

Review Article

A critical assessment of supported decision-making for persons aging with intellectual disabilities

Nina A. Kohn, A.B., J.D.^{a,*}, and Jeremy A. Blumenthal, A.B., A.M., Ph.D., J.D.^b

^aPrinceton University, Harvard Law School, Professor of Law, Judith Greenberg Seinfeld Distinguished Faculty Fellow, Syracuse University College of Law, Syracuse, NY 13244, USA

^bHarvard University, University of Pennsylvania Law School, Professor of Law, Syracuse University College of Law, USA

Abstract

Supported decision-making is increasingly being promoted as an alternative to guardianship for persons aging with intellectual disabilities. Proponents argue that supported decision-making, unlike guardianship, empowers persons with disabilities by providing them with help in making their own decisions, rather than simply providing someone else to make decisions for them. To evaluate the empirical support for these claims, we reviewed the evidence base on supported decision-making. Our review found little such empirical research, suggesting that significant further research is warranted to determine whether—and under what conditions—supported decision-making can benefit persons with intellectual disabilities. Indeed, without more empirical evidence as to how supported decision-making functions in practice, it is too early to rule out the possibility it may actually disempower individuals with disabilities by facilitating undue influence by their alleged supporters. We therefore suggest several key areas for future research. © 2014 Elsevier Inc. All rights reserved.

Keywords: Supported decision-making; Guardianship; Intellectual disability; Aging; Law

The article reviews the evidence base for supported decision-making (SDM), a process by which a third party “helps” an individual with intellectual or cognitive disabilities make legally enforceable decisions for him- or herself. Disability rights advocates increasingly hail SDM as an alternative to the use of court-appointed guardians. However, there has not yet been any systematic attempt to evaluate the claims and arguments made by its promoters. We seek to fill this void by conducting a “state of the art review”¹ analyzing the existing empirical literature on SDM.

SDM’s goals

SDM has the potential to be of great importance to persons aging with intellectual disabilities (ID). The parents of persons with ID are typically a primary source of decision-making support and assistance.² As parents age and pass away, however, decision-making systems can become destabilized. Currently, the U.S. legal system’s primary response to

addressing and planning for such changes is to allow parents or other interested parties to petition a court for guardianship over an individual with ID. If the court determines that the individual is incapacitated—as is routinely done³—the court can then appoint the petitioner or another person to make some or all decisions on behalf of that individual.

While SDM can take a variety of forms, a commonly cited model is British Columbia’s Representative Agreement, in which a person with cognitive challenges authorizes a third party to act on his or her behalf for a broad range of personal and financial decisions.⁴ The person creating the agreement retains legal capacity, must be consulted by the representative, and can revoke the agreement at any time.⁴ Because there is only a minimal capacity requirement to execute a standard Representative Agreement, and it is presumed, absent evidence to the contrary, that all people can execute one, persons who might be found lacking in capacity to enter other forms of contracts can execute a Representative Agreement.⁴

Prompted in part by the new United Nations Convention on the Rights of Persons with Disabilities, there are growing calls for using SDM to replace guardianship,^{5–9} or at least supplement it.^{10,c} Proponents typically describe

Support for development of this paper was provided by the National Institute on Aging grant no. P30 AG012846 to the University of Michigan and P30 AG034464 to Syracuse University. Portions of the research included in this paper were presented orally at the meeting titled “Aging with disability: Demographic, social and policy considerations” organized by the Interagency Committee on Disability Research in Washington, D.C. on May 17–18, 2012.

* Corresponding author. Tel.: +1 (315) 443 6565.

E-mail address: nakohn@law.syr.edu (N.A. Kohn).

