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## Supported Decision Making in Serious Mental Illness

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### Abstract

**Objective:** Making decisions is central to the exercise of control over one's well-being. Many individuals with serious mental illnesses (SMI) experience limitations in their decision making capacity. These individuals have often been placed under legal guardianship, and substitute decision makers have been appointed to make decisions on their behalf. More recently, Supported Decision Making (SDM) has emerged as a possible alternative in some cases. SDM involves recruitment of trusted supports to enhance an individual's capacity in the decision making process, enabling them to retain autonomy in life decisions. This overview examines issues associated with decision making capacity in SMI, frameworks of substitute decision making and SDM, and emerging empirical research on SDM.

**Method:** Overview of medical and legal literature.

**Results:** Many, but not all, individuals with SMI exhibit decrements in decision making capacity and skill, in part due to cognitive impairment. There is no published data on rates of substitute decision making/guardianship or SDM for SMI. Only three empirical studies have explored SDM in this population. These studies suggest that SDM is viewed as an acceptable and potentially superior alternative to substitute decision making for patients and their caretakers.

**Conclusions:** SDM is a promising alternative to substitute decision making for persons with SMI. Further empirical research is needed to clarify candidates for SDM, decisions in need of support, selection of supporters, guidelines for the SDM process, integration of SDM with

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emerging technological platforms, and outcomes of SDM. Recommendations for implementation of and research on SDM for SMI are provided.

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The freedom to make decisions about important matters in one's life is fundamental to individual autonomy and self-determination. For persons with serious mental illnesses (SMI) such as schizophrenia, bipolar disorder, and major depressive disorder, however, the capacity and skill to independently render appropriate social, medical, and financial decisions may be limited, in part, by cognitive conditions (Srebnik, Livingston, Gordon, & King 1995). As a result, many of these individuals are placed under full/plenary legal guardianship, which occurs when a substitute decision maker is granted authority to make all the decisions (rather than specific ones related to finances or healthcare, etc.) on another person's behalf (Blanck & Martinis 2015). Emerging research involving individuals with cognitive (e.g., intellectual and developmental) disabilities suggests that plenary guardianship presently may be applied too broadly and may have potentially harmful effects, such as lowered self-esteem, lowered perceived self-efficacy, behavioral passivity, and the potential for abuse of privilege by appointed guardians (Jameson et al. 2015). Due to these concerns, there has been growing interest in Supported Decision Making (SDM) as an alternative to plenary guardianship and substitute decision making in at least some cases.

In SDM, typically individuals with cognitive disabilities receive assistance from family, friends, or other trusted persons to enhance their decision making capacity and skill so that they may retain autonomy during the decision making process (Blanck & Martinis 2015; Jameson et al. 2015). However, to date, little systematic research has explored the potential benefits of SDM for persons with SMI (Pathare & Shields, 2012). This overview discusses decision making capacity in general and in people with SMI, the frameworks of substitute decision making and SDM, empirical research on SDM among persons with cognitive disabilities and SMI, and guidelines for future research on SDM by individuals with SMI.

## Competency and Decision Making Capacity

Restrictions on a person's autonomy and preferences in decision making often stem from concerns about their competency and decision making capacity. Capacity, competency, and decision making ability are closely related, but distinct concepts, and their definitions vary depending upon the context of usage. Generally, capacity (or incapacity) and competency are concepts that refer to a person's eligibility to participate in legal proceedings, enter into transactions, and assume legal responsibility for his or her decisions and acts. The term 'capacity' is often used to refer to the clinical assessment of an individual's ability to engage in authentic autonomous decision making (and generally treated as a continuum), whereas 'competence' is a categorical legal/court determination, generally informed by evidence from clinical assessment of decisional capacity, but not synonymous with that assessment (Buchanan, 2004).

Decision making capacity typically refers to a set of learned skills and abilities necessary for making rational decisions. Decision making capacity includes four core components: (1) comprehension – ability to understand the information presented to the person; (2) appreciation – ability to understand the relevance of the information presented to the

person's own situation; (3) reasoning – ability to manipulate information rationally, especially when evaluating the stated risks and benefits of alternative courses of action; and (4) choice – ability to communicate clearly and consistently her or his decision (Appelbaum & Grisso, 1995). Decision making capacity is dimensional, with people having varying degrees of the above mentioned underlying abilities, which may fluctuate over time and with the context, type of decision, and motivation and emotion (Buchanan, 2004).

## Decision Making Capacity in People with SMI

In recent decades, increasing attention has been devoted to examining the decision making capacity and skills of persons with SMI. Persons with SMI differ from those with intellectual and developmental disabilities in that decision making capacity typically is impaired only in a subset of individuals with SMI (Palmer, Dunn, Depp, Eylar, & Jeste 2007), and it may fluctuate over time, depending on the individual's emotional state. Nonetheless, similar to persons with intellectual and development disabilities, cognitive impairment (not psychopathology, demographic characteristics, and level of insight) is the largest single contributor to decision making difficulties among persons with SMI (Palmer, Dunn, Appelbaum, & Jeste, 2004; Palmer et al., 2007). Owing to the impact of cognitive impairment on functional decision making, some persons with intellectual and developmental disabilities, and some of those with SMI (or comorbidity), may be said to have a cognitive disability.

