Supported decision making: a review of the international literature

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Title: 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.

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 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. 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 entails 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 their 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 people's legal and personal capacity to make decisions is 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 feel 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 (McKenna, Simpson & Coverdale, 2000; Galon & Wineman, 2010). 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; and Supports 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-centred care; advance directives; living wills; informed consent; advance care planning; advance plan; advance decision; advance statement; mental capacity; mental incapacity; mental competency; decision making capacity; substitute decision making; guardianship; person centred.

The searches were limited to literature from 2000-2011 and the English language. The searches were also limited by a number of key jurisdictions that were selected to provide a range of examples and comparisons of law and policy frameworks: England and Wales, Scotland, and Ontario in Canada were included because they have mental capacity laws in

place; Victoria in Australia and Northern Ireland were included because both these jurisdictions are exploring innovative approaches to capacity legislation and SDM (Chesterman, 2010; Department of Health, Social Services and Public Safety, 2010). Relevant studies that were found which did not refer specifically to these jurisdictions were still included.

A number of electronic databases were searched to identify a range of different studies of relevance to this review: Cochrane Library, Embase, Medline, PsycInfo, Campbell Library, SocIndex, Web of Science, CRD (NHS EED) and EconLit. A number of websites were also searched for additional relevant reports or documents.

Summaries of all studies identified from the electronic search were imported into a database, duplicate studies removed, and then those studies that were directly relevant to the topic were shortlisted for more detailed examination of their full texts. Additional reports from the 'grey literature' website searches were also screened and those determined to be relevant were also assessed in detail. To be included the reference had to be relevant to SDM for people with long term physical or mental impairment or disability or older people or people requiring long-term care. Relevant data from each study was summarised in a structured table and each included study was also assessed for overall methodological quality and for relevance to this review.

There were 3756 references located through the database searches with 324 identified as duplicates. 3283 were excluded on the basis of the abstract and so 149 full text versions were screened. A further 124 were excluded on the basis of the full text and 25 were included in the evidence review. In addition 47 references were assessed from the grey literature and 28

references were used to inform the background and discussion. The full list of references, quality scoring and evidence tables are available on request from the corresponding author.

4. Results

The results are organised into four main themes: 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.

4.1 Stakeholders' views on supported decision making

Five studies explored the views of service users and providers on advance care directives. Service users were in long term care facilities in Canada; people with Huntington's chorea in Wales and older people in hospital in Sweden and Switzerland. In general they wanted clear information about their likely care needs, presented simply, to be able to discuss the information with trained staff, and to be supported in having the level of involvement in decision making that they were comfortable with.

Pauls, Singer and Dubinsky (2001) aimed to describe an ideal model for the transfer of advance care directives relating to patients from long-term care facilities who attended emergency departments in Ontario, Canada. The study found that staff working in both types of setting wanted the advance care directive form to use simple language; to provide three or four levels of care from which residents could choose from; contact details about any substitute decision maker; to be available in other languages; and to use culturally appropriate terms. Staff wanted the process for the use of advance care directives to include: educational sessions for residents and relatives about the directive and advance care planning; and for there to be regular reviews of advance care directives. Staff were concerned that even if a

form was available it may not be followed; and had reservations about abiding by an advance care directive if they felt the treatments requested (or declined) were not "appropriate" to the resident's medical condition.

The assumption underpinning SDM is that everyone should have the opportunity to participate in decisions about their care if they have the ability to do so. A second Canadian study identified that people may differ in their desire to participate actively in decision making. Funk (2004) evaluated the preferences of people in long-term care in Canada (British Columbia) regarding four care decisions: bedtimes, medication choice, room transfer, and advance care directives, and the predictors to these responses. The study found that, for all four care decisions, patients were significantly more likely to prefer to be actively involved in decision making if they had higher levels of education ($p<0.01$); greater self-confidence ($p<0.001$); and a greater number of chronic conditions ($p<0.05$). The study suggests that people in long-term care have different preferences for making decisions, with some wanting active involvement and others wanting no involvement.