^c SDM approaches might also be integrated into guardianship proceedings, as is implicitly called for in the recommendations of the Third National Guardianship Summit.¹¹

SDM as preferable to guardianship on the grounds that it engages and empowers persons with disabilities, and avoids the problems associated with the much-maligned guardianship process. Indeed, the guardianship process has been criticized on many grounds, including that it is anti-therapeutic,¹² that it stigmatizes and undermines the human dignity of those subjected to it,^{10,13} and that it is used to inappropriately and illegally strip individuals of their legal personhood with insufficient evidence of decision-making incapacity.^{3,13,14} Proponents of SDM describe SDM, by contrast, as an empowering process in which an individual with cognitive challenges is the decision-maker but is provided support from one or more persons who explain issues to the individual and, where necessary, interpret the individual's words and behavior to determine his or her preferences.^{9,15,16} Whether a move toward SDM and away from guardianship is desirable will depend in large part on whether it achieves these goals.

Findings of literature review

We conducted this review of the relevant empirical literature to evaluate whether, and under what conditions, SDM processes are likely to achieve the goals set forth by their proponents. We canvassed the psychological, sociological, social work, and legal literature to identify empirical reviews or analyses of SDM, or evaluations that included or referenced empirical work. We did no formal quality evaluation—after finding how sparse the empirical literature is—but focused instead on summarizing that literature and identifying, as noted below, important directions for future research.

Overall, our review indicated that there has been very little empirical work done on SDM. Even articles with extensive discussions of the benefits and potential drawbacks of SDM provide little or no empirical support for their claims.^{9,17} This lack of evidence is unfortunate not only because it means that there is insufficient information to know whether SDM is achieving its goals or how to develop effective evidence-based SDM practices, but also because it means that (without substantial further research) policy choices regarding SDM will be made without the benefit that insight from empirical research can provide.¹⁸

One gap in the literature is that there is little evidence on how SDM is utilized in the jurisdictions in which it is available. First, there are almost no data indicating the rate of utilization. The studies that exist^{19,20} do not provide adequate data to give a good estimate of either the *number* of such agreements or of the *proportion* of persons potentially eligible for SDM who utilize it.

Second, there is little indication of *who* uses such agreements as few studies on demographics exist. There is some evidence to suggest that women may be more likely to employ such relationships, as one study found that sex ratios of women to men vary from approximately 1:1 to

2:1.²⁰ Existing evidence also suggests that such arrangements are most likely to be entered into by young adults and by the elderly, as compared to the middle aged. Specifically, a report on the utilization of Representative Agreements in British Columbia found that about 23% of such arrangements were entered into by people in their twenties and about 20% by those in their eighties, with other age groups selecting such arrangements at lower rates.²¹

Third, there is little information about the demographics of *supporters*. A study of such arrangements in British Columbia found that relatives are usually (80%+) selected, and that these relatives are usually immediate family members.²¹ However, the study also found that principals often select non-family members as secondary or primary supporters and that when they select monitors (i.e., someone to oversee the representative), “other relatives” and “friends” predominate, perhaps suggesting the desire to have a more objective level of “checks and balances”.²¹

Fourth, none of the studies include information about race or ethnicity of the people involved in SDM. Such information would be helpful in part because it might provide insight into decision-making behavior; for example, racial and ethnic differences exist in patients' approaches to medical decision-making, with certain groups tending to prefer a more distributed, non-patient-centered approach.²² Moreover, even where data exist it is not clear whether results are representative of individuals with ID, or even whether the underlying studies^{19–21} in fact included people with ID in the samples they identified.

Another, even more serious gap, is that there is very little information about the *outcomes* of SDM procedures. For convenience we divide such outcomes into *process* outcomes (e.g., regarding what types of discussions occur in SDM relationships) and *substantive* outcomes (e.g., regarding what decisions are reached).

The most serious concern in terms of *process* is the potential for coercion or other inappropriate influence by a representative or supporter.²³ In informal arrangements such as SDM, which may occur in private and with less accountability than formal procedures such as guardianship, the potential for financial or other abuse likely increases. Moreover, even if the supporter or representative does not deliberately take advantage of or influence the principal decision-maker, there is the potential for the supporter to lead the principal to particular or pre-determined outcomes by issue-framing, inaccurate assessment of the principal's preferences, or simple conversational style. Finally, undue influence may result from the principal's deference to the supporter, which may be frequent given that a substantial portion of elderly patients prefer to trust a proxy than to express a treatment preference.²⁴ Despite these significant concerns, we were unable to locate any data on the incidence of either the presence or absence of such abuse in SDM relationships.