Given the prominence of cognitive impairment in SMI and its potential impact on decision making capacity, subsequent research has explored strategies to enhance decision making capacity by providing additional cognitive supports during the informed consent process. This research has shown that interactive consent procedures that include repeated presentation of information and multimedia presentation of information can improve decision making in adults with SMI, resulting in greater capacity to consent (Palmer et al., 2007; Palmer & Jeste, 2006). Thus, despite having diminished decision making capacity due to cognitive impairment, individuals with SMI often may provide adequate consent with additional supportive interventions designed to reduce cognitive demands.

The question of identifying optimal candidates for SDM, also touches on the issue of appropriate assessment of decision making capacity. As noted above, empirical research has consistently shown that severity of cognitive deficits, rather than severity of primary psychopathologic symptoms, to be the strongest predictor of decisional capacity (reviewed in Palmer & Harmell, 2016). However, decision making capacity is an inherently context-dependent construct – affected by the inherent complexity of the information and decision, as well as the manner in which the information is communicated complexity (Dunn, Palmer, & Karlawish, 2007). Neuropsychological testing can be helpful in identifying a patient's pattern of cognitive strengths and deficits, thereby understanding (and potentially remedying) the underlying nature of any decision making impairments, but cognitive testing does not substitute for direct functional assessment of decision making capacity (Moye et al. 2007). This situation directly parallels the broader approach to functional impairment in SMI, in that direct assessment of functional capacity has more validity than inferences drawn from cognitive test performance in guiding an individual patient's capacity for

independent functioning (Harvey, Stone, Loewenstein et al. 2013; Moore et al., 2007). It suggests that direct functional assessment of decisional capacity, both independently, and in the context of available supports, should be made in determining who needs and can benefit from a SDM approach. At present, there is no empirical evidence or recognized consensus regarding how frequently such functional capacities should be reevaluated, but the frequency/likelihood of change, is probably dependent on the cause and nature of the underlying impairment.

## Substitute Decision Making

As mentioned, many individuals with SMI face challenges in making decisions due to cognitive impairment. Traditionally, when a U.S. court has deemed an individual legally “incompetent” (i.e., incapable of making some or all decisions for himself or herself), a third party, often termed a substitute or surrogate decision maker, is appointed to make decisions on that individual’s behalf (e.g., Martinis, 2015). Most often, the appointment of a substitute decision maker occurs through a formal guardianship proceeding.

In the U.S., guardianship proceedings are governed by individual state laws, with each state establishing its own statutes, policies, and procedures. In many, but not all, states, a person may not be placed under guardianship if there is a less restrictive option available (Quality Trust for Individuals with Disabilities, 2014). In California, guardianship for individuals with SMI is processed through a Lanterman Petris Short (LPS) conservatorship proceeding. In guardianship and LPS conservatorship proceedings, when an individual is found to lack legal capacity to make her/his own decisions, the court appoints a third party guardian or conservator who has the authority to make decisions for the individual, who thereby becomes a ward of the state (Jameson et al., 2015).

Guardianship is commonly divided into two main types. Limited or partial guardianship occurs when an individual has been deemed incapable of making decisions in only specific areas of life, and thus a guardian has the authority to decide for the individual in those specific areas only. In contrast, full or plenary guardianship occurs when the court has found that an individual lacks capacity to make all legal decisions, and the guardian is thereby authorized to make all decisions for the ward (Blanck & Martinis, 2015).

Substitute decision makers are guided by two decision making standards. A substituted judgment standard maintains that guardians should make decisions that the patient would have wanted, if capable. In contrast, a best-interest standard holds that guardians should make decisions based on what the guardian determines to be in the ward’s best interest. Most state laws argue that a substituted judgment standard should guide guardian decision making, and a best-interest standard is allowable when guardians lack sufficient evidence to determine what decision the ward would have made if s/he had the capacity (Shalowitz, Garrett-Mayer, & Wendler, 2006).

The precise number of individuals in guardianship in the U.S. is not known, largely because of the state-specific nature of guardianship laws and the fact that many states do not release guardianship data. Nonetheless, based on data released from four states in 2008 (i.e.,

Vermont, Kansas, Ohio, and the District of Columbia), it is estimated that approximately 1.5 million American adults are under guardianship at any given time (Uekert & Van Duizend, 2011). This number includes approximately one million people who have been placed under guardianship in the U.S. since 1995, reflecting a recent increase in the application of guardianship (Blanck & Martinis, 2015). Research among young adults with intellectual disabilities suggests that a majority of these individuals are placed under guardianship, that plenary guardianship is far more common than partial guardianship, and that alternatives to guardianship are rarely broached (Blanck & Martinis, 2015; Jameson et al., 2015). Similar data on persons with SMI have not been published.

