than 160 international signatories. The purpose of the CRPD as articulated in Article 1 is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disability, and to promote respect for their inherent dignity.

It was during the drafting of Article 12 (Equal Recognition before the Law) of the CRPD that supported decision-making began to be discussed on the international stage. Supported decision-making was introduced as the mechanism through which State Parties could provide people with cognitive disability with the support they may require to be able to exercise their legal capacity on an equal basis with others. The provision of substituted decision-making does not meet this obligation (Bach & Kerzner, 2010) and Article 12 created an imperative to review guardianship legislation and other forms of substituted decision-making and replace them with mechanisms of supported decision-making (UN General Comment, 2014; Flynn & Arstein-Kerslake, 2014).

### **Development Of The Concept Of Supported Decision-Making In Canada**

The concept of supported decision-making developed in Canada in the late 1980s and early 1990s (Bach, 1998; CACL Task Force, 1992; CACL, 1998; Gordon, 2000; Rutman & Taylor, 2009). In this context supported decision-making was about removing the barriers that prevented people with disability from exercising their right to make decisions and providing them with the support necessary to make decisions and communicate their choices (Bodnar & Coflin, 2003). Supported decision-making was developed as a mechanism of obtaining equal legal rights for people with disability in the area of decision-making.

The first clearly articulated principles of supported decision-making were

written by the Canadian Association for Community Living (CACL) Taskforce in their report on Alternatives to Guardianship in August 1992. In the report, they suggested guardianship or substituted decision-making legislation was based on a "misconception that personal autonomy can only be exercised independently" (p.2). The group proposed supported decision-making as an alternative conceptual framework for decision-making which recognised that personal autonomy can be expressed interdependently. Supported decision-making was seen as a model of self-determination designed to accomplish the objectives of inclusion and participation. The supported decision-making model they were seeking to have legislated was based on a set of assumptions and principles which included: all adults have the right to self-determination and the right to make decisions affecting their lives with the support of family and friends of their choosing; everyone has a will and is capable of making choices; and the law must recognise the support provided and not discriminate on the basis of perceptions of mental capability (CACL Task Force, 1992 p. 6-7).

A strong movement formed to have these principles legislated and in June 1993 the government of British Columbia passed four interrelated pieces of legislation designed to protect the rights of people with disabilities: the *Representation Agreement Act*, the *Adult Guardianship Act*, the *Public Guardian and Trustee Act* and the *Health Care (Consent) and Care Facility (Admission) Act*. The *Representation Agreement Act* did not come into effect until February 2000 as a result of long and complex political negotiations.

### **Representation Agreement Act In British Columbia**

The *Representation Agreement Act (1996)* allows people to authorize one or more personal supporters to become representatives to assist in the management of personal affairs and if necessary make decisions on their behalf in the case of illness, injury or disability. The Act was created to offer all adults in British Columbia the ability to plan for future incapability and avoid the need for court appointed committeeship (the term used to refer to guardianship and financial management in British Columbia). It also aimed to provide an alternative to the court appointment of a committee for young people with developmental disability (intellectual disability), who were cared for by their families, at the time they become adults (Gordon, 2012a).

There are two types of representation agreements under the Act; section 7 and section 9 agreements. A section 7 agreement is designed for adults who need assistance with decision-making about some or all aspects of their lives because their competency to make decisions is in question. An agreement with these standard powers has a relaxed definition of incapability and provides legal status to the adult's personal supporters when informal help is not enough. The flexible definition of capability is one of the greatest strengths of the legislation as it shifts the burden of proof for incapability to others and challenges legal practitioners to develop new ways to understand how their clients with cognitive disability demonstrate capability and respect the unique

ways in which they communicate (Gordon, 2012c). The test of incapability for section 7 agreements recognises the "shades of grey" (Kerzner, 2011, p.39) inherent in the process and moves away from the traditional all or nothing notion of capacity.

A section 9 agreement has broader powers including major medical decision-making. A person must understand the type of decision covered by the agreement and the possible effects of giving these powers to a representative.

