

Capítulo II

“THE RIGHT TO MAKE CHOICES”: SUPPORTED DECISION-MAKING ACTIVITIES IN THE UNITED STATES*

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ABSTRACT

Research shows that self-determination and the right to make life choices are key elements for a meaningful and independent life. Yet, many Americans with disabilities and older adults often are placed in broad and restrictive guardianships, denying them their right to make daily life choices about where they live and who they interact with, their finances, and their health care. Supported decision-making (SDM)—where people use trusted friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions—is a means for increasing self-determination by encouraging and empowering people to make decisions about their lives to the maximum extent possible. This article examines the implications of overly broad guardianship and the potential for SDM to address such circumstances. It introduces the National Resource Center for Supported Decision-Making and a program of study to advance the use of SDM and self-determination.

Today, many Americans with disabilities and older adults are placed in overbroad and unwarranted guardianships, losing their right to make choices regarding where to live, what to do during the day, with whom to interact, their personal finances and health care (Dinerstein, 2012). To advance and protect the right of these citizens to make core life choices and direct their lives to the maximum of their abilities, Quality Trust for Individuals with Disabilities, the Burton Blatt Institute at Syracuse University (BBI), and the Kansas University Center on Developmental Disabilities, together with a broad coalition of community partners and stakeholders, have launched the National Resource Center for Supported Decision-Making.

Funded through a five-year agreement with the U.S. Administration on Community Living, the National Resource Center leads and coordinate efforts

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to make supported decision-making (SDM)—where people use trusted friends, family members, and professionals to help them understand the situations and choices they face, so they can make their own decisions (Quality Trust for Individuals with Disabilities, Quality Trust, 2013)—a recognized and, as appropriate, preferred alternative to guardianship.

This article provides an overview of the negative effects of overly broad and unnecessarily restrictive guardianship arrangements, the potential benefits of SDM as an alternative to guardianship, recent developments in research and practice in SDM, and the National Resource Center’s efforts to increase awareness and advance the practice of SDM.

NEGATIVE EFFECTS OF OVERLY BROAD AND RESTRICTIVE GUARDIANSHIP

In the U.S. guardianship is governed by state law, with each of the fifty states enacting their own statutes, policies, and procedures. Guardianship is ordered when a state court determines that a person is not able to make some or all life decisions, the person is thereby in need of *protection*, and there are no less restrictive options other than court-ordered guardianship. (*Less restrictive options* are other ways of making decisions that protect the person’s rights and self-determination as well as or better than guardianship.) The court appoints a third party to make some or all decisions for that person, who becomes known as the “ward.” (Broadly speaking, *limited* guardianship occurs when the guardian is authorized to make some, but not all, decisions for the ward. *Full, general, or plenary* guardianship occurs when the guardian is authorized to make all decisions for the ward.)

American society, as in other countries, generally conceives of guardianship as “a humanitarian response to the vulnerability of the incompetent” (Frolik, 1998, p. 350), protecting those who “cannot take care of themselves in a manner that society believes is appropriate” (Kapp, 1999, p. 109). Because guardianship has traditionally been assumed to be benevolent and protective of those “less able” to decide for themselves, many state laws and courts have not closely reviewed whether people with disabilities and older adults in fact require forms of guardianship or, once guardianship is established, “whether the protected person continue[s] to need or benefit” from it (Wright, 2004, p. 60).

With the development of the disability civil rights movement, as embodied in the Americans with Disabilities Act of 1990 (ADA) (2006; Blanck, 2014a, 2014b), researchers and practitioners are finding that overly restrictive guardianship regimes may be associated with decreased life competencies and health. This is because guardianship may “set up expectancies of failure ... that diminish subsequent [life] performance” (Winick, 1995, p. 15), thereby decreasing and denying individual self-determination.

Self-determination describes actions that enhance the possibilities for people to make or cause things to happen in their lives (Shogren, Wehmeyer, Palmer, Forber-Pratt, et al., in press). Individuals exercise self-determination when making simple and complex everyday life choices regarding where, how, and with whom they live (Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000, p. 440). A person

denied self-determination often “feel[s] helpless, hopeless, and self-critical, and will not behave because he can see no use in behaving” (Deci, 1975, p. 208).