## Supported Decision Making (SDM)

In a broad sense, the term SDM may include practically any decision by any person that involves support by others (Martinis, 2015). In the present context, however, SDM is defined as an attempt to provide a less restrictive alternative to guardianship and substitute decision making to promote the self-determination of an individual with a cognitive disability (Blanck & Martinis, 2015). At the core of SDM is the recognition that individuals with cognitive disabilities may require a higher level of support to make decisions in their lives and that they have a right to this support (Kohn, Blumenthal, & Campbell, 2013). SDM is said to take place when a person with a cognitive disability remains the ultimate decision maker, but enlists family, friends, and other trusted people to help clarify the problems at issue, the options available and, when needed, interpret and communicate her or his will and preferences to others (Blanck & Martinis, 2015). While individuals with cognitive impairments may require greater support in the decision making process, the use of support to make decisions is rather similar to the typical decision making process among most adults, in which consultation with trusted partners on major life decisions is common (Blanck & Martinis, 2015). Although SDM better matches typical everyday decision-making processes, the current legal framework generally recognizes only the individual/unaided decision maker in determining competence/incompetence, without provisions for SDM as an alternative to guardianship.

SDM arrangements take several different forms. In general, there are two dimensions along which these arrangements vary: the types of supports involved and the way in which supports provide assistance. Supports may include: (1) a person familiar with the individual (e.g., family member or friend), (2) an unfamiliar court appointed representative, (3) a "circle of support" (i.e., a group of people familiar to the individual, who meet regularly with him or her to determine his hopes and wishes), and (4) more formal organizations (e.g., non-profit organizations), often referred to as "microboards," which help an individual understand his or her choices and options (Kohn et al., 2013). Of note, the legal capacity required to voluntarily designate supporters through such an arrangement may differ from the capacity required to formally appoint supporters through a Power of Attorney or Advanced Directive. In addition, these supports may be used to help during the decision making process in different ways: (1) assisting in clarifying the individual's goals, range of choices, and making a decision, (2) facilitating communication with other parties to come to agreements when required, and (3) helping, after a decision has been made, that the individual meets his/her obligations under any agreements (Bach & Kerzner, 2010).

To fully achieve the goal of enhancing individual autonomy, implementation of SDM must involve several core elements: (1) information is presented to the individual (including possible alternatives), (2) the individual consults with supports as he or she prefers, (3) the individual reaches a decision, and (4) the decision is documented, carried out, and legally enforceable. Examples of questions around which to engage an individual with SMI in a decision may be as follows: If the decision pertains to taking a prescribed antipsychotic medication, the questions may include: What do you think about this medication? Have you ever taken it before and what was it like? Have you taken different medications and what were they like? How do you understand the risks and benefits of this treatment and what do you think about those in your own case? What is your general attitude about taking medications? Are there alternatives (drugs or other treatments) that you would rather try first? How do your values, desires, and goals in general bear on this issue?

## **Historical Background and Recent Legal Developments regarding SDM in the U.S.**

Advocacy for the legal recognition of SDM as an alternative to guardianship was the result of sustained international efforts. Initial promotion of SDM occurred in the early 1990s in British Columbia as a part of the disabilities rights movement. This initial advocacy resulted in the first legislative recognition of SDM in the 1996 Representation Agreement Act in British Columbia. This Act established a set of decisions regarding how individuals with cognitive disabilities may seek support, criteria for appointment of a supporter, and a mechanism by which decisions reached through SDM would be legally recognized (Browning, Bigby, & Douglas 2014). SDM achieved a significant breakthrough with the 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). In a landmark statement, the UNCRPD declared that member states must provide assistance to individuals with disabilities so that they can exercise their right to legal capacity. Furthermore, the UNCRPD identified SDM as a crucial legal mechanism toward achieving this basic human right. Spurred by this development, several countries—including Canada, Ireland, Israel, the UK, Germany, Australia, and the U.S.—have begun to promote integration of SDM into their respective legal systems (Blanck & Martinis, 2015).

The last decade in particular has seen an expansion in recognition of and respect for SDM by U.S. courts, legislators, policy makers, and national organizations. In 2009, the Texas legislature created a pilot program to “promote the provision of supported decision making services to persons with intellectual and developmental disabilities and persons with other cognitive disabilities who live in the community.” [Tex. Government Code Ann. § 531.02446 (2009) (expired on Sept. 1, 2013)]. After that program ended, Texas passed new laws recognizing the availability and effectiveness of SDM and required courts to find that a person cannot make decisions using SDM before appointing a guardian [Tex. Est. Code § 1101.101(a)(D) & (E)].