Evidence on the *substantive* outcomes of SDM is also lacking. We found no research evaluating the quality of

decisions reached using SDM. This is perhaps unsurprising given the difficulty of establishing particular criteria against which to measure such decision quality. However, determining whether SDM tends to achieve the goals of its proponents would seem to require—at a minimum—research on two key indicators of quality: (1) whether decisions arrived at through SDM truly express and effectuate the preferences of the principal; and (2) whether such decisions are more beneficial to the principal than a decision made alone, or than the decision of some proxy, whether formally or informally appointed.^d The first question is important in part because it may be difficult to reconcile an acknowledgment of a person's diminished capacity to make decisions, with an assertion that she can contribute meaningfully to discussions in order to reach decisions that reflect her wishes. Research on the second question is important, in part, because the state has a significant interest in protecting the welfare of its citizens. Research on other potential indicators of quality would be helpful as well. For example, proponents of SDM tend to describe it as promoting important values such as autonomy, dignity, self-determination, as well as providing persons with disabilities with the opportunity to learn to make decisions.^{10,25} Yet it remains unclear to what extent principals experience autonomy or dignity, or learn from participation in SDM processes.

Determinations of whether SDM effectuates principal's wishes may ultimately vary based on how "wishes" are conceptualized. For example, it may be that SDM yields a process that is consistent with principals' wishes but a substantive outcome that is inconsistent with those wishes. Given that individuals sometimes place greater priority on obtaining a satisfactory decision-making process than on obtaining a particular decision outcome,²⁶ some might consider SDM to effectuate principals' wishes so long it effectuates principals' process-related wishes. This narrow conception of success, however, might be rejected by others on the grounds that it would condone SDM regardless of whether it results in decisions that the principal perceives to be (or objectively are) substantively harmful.

A final, significant gap in the research is that, assuming that third parties can assist others to reach decisions, there is no empirical research as to *how* supporters can do so. This is an important question because reaching decisions consistent with one's own preferences can be very difficult even for those without ID—for example, people of all cognitive abilities have surprising difficulty with *affective forecasting*, that is, with predicting their emotional reactions to future events.²⁷ As a result, it is often difficult to know how happy or unhappy an event will make one, and that much more difficult to know which preferences to pursue.

^d Thus, empirical research comparing the decisions reached using SDM to those reached by guardians would greatly enhance the understanding the relative value of each process.

Conclusion

Our review indicates that the evidence base on SDM is currently insufficient to determine whether SDM processes either can or do achieve their goals. Given the problems with guardianship, and the need to develop less restrictive alternatives to guardianship in order to reduce the incidence of those problems, SDM should be explored as an alternative to guardianship. Nevertheless, in order for policy-makers to make informed decisions as to whether and under what conditions SDM should be used in lieu of guardianship, significant further research is necessary. Key questions include: (1) How do decision-making supporters and persons with ID engage with one another?; (2) How do different techniques influence the decisions made and whether persons with ID feel satisfied with and empowered by the process?; (3) To what extent and under what conditions is SDM coercive?; and (4) Do SDM processes result in decisions that are substantively different than the decisions reached under surrogate decision-making models and if so, what is the nature and impact of these differences?

References

1. Grant M, Booth A. A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Info Libr J.* 2009;26: 91–108.
2. Bigby C. *Ageing With a Lifelong Disability*. Jessica Kingsley Publishers; 2004.
3. Teaster P, et al. *Wards of the State: A National Study of Public Guardianship*. 15–16; 2005.
4. *Representation Agreement Act, R.S.B.C.* ch. 405, pt. 2.8; 1996. Can..
5. Dimopoulos A. *Issues in Human Rights Protection of Intellectually Disabled Persons*. Ashgate; 2010.
6. Mental Disability Advocacy Center & Association of Social Affirmation of People with Mental Disabilities. *Out of sight: Human rights in psychiatric hospitals and social care institutions in Croatia*. Available from: http://www.mdac.info/sites/mdac.info/files/croatiareport2011_en.pdf; 2011 [cited 05.11.12].
7. Inclusion International. *Position Paper – Key Elements of a System for Supported Decision-Making*. Available from: http://www.inclusion-international.org/wp-content/uploads/Position_Paper-Supported_Decision_Making1.pdf; 2008.
8. Dhanda A. Legal capacity in the disability rights convention: stranglehold of the past of lodestar for the future. *Syr J Int Law Comm.* 2007;34(2):460–462.
9. Devi N, et al. Moving towards substituted or supported decision-making? Article 12 of the convention on the rights of persons with disabilities. *Eur J Disabil Res.* 2011;5:249–264.
10. Salzman L. Guardianship for persons with mental illness—a legal & appropriate alternative? *St. Louis Univ J Health Law Pol'y.* 2001;4: 279.
11. National Guardianship Network. *Third National Guardianship Summit*. Available from: <http://www.guardianshipsummit.org>; 2011. cited 05.11.12.
12. Wright J. Guardianship for your own good: improving the well-being of respondents and wards in the USA. *Int J Law Psychiatry.* 2010;33: 350.
13. Salzman L. Rethinking guardianship (Again): Substituted decision making as a violation of the integration mandate of title II of the Americans with disabilities act. *Univ Colo Law Rev.* 2010;81:157.

14. Frolik L. Guardianship reform: when the best is the enemy of the good. *Stan Law Pol'y Rev.* 1998;9:347.
15. Bach M, Kerzner L. *New Paradigm for Protecting Autonomy and the Right to Legal Capacity. Prepared for the Law Commission of Ontario.* Available from: <http://www.lco-cdo.org/disabilities/bach-kerzner.pdf>; 2010 [cited 05.11.12].
16. United Nations Enable. Handbook for Parliamentarians on the Convention of Rights of Persons with Disabilities. Ch. 6. Available from: <http://www.un.org/disabilities/default.asp?id=242>. [cited 05.11.12].
17. Burningham S. Developments in Canadian adult guardianship and co-decision-making law. *Dal J Leg Stud.* 2009;18:119.
18. Schalock R, Verdugo MA, Gomez LE. Evidence-based practices in the field of intellectual and developmental disabilities: an intentional consensus approach. *Eval Program Plann.* 2011;24:273–282.
19. Surtees D. The evolution of co-decision-making in Saskatchewan. *Sask Law Rev.* 2010;73:75.
20. Harrison W. *Representation Agreements in British Columbia: Who is Using Them and Why?*. unpublished Master's thesis. Burnaby (BC): Simon Fraser University; 2008.
21. Nidus. *A Study of Personal Planning in British Columbia: Representation Agreements with Standard Powers.* Available from: www.nidus.ca/PDFs/Nidus_Research_RA7_InAction.pdf; 2010 [cited 05.11.12].
22. Blackhall L. Ethnicity and attitudes toward patient autonomy. *JAMA.* 1995;274(10):820–825.
23. Gordon R. The emergence of assisted (supported) decision-making in the Canadian law of adult guardianship and substitute decision-making. *Int J Law Psychiatry.* 2000;23:61.
24. Miles S, Koepp R, Weber EP. Advance end of life treatment planning: a research review. *Arch Internal Med.* 1996;156(10):1062–1068.
25. Office of the Public Advocate, Victoria, Australia. *Supported Decision-Making: Background and Discussion Paper.* Available from: http://www.publicadvocate.vic.gov.au/file/file/Research/Discussion/2009/0909_Supported_Decision_Making.pdf; 2009 [cited 05.11.12].
26. Kohn NA, Blumenthal JA. Designating health-care decision-makers for patients without advanced directives: a psychological critique. *Ga Law Rev.* 2008;42:979–1018.
27. Blumenthal JA. Law and emotions: the problems of affective forecasting. *Indiana Law J.* 2005;80:155–238.