Accordingly, many people labeled *incompetent* or *incapacitated* and placed in overbroad guardianships are deprived of self-determination and the opportunity to be causal agents in their own lives. In these circumstances, people often experience “low self-esteem, passivity, and feelings of inadequacy and incompetency,” decreasing their ability to function (Winick, 1995, p. 21). Thus, imposing a guardianship to “protect” a person for his or her “own good” may be associated with negative behaviors and symptoms that led to the guardianship in the first place.

Despite such findings, there are “deeply embedded tendencies toward protection over autonomy, and courts continue to issue guardianship orders that are not necessary and are overly broad in scope” (Salzman, 2010, p. 178). Indeed, since 1995, the estimated number of American adults under guardianship has increased from 500,000 to 1.5 million (Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011).

More troubling, plenary guardianship (in which a court gives a guardian authority across all legal rights) is ordered in the vast majority of cases (Frolik, 2002). One study found that less than 10% of the public guardianships it reviewed were limited—meaning that in nine of 10 cases, the guardian had authority to make all life decisions for the ward (Teaster, Wood, Lawrence, & Schmidt, 2007). Another found that only 13% of the guardianships it reviewed across ten states were limited in scope (Lisi, Burns, & Lussenden, 1994). A third found that plenary guardians were appointed in 54% of the cases reviewed and that there was little difference between the authority given to full and limited guardians (Millar & Renzaglia, 2002). As demand for plenary guardianships increases, one “cannot say with confidence that if any one of us becomes incapacitated that a robust system is in place to protect our person and our financial assets” (Uekert, 2010, p. 6).

The present trend favoring plenary guardianship continues despite federal laws and U.S. Supreme Court decisions mandating community integration (e.g., ADA, 2006; Developmental Disabilities and Bill of Rights Act, 2006; *Olmstead v. L.C.*, 1999; Rehabilitation Act of 1973, 2006). Consequently, there is a compelling need to develop and implement the opportunity for alternatives to guardianship that respect individual self-determination and empower individuals to make their own life choices to the maximum of their abilities.

SELF-DETERMINATION AND SUPPORTED DECISION-MAKING

SDM has shown promise to increase self-determination and quality of life, and to alter the prevalent view that people with disabilities inevitably require guardianship (Blanck & Martinis, 2019). Although there is no one model of SDM, it generally occurs when people use one or more trusted friends, family members, professionals, or advocates to help them understand the situations and choices they face so they may make their own informed decisions. SDM mirrors how most adults make daily decisions—whether to sign legal documents, consent to medical procedures, review financial documents, and the like. In each instance, individuals

seek advice, input, and information from knowledgeable friends, family, and professionals so they may make their own informed choices.

SDM increasingly is used in the United States and internationally (Kohn, Blumenthal, & Campbell, 2013). In the U.S., Texas and Virginia have passed laws authorizing and studying the use of SDM. Supported decision-making also is recognized in Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which presumes that all people have legal capacity and that governments must take appropriate action to provide people with access to the supports they need and want to make their own life decisions (Dinerstein, 2012). Among others, the governments of Australia, Canada, Germany, Great Britain, Israel, and Ireland have implemented forms of SDM.

By ensuring the individual is the final decision maker on his or her own life circumstances, SDM empowers people to be causal agents in their lives, increasing their self-determination (Kohn et al., 2013). Research indicates that people who exercise greater self-determination have more positive quality of life outcomes and improved quality of life. Studies find that young adults who receive instruction designed to increase self-determination enhance their employment circumstances, independence in daily life, and community integration (Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenshark, & Little, in press).

These findings build on those from other studies showing a positive relationship between self-determination and quality of life. Wehmeyer and Schwartz (1997) found that young adults with greater self-determination were more likely to want to live independently, manage their money, and be employed. In another study, adults who exercised more self-determination were more likely to live independently, have greater financial independence, be employed at higher paying jobs, and make greater advances in their employment (Wehmeyer & Palmer, 2003). Khemka, Hickson, and Reynolds (2005) found that women with intellectual disability (ID) provided with education to improve problem solving and independent decision-making were more likely to identify situations where they could be abused and less likely to suffer abuse.