In 2016, a similar law was passed and signed in Delaware. The Delaware law allows people with disabilities to designate a person as a “supporter” (SB 230 2016). The supporter is given legal status and authorization to assist the person in making life choices, including

health, safety, and educational decisions, but is not allowed to make decisions on their behalf.

In 2014, the Virginia General Assembly directed the state Secretary of Health and Human Services to “recommend strategies to improve the use of supported decision making in the Commonwealth and ensure that individuals ... are consistently informed about and receive the opportunity to participate in their important life decisions” [H.J.Res. 190, Reg. Sess. (Va. 2014)]. The resulting report made several recommendations, including: amending state law to recognize SDM as a “legitimate alternative to guardianship;” requiring anyone appointed as a substitute decision-maker to be trained in and commit to using SDM; and developing a required training on SDM for providers and professionals (Report of the Secretary of Health and Human Resources, 2014).

Two private organizations have also endorsed SDM. In 2012, the American Bar Association (ABA) convened stakeholders “to explore concrete ways to move from a model of substituted decision-making, like guardianship, to one of supported decision making, consistent with the human right of legal capacity” (American Bar Association, 2012). In 2015, the ABA published an article calling for the use of SDM as an alternative to guardianship, stating “In contrast to overbroad or undue guardianship, SDM can increase self-determination by ensuring that the person retains life control to the maximum extent possible” (Martinis, 2015). In 2016, the ABA released the PRACTICAL guide, focusing on ways attorneys may examine alternatives, such as SDM, before seeking guardianship (American Bar Association 2016).

In 2015, the National Guardianship Association (NGA), which represents “over 1,000 guardians, conservators and fiduciaries from across the United States,” also published a position paper on SDM. It states that “[m]odern day respect for individual rights dictates that we must allow each individual to make or participate to the extent possible in personal decisions.” The NGA concluded “[s]upported decision making should be considered for the person before guardianship, and the SDM process should be incorporated as a part of the guardianship if guardianship is necessary” (National Guardianship Association, 2015). The NGA’s position is consistent with most state laws, which require that less restrictive alternatives be considered or attempted prior to placing a person under guardianship.

The Veterans Affairs healthcare system has a supervised direct pay system for veterans having difficulties independently managing their benefits that shares some characteristics with SDM. According to this system, ‘cases where medical evidence indicates that a beneficiary cannot manage their VA benefits, VA may decide that the beneficiary needs the assistance of a fiduciary. This determination may also be made based upon notice that a court has appointed a guardian for the beneficiary. VA’s decision that a beneficiary needs a fiduciary may be appealed to the Board of Veterans Appeals’ (<http://benefits.va.gov/BENEFITS/factsheets/fiduciary/FiduciaryFactSheet.pdf>). However, the VA also incorporates a notion similar to SDM, specifically “In deciding who should act as fiduciary for a beneficiary, VA will always select the most effective and least restrictive fiduciary arrangement. This means that VA will first consider whether the beneficiary can manage their VA benefits with limited VA supervision under supervised direct pay. VA will consider

the choice of the beneficiary, then the beneficiary's spouse, family members, friends, caregivers who are qualified and willing to provide fiduciary services for the beneficiary without a fee or, a temporary fiduciary, if necessary. As a last resort, VA will consider appointment of a paid fiduciary. This system raises important empirical questions of relevance to the SDM model – Can some people with SMI who demonstrate an inability to manage their benefits, nonetheless manage them effectively with decisional support, rather than full dependence on/deference to the decisions of a fiduciary? The answer to that question is presently unknown, but clearly warrants empirical investigation.

## Concerns about SDM

Despite its potential promise, concerns have been raised about wider adoption of SDM. Most of these concerns arise from a dearth of empirical research on SDM. For example, no research to date has compared systematically outcomes from SDM to those from substitute decision making, although such studies are now beginning (Blanck & Martinis, 2015). As an empirical matter, it is not proven whether, and to what extent, SDM may be associated with better decisions (taking into account challenges around classifying which decisions are “better or worse”), greater satisfaction with the decision making process, and an increased sense of empowerment among individuals with cognitive disabilities. Some authors have expressed concerns that SDM, like substitute decision making, may expose individuals with disabilities to undue influence or coercion by their alleged supporters, thereby effectively disempowering them (Kohn et al., 2013). Of course, this possibility is mitigated when there are a number of supporters involved, unless we imagine they are colluding. In addition, it is possible that SDM may be applied too broadly and that people who could have made a choice independently will be required to seek supports during the decision making process.

## Empirical Research on SDM in Persons with Developmental and Intellectual Disabilities

While research on interventions designed to foster self-determination among persons with cognitive disabilities suggests that SDM holds promise, researchers, commentators, and scholars agree that research is required to examine and evaluate SDM methodologies and their effect on life outcomes (Kohn, et al., 2013).

