



SUPPORTED DECISION MAKING IN THE UNITED STATES:
A WHITE PAPER BY CQL | THE COUNCIL ON QUALITY AND LEADERSHIP





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ACKNOWLEDGEMENTS



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Executive Summary

Guardianship is a legal process “allowing a state court to appoint decision-making powers to another person on behalf of an individual based on a determination of impaired decision-making capacity” (Dinerstein, Grewal & Martinis, 2016, p. 436). Guardianship in various forms (full or partial), and other approaches such as substitute decision-making or power of attorney, presume a person is incapable of making decisions, or lacks the legal capacity to self-determine life choices because of a determination of reduced mental or cognitive capacity (Pathare & Shields, 2012).

Supported decision making (SDM) is a flexible alternative to guardianship which provides a process that recognizes people with disabilities as persons before the law, providing a pathway to exercise legal capacity by focusing on developing supports to enable autonomous decision-making. While there is growing interest from many stakeholder groups within the United States to implement SDM, there is little understanding or evidence that supports SDM, or identifies or describes best practice approaches. The laws and nature of guardianship are very unique to each country, and to understand how SDM might be applied in a United States legal system it is critical to explore the evidence of what exists within the constraints of the law of the land. Therefore, the main aim of this white paper was to synthesize published literature that might apply to use of SDM within the United States, describing policy, procedure, and practice approaches of SDM, as well as any pertinent empirical evidence to provide insight and inform stakeholder groups of best practices and benefits of SDM over other forms of legal representation.

Our findings reveal, using a social justice lens, SDM provides for a much greater pragmatic approach to legal determinations concerning an individual’s personhood, legal, and human rights. However, opponents of SDM as well as advocates, and people with intellectual and developmental disabilities (IDD), voice serious concerns that without formalized mechanisms this approach has the potential to be abused. Concerns from across the literature echo a history of the conundrum courts face in determining what is best for a person with IDD when faced with balancing between concerns of safety and supervision versus allowing individuals to maintain control over their own decision-making and their own legal capacity. However, SDM upholds a philosophic view that all people are interdependent when making decisions; SDM also honors self-advocates’ call for equality, autonomy, and self-determination to make decisions – and at times take risks – as a part of full personhood.

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Supported Decision Making in the United States

INTRODUCTION

Guardianship is a legal process “allowing a state court to appoint decision-making powers to another person on behalf of an individual based on a determination of impaired decision-making capacity” (Dinerstein, Grewal & Martinis, 2016, p. 436). Guardianship in various forms (full or partial), and other approaches such as substitute decision-making or power of attorney, presume a person is incapable of making decisions, or lacks the legal capacity to self-determine life choices because of a determination of reduced mental or cognitive capacity (Pathare & Shields, 2012). Reduced mental or cognitive capacity is linked to the “assumption that people with intellectual or developmental disabilities (IDD) lack the ability to make informed decisions that may have long-term repercussions on their lives” (Jenkinson (1999) as quoted by Devi, 2013, p. 793). Guardianship is based on perceptions that people with disabilities, especially those with IDD or psychiatric disabilities, need guidance or advice from others on how best to reach a decision because they require counsel in making decisions on important matters. This arguably positions people with disabilities to inequitable standards compared to people without disabilities who also need outside support to make decisions in areas where their knowledge base is limited. Some advocates feel guardianship appointment, as an approach to providing support and services, violates a person’s constitutional rights as described in Title II of the Americans with Disabilities Act (ADA). As such, guardianship has been criticized by the disability community as an unnecessary and unjust approach to providing decision-making services and supports, especially when considered as the first option for people with IDD (ASAN, n.d.; Jameson et al., 2015).

People with disabilities are supported by the United States (US) Constitution and the Americans with Disabilities Act (ADA) to full inclusion in community living, and nondiscrimination in public policy. Despite this, socially accepted and routine practices persist throughout the US legal system that remove people with disabilities’ rights to full citizenship. Many advocates feel one of the most deeply imbedded of these practices is removing legal capacity through appointed guardianship, designed to ‘protect’ people with disabilities who are considered to “lack the cognitive capacity to understand the consequences and risks concerning life decision-making and incapable of managing life affairs” (People with Disability – Australia & Waldron, 2006, p. 11). Guardianship removes a person’s legal capacity to act in decision-making concerning finances, medical decisions, social choices, and living situations – the many choices and rights enjoyed by people without disabilities (Jameson et al., 2015, p. 37). The disability community recognizes this as another form of discrimination, stigmatization, and marginalization, and suggests a response of protest (International Disability Caucus, n.d.), similar to those in the past, which culminated in policy and legislative mandates such as *Olmstead v. L.C.* (1999), and the Developmental Disabilities and Bill of Rights Act (Public Law, 106-402). Each of these legislative mandates – and others – reinforce that people with disabilities must receive services and supports in the least restrictive manner to optimize community integration and self-determination (Americans with Disabilities Act (ADA), 1990; Developmental Disabilities and Bill of Rights Act, 2000; *Olmstead v. L.C.*, 1999; Rehabilitation Act of 1973, 1973). Despite this, entrenched legislative practices supporting guardianship that often unjustly and unnecessarily erase a person’s legal capacity for decision-making became the focus for a new mandate by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006).