Kohn et al. (2013) concluded that SDM has the “potential to be an empowering alternative to the much-maligned process of guardianship.” The question, however, is whether SDM “can fulfill that promise” (p. 1157). The authors cautioned, though, that:

It is imperative that substantial further research be conducted to examine how supported decision-making actually operates ... Research is needed to determine the extent to which supported decision-making approaches achieve their goals, and the conditions under which they are likely to do so (Kohn et al., 2013, p. 1157).

RECENT DEVELOPMENTS IN SUPPORTED DECISION-MAKING

As noted, the call for and use of SDM is increasing. In 2009, the Texas legislature created a pilot program to promote provision of SDM to persons with intellectual and other cognitive disabilities who live in the community (Volunteer-Supported Decision-Making Advocate Pilot Program, Tex. Gov’t Code Ann. § 531.02446, West 2009). The program called for training volunteers to provide support needed to

empower people “to make life decisions such as where the person wants to live, who the person wants to live with, and where the person wants to work, without impeding the self-determination of the person” (§ 531.02446(a)(4), West 2009).

In 2012, a group of stakeholders met in New York to discuss the rights of people with ID to make their own decisions in light of the CRPD. The goal was to explore concrete ways to move from a model of substituted decision-making, like plenary guardianship, to one focusing on alternatives like SDM. The participants identified a number of important and difficult issues, including the need to revise guardianship standards to stress supported, independent decision-making; set standards and expectations for “supporters”; and, prevent abuse, undue influence without denying legal capacity (Quality Trust, 2013, p. 2).

The following year, in 2013, a 29-year-old woman named Margaret “Jenny” Hatch won a landmark legal battle protecting her right to make her own life decisions using SDM, instead of being subjected to a permanent, plenary guardianship. (Professor Blanck served as an expert witness for Ms. Hatch. Mr. Martinis served as her lead counsel.) Like many people with disabilities, Jenny faced a guardianship petition challenging her right to make decisions, including choices she had made for herself such as where to live, whether to work, how to use the Internet and a cellular telephone, and whom to see (*Ross and Ross v. Hatch*, 2013). At the request of her parents, the court placed Jenny in a temporary guardianship and placed her in a group home, where her phone and laptop were taken away and she was not allowed to go to her job and see her friends.

Fortunately, after a year of litigation and a trial before a state court judge, Jenny won her right to make her own decisions using SDM and “now lives and works where she wants, has the friends she chooses, and encourages others to do the same” (Quality Trust, 2013, p. 2). Jenny’s court victory received national and international attention for highlighting “an individual’s right to choose how to live and the government’s progress in providing the help needed to integrate even those with the most profound needs into the community” (Vargas, 2013). After the trial, Jenny and Quality Trust partnered to form the Jenny Hatch Justice Project (JHJP). In its first year, the JHJP provided representation and technical assistance in over 100 guardianship matters; co-led coalitions that advanced alternatives to guardianship by successfully advocating for changes in state laws, policies, and practices; and trained and worked with individuals and public and private entities to implement policies advancing the use of supported decision-making and other alternatives to guardianship.

Later in 2013, Quality Trust, the Burton Blatt Institute, and the Council on Quality and Leadership convened a group of national and international thought leaders for an Invitational Symposium on SDM. The Symposium brought together stakeholders, leaders, and policymakers to discuss principles of education, research, and advocacy to guide future actions to advance SDM. Symposium attendees were organized into four working groups, which reached consensus on the fundamental principles that should guide future action, including: compiling information and data on SDM usage and disseminating it to stakeholders; researching how SDM is working in the U.S. and abroad; developing and implementing best practice standards for SDM; and, identifying barriers to guardianship reform and the actions needed to overcome them (Quality Trust, 2013, p. 11).

In 2014, the Virginia General Assembly, based in part on the advocacy of Jenny Hatch and the JHJP, directed the state Secretary of Health and Human Services to study SDM (VA H.J.R. 190, 2014). The Secretary reviewed ways SDM may be used in Virginia and has been implemented elsewhere (VA H.J.R. 190, 2014).

In 2014, the Administration for Community Living in the U.S. Department of Health and Human Services also made funding available for a first-of-its-kind training and technical assistance center on SDM. After receiving and reviewing proposals from leading organizations, the Administration selected the National Resource Center for Supported Decision-Making to lead this effort. The National Resource Center began operation October 1, 2014.

NATIONAL RESOURCE CENTER FOR SUPPORTED DECISION-MAKING

In partnership with people with disabilities and others, the National Resource Center is conducting research, creating educational programs, and developing best practices to advance policy and practice to establish SDM as a recognized alternative to guardianship. The National Resource Center's 5-year plan includes: changing attitudes in the judicial system that judges consider SDM as a less restrictive alternative to guardianship; creating a multi-disciplinary national dialogue on SDM as a preferred alternative to guardianship; analyzing and suggesting modifications to the U.S. model Uniform Guardianship and Protective Proceedings Act to recognize SDM as a potential alternative to guardianship; identifying and analyzing local, state, and national laws, policies, and practices that promote the use of SDM and those that are barriers to the acceptance and implementation of SDM; implementing SDM best practices across multiple domains, throughout the lifespan, including in the education, health care, financial, and legal systems; and, developing and disseminating education, technical assistance, and training material about SDM.

RESEARCH AGENDA

Kohn and colleagues (2013) argue that the greatest impediment to the full implementation of SDM is the lack of valid and reliable data demonstrating its tie to improved life outcomes. To help fill this gap, the National Resource Center will use multiple methods of data collection and analysis to document the use of SDM, focusing on decision making networks and the ways in which legal, programmatic, and policy systems may enhance or constrain opportunities to practice supported decision-making. The research will seek answers to questions raised by Kohn and others, including: How do different people and groups use SDM?; Does SDM result in measurable improved life satisfaction and outcomes? What are the key elements of successful SDM methods?; and, What barriers hinder the use of SDM?; How do legal, policy, and program frameworks impact SDM?

To examine SDM, the National Resource Center is using a three-pronged approach. First, it is implementing a conceptual model for measuring SDM and its relationship to legal decision making status (e.g., having a guardian or not), self-determination, and quality of life. This work is groundbreaking because there

are no validated measures of SDM. The measures and tools developed will create a template that may be built upon and replicated by other researchers, providers, policy makers, and advocates (Shogren, Wehmeyer, Martinis, & Blanck, P. (2019).

Next, the Center is examining the ways people build and use effective SDM systems. This program of study analyzes the relationship of SDM to factors such as individual capacity and differences over the life course, environmental context and demands, and public and private support mechanisms such as person-centered life planning (e.g., McDonald & Raymaker, 2013). The goal is to validly identify and assess SDM methods that are associated with high quality of life outcomes, reductions in guardianship, and increased self-determination. This information will be used to create a guidebook for best practices in SDM.

Finally, the Center is conducting a 50-state and international review to identify patterns and trends in guardianship and SDM across jurisdictions and countries. This review includes examination and analysis of: (1) existing state laws and policies on guardianship, (2) state and local services and funding means and their relation to decision making (i.e., guardianship and alternatives like supported decision-making), and (3) international SDM laws and policies to catalogue replicable best practices.

POLICY AND PRACTICE AGENDA

The National Resource Center is working to ensure that multidisciplinary policies and practices recognize, encourage, and empower the use of SDM. The Center's policy and practice goals include: developing and implementing best practice standards for SDM; effectuating policies and procedures in support of SDM; and identifying and analyzing local, state, and national laws that advance the use of SDM and those barriers to implementation of best practices in SDM.

Through evidence-based study and analysis, the National Resource Center is identifying the elements of successful SDM relationships, such as those that decrease the perceived need for guardianship, increase self-determination, and improve life outcomes. The Center is incorporating effective SDM methods into outreach, training, and educational materials.

The National Resource Center is advancing the use of SDM across multiple domains through-out the life course. To support SDM as a recognized method for increasing self-determination, the Center is advocating for use of SDM best practices in local, state, and national education, employment, health, economic, legal, and other systems to ensure that people may participate fully in all aspects of life throughout the life course, with the support they want and need (e.g., McDonald, et al., in press). Additionally, the National Resource Center is advocating for changes in existing guardianship policy and practice to increase the use of SDM. Furthermore, the National Resource Center is working to educate attorneys and judges about supported decision-making by conducting targeted outreach and training. Another element of the National Resource Center's activities is the design and implementation of demonstration programs. The Center is bringing together state-based workgroups to recommend ways to increase SDM recognition and use.

Central to these efforts is the Center's accessible web portal, *www.SupportedDecisionMaking.Org*, which is a: (a) repository of research, resources, information, and tools; (b) communication platform to share knowledge and best practices; (c) technical assistance vehicle for users to request information, training, and other services; and (d) gateway to external resources and organizations with experience in SDM. The online portal supports advocacy efforts by offering user-friendly, plain language, and responsive information, training, and technical assistance materials. It includes Listservs to inform participants about SDM as well as a community of practice virtual learning community, in which participants will post questions, benefit from group problem solving, and share documents and resources.

EDUCATION GOALS

The National Resource Center offers interactive and user-friendly information and training materials focused on educating people, professionals, and policy makers about SDM. The Center's education efforts include: ensuring stakeholder and public access to research and educational material; providing customized training programs for individuals, families, professionals, providers, and policymakers; developing and disseminating SDM forms, templates, and practice guides; and creating a continuing community of practice through in-person and virtual presentations, training material, and social media.

The National Resource Center's web portal serves as its educational and training hub, providing an accessible, plain language, user-friendly, and interactive clearinghouse. The portal provides reports, research, and practical articles, training, and multimedia resources categorized by topic area, resource type, and intended audience. The portal will translate research findings and educational materials for diverse audiences by making resources available through a content management system using appropriate writing styles, navigation structures, and accessibility features that will, for example, make it easy for people with disabilities and older adults to access, use, and comprehend the materials (e.g., Blanck, 2014b).

The Center provides training by multiple means. In addition to in-person presentations, it: (a) conducts webinars to increase awareness and dialogue; (b) disseminates online toolkits for diverse audiences; (c) provides customized assistance to communities; and (d) conducts video conferencing, webinars, and in-person meetings to build consensus. Current and archived training, research, and educational materials are available via the web portal. The portal provides educational resources, training, Listservs, and forums for people with questions about facets and applications. This offers opportunities to share resources, education, and assistance across domains and disciplines.

CONCLUSION

Self-determination is self-sustaining; exercising it leads to greater opportunities and ability to do so, making people causal agents in their lives, prepared to make

life choices to the maximum of their abilities. SDM has the potential to increase the self-determination, empowering people to reap the benefits from increased life control, independence, employment, and community integration.

The Burton Blatt Institute and its partners have several large ongoing and proposed studies to examine the efficacy of supported decision-making. These are quantitative and qualitative studies on: (1) use of SDM by persons across the United States with varying types of supports; and (2) use of SDM by persons with serious mental illness, such as with schizophrenia and bipolar disorders across the U.S., in collaboration with the Saks Institute for Mental Health Law and Ethics (Jeste et al., 2017; Logue & Blanck, 2018), and in Spain with King Juan Carlos University in Madrid.

The efforts and research activities are aimed at changing centuries of overly paternalistic guardianship policy, practice, and perception. Society's preference for guardianship persists. However, the Center and a wide array of national and multi-national partners are committed to developing and disseminating evidence-based best practices, with coordinated advocacy and education, to advance SDM and that each person has "The Right to Make Choices¹."

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The phrase "The Right to Make Choices" reflects National Resource Center for Supported Decision-Making's mission: Advancing the right all people have to direct their own lives to the maximum of their abilities, while receiving the support they need and want to do so; see www.SupportedDecisionMaking.Org.

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