A few studies have investigated the impact of instructional coursework designed to enhance goal setting, expression of goals, and self-advocacy in educational and transition planning among high school students with intellectual and learning disabilities. This research has demonstrated a benefit of this coursework, leading to better employment outcomes, greater independence, and improved community integration (Powers, et al. 2012). In other studies, higher levels of self-determination have been associated with better outcomes across areas including quality of life, employment status, access to health care, financial independence, and independent living (Wehmeyer & Palmer, 2003). This research, albeit limited at present, suggests that interventions that target aspects of the decision making process may enhance the ability of individuals with compromised decision making capacity to exercise control over their lives, which in turn leads to meaningful functional improvements.



## Empirical Research on SDM in Persons with SMI

There is a scarcity of empirical research on the efficacy of SDM by individuals with SMI. We found only three related studies; yet, each evaluated the need for, rather than the outcomes of, SDM in persons with SMI. A study conducted by Amnesty International (2009) in Ireland interviewed eight individuals with unspecified mental illnesses. Participants acknowledged that periods of acute emotional distress can impair their decision making ability. These participants identified the personal support they received from others as key to enhancing their capacity during these times. The specific nature of this support varied widely, including clarification of available choices, affirmation of self-efficacy, and non-specific emotional support (e.g., instilling hope).

Werner and Chabany (2016) reported that individuals with unspecified mental illnesses attached high importance to retaining independence in their lives, as did the parents of these individuals, and both the patients and their parents were broadly supportive of SDM as an appropriate strategy towards achieving this aim. However, these groups expressed concern about SDM during crisis periods when individuals' decisional capacity may be compromised.

Roberts and Kim (2016) explored treatment-related decision making among twenty individuals with schizophrenia, six individuals diagnosed with anxiety or mood disorders, and their preferred alternative decision makers. Mentally ill individuals and their preferred alternative decision-makers were largely in agreement regarding treatment-related decisions and the life values underlying those decisions. Thus, while SDM seems to be viewed favorably among at least some individuals with mental illnesses and their close associates, it is unclear whether the decisions reached through such an arrangement would differ significantly from those achieved through substitute decision making. Nonetheless, SDM may enhance feelings of self-empowerment and yield improved functional outcomes for persons with SMI, as has been shown in studies involving individuals with cognitive disabilities.

## Emerging and Proposed Research on SDM

In 2014, the Administration for Community Living (ACL) in the U.S. Department for Health and Human Services made federal funding available for the creation of "a national training and technical assistance center on ... supported decision making" (Administration for Community Living, for Cmty Living, U.S. Dep't of Health & Human Servs., Funding Opportunity HHS-2014-ACL-AIDD-DM-0084, Supported Decision Making). The recipient of the funding, the National Resource Center for Supported Decision-Making (NRC-SDM), has launched a five-year action plan to increase knowledge of and access to SDM through education, outreach, advocacy, and research (Blanck & Martinis 2015). The NRC-SDM is conducting first-of-its-kind research to review whether and to what degree SDM is an appropriate and effective alternative to plenary guardianship for people with intellectual and developmental disabilities.

In addition, the Burton Blatt Institute at Syracuse University, a partner in the NRC-SDM, has received funding from ACL to examine the efficacy of SDM as an alternative to guardianship and a means of improving health and life outcomes. In this project, two core studies are underway. The first study examines associations among SDM, demographic and environmental factors, including age, gender, socioeconomic factors, opportunities to make life choices such as where to live, and the effect of service provider recognition and respect of the person's decision-making (Blanck, 2014b). The second study uses a randomized controlled trial methodology to examine whether, how, and to what degree, people with cognitive disabilities may be supported to solve problems, and to set and reach goals related to decision making, and whether and to what extent use of SDM impacts their actual and perceived self-determination and quality of life. These studies aim to further inform research and practice in SDM, leading to the development of new SDM models and intervention-based research, with the ultimate goal of increasing individual and societal integration, self-determination, and flourishing (Blanck 2014b).

In 2016, the Saks Institute for Mental Health Law, Policy and Ethics, at the USC Gould School of Law, and the Burton Blatt Institute at Syracuse University received funding to begin a SDM implementation and research project focused on developing and examining SDM for people with SMI. The project is reviewing existing SDM research and practice and developing a set of tools or interventions to help people with SMI use SDM in their lives. The project is identifying people with SMI who do not currently use SDM and will collaborate with them to gather baseline data and implement individualized SDM tools and systems. Over the coming years, the project will work with the participants to implement and, as necessary, refine the SDM tools and, at regular intervals, collect data to determine whether their life outcomes have improved.

In addition to these new lines of research, further empirical research is needed on SDM among persons with SMI. Questions remain regarding who are the optimal candidates for SDM, what kinds of decisions they need support with, how supports should be selected, what guidelines the process of SDM should follow, whether SDM improves functional outcomes, and how emerging technologies (e.g., on-line supports) may be integrated to enhance SDM. We offer next some tentative suggestions for practical use of SDM regarding these key questions.