The development and implementation of the Representation Agreement Act in British Columbia is considered an important example of supported decision-making in law, policy and practice (UN Enable, 2006). However, it is acknowledged that while the Representation Agreement Act has spearheaded international thinking and developments in the area of supported decision-making the suite of legislation it is part of in British Columbia does not comply with the obligations in the CRPD because it also maintains a mechanism for substituted decision-making (Kerzner, 2011). Canada, like many other countries, is continuing to reevaluate their legislation and policy in light of the CRPD. [1](#)

## Supported Decision-Making Projects in Australia

The concept of supported decision-making was introduced to Australia, in the context of discussions regarding the CRPD and determining how to enable people with disabilities to exercise their legal capacity on an equal basis with others (Carter & Chesterman, 2009). It was seen as an alternative to traditional adult guardianship (Carney, 2012) in the context of growing recognition that guardianship legislation had become out-dated (Chesterman, 2010; NSW Legislative Council Standing Committee on Social Issues, 2010; Victorian Law Reform Commission, 2012).

As a signatory to the CRPD, Australia has begun to re-evaluate its guardianship, trusteeship and mental health laws (Gooding, 2012; NSW Legislative Council Standing Committee on Social Issues, 2010; Victorian Law Reform Commission, 2012; Weller, 2008). In 2014, the Australian Law Reform Commission in its report 'Equality, Capacity and Disability in Commonwealth Laws' established a set of national supported decision-making principles to guide the reform of all Commonwealth, state and territory laws relating to decision making. The principles set out to reflect the paradigm shift enshrined in the CRPD that people with disabilities are persons before the law who have the right to make decisions and control their lives.

In Australia, disability groups, advocacy organisations and service agencies have demonstrated their support for the development of supported decision-making by developing practice material (Advocacy for Inclusion, 2012; Watson & Joseph, 2015); and trialling practices (Advocacy for Inclusion, 2012; Westwood Spice, 2015; South Australian Office of the Public Advocate, 2009; Victorian Office of the Public Advocate, 2015; Watson, 2016a, 2016b). Conferences have been facilitated, one of which has guided this paper (University of Melbourne, 2015; Queensland



Advocacy Inc., 2013; Victorian Office of the Public Advocate, 2013; VALID, 2012; World Guardianship Congress, 2012). The following is a summary of some of the supported decision making projects that have occurred in Australia over the last five years.

**South Australia (SA).** Exploration of the practice of supported decision making in South Australia was led by Mr John Brayley the Public Advocate of South Australia. In 2010, the Office of the Public Advocate in South Australia obtained funding from the Julia Farr Benevolent Fund to conduct a two-year trial of supported decision-making which was completed in October 2012. The trial assisted people with a variety of cognitive disability who needed decision support to set up a non-statutory supported decision-making agreement with people already in their life. The trial resulted in 26 agreements being made over the two-year period for people with brain injury, intellectual disability, autism, and motor neuron disease. An independent evaluation of the trial suggested there were specific benefits to the majority of the participants including increased confidence in themselves and their decision-making, improvement in decision-making skills, growth in support networks and increased community engagement (Wallace, 2012).

The work commenced in this pilot has continued and been furthered by Cher Nicholson, the project coordinator, who now trains and mentors community disability organisations in the practice of their model of supported decision-making.

**Australian Capital Territory (ACT).** In 2013, ACT Disability, Aged and Carer Advocacy Service (ADACAS) carried out a project in preparation for the roll out of the National Disability Insurance Scheme (NDIS). Their project expanded on the model developed in South Australia and was implemented with six people who experience psychosocial and intellectual disability. The project aimed to understand how people with a decision-making impairment or whose decision-making capacity is undervalued, might be supported to make more decisions. The project worked with the communities of the participant 'decision-makers' to build the capacity of the whole community to engage in supported decision-making. The project concluded "...each person's capacity for self-determination was limited, not by their ability to make a decision, but by the support they received to exercise decision-making." (ADACAS, 2013, p.5) The recommendations that emerged from the project focused on the importance of recognising the wide range of support required, on a spectrum from formal to informal, and the importance of cultural change that normalises the active participation of people with cognitive disability in decision making (ADACAS, 2013).