The UNCRPD was adopted by the United Nations General Assembly in 2006 as an international treaty of human rights for people with disabilities. One of the primary efforts of the UNCRPD is protecting the human rights of people with disabilities, with a focus on equality in the laws (Council of Europe Commissioner for Human Rights & Nilsson, 2012). Articles 12.1-12.3 of the UNCRPD state:

[12.1] States Parties reaffirm that people with disabilities have the right to recognition everywhere as persons before the law; 12.2 States Parties shall recognize that people with disabilities enjoy legal capacity on an equal basis with others in all aspects of life; 12.3 States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. (United Nations, 2006)

These declarations by the UNCRPD effectively illustrate the concerns with substitute decision-making or guardianship practices, and call for a shift in the approaches nations and states use to provide services and supports in decision-making for those with IDD or other cognitive disabilities (Pathare & Shields, 2012). Supported decision-making (SDM) has emerged and is being embraced by the disability community as the replacement, and a least-restrictive alternative to guardianship and substitute decision-making practices – the most restrictive – to maintaining personhood and legal capacity for people with disabilities.

As an alternative to guardianship, SDM first emerged in Canada in 1993. A nonprofit group in British Columbia proposed that the Province should enact the first Representation Agreement Law for people with disabilities, and by 1995 the law was passed (RARC, 2006). This law in essence outlines SDM and provides a process that recognizes people with disabilities as persons before the law, providing a pathway to exercise legal capacity by focusing on developing supports to enable autonomous decision-making (Parker, 2016). SDM is clarified and defined in the UNCRPD Committee’s Handbook for Parliamentarians as a flexible approach dependent on the specific needs of the individual where “support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to the wishes of the individual” (Gooding, 2013). Since the passage of the Canadian act as well as the UNCRPD articles, other countries – Australia, Canada, Germany, Ireland, Scotland, England, Norway, Sweden, and Israel – have adopted SDM nationally or within areas of their country. There is a growing momentum from these government actions trickling into other parts of the world through “academic journal articles, case law, formation of institutes, and presentation at conferences on SDM” (Parker, 2016, p. 5). Advocates of SDM describe the impact it has as a means to “empower people with disabilities by providing them with help in decision-making rather than offering up someone to make decisions for them,” and coupling this with disability rights concepts of self-determination, and autonomy to help SDM gain political momentum (Kohn, Blumenthal & Campbell, 2012, p.1113).

Purpose

While there is growing interest from many stakeholder groups within the United States to implement SDM models that align with these UNCRPD mandates, there is little understanding or evidence that supports SDM, or identifies or describes best practice approaches. To collect evidence, reviews of literature have been published but these focus on international SDM or have used broad diagnostic nets (Davidson et al., 2015; Kohn & Blumenthal, 2014; Pathare & Shields, 2012). The laws and nature of guardianship are unique to each country, and to the states or provinces within those countries, and to understand how SDM might be applied in a United States legal system it is critical to explore the evidence of what exists within the constraints of the law of the land. Therefore, the main aim of this white paper was to synthesize published literature that might apply to use of SDM within the United States, describing policy, procedure, and practice approaches of SDM, as well as any pertinent empirical evidence to provide insight and inform stakeholder groups of best practices and benefits of SDM over other forms of legal representation. Legal manuscripts, government documents, as well as grey literature were also included to expand the review.