The following groups of individuals with SMI may be considered for SDM: (1) persons declared incompetent by a court of law or those who are at risk of being found incompetent; (2) persons identified with low skills by measures and scales designed to assess decision making capacity (e.g., the UCSD Brief Assessment of Capacity to Consent (UBACC; available at no charge, with guidelines for use and interpretation, in Jeste et al. 2007 and/or directly from the authors upon request); (3) individuals with significant impairments that do not amount to incapacity, but render their decision making extremely limited; (4) persons living in assisted living facilities (e.g., board-and-care homes) and nursing homes; and (5) individuals in hospice care. The categories of decisions relevant for SDM include: (1) medical decisions, (2) financial decisions, (3) social decisions, and (4) other decisions such as those related to sexual consent and independent living. It is noted that different aspects of

decision making, such as sexual consent versus financial consent or research consent, may have qualitatively distinct ramifications that could impact incorporation of a SDM model.

In addition, in their non-impaired state of mind, persons with SMI often plan for times in the future when they may be impaired. There is a role for SDM here. Yet, some individuals have chronic SMI and cannot plan by themselves even while in a less impaired state of mind, and some patients may reject their earlier decision made while they were impaired. Researchers should examine ways to support such individuals make these advance care decisions consistent with their will and preference by providing them with appropriate supports over the life course.

Moreover, for persons with SMI, symptoms tend to fluctuate over time, which may limit their ability to engage with and arrive at appropriate decisions through SDM. Research is needed to examine scenarios for when the choice for making decisions with the help of supports may be lessened or even restricted. Unfortunately, the presently extant empirical research base is not sufficient to draw firm conclusions about best practices for use of SDM among patients in acute crisis. Research is needed to examine scenarios for when the choice for making decisions with the help of supports may be lessened or even restricted, and will be critical for developing standards and best practices in regard to use of SDM in such contexts.

Several criteria also may be examined in regard to guiding selection of supporters. At a minimum, supporters should: (1) be approved by the individual with SMI, (2) themselves have decision making capacity and skill, (3) be knowledgeable about the individual with SMI and the individual's condition, and will and preferences; (4) be willing to act as a supporter; and (5) not have a conflict of interest that may compromise their ability to provide impartial support. Possible categories of supports may include family and friends, mental health professionals, lawyers, and clergy.

It remains to be determined what the best process may be to ensure that the supporters selected by the individual with SMI meet these criteria. Clearly, this process must be done in a thoughtful way to survive court scrutiny if it came to that. Other questions to address include: how many, and the type of supporters, needed and appropriate, and whether supporters should be the same for all decisions or vary by the type of decision. There is a need to study the selection process, as well as the efficacy of the decision making process with different kinds of supports and supporters.

As described above, SDM requires that: (1) information is presented to the individual, (2) the individual consults with supporters as s/he prefers, (3) the individual reaches a decision, and (4) the decision is documented and legally enforceable. Future research may explore use of planning templates for supports to enhance the SDM process, as compared to a free-form approach. Such templates may vary according to the type of decisions. Research is also needed to evaluate frequency of adherence to such plans.

Several categories of outcomes are important to study: (1) increases in self-determination of individuals with SMI; (2) satisfaction with the process of SDM among these individuals, including happiness with, feelings of empowerment resulting from, and acceptance of SDM;

(3) consistency of decisions reached through SDM with the person's preference and value system, which may be determined according to self-report and informant-report approaches; and (4) the impact of SDM on a range of meaningful functional outcomes including well-being, quality of life, treatment engagement and adherence, community integration versus hospitalization rates, overall health, and a reduction in health care costs. In instances where the value system of the individual with SMI is difficult to determine, quality of decisions may need to be determined by evaluating whether the decision was in accord with the person's will and preference.

Another area of development for SDM involves the use of technology (Blanck, 2014a). Multi-media technology has previously been shown to enhance the informed consent process among individuals with SMI (Jeste et al., 2009). Integration of technological platforms, such as mobile applications, Skype, and social media, may enable a person to access supports and supporters in real time. There is a need to study the feasibility, acceptance, benefits and risks, of integrating technology within SDM for persons with SMI.

## Conclusions

SDM has the potential to meaningfully improve the well-being and quality of life of persons with SMI. Additional empirical research is warranted to examine its feasibility and efficacy, acceptance by participants, comparison with other modes of substitute decision making, and longer-term outcomes.