Ekdah, Andersson and Friedrichsen (2010) also found that not everyone with the ability to make decisions wants to be actively involved in making decisions about their medical care. They explored the views of older people in hospital in Sweden on the implementation of SDM in medical decisions. They found that patients could be categorised into three groups: those who felt satisfied with the information and participation provided; those who wanted more information and more participation in the decision-making process; and patients who did not feel a sense of participation, but did not wish to participate. The study suggests that healthcare staff and organisations should try to minimise the barriers to SDM, so that everyone who wants to participate can do so. However, it also suggests that patients'

individual preferences for involvement with SDM should be taken into account so that people are not pushed into having to make decisions they are not comfortable about.

Bisson, Hampton, Rosser and Holm (2009) conducted a qualitative study of stakeholders' views as a first step in conducting a thematic analysis designed to support the development of a care pathway for advance decision making for people with Huntington's disease in Wales. They found that stakeholders wanted consistent verbal and written information, with specific information regarding Huntington's disease; for advance decisions to be conducted with a known, approachable healthcare worker, in the home or clinic setting; service users preferred an early introduction to advance decisions (in contrast with professionals who thought it should be delayed), and a single, short and easy to follow advance decision form, with space for personal statements and wishes.

People may have many reasons to choose to complete an advanced care directive. Pautex, Notaridis, Déramé and Zulian (2010) explored the reasons why elderly cancer patients completed advanced care directives during hospitalisation in Switzerland. Reasons for completion included enhanced autonomy (31/50, 62%); enhanced communication with caregivers (20/50, 40%); fear of treatment (17/50 (34%); avoiding becoming a burden (14/50, 28%); enhanced communication with their surrogates (7/50, 14%); and to be sure their preferences would be respected (6/50, 12%).

One study, which was published after the searches had been completed, but is included because of its relevance and importance, was the evaluation of the Supported Decision Making Project in South Australia. The Project evaluated the use of Supported Decision Making Agreements that identified a specific supporter and monitor. Most participants had

intellectual disabilities and/or brain injury. People with mental health problems and/or dementia were excluded. The evaluation reported that "there were specific benefits to most of the participants. These were seen in their increased confidence in themselves and in their decision making. There was evidence of improvement in decision making skills. Participants described the growth in their support networks. Many reported that they felt more in control of their lives. Participants gave evidence that they had increased their engagement with the community, either through expanding their options or through making decisions that changed their circumstances" (Wallace, 2012, p. 4).

4.2 Barriers to the implementation of supported decision making
The evidence suggests that implementing SDM is not a simple process, it takes time and resources, and may require a shift in attitudes of some care providers and in some service users themselves.

An important aspect of implementing supported decision making is the process of obtaining informed consent. Goldsmith, Skirton and Webb (2008) conducted a review of the international literature on obtaining informed consent to healthcare interventions from people with an intellectual disability (ID). They reported that the main barriers to obtaining informed consent by healthcare staff were staff attitudes. Several of the included studies reported that staff assumed that individuals with ID were unable to consent to treatment, and one study demonstrated that staff were unaware of guidelines relating to consent. Five studies reported that informed consent could be better achieved if the information was broken down into stages, as this improved the understanding of consent. The included studies also concluded that people with ID lack experience in decision making and that this may affect their ability to make informed choices. The review also found a high level of acquiescence from people

with ID. Healthcare decisions were usually made by the professionals, with the individuals often just agreeing with them, because they considered themselves as having no real choice in their treatment. The review suggested that a more active approach to SDM making is needed to ensure the collaboration of people with ID in decision making.

Two studies identified a number of barriers to effective person-centred planning (PCP), which again overlaps with SDM, with people with intellectual disability. Dowling, Manthorpe and Cowley (2007) identified a number of barriers and facilitators to the implementation of PCP in social care services for people with a learning disability in England. They carried out a literature review, which concluded that implementation of PCP was slow due to the ambitious nature of the policy. Other barriers included: insufficient time and resources to adequately implement PCP; insufficient staff training; managers who do not take into account the views of frontline staff on how to implement PCP; conflict between staff and service users in relation to choices; and an organisational culture that was not supportive of the adoption of PCP.

McConkey and Collins (2010) evaluated goal setting as a way to increase choice and engage support staff in personalised planning of care for people with intellectual disabilities in Northern Ireland. Goals related to participating in social, entertainment or sporting activities, increasing independence or working opportunities, and increasing contacts socially or with families. The majority of people with intellectual disability (60/84; 71%) felt that it was easier for them to meet goals around social activities if staff helped them to make arrangements and accompanied them to the relevant activities. Some participants (12/84; 14%) also valued having staff assistance in-house, for example, when cooking and managing budgets. Barriers that hindered achievement of these goals included: inadequate planning or

information available about the activity; a risk assessment not being done (35/74, 47%); the facility or resource not being available or considered not to be suitable (16/74, 22%); and not enough staff to help with the activity (10/74, 14%).

One Randomised Controlled Trial (RCT) in England (Papageorgiou, King, Janmohamed, Davidson & Dawson, 2002, 2004) identified several barriers to the implementation of advance care directives with psychiatric in-patients who were receiving compulsory treatment. Most of these barriers related to attitudes and expectations of staff and patients. Ninety per cent of staff and 85 per cent of patients said that they did not find advance care directives useful in managing care. The reasons staff gave for this included: unrealistic preferences (reported by 5/26 staff, 19%); advance care directives not being integrated into the care programme approach (5/26, 19%); and that the consultant/team were not aware of them (14/26, 54%). Patients thought that the problems were that staff were not aware of the directives or did not refer to them (10/24, 42%); their instructions were not acted upon (2/24, 8%); and that the individual's care did not require it (7/24, 29%). Patients had some recommendations for how to improve the booklet which included: changing the design of the booklet so that they could carry it around (e.g. more like a bus pass); making staff more aware of it and use it; making its existence prominent in the medical notes; involving consultants/professionals in its preparation; and allowing people more time to fill it in.

One study from Scotland identified problems around adherence with guidance or protocols for completing advance statements for patients with mental health problems. Reilly and Atkinson (2010) found that many advance statements that were presented to the Mental Health Tribunal in Scotland had not been completed according to agreed guidance or protocol. The format of the statements was not consistent and did not always conform to the

template suggested by the Scottish Executive. For example, of the statements analysed, 28% were not prepared on the form and were either put together on 'unofficial' forms or on blank sheets of paper. There were considerable differences in the content of the statements, from a simple, single page which consisted of 'I do not want ECT' to three to four page documents outlining a wider variety of medical and personal issues. The statements usually included at least one specific treatment refusal (96%) and/or named specific medications they were prepared to take (45%).

Ekdahl et al. (2010) also identified the barriers to the implementation of SDM in medical decisions with older people in hospital in Sweden. They found that barriers to the communication needed for SDM included the patient being too ill; having multiple doctors involved in their care, and the stress level of staff.

4.3 Improving the implementation of supported decision making

Eight studies reported on ways to improve the implementation of SDM. Three focused on issues to do with communication of information, and found that supporting people to make decisions involves listening to them (Hoole and Morgan, 2011), asking about their preferences and choices in an open and non-challenging way (Antaki, Finlay, Walton & Pate, 2008), and providing clear and simple written information (Wong, Clare, Holland, Watson & Gunn, 2000). The next three studies reported beneficial effects of support training (Koritsas, Iacono, Hamilton & Leighton, 2008; Robertson et al, 2005) and end of life decision support tools for staff (Karp 2009) on patient choice and the quality of support offered. The final two studies in this theme (Foy, MacRae, Thom & Macharouthu, 2007; Hossler, Levi, Simmons & Green, 2011) explored the use of different media to improve implementation.

Hoole and Morgan (2011) conducted a qualitative study on the experiences of people with intellectual disabilities involvement in services in England. The study found that service users felt left out of the decision-making process. However, there were some instances where people felt their personal and professional networks encouraged empowerment and inclusion. This tended to be when people listened to them and advocated on their behalf. Participants also expressed hope for further involvement in decision making.

Antaki et al. (2008) conducted an observational study of the routine practice of staff offering support and choice to people in a residential service for intellectual disabilities in England. Using conversation analysis they concluded that there were some successful ways to offer choice and other practices that were less successful. Some of the most successful practices included open questions and immediate multiple-option alternatives. A practice considered to be less successful was asking for repeated clarifications/checks as this can be interpreted as querying the decision and result in the resident changing their decision.

Wong et al. (2000) evaluated how simplifying the provision of information affected the ability of people with disability in England to make decisions regarding blood tests. They noted that decision making ability significantly improved as the decision-making tasks were simplified for those with mental health problems, but not for those with intellectual disabilities or dementia. Uninterrupted disclosure (giving verbal information in one sequence while participants followed the written information on a sheet, followed by patients paraphrasing the content) was the most effective strategy, accounting for a shift in decision making ability for nine (out of 82) people.

In Victoria, Australia, Koritsas et al. (2008) conducted a before-and-after study to evaluate the impact of active support training delivered to support workers of people with intellectual disabilities. Active support was designed to enhance the interactions between support workers and people with disabilities in a structured manner, through the use of domestic activities. The study found a statistically significant improvement over time in completion of domestic tasks, reduction in problem behaviour and increase in overall choice. However, these improvements were measured by the nurses who received the training who may be more inclined to perceive improvements following their training.

Robertson et al. (2005) reported that staff training on PCP for people with ID significantly improved the number of choices offered, the amount of active contact with family and friends, and community involvement, but also increased scores measuring problematic behaviour.

Karp (2009) conducted a before-and-after study of a two-component intervention designed to improve end-of-life decision making in Ontario, Canada. The first component was an end-of-life decision-making toolkit, and the second was a resident-centred end-of-life decision-making education course delivered to nurses in long-term care facilities. The study found that nurses' knowledge and skill in facilitating resident and family end-of-life treatment decisions improved after the toolkit and education course were introduced. However, due to the small sample size (N=9) the study did not explore whether there was statistically significant improvements from pre- to post-intervention.

Two studies explored the effects of different media for conveying information to people to support their decision making about advance care directives. The studies concluded that

written information could inform some people but was not enough to allow everyone to fully understand the concepts (Foy et al. 2007). New media such as a computer programme could also be useful, but might also make it easier to overwhelm users with too much information (Hossler et al. 2011).

Foy et al. (2007) explored the knowledge of patients with severe mental illness in Scotland about advance statements before and after the implementation of an information booklet. The number of respondents who had heard about advance statements prior to the booklet was 8.6% (5/58); with 3.4% (2/58) saying that they had a reasonable understanding of what advance statements were. After receiving the booklet, 47 per cent (16/34) demonstrated a definite knowledge of advance statements, however, 32 per cent (11/34) still did not fully grasp the concept. Of those respondents who read the book, 70 per cent (19/27) said they would now consider having an advance statement.

Hossler et al. (2011) conducted a before-and-after study to evaluate the impact of a computer interactive program to help patients in the US with moderate physical impairment (due to amyotrophic lateral sclerosis) develop an advance care directive. The study found that, on a scale of 0-10 (where 10 equals extremely satisfied or extremely accurate) patients overall were satisfied with the computer program (mean score= 8.5). The perceived accuracy of the advance care directive at reflecting their wishes for end-of-life healthcare was similarly high (mean =8.6). Participants thought the amount of information provided by the computer program was slightly too much (mean rating=6.8; when 1=too little; 5=about right; 10=too much).

4.4 The impact of supported decision making

Although Ontario in Canada has had legislation on consent and substitute decision making since the 1990s, one study found that this had not been translated into real support for people receiving in-home care. McWilliam, Ward-Griffin, Sweetland, Sutherland and O'Halloran (2001) found that service providers still took the role of experts, tending to assume full responsibility and pay little attention to the knowledge, status and authority of clients as potential partners in care. Some providers understood the importance of involvement in decision making, and yet still had reservations about the potential of their clients to contribute knowledge, status, and authority to the care partnership.

Two studies from England suggest that advanced care planning may not have a substantial effect on the lives of older adults. Froggatt, Vaughan, Bernard and Wild (2009) conducted a postal survey of managers of care homes for older adults in England on their implementation of advance care planning. The survey, which had a low response rate, revealed that the majority of care home organisations required completion of advanced care plans (189/213; 88.7%), and just under half of the organisations used a specific end-of-life planning tool (101/213; 47%). Despite this requirement, only 38 per cent of managers stated that any residents in their care homes had completed the advanced care plan process, and fewer than 25 per cent of residents in these participating care homes had an advanced care plan.

Similar issues were identified for patients treated in hospital. Ahmed, Daniels, Aswad, Ng and Cohen (2011) audited the implementation of the Trust Resuscitation Policy on the older adult psychiatric wards of a London hospital in England. The study found that in the majority of cases (20/22, 91%), resuscitation status was not discussed. In the two patients (9%) who had their resuscitation status discussed, one patient was not involved in the decision making (the decision was made by a family member, despite there being no evidence that the patient

was unable to consent); the other patient was involved in the decision making. The study suggests that advance planning is not consistently being implemented on older adult psychiatric wards.

The literature searches identified two randomised controlled trials (Papageorgiou et al., 2002, 2004; Molloy et al., 2000) and one systematic review which included Papageorgiou et al. (2002) (Campbell and Kisley, 2010) which found limited evidence of the clinical benefits from the use of advanced care directives, although, as highlighted by the stakeholders' views there are many reasons for supporting decision making.

The first RCT assessed the effectiveness of providing psychiatric inpatients in England (receiving compulsory treatment) with a booklet on advanced care directives, with the opportunity for these patients to make advance decisions regarding their treatment. Patients who received information about advanced care directives were compared with a group receiving usual care. The study found that there was no statistically significant difference in compulsory readmissions to hospital within one year of discharge (p=0.8). In addition, there was no statistically significant difference between groups (p=0.368) on symptom scores of severe mental illness, or satisfaction with hospital care (p=0.910) (Papageorgiou et al., 2002, 2004).

The systematic review (Campbell and Kisley, 2010) compared the impact of advanced care directives with standard care. Campbell and Kisley found no statistically significant differences in psychiatric admissions and compliance with mental health treatment for patients who had advanced care directives. However, the study did find that people provided

with an advanced care directive were less likely to be assessed under the Mental Health Act

(WMD= -0.20, 95% CI: -0.32 to -0.08; p=0.0016).

The second RCT (Molloy et al., 2000) assessed an advanced care directive programme that

provided nursing home residents and families in Ontario, Canada, with a range of healthcare

choices for life-threatening illnesses. This intervention was compared with usual treatment.

The study found that introducing the advanced care directive programme did not significantly

increase residents' reported satisfaction with their healthcare. However, residents who had

used the intervention had significantly fewer days in hospital (p=0.01) and therefore lower

hospitalisation costs (p=0.003) compared with those receiving treatment as usual.

5. Discussion

5.1 Limitations of the existing research

Of the 25 studies included in the literature review, 14 (56%) were from the UK and five

(20%) were from Canada. To some extent this reflects the limits of the search strategies but

as a result, it is difficult to be sure that the findings are generaliseable across other

jurisdictions. The quality of the types of included studies used to evaluate the impact of SDM

on people is relatively limited, only two RCTs were found, meaning that the conclusions

which can be drawn from the evidence are also limited. Only six (24%) of the included

studies focused specifically on people with mental health problems with most concentrating

on either people with intellectual disabilities (9/25, 36%) or older people/physical and/or end

of life care (10/25, 40%). There are common themes across all areas of supported decision

making but the issues which may be more commonly associated with mental health problems

(such as relatively rapidly fluctuating capacity, delusional beliefs and risks of deliberate self-

harm or suicide) have not been explored in depth. Generalisability to all forms of mental

health problems and disabilities is also low as the majority of studies excluded more severe populations from the research. For example, people with severe dementia were often excluded, as well as those with limited verbal communication ability. The majority of studies include small sample sizes, which may also limit their generalisability. The included studies also tended to focus on advance care planning, person-centred planning and the provision of information and training. In Bach and Kerzner's (2010) categories of support the focus of the research was therefore on supports to assist people make decisions themselves or identify others to make decisions if needed rather than on supports to act on the decisions that have been made.

5.2 Implications of the existing research

There are a range of implications from the research. The first is that it is appears very difficult to ensure that good practice in supported decision making is consistently provided across all settings if it is not clearly required. Even in jurisdictions where there is clear commitment in law and/or Code of Practice guidance, inconsistencies arise and so an important, but not sufficient, implication is that reference to supported decision making, along with the associated provision of advance care planning and independent advocacy, should be explicitly included in the relevant legal framework. The need for inclusion in the legal framework has been argued by Brayley (2009, p. 15): "If personhood is to be respected, if peoples' intentions and wishes are to be listened to, then this should be stated by [Government] ... legislation can make it clear that all persons can expect decision support". This does not necessarily entail that a separate law, such as the Representation Agreement Act in British Columbia, is needed for supported decision making, but that there should be a commitment in the relevant law that all practicable steps must be taken to support the person to make their own decision before substitute decision-making powers are considered.

There is a theme through the included studies of the need for staff training due to concerns about levels of knowledge; inconsistent practice; and the lack of involvement of service users (Goldsmith et al., 2008; Froggatt et al., 2009; Ahmed et al., 2011). There was also clear evidence of how effective the provision of training and information was for both staff and service users in relation to decision making (Karp, 2009) and advance care planning (Foy et al., 2007). It was also found that advance care planning is not useful for everyone and that an individual's preferences and circumstances need to be considered when all forms of supported decision making are being provided (Papageorgiou et al., 2002). The research (Funk, 2004; Ekdahl et al, 2010) also highlighted that some people make the entirely legitimate decision not to be involved in the decision-making process but a supported decision-making approach should still ensure that meaningful options for involvement with decisions must be available and that on-going efforts to engage the person in decisions ought to be made.

There is a wide range of strategies within supported decision making approaches. At the most basic level the provision of clear information and the simplification of decision-making tasks can provide support for decision making (Wong et al., 2000). Person-centred planning is also supported although there may be complexities in its implementation (Robertson et al., 2005; Dowling et al., 2007). Independent advocacy, representation and supportive networks can also be used to support people to make their own decisions and prevent the need for substitute decision making. A clear theme throughout the literature is that there are people with a range of disabilities who, without support, would be assessed as incapable of making certain decisions. With the appropriate support some people are able to make those decisions and so,

to not provide that support infringes their rights, undermines their autonomy and reinforces their exclusion from society.

6. Conclusions

SDM is an evolving aspect of law, policy and practice. The available evidence on implementation and impact is limited, and mainly comes from the areas of intellectual disabilities and end-of-life care, but there are important rights-based, effectiveness and pragmatic arguments for further developing and researching this approach in mental health services. This should address the full range of SDM approaches as the need for SDM, and the approaches that will be most effective, will vary across people, time and decisions.

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