METHODS

This review of the literature was performed to identify evidence for supported decision making (SDM) as well as reports on the current status of SDM in the United States. The goal for this search was to synthesize available academic literature describing processes, policy, and practice of SDM as well as any pertinent empirical evidence to provide descriptive insight and inform stakeholder groups of best practices, and perceived benefits of SDM over other forms of legal representation. Legal manuscripts as well as grey literature and advocacy group resources were also included to expand the review due to limited academic resources. Grey literature includes published and unpublished non-research literature, in print and electronic formats, and is considered important to include in literature reviews that might inform “policy and practice decision-making” (Benzies, Premji, Hayden, & Serrett, 2006, p. 55). Complementary search strategies were used as recommended by Cooper (2009) in order to identify “relevant studies from more than one channel of entry to the literature base” (p. 75). As suggested by Cooper (2009) this literature search explored primary and secondary “reference databases, relevant journals, review of references from previous syntheses” (p. 78) as well as grey literature – including advocacy group literature - and statewide legislation and policy recommendations. Inclusion and exclusion criteria were used to review the abstracts. A study was included if it described SDM as an approach for providing support and services to facilitate autonomy of an individual with intellectual disability, developmental disability, and/or psychiatric disability in decision-making. Abstracts were excluded if they focused solely on analysis of SDM policy or legislation processes from another country outside of the United States, or if they dealt with an approach to self-management of a chronic disease, illness, or condition. However, if an abstract was an internationally based analysis of SDM describing the supports, barriers, benefits or risks of SDM it was included as this directly informs the primary aim of this search. An exhaustive search of abstracts was used following the recommendations established by the Preferred Reporting Items for Systematic reviews and Meta-Analysis guidelines (PRISMA) (Moher et al., 2009).

The academic literature search databases used were PubMed, Cinhal, and Google Scholar. For all searches, search words used were: “supported decision-making” AND “intellectual disability” OR “disability” in addition to adding combinations of: “assisted decision-making” AND/OR “guardianship” AND “disability” OR “intellectual disability.” “Supported decision-making” AND “intellectual disability” resulted in a total of 31 abstracts, 24 of which were eliminated as not pertinent because they explored other issues specifically around approaches such as: informed choice; shared decision making approaches used by providers with the people they support; substitute decision making; or self-determination. Abstracts were also rejected if they addressed supported decision making for women in fertility, prenatal testing, or genetic testing, or were concerned with legal consequences of choice processes (Nieboer, Cramm, van der Meij, & Huijsman, 2011), educational decisions (Nachshen & Minnes, 2005) or medical decisions made by families for a child (Diekema & Fost, 2010).

Finally, searches were made using only “supported decision-making” and using variations in the phrase “supported decision-making” found while searching the literature to apply a wider net for literature abstraction. Variations included “shared decision-making” and “inter-dependent decision-making.” Using “supported decision-making” alone, 10 additional abstracts were identified. However, no new relevant literature was identified using the variations in terminology. The combination of abstracts using search terms totaled 14 publications from the academic literature.

Grey literature databases including Open Access, ClinicalTrials.gov (US National Institute of Health (NIH)) showed no additional studies addressing SDM as defined. Review of relevant journals - using the same search words described previously - were also explored and contributed no new abstracts. Reference lists of all selected articles, including previously published literature reviews on SDM, were hand searched and key researchers’ names were searched for related studies providing two new abstracts not previously found (figure 1). This provided a total of 16 academic articles found to be relevant for inclusion in this review. Extraction of themes came from identifying and summarizing the major findings of each article to determine priority concerns from the academic literature to inform the primary gaps that exist, evidence of best practice, as well as suggestions for future research.

Other grey literature searches were done through searching the Internet using the term “supported decision-making” and included policy documents, national research and assistance centers, legislative reports, presentations, and advocacy group educational literature. An abundance of literature can be found describing SDM with the intended audience including legal scholars and practitioners, mental healthcare providers, legislators, advocates with IDD, and family members and individuals with IDD. The literature explored from this category required its own inclusion criteria. It was determined that literature would be included if it was considered a primary informational resource (e.g., advocacy group, national resource center), or critical legislative document from within the identified academic literature. Finally, eleven US states are in different stages of evaluating, implementing, or recently passing legislation on SDM. Each state’s documentation on this process provides insight into the social and political considerations leading up to formally recognizing SDM as an alternative to guardianship and maintaining human and legal rights to personhood. This literature was also included to provide valuable insight into best practices, benefits, and risks of SDM.