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## References

- Administration for Community Living. U.S. Department of Health & Human Services., Funding Opportunity HHS-2014-ACL-AIDD-DM-0084, Supported Decision Making, available at <http://www.grants.gov/web/grants/view-opportunity.html?oppId=256168>(last visited Nov. 15, 2016).
- American Bar Association, Beyond Guardianship: Supported Decision-Making by Individuals with Intellectual Disabilities: A Short Summary from the 2012 National Roundtable, available at: [http://www.americanbar.org/content/dam/aba/administrative/mental\\_physical\\_disability/SDMRoundtable\\_Summary.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/administrative/mental_physical_disability/SDMRoundtable_Summary.authcheckdam.pdf)
- Amnesty International (2009). Decision-making capacity in mental health: Exploratory research into the views of people with personal experience. Ireland: Amnesty International Ireland.
- Appelbaum PS , & Grisso T (1995). The MacArthur Treatment Competence Study. *Law and Human Behavior*, 19(2), 105–126. [PubMed: 11660290]
- Bach M , & Kerzner L (2010). A new paradigm for protecting autonomy and the right to legal capacity. Law Commission of Ontario. Retrieved from <http://www.lco-cdo.org>.
- Blanck P (2014a). *eQuality: The Struggle for Web Accessibility by Persons with Disabilities*.Cambridge University Press.

- Blanck P (2014b). Community Living and Supported Decision-Making, Grant funded by the Administration on Community Living, HHS.
- Blanck P , & Martinis JG (2015). “The right to make choices”: The national resource center for supported decision-making. *Inclusion*, 3(1), 24–33.
- Bradock D , Rizzolo M , Thompson M , & Bell R (2004). Emerging technologies and cognitive disability. *Journal of Special Education Technology*, 19(4), 49–56.
- Browning M , Bigby C , & Douglas J (2014). Supported Decision Making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice. *Research and Practice in Intellectual and Developmental Disabilities*, 1(1), 34–45. doi: 10.1080/23297018.2014.902726
- Buchanan A (2004). Mental capacity, legal competence and consent to treatment. *Journal of the Royal Society of Medicine*, 97, 415–420. [PubMed: 15340019]
- Delaware State Senate, 148th General Assembly, Senate Bill 230 as amended by Senate Amendment No. 1
- Dunn LB , Palmer BW , & Karlawish JHT (2007). Frontal dysfunction and capacity to consent to treatment or research: Conceptual considerations and empirical evidence In Miller BL & Cummings JL (Eds.), *The human frontal lobes –Second edition* (pp. 335–344). New York: Guilford Press.
- Harvey PD , Stone L , Lowenstein D , Czaja SJ , Heaton RK , Twamley EW , Patterson TL .(2013). The convergence between self-reports and observer ratings of financial skills and direct assessment of financial capabilities in patients with schizophrenia: more detail is not always better. *Schizophrenia Research*, 147(1), 86–90. [PubMed: 23537475]
- Res HJ 190, Reg. Sess. (Va. 2014). *In re Dameris L.*, 56 N.Y.S.2d 848 (N.Y. County Sur. Ct. 2012).
- Jameson JM , Riesen T , Polychronis S , Trader B , Mizner S , Martinis J , & Hoyle D ((2015). Guardianship and the Potential of Supported Decision Making With Individuals With Disabilities. *Research and Practice for Persons with Severe Disabilities*, 40(1), 36–51. doi: 10.1177/1540796915586189
- Jeste DV , Palmer BW , Appelbaum PS , Golshan S , Glorioso D , Dunn LB , ... Kraemer HC (2007). A new brief instrument for assessing decisional capacity for clinical research. *Archives of General Psychiatry*, 64(8), 966–974. doi:10.1001/archpsyc.64.8.966 [PubMed: 17679641]
- Jeste DV , Palmer BW , Golshan S , Eyler LT , Dunn LB , Meeks T , ... Appelbaum PS (2009). Multimedia consent for research in people with schizophrenia and normal subjects: a randomized controlled trial. *Schizophrenia Bulletin*, 35(4), 719–729. doi:10.1093/schbul/sbm148 [PubMed: 18245061]
- Kohn NA , Blumenthal JA , & Campbell A (2013). Supported decision making: A viable alternative to guardianship? *Penn State Law Review*, 117, 1111–1157.
- Martinis J (2015). Supported decision-making: Protecting rights, ensuring choices. *Bifocal: A Journal of the ABA Commission on Law and Aging*, 36(5), 107–110.
- McSheery B (2009). Rethinking mental health laws: International trends. Paper presented at the 12th Gree/Australian International Legal and Medical Conference, Samos Island, Greece.
- Moore DJ , Palmer BW , Patterson TL and Jeste DV : A review of performance-based measures of functional living skills. *Journal of Psychiatric Research* 41:97–118, 2007. [PubMed: 16360706]
- Moye J , Butz SW , Marson DC , Wood E , & the ABA–APA Capacity Assessment of Older Adults Working Group. (2007). A Conceptual Model and Assessment Template for Capacity Evaluation in Adult Guardianship. *The Gerontologist*, 47(5), 591–603. [PubMed: 17989401]
- National Bioethics Advisory Commission. (1998). *Research involving persons with mental disorders that may affect decisionmaking capacity*. Rockville, MD: National Bioethics Advisory Commission.
- National Guardianship Association, “Position Statement on Guardianship, Surrogate Decision Making, and Supported Decision Making,” (2015), available at: [http://www.guardianship.org/documents/NGA\\_Policy\\_Statement\\_052016.pdf](http://www.guardianship.org/documents/NGA_Policy_Statement_052016.pdf)
- Palmer BW , Dunn LB , Appelbaum PS , & Jeste DV (2004). Correlates of treatment-related decision-making capacity among middle-aged and older patients with schizophrenia. *Archives of General Psychiatry*, 61(3), 230–236. doi:10.1001/archpsyc.61.3.230 [PubMed: 14993110]