**New South Wales (NSW).** In 2013 and 2014 the NSW Department of Family and Community Services, Ageing Disability and Home Care conducted a joint initiative with the NSW Trustee and Guardian and the NSW Public Guardian to explore what a supported decision-making framework might look like that included financial decision-making. The pilot aimed to produce tools and resources that could be used to educate the community about supported decision-making and to test those resources with people with cognitive disability receiving services from two of the three agencies involved. The pilot project recruited 26 participants who were

supported by 19 supporters of whom 10 were paid staff, 7 family members, 1 friend and 1 paid advocate (Westwood Spice, 2015, p.10).

The pilot demonstrated that tools and resources were insufficient to enable supported decision-making and that a facilitator was crucial to the effectiveness of supported decision-making (Westwood Spice, 2015). The participants made more of their own decisions and in new areas as a result of their involvement in the pilot. The barriers participants experienced with their decision-making were not intrinsic to them but "related to issues such as social isolation (leading to difficulties with supporter recruitment), lack of power and familiarity with making-decisions, low expectations by others, power imbalance and conflict of interest in relationships and the length of time that it takes for someone to be supported to become 'decision ready'." (Westwood Spice, 2015, p.13)

**Victoria (VIC).** In 2014 the Office of the Public Advocate in Victoria created a pilot supported decision-making project to address an issue encountered in the NSW trial: that many people wanting and needing support with their decision-making do not have people in their lives who can offer this assistance. The pilot project matched 18 volunteers who were trained in the practice of supported decision-making with 18 people with 'mild to borderline' intellectual impairments who were experiencing social isolation. The participants ranged in age from 20 to 65 years and lived in the Melbourne Metro and Geelong regions of Victoria (Burgen, 2016). Participants made decisions about where to live, whether to pursue work or educational opportunities, whether or not to try new social activities; they also made decisions about health care. The project found most participants indicated improvement in their capacity for decision-making and their quality of life. The key to the success of the project was a pool of skilled volunteers who were committed to spending many months developing a relationship with participants and persevering through many barriers when supporting them to make and act on their own decisions (Burgen, 2016, p.13). While resource intensive, the provision of support for decision-making by volunteers did address the neglect that appeared endemic in the lives of socially isolated participants (Burgen, 2016).

The Office of the Public Advocate has continued its involvement with supported decision-making in a joint venture with the Victorian Advocacy League for People with Intellectual Disabilities (VALID), Deakin University and the National Disability Insurance Agency (NDIA). The project continues the work of the previous pilot matching volunteers with people receiving services from the NDIS who want support making decisions about their individualised funding and service plans.

In Victoria, the practice of supported decision-making has also been explored with people with severe or profound intellectual disability (Watson, 2016a, 2016b). In a study by Watson (2016), five people with severe or profound intellectual disability and their supporters participated in a supported decision-making process each over a period of six months. This study's findings have been used to characterise supported decision-making for this population, in terms of the existence of two distinct but highly interdependent roles shared between supporters and supported. The role of the person with a disability in this dynamic is their expression of

preference, and the role of supporter is to respond to this expression of preference by acknowledging, interpreting and acting on this expression in some way. Several factors were found to underlie supporter responsiveness, providing a focus for practice and policy efforts for ensuring people with severe and profound disability receive appropriate support in decision-making (Watson, 2016).

### **The Future Of Australian Supported Decision-Making Practice**

Concerns have been raised about the viability of supported decision-making in the current climate of limited resources in the disability sector in Australia. Particularly when there are high numbers of people who are socially isolated and without natural supporters (Brayley, 2011; Browning, 2011; Victorian Law Reform Commission, 2012). However, the introduction of the National Disability Insurance Scheme (NDIS), has the potential to better resource the disability service sector in Australia (Bigby, 2013). The NDIS is a new individualised budgeting system for eligible people with permanent and significant disability, their families and carers (NDIS, 2013). Supported decision-making has been discussed in the planning and roll out of the NDIS as a means by which people with cognitive impairment can be supported to remain in control of their financial packages and service delivery (ADACAS, 2013). The initial work done in developing and trialing supported decision making in Australia suggests the practice offers significant benefits to people receiving and providing support with decision making.

### **Emerging Research and Evidence-Based Practice in the United States**

The Burton Blatt Institute (BBI), the Kansas University Center on Developmental Disabilities (KUCDD), and Quality Trust for Individuals with Disabilities (QT) recently began a first-of-its kind five-year project to help address existing gaps in research on supported decision-making. They studied whether and the extent to which people with intellectual and developmental disability who use supported decision-making show associated increases in self-determination and improved life outcomes (Blanck & Martinis, 2015; Kohn et al., 2013; Shogren & Wehmeyer, 2015). The researchers hypothesize that a positive association between the use of supported decision-making and increased self-determination will lead to other measurable benefits in daily life, such as improved community-living outcomes (Schur, Kruse, & Blanck, 2013).

This research is the first attempt to systematically study these interrelationships and benefits. The research program also aims to identify best practices in supported decision-making that provide the best opportunities for enhanced quality of life for people with cognitive disabilities (Blanck & Martinis, 2015; James & Watts, 2014; Kohn, et al., 2013; Office of the Public Advocate, 2014; Shogren & Wehmeyer, 2015).

The growing international call for the use of supported decision-making has begun to make strides in the United States (Bach, 2014; Blanck & Martinis, 2015; Campanella, 2015; Kohn et al., 2013). In 2013, a young woman named Margaret

"Jenny" Hatch won a year-long legal battle protecting her right to make her own life decisions using supported decision-making, instead of being subjected to a permanent, plenary guardianship (*Ross and Ross v. Hatch*, Circuit Court of Newport News, Virginia, Case No. CWF-120000-426, 2013). Like many people with cognitive disability, Jenny faced a guardianship petition challenging her right to make her own decisions. At the request of her parents, a court had ordered Jenny to be placed in temporary guardianship and to live in a group home, where they took away her cell phone and laptop, and would not let her visit with her friends (Hatch, 2015).

At the subsequent legal trial, Jenny won back her right to make her own decisions, including choices she had freely made prior to being placed under guardianship, such as where to work, what to do in her spare time, and who to see (Hatch, Crane, & Martinis, 2015).

Jenny's legal victory led to QT and BBI forming the "Jenny Hatch Justice Project" (JHJP), which is dedicated to protecting and advancing the legal rights of people with intellectual and developmental disability to make their own decisions using supported decision-making (Quality Trust for Individuals with Disabilities, 2013). In 2014, QT, BBI and KUCDD received funding from the U.S. Administration on Community Living to establish the National Resource Center on Supported Decision-Making (NRC-SDM), which serves as a clearinghouse for information, education, and research on supported decision-making ([supporteddecisionmaking.com](http://supporteddecisionmaking.com)). The JHJP and NRC-SDM annually convene a national symposium bringing together people with intellectual and developmental disability, their families, supporters, professionals, advocates and others to discuss the legal, research, and practice actions needed to advance knowledge, acceptance, and use of supported decision-making.

The first symposium was held in Washington, D.C., in 2013. Among other core recommendations, symposium attendees reported that research is needed to determine the efficacy of and best practices for supported decision-making. This recommendation was consistent with those of leading U.S. and international organizations, which contend that a robust research agenda is needed to evaluate supported decision-making practices, prevalence, and outcomes (James & Watts, 2014; Kohn, et al., 2013; Office of the Public Advocate, 2014). The recently funded supported decision-making research project aims to address the existing gaps in research. There are two central studies to be undertaken. The first study is descriptive and examines whether and the extent to which the use of supported decision-making is associated with demographic and individual factors such as age, gender, disability type and severity, and socioeconomic status. It further examines environmental factors, such as opportunities for choice in residential placement, use of technology, and service provider policies and practices (Blanck, 2014). The research will additionally explore the effects of these variables on actual and perceived self-determination, daily choice in life activities and community living, and overall satisfaction with quality of life.

Individual and environmental levels of supported decision-making (and not

individual mental capacity or legal capacity) will be assessed using the *Supported Decision Making Inventory System* (SDMIS), which is based on a social-ecological model of SDM as proposed by research partners Shogren and Wehmeyer (2015). The research will measure the association among personal and environmental factors and supported decision-making, and the degree to which personal and environmental factors mediate and moderate the relationship between legal decision-making status and supported decision-making. In addition, the project will examine the relationship between supported decision-making and perceived and actual self-determination, and the extent to which supported decision-making predicts overall life satisfaction and integrated community outcomes.

The second core study is experimental and will evaluate the efficacy of supported decision-making interventions, using the *Self-Determined Decision Making Model* (SDDMM). Using randomized control trials, this study explores the degree to which people with intellectual or developmental disability may be supported to engage in self-regulated problem solving, goal setting, and goal attainment pertaining to making decisions in their lives. The SDDMM is based on a similar instrument, the *Self-Determined Learning Model of Instruction* (SDLMI), which was developed and validated by researchers at the University of Kansas. This study examines whether and to what extent implementation of the SDDMM for people with intellectual or developmental disability is associated with their perceived and actual self-determination. In addition, the study explores the ways in which implementation of the SDDMM for people with intellectual or developmental disability improves engagement with supported decision-making.

Together, the two core studies will help to address whether and the extent to which supported decision-making is associated with increased self-determination, enhanced life and health outcomes, and greater community integration and participation. These initial studies will inform and guide researchers, practitioners, individuals, and their circle of supports and advocates, as to the development and use of future intervention-based research and practice in supported decision-making.

## **The Danger Zone: Ensuring Supported Decision-Making Protects Autonomy**

There is no doubt that Article 12 of the CRPD has driven a paradigm shift in the way decision-making capacity is conceptualized for those with cognitive disability – affirming the full and equal legal right to not only make decisions, but to have the necessary support to do so. Despite this shift, there is a concern that notwithstanding signatory nations' "best intentions"; there is an impending danger, that in the rush to operationalize supported decision-making, the objective of Article 12 may be lost.

Without close attention to the mechanics of how supported decision-making is implemented, there is a risk that it will become another tick box exercise, more to serve a bureaucratic purpose than to provide genuine choice and control for people with disability. Articulating this concern, a focus group participant at the Future

Directions in Supported Decision-Making Research Symposium (15 July 2015) that inspired this article said, "I think we are at risk of supported decision-making becoming another thing that services are just required to do, like planning. There is no real focus on how and why, just that it is done". Another participant replied to this comment with, "Yes, I think you're right... there needs to be focus on the how. How do we really work out what people want? A written plan or a supported decision-making agreement is well and good, but how do we get there?" This expressed lack of focus on the operationalization of supported decision-making is increasingly being raised in the literature. As argued by Bigby et al., "there is little evidence on what works in terms of ensuring the will, preference and rights of people with cognitive disability are actually at the centre of decision-making" (Bigby, Whiteside, & Douglas, 2015 p.9)

Although symposium participants expressed concern around a lack of direction regarding the operationalization of supported decision-making generally, their concern was particularly focused on people with high and complex support needs. In referring to this group, a focus group participant used a colourful metaphor to describe their exclusion. "These people are in real danger of not receiving an invitation to the party, and if they do, it will be tokenistic, you know... I'm pretty sure they won't be asked to dance". Symposium participants responded to this comment, suggesting that there may be lessons to be learned from past self-determination movements such as self-advocacy and person-centred practice. As is the case for supported decision-making, to date, these movements have been dominated by people with mild, as opposed to more severe cognitive disability. As articulated by one of the symposium participants "I think we are once again leaving a whole group of people out. We've been there before. Like with planning. For these people it's different, and it's not easy. I don't know, perhaps they will always be in the too hard basket". [2](#)

There is a shallow evidence base around how best to hear the preferences of people with more complex support needs. Some may argue that the promises embedded in Article 12, regarding supported decision-making may not be relevant to this group. This argument is often centered on the inability of people with severe or profound cognitive disability to understand and process information rationally, engage in purposive behaviour, or communicate preference intentionally. Due to the highly dependent nature of their lives, for them, autonomous decision-making is challenging. However, if Australia and other signatory nations to the CRPD are to live up to their obligations under Article 12, significant questions need to be asked. These questions are centred around how best to support people with severe to profound intellectual disability to have their will and preference drive decisions made about them rather than what is perceived to be in their best interest.

The challenges of responding to the expression of will and preference for people with severe or profound cognitive disability, are well documented in the literature. The expression of preference, choice and therefore self-determination for this group is rarely straightforward. This demands dedicated time and attention (Finlay, Walton, & Antaki, 2008; Grove, Bunning, Porter, & Olsson, 1999; Hogg, Reeves, Roberts, & Mudford, 2001). However, if we are to live up to our obligations we need

to radically reframe the debate (Quinn, 2010 p.2).

Beamer and Brook's (2001) early characterization of supported decision-making suggests that the process of decision-making support should not be defined in terms of capacity but rather in terms of the quality and quantity of support available to the person being supported.

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

For signatory nations to live up to their obligations under Article 12 of the UNCRPD, they need to take care, to ensure all citizens are considered when developing legislation, policy and practice guidelines around supported decision-making. This includes those who historically, have not been invited to the self-determination "party".

There remains much work to be done to discover how supported decision-making is best implemented. Bigby et al. recently noted that "there is little evidence on what works in terms of ensuring the will, preference and rights of people with cognitive disability are actually at the centre of decision-making" (Bigby et al., 2015 p.9). More evidence needs to be gathered on how to meaningfully and accurately discover an individual's will and preference and how that process can become part of service provision and other more formal structures. In addition, more information is needed on how to realise an individual's will and preference, especially in difficult situations where the decision may pose some harm to the individual or where an individual may be expressing one preference for the immediate-term which conflicts with their longer-term will or goals. Scholars have begun to explore these areas Flynn & Arstein-Kerslake, 2014a; Flynn & Arstein-Kerslake 2014; Gooding 2015) and much work remains to be done. More robust knowledge in these areas will allow us to ensure that supported decision-making is used in the manner which most thoroughly fosters autonomy and well-being.

## Conclusion

At its core, supported decision-making is about taking the time to listen and communicate. For some people, including some people with cognitive disability, this may mean more time spent for the processing of information and for effective reciprocal communication between parties. As we have outlined in this article, research is underway to discover how best to achieve such supported decision-making, yet more is needed.

Our concern in this field is two-fold: that the research conducted in the area is conducted in such a way that does not foster the participation and autonomy rights of people with cognitive disability; and that the practice of supported decision-

making is co-opted by service providers and becomes merely positive rhetoric as opposed to transformative practice. One way to help avoid both of these potential pit-falls is to ensure that people with cognitive disability are guiding the design and practice of research as well as of the implementation of supported decision-making.

Research and practice in this area began in Canada over 25 years ago. After the CRPD, Australia and the United States are now engaged in similar work, which is guided by the principles of the CRPD. It seems imminent that these jurisdictions will continue to progress work in this area and that others will soon follow. We hope that this article has provided information on supported decision-making research and practice that currently exists and that our cautionary notes will be heeded for future work in these jurisdictions and elsewhere.

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## Endnotes

1. See Law Commission of Ontario <http://www.lco-cdo.org/en/capacity-guardianship>

Assisted Decision Making (Capacity) Bill 2013 in Ireland

<http://www.oireachtas.ie/viewdoc.asp?DocID=24147&&CatID=59>

The Draft Rights of Persons with Disabilities Bill (2012) in India

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2. Participants at the Future Directions in Supported Decision-Making Research Symposium at the University of Melbourne (15 July 2015) were informed that the information gathered and contributions made during the focus groups would be used in the development and text of this article. All comments are anonymized, unless otherwise noted.

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