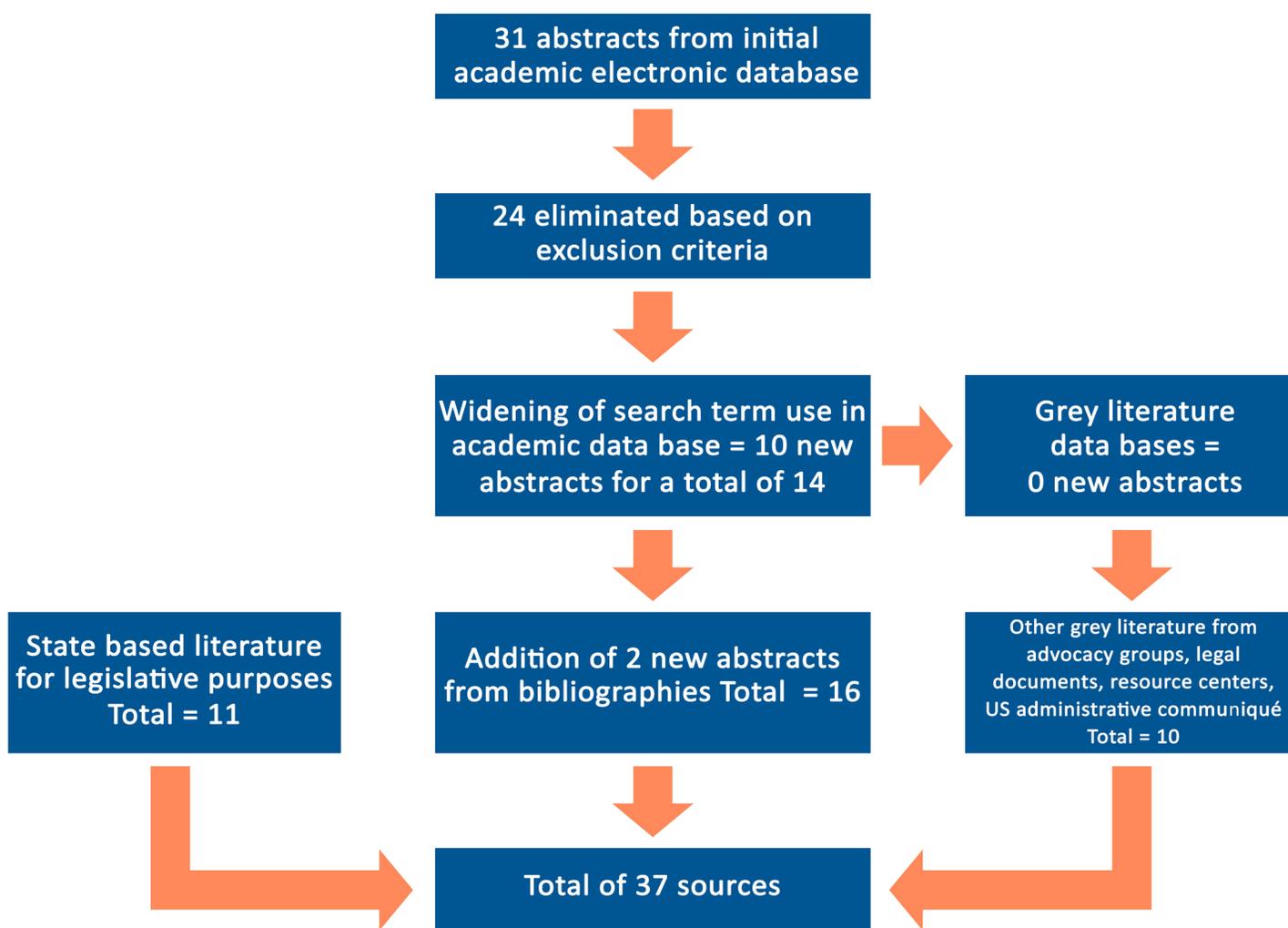


Figure 1. Search Strategy

Taken and adapted from: Moher et al. (2009)

Academic Literature

The abstracted academic literature included three literature reviews (Davidson et al., 2015; Kohn & Blumenthal, 2014; Pathare & Shields, 2012), one editorial (Kripke, 2016), nine analyses or descriptions of concepts and practices of SDM (Agoratus, 2016; Coleman, 2016; Devi, 2013; Dwyer, 2016; Gooding, 2013; Gordon, 2000; Jamieson, Theodore & Raczka, 2016; Parker, 2016; Salzman, 2010), and three qualitative studies (Jamieson et al., 2016; Mitchell, 2015; Werner & Chabany, 2016).

There were three primary themes that emerged from this extracted academic literature: 1) a need for mechanisms of oversight; 2) concern over the lack of evidence for process and outcomes of SDM; and, 3) belief that SDM is a viable alternative to guardianship. The most common theme was concern regarding limited or non-existent legal mechanisms for protection or oversight for the individual (Coleman, 2016; Davidson et al., 2015; Dwyer, 2016; Jameson et al., 2015; Kripke, 2016; Mitchell, 2015; Salzman, 2010). This argument identified that various levels of SDM can occur – from very formal court appointed contracts to informal family and community social networks – however, arguments exist recommending that SDM should have formalized court appointed mechanisms as precedent to protect the individual, reduce potential for risk, and facilitate the support networks of the individual (Coleman, 2015; Dwyer, 2016).