- Palmer BW , Dunn LB , Depp CA , Eyler LT , & Jeste DV (2007). Decisional capacity to consent to research among patients with bipolar disorder: comparison with schizophrenia patients and healthy subjects. *Journal of Clinical Psychiatry*, 68(5), 689–696. [PubMed: 17503977]
- Palmer BW , & Harmell AL (2016). Assessment of healthcare decision-making capacity. *Archives of Clinical Neuropsychology*, 31(6), 530–540. [PubMed: 27551024]
- Palmer BW , & Jeste DV (2006). Relationship of individual cognitive abilities to specific components of decisional capacity among middle-aged and older patients with schizophrenia. *Schizophrenia Bulletin*, 32(1), 98–106. doi:10.1093/schbul/sbj002 [PubMed: 16192412]
- Pathare S & Shields LS (2012). Supported decision-making for persons with mental illness: A review. *Public Health Reviews*, 34(2), 1–40.
- Powers LE , Geenen S , Powers J , Pommier-Satya S , Turner A , Dalton LD , ... Swank P (2012). My Life: Effects of a longitudinal, randomized study of self-determination enhancement on the transition outcomes of youth in foster care and special education. *Children and Youth Services Review*, 34(11), 2179–2187. doi:10.1016/j.childyouth.2012.07.018
- Quality Trust for Individuals with Disabilities. (2013). Supported decision-making: An agenda for action. Retrieved from <http://jennyhatchjusticeproject.org/node/264>
- Report of the Secretary of Health and Human Resources, HJR 190 (2014). Available at <http://supporteddecisionmaking.org/sites/default/files/Virginia-Supported-Decision-Making-Report-Recommendations.pdf>
- Roberts LW , & Kim JP (2016). Are individuals living with mental illness and their preferred alternative decision-makers attuned and aligned in their attitudes regarding treatment decisions? *Journal of Psychiatric Research*, 78, 42–47. doi:10.1016/j.jpsychires.2016.03.004 [PubMed: 27058644]
- Ross v. Hatch, No. CWF120000426P-03, slip op. at 7 (Va. Cir. Ct. Aug. 2, 2013)
- Salgo v Leland Stanford Jr University Board of Trustees, 154 560, 317 P.2d 170 (Cal.App.2d 1957).
- Shalowitz DI , Garrett-Mayer E , & Wendler D (2006). The accuracy of surrogate decision makers: A systematic review. *Archives of Internal Medicine*, 166(5), 493–497. [PubMed: 16534034]
- Shogren KA , Wehmeyer ML , Palmer SB , Rifenburg GG , & Little TD (2013). Relationships Between Self-Determination and Postschool Outcomes for Youth With Disabilities. *The Journal of Special Education*, 48(4), 256–267. doi:10.1177/0022466913489733
- Srebnik D , Livingston J , Gordon L , & King D (1995). Housing choice and community success for individuals with serious and persistent mental illness. *Community Mental Health Journal*, 31, 139–152. [PubMed: 7789122]
- Tex. Est. Code § 1002.031.
- Tex. Est. Code § 1101.101(a)(D) & (E)
- Uekert B , & Van Duizend R (2011). Adult guardianships: A “best guess” national estimate and the momentum for reform. *Future trends in state courts 2011: Special focus on access to justice*.
- Volunteer-Supported Decision-Making Advocate Pilot Program, Tex. Gov’t Code Ann. § 531.02446 (2009) (expired on Sept. 1, 2013).
- Wehmeyer ML , & Palmer SB (2003). Adult outcomes for students with cognitive disabilities three-years after high school: The impact of self-determination. *Education Training in Developmental Disabilities*, 38(2), 131–144.
- Werner S , & Chabany R (2016). Guardianship law versus supported decision-making policies: Perceptions of persons with intellectual or psychiatric disabilities and parents. *American Journal of Orthopsychiatry*, 86(5), 486–499. doi:10.1037/ort0000125 [PubMed: 26652607]
- World Health Organization. (2001). International Classification of Functioning, Disability, and Health (ICF). Retrieved from <http://www.who.int/classifications/icf/en/> [Accessed November 14, 2016]