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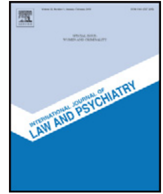

# Supported decision making: A review of the international literature

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ABSTRACT

Supported decision making (SDM) refers to the process of supporting people, whose decision making ability may be impaired, to make decisions and so promote autonomy and prevent the need for substitute decision making. There have been developments in SDM but mainly in the areas of intellectual disabilities and end-of-life care rather than in mental health. The main aim of this review was to provide an overview of the available evidence relevant to SDM and so facilitate discussion of how this aspect of law, policy and practice may be further developed in mental health services. The method used for this review was a Rapid Evidence Assessment which involved: developing appropriate search strategies; searching relevant databases and grey literature; then assessing, including and reviewing relevant studies. Included studies were grouped into four main themes: studies reporting stakeholders' views on SDM; studies identifying barriers to the implementation of SDM; studies highlighting ways to improve implementation; and studies on the impact of SDM. The available evidence on implementation and impact, identified by this review, is limited but there are important rights-based, effectiveness and pragmatic arguments for further developing and researching SDM for people with mental health problems.

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## 1. Introduction

There are people with mental health problems who, without support, would be assessed as incapable of making certain decisions but, with the appropriate support, are able to make those decisions. Supported decision making (SDM) refers to the process of providing support to people whose decision making ability is impaired to enable them to make their own decisions whenever possible. The central principle underlying SDM is autonomy, that "no person should have another person appointed to make a decision on their behalf, if they could make the decision themselves with assistance and support" (Chartres & Brayley, 2010, p. 1).

SDM has perhaps been the focus of more attention in the areas of intellectual disability and end-of-life care but it is also of great relevance to mental health services, especially when compulsory intervention, at any level, is being considered. SDM should be considered as an important part of a continuum of decision making from autonomous decision making through to substitute decision making. Law, policy and practice have tended to focus on either end of the spectrum and have sometimes approached decision making as if people are either globally capable or incapable, but most people require some level of support with decision making.

Over the past twenty years legal frameworks for substitute decision making, usually some form of mental capacity/incapacity law, have been developed across many jurisdictions, including the Adults with Incapacity (Scotland) Act 2000; the Mental Capacity Act 2005 for England and Wales and the proposed Mental Capacity (Health, Welfare and Finance) Bill for Northern Ireland. Implementation of these laws has highlighted the need for support to prevent the need for substitute decision making (Richardson, 2012). One of the other main drivers for the recent developments in the theory and practice of SDM is the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) 2006. It requires States to "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity" (Article 12(3)). Article 1 of the UNCRPD states that "Persons with disabilities include 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" and so clearly includes people with mental health problems.

In some ways the use of 'capacity' in both 'legal capacity' and 'mental capacity' in the debate around supported and substitute decision making seems to have led to some level of overlap and confusion. McSherry (2012) suggests that 'legal capacity' encompasses both a person's legal standing and their legal agency or power to act, and so a

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person may lack the mental capacity to make the relevant decisions but retain legal capacity. It seems relatively straightforward that legal standing or status should apply universally but the second component, of legal agency, seems more complex. It has been argued that, even in the relatively rare situations when a person, regardless of the supports available, is unable to make the relevant decision, the process to make that decision should still be framed as supported or facilitated decision making (Bach & Kerzner, 2010) rather than as substitute decision making. In these situations, however, someone else will be making the decision and so it would seem important to clearly acknowledge that, partly at least, to ensure the appropriate safeguards are in place. In this article the focus is not on these on-going and evolving debates and the phrase 'decision making ability' is used.

SDM is important for a range of reasons, which can be divided into three main groups: rights-based, effectiveness and pragmatic arguments. It could be argued that the rights-based arguments are sufficient on their own, but the effectiveness and pragmatic arguments are also relevant, especially in the context of limited resources.

The rights-based arguments state that if a person has the ability, with the appropriate support, to make decisions about their own life then the appropriate support should be provided and the individual's subsequent decisions should be respected. The UNCRPD is the clearest expression of these rights. The rights-based arguments have been summarised by Bach and Kerzner (2010, p. 6):

> "The ability to make one's own decisions based on personal values and in the context of meaningful choices is a defining feature of what it means to be a person and a full citizen. A basic tenet of liberal–democratic philosophy is that the state has a primary role in protecting autonomy or the right of individuals to choose and pursue their own life path, and all the decisions that entail along the way".

Bach and Kerzner (2010) therefore argue that the central question should no longer be, 'does this person have the capacity to make that decision?' but, rather, 'what supports are needed to ensure that this person can best exercise his/her rights?'

The effectiveness arguments focus more on the benefits that SDM provides for individuals, families and societies. Chartres and Brayley (2010) suggest that SDM has three broad benefits. First, it supports personal autonomy, the authority and control that people have over their own lives. Second, it provides a clearer structure for individuals and families negotiating and making decisions and plans in the context of family, friends, informal carers and services. Third, they suggest that it provides a more comprehensive means of ensuring that people's legal and personal capacity to make decisions are promoted and respected. Chartres and Brayley (2010, p.32) go on to list the potential benefits for a person as: "citizenship, personal empowerment; self-determination; self-esteem; respect for decisions; control over their lives; confidence in decision making; confidence in rights; development of decision making skills and capacity; increase in areas of decision making; and increase in support networks".

The process of developing and implementing SDM may also provide societal benefits. These may include: contributing to a better and wider understanding of the importance of respecting the rights of all citizens; a more inclusive approach to mental health and disability; and generally enabling better decisions to be made.

The last potential benefit to society, enabling better decisions to be made, overlaps with the pragmatic arguments for SDM. These are based on the procedural justice research in mental health services which suggests that, in an assessment process, if people are listened to, respected and felt that their views are being considered, even if they do not agree with the outcome of that process, they are less likely to feel coerced and dissatisfied (Galon & Wineman, 2010; McKenna, Simpson, & Coverdale, 2000). In general terms, it seems reasonable to assume that if a person has received the support necessary to make their own decision, such as the type of service to use, they may be more willing to fully engage and benefit from that service.

## 2. Approaches to supported decision making

SDM is located on a continuum of decision making, but within SDM there is also a wide range of possible approaches.

Bach and Kerzner (2010) suggest that three main types of support are required to meet the UNCRPD Article 12(3) requirement for SDM. These are:

> "Supports to assist in formulating one's purposes, to explore the range of choices and to make a decision;Supports to engage in the decision-making process with other parties to make agreements that give effect to one's decision, where one's decisions requires this; andSupports to act on the decisions that one has made, and to meet one's obligations under any agreements made for that purpose" (p. 73).

They break this down further into some of the types of support services that should be provided. These include: life planning supports such as person-centred planning; advocacy; communication and interpretive supports; representational supports which involve people who know the person well contributing to the process (these may overlap with substitute decision making); relationship-building supports; and administrative supports.

Chartres and Brayley (2010, p.28) also provide a list of the range of SDM services which need to be provided. These include: informal assistance of family and friends; the range of approaches to communication; SDM representatives/networks; support to the other people involved; practice guidelines; information, education and awareness campaigns; advocacy; community support systems; and practical assistance.

Advance care planning may also facilitate SDM. This refers to a process of making decisions when you have the ability to do so, for a time in the future when your ability may be impaired. There is a range of possible approaches to advance care planning. The two main provisions are advance care directives or decisions, and advance statements. Advance care directives or decisions are legally binding, advance refusals of specific forms of intervention. Advance statements are much broader communications of a person's preferences and can cover all aspects of decision-making but, while they should be considered and respected where possible, they are not legally binding. Advance care planning can therefore be thought of as a form of support for future decision making.

Gooding (2012) suggests that it may be useful to distinguish between formal SDM, a legal process in which someone is appointed to assist with decision making, and more general informal supports for decision making. For the purposes of this review a broad definition of SDM, which covers both formal and informal supports, was used.

## 3. Method

The main aim of this review was to provide an overview of the available evidence relevant to SDM and so facilitate discussion of how this approach could be further developed in mental health services. The objectives were therefore to gather, appraise and summarise international evidence; consider and discuss the implications of the research for policy makers and practitioners, and identify gaps/limitations in the research.

The method used for this review was a Rapid Evidence Assessment (REA). REAs provide more thorough syntheses than narrative reviews, and are valuable where a robust synthesis of evidence is required, but the time or resources for a full systematic review are not available. The search strategies used a range of terms to identify relevant research including: decision making; support; legal guardians; proxy; patient-

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