A second theme found in the majority of the manuscripts of amplified concern was the lack of evidence on SDM approaches and the urgency for research on best-practices (Pathare & Shields, 2012) in order to develop guidelines for SDM practice and processes (Davidson et al., 2015; Jameson et al., 2015). In this theme was recognition of the dearth of literature on substantive outcomes of the decisions individuals make (Kohn & Blumenthal, 2014), and a paucity of any descriptions of demographics, individual factors, and characteristics that impact outcomes for the decision-maker as well as supporters (Davidson et al., 2015; Salzman, 2010). Jamieson et al. (2016) highlighted the need for more research on how individual differences and contextual factors can impact satisfaction and outcomes with SDM. In Jamieson et al.'s (2016) study on support networks and decision-making of women with IDD and pregnancy, the researchers found that individual differences between the woman with IDD, and the support providers made a significant difference in both satisfaction and decision-making process. One individual factor for both groups was whether a past service support relationship was perceived as being positive or negative - this appeared to lay a foundation for trust, open communication, and greater flexibility in support processes (Jamieson et al., 2016). Kohn and Blumenthal (2014) cite the need to understand and describe processes that supporters might use to best facilitate truly autonomous decision-making to stay true to the goals of empowering the individual through SDM.

Finally, a third major theme that was found in the academic literature - even by opponents of SDM - was the acknowledgement that SDM does appear to provide a viable alternative to more restrictive guardianship laws (Agoratus, 2016; Devi, 2013; Gooding, 2013) and appears better aligned with conceptual elements of autonomy, self-determination, and dignity of risk (Gooding, 2013) than guardianship or substitute decision-making approaches. Werner and Chabany (2016) suggest that SDM is important conceptually in that it shifts perceptions away from the idea that people with disabilities are utterly dependent, and incapable of making life decisions to the idea that people with disabilities are capable of living inter-dependently.

Unique findings from two of the extracted pieces of academic literature identify some possible early evidence to inform practice and application of SDM. The qualitative study by Mitchell (2015) exploring self-directed support skills of adolescents in transition to adult services found that skills in decision making were stronger if fostered over time, and that young adults with IDD are at risk for potentially internalizing low expectations of capacity for decision-making skills from parents, and significant caretakers. Similar findings were described by Werner and Chabany (2016) of parents' and professionals' lack of understanding of distinctions between parenting responsibilities, and guardianship designation, as a causal factor for guardianship appointment for a young adult. These researchers also noted that individuals with IDD elected to choose guardianship over SDM, possibly as a result of internalized parental beliefs of incapacity for supported decision-making. Both of these research studies recommend that early introduction of SDM approaches for children may provide for greater autonomy in decision-making in transition into and in adulthood. Additionally, results from a nationwide survey recommend that SDM be initiated in school curriculums for students with IDD and include financial, medical, career, living and contract supports for individuals with IDD as a means of adhering to self-determination principles (Jameson et al., 2015).

Lastly, of interest was the conceptual and philosophic implications of formalizing SDM as an alternative to guardianship (Gordon, 2000). Gordon (2000) recognizes that supported or assisted decision-making has historically been provided informally and through assistance of family and community networks. By legitimizing it with court orders, Gordon feels, the essence of what makes this approach work - "informal arrangements involving caring and trusting individuals" - may be destroyed (p. 73). Literature on the development of self-advocacy skills describes the critical role of life-long learning through informal relationships (Alper, Schloss, & Schloss, 1995). Gordon also reflects on possible ethical and moral struggles supporters might face in adhering in practice to a dignity of risk (Perske, 1972) when honoring the decisions of the individual. Lastly, Gordon worries that people with IDD should be, but likely will not be, at the table if and when formalized mechanisms for the approach are determined (Gordon, 2000).

Precedent-Setting Court Decisions

Although legal battles may not traditionally be used as evidence for best practice approaches, precedent setting court decisions can stand as examples of single case studies. Two well-documented cases of an individual seeking to avoid or remove guardianship appointments can be found in the cases of Dameris L., and Margaret "Jenny" Hatch. The Matter of the Guardianship of Dameris L. (No. 2009-0892, December 28, 2012) is an example of how SDM can be the better alternative for a person with IDD who has been assigned guardianship. Dameris was a 29-year-old woman diagnosed with mild to moderate cognitive impairment, and at the time of petition for guardianship by her mother Maria, attended adult day habilitation. Shortly after this petition Dameris married and became pregnant, motivating her husband to seek guardianship. A lawyer was appointed by the court as a temporary guardian. Following legal counsel and mediation, it was decided that her husband and mother would act as co-guardians. Over time Dameris and her husband acquired a reliable and comprehensive support network including family, and a strong community of neighbors to assist the entire family, including Dameris, to live independently and make decisions. Following a second pregnancy Dameris began exploring birth control methods and believed the decision was hers to make. Subsequently, she initiated the process to terminate guardianship. During the trial, the court was provided with evidence that Dameris had a documented history of, and was capable of, making her own decisions if provided with support. Dameris was able to terminate the guardianship roles of her mother and husband, allowing her to use them instead as supporters in her decision-making. This termination occurred primarily because of; 1) a documented system of informal supported decision-making in place with a demonstrated history of success, as well as, 2) documented mechanisms in place to continue to provide for SDM as a less restrictive alternative to guardianship.

The second notable court case began in 2012 when Margaret “Jenny” Hatch petitioned to terminate guardianship in favor of SDM (Terrill, Campanella, & Melda, 2014). Jenny’s parents – believing she needed greater supervision in everyday life following a bicycle accident – petitioned the court for guardianship before she was discharged from the hospital. The court admitted Jenny into a group home under temporary guardianship while they deliberated the case (Dinerstein et al., 2016). Despite a long history of living and working in the community with support, her parents petitioned for guardianship, which would give them authority to make all decisions for Jenny, including where she lived, who she saw, whether or not she received medical care. Jenny argued that she understood her need for support and services and to live in the community, and because of this had established a rich network of both professional service supporters, and trusted friends to support her. The case was highly publicized and concluded with the court determining that Jenny should live with guardians of her choice – individuals that would come from her standing network of supporters. The court also limited this guardianship to only two facets of her life that would be terminated after a one year period at which time Jenny would regain all decision-making authority (Ross v. Hatch, 2013; The Justice for Jenny Project, n.d.). During this year and while in this temporary guardianship, the court held that informal SDM approaches should be implemented and practiced to allow for a smooth transition to Jenny having guardianship totally removed.

It is arguable that the primary reason the court made this determination was that the lawyers representing Jenny demonstrated that Jenny was not, as her guardians claimed, an incapacitated person. In fact, the court evidence showed a long history of Jenny using supporters to make informed decisions regarding healthcare and living arrangements. Jenny’s lawyers provided statements from individuals dedicated to providing individualized supports and services, available to Jenny whenever she needed them in order to live independently. They offered evidence of past and current supporters for health and financial decisions and application and adherence to protocols for receipt of Medicaid Waiver services and supports. The lawyers also provided documentation of training and tailored support specific to Jenny’s needs. Finally, the lawyers provided evidence of the oversight mechanisms in place to safe guard Jenny against abuses or risks that the court might worry would occur without the oversight of a guardian. They provided a record that Jenny had a history of not taking risk or making poor decisions, and they provided testimony that Jenny was happier and healthier living in a supported environment versus under guardianship. The lawyers did not deny that Jenny needed supporters to assist her, and described Jenny’s own recognition of this, but emphasized that she did not need someone to make decisions for her, but rather to support her.

Advocacy Group Efforts

A surge in interest from advocacy groups and individuals with IDD, national organizations (United States Administration on Community Living), states (Massachusetts, North Carolina, Texas), advocacy networks (Autistic Self Advocacy Network), and non-profit organizations (CQL | The Council on Quality and Leadership; Burton Blatt Institute) have resulted in various activities around SDM, including grant projects and pilot studies to identify how best to advance SDM, and develop evidence-based recommendations for best practice or model approaches.

One of the leading advocacy groups in the United States for promoting SDM as an alternative to guardianship is the Autistic Self Advocacy Network (ASAN). This organization has worked to develop and provide supports and structures to guide individuals, families, and other advocacy organizations on guardianship options. ASAN has developed a toolkit that includes SDM Model Laws¹ that let people sign SDM agreements specific for health care (ASAN, 2014).

¹ Model Laws are designs for a law, not an actual law.

The ASAN model provides a formalized process for individuals who only need support in healthcare decision making. The ADA and US Constitution make plenary or full guardianship designation a difficult and lengthy legal process specifically because this determination removes individual freedoms and constitutional rights (ASAN, n.d.). Judges often welcome alternatives if any exist and make sense for the individual, such as limited guardianship designation. The ASAN Model Law, developed in collaboration with Quality Trust for Individuals with Disabilities, creates an alternative that maximizes autonomy by permitting adults with disabilities to name supporters to help them understand health-related information, and so they can make their own decisions.

The ASAN Model Law also provides a framework for legal counsel to develop alternatives to court orders of guardianship, and a platform for advocates to use in working with state legislators on alternatives that might be developed to guardianship (ASAN, 2014) The ASAN Model Law is informed by SDM legislation in other countries (i.e., Canada, Sweden, United Kingdom) and has created formalized support arrangements as well as introduced mechanisms of oversight and guidelines for process (Kripke, 2016). ASAN has used its knowledge and this Model Law in advocacy efforts with states regarding legal recognition of SDM.

In 2014, a small two-year pilot study was conducted by The Human Services Research Institute (HSRI), the Center for Public Representation (non-profit law firm), and Nonotuck Resources (a service provider of residential supports contracted with the HSRI) to offer SDM to a group of 10 individuals (Pell & Mulkern, 2015). In the pilot, participants – people under or at risk of guardianship – were provided with a structured approach to SDM (Pell & Mulkern, 2015). Year one of this pilot described the process of establishing SDM and offered recommendations for developing a comprehensive approach to successful SDM. One of the ‘lessons-learned’ in the development and implementation of the pilot was the need to educate providers of the background and philosophy of SDM in order to get ‘buy-in’ for use of the approach. Education efforts targeted families as well as judges that would typically be assigned guardianship cases. Recommendations from the implementation phase of the pilot indicated the need to have a well-defined process of pilot safeguards that included: an advisory committee; independent monitoring; and, regulations to define SDM concepts in addition to widespread community education. The administrative team for the pilot included two attorneys (one a senior attorney in guardianship law), one legal advocate, three program directors, one vice president of Clinical Services, and five care managers. Recommendations included starting with a small group of adopters, simplifying the SDM representation agreement (as well as all adopter documentation) into plain language, formalizing the SDM agreements (with a notary public), and ongoing community awareness and education (Pell & Mulkern, 2015). Supporters in the project were used flexibly and SDM was most frequently used for healthcare decisions followed by financial, social and leisure, employment/volunteer work/day supports, relationships, and legal matters. Less frequent were SDM arrangement decisions such as changing a decision supporter (Pell & Mulkern, 2016). The overall results indicated the model had positive outcomes and participants were satisfied with the approach. Changes that were documented in the SDM adopters (decision makers) were increased self-esteem and self-advocacy, more engagement in decision-making and increased happiness (Pell & Mulkern, 2016). Researchers concluded that SDM was a viable alternative to guardianship.

The Administration on Community Living (ACL) and the Quality Trust for Individuals with Disabilities have worked to build a national training, technical assistance, and resource center to explore, develop, and extend SDM as an alternative to guardianship (Bishop & Walker, 2015). This resource evolved from the court case of Margaret “Jenny” Hatch (The Jenny Hatch Justice Project, n.d.), which resulted in empowering national and international stakeholders and opinion leaders to advance SDM as a viable legal alternative to guardianship (Terrill, Campanella, & Melda, 2014). The Jenny Hatch Justice Project, the Quality Trust for Individuals with Disabilities, and ACL created the National Resource Center for Supporting Decision-Making (NRC-SDM) (Supported Decision Making Pilot Project, n.d.) funding five pilot projects in different states (i.e., Delaware, Wisconsin, Maine, North Carolina, and Indiana) to explore and fill the gaps in the SDM evidence. These pilot projects, advocacy campaigns, and legal court orders and opinions have stimulated a small avalanche of change across the US on how guardianship decisions are viewed.

State-Level Efforts

In the US, legal guardianship legislation is controlled at the state level and “across the fifty states there exist many various processes and standards” for determining guardianship (Dinerstein et al., 2016, p. 436). This state flexibility has spurred at least eleven US states [Delaware, Indiana, Maine, Maryland, Massachusetts, Michigan, New York, North Carolina, Texas, Wisconsin, and Virginia] to begin implementing or examining SDM as a possible alternative to guardianship for people with IDD. These are: Two of these states have recently passed legislation on SDM as a viable alternative to guardianship while others, such as Wisconsin, are in early phases of community education and surveys. Some states have options for SDM for support in specific context areas, and others have introduced SDM into parts of informed consent.

Texas

In 2009, the 81st Texas Legislature H.B. 1454 established a pilot volunteer-supporter decision-making advocacy program, run by the Department of Aging and Disability Services for people with IDD who live in a community setting. With a working group consisting of individuals with IDD and family members, rules, processes, and structures of the pilot were developed. These included criteria for volunteer supporters and as well as those adopters of support. Early challenges with recruitment - in part due to negative provider perspectives of SDM - caused the pilot to shift focus from implementing the intervention to educating and increasing understanding of how SDM aligns with shared beliefs in the philosophies of self-determination for people with disabilities. The pilot ultimately identified positive evidence for SDM used by the 84th Texas Legislative session in 2015 to make Texas the first state to recognize that courts must consider SDM agreements as an alternative to guardianship prior to guardianship appointments (S.B.1881, 2015 Leg., 84 Session (Tex. 2015)). Texas provides formal guidelines, documentation, and suggested mechanisms of monitoring a SDM agreement but allows for flexibility and customization within the statutory guidelines on an individual basis (Disability Rights Texas, n.d.).

Delaware

Delaware became the second state to pass legislation enacting SDM into state law in July of 2016. Senate bill No. 230 allows people with disabilities in Delaware to form legally recognized SDM agreements (Delaware Supported Decision Making Act, 2016). Delaware’s Working Group used ASAN’s Model Law, recent legislation passed in Texas, as well as models from Canada to inform and draft their own bill. Through knowledge gained from past advocacy groups’ efforts this pilot project focused on extending the level of awareness of SDM as an option to guardianship through educational experiences directed at the community, as well as individuals who would be supporters, providers, professionals providing services (and referral), legislators, and the general public.

Indiana

Indiana’s Arc of Indiana Foundation, in conjunction with the National Resource Center (NRC) for SDM, has been actively working within the state to educate and inform legislators on the benefits of SDM (Indiana, 2016). These advocacy groups funded and implemented a pilot study of SDM in 2016 to gather and document support to move SDM into Indiana legislative code. On April 18th, 2017 the Indiana 120th General Assembly adopted Senate Resolution No. 44 to assign a committee to study the topic of SDM as an alternative to adult guardianship (S. Res. 44, Ind. 2017). Advocates hope that Indiana will be the third state, following Texas and Delaware, to formalize SDM as a legal process. The current focus for the State is to target new cases considering guardianship – students with individualized education plans (IEPs) as they begin transitioning to adult life, and who are at risk for having guardianship appointments. The state’s SDM working group feels schools are the gatekeepers of guardianship information, including alternatives to guardianship. They argue that SDM has benefits for individuals with IDD as well as the potential for a positive impact on the state budget, but that gaining the support of judges, legislators, schools and families is currently the biggest challenge. The current efforts are on education of these communities on the background and benefits of SDM as an alternative to guardianship.

Maine

As a recipient of the National Resource Center's (NRC) SDM grant award, Maine is also piloting a two-year project to educate and provide resources to community members on SDM. The most recent report from this pilot identified major 'lessons-learned' in the process toward establishing SDM. Of primary concern (but not the only obstacle) to educating individuals and families on SDM was a lack of understanding of guardianship procedures, and implications that exist making distinguishing SDM from guardianship complicated. This pilot found initial first steps had to occur in educating the community on broader issues of legal capacity (Disability Rights Maine, 2016).

Massachusetts

Despite the pilot project of The Human Services Research Institute (HSRI), The Center for Public Representation, and Nonotuck Resources based in an organization within the State, Massachusetts currently only provides for SDM in the context of medical decision making at the time of this publication.

Maryland and Michigan

While both Maryland and Michigan have made some recognition or passed measures on SDM, they have done so in small ways. Michigan has recognized SDM as a fundamental human right, similar to the approach taken by New York, and Maryland recognizes SDM only as an auxiliary aid in medical decision making at this time.

New York

New York has approached SDM differently than other states. In the court decision of *Dameris* described earlier (*In re Dameris L*, 956 N.Y.S. 2d 848, NY Cty., 2012) a precedent was established "affirming *Dameris's* constitutional and human rights" that upheld SDM as, in fact, a logical first choice that should be considered when interpreting laws concerning guardianship (Glen, 2012).

North Carolina

The First in Families of North Carolina (FIFNC) is one of the grant recipients of the National Resource Center for Supported Decision-Making's State Grant Program. North Carolina has initiated a pilot project in conjunction with The Arc of North Carolina to identify and train individuals with IDD and their families on a tool to increase self-directedness in decision-making (First in Families of North Carolina, 2016). Reports on the early uses of the tool describe broadly an increase in skill development and help in making financial decisions. Significant obstacles and lack of follow through with use of the decision-making tool were described as causal factors in poor outcomes (Secor, Torres, & MacMichael, 2016). Limited understanding by participants of the rationale behind the tool was also described. Some of these outcomes appear similar to many of the factors identified in the academic literature, specifically individual factors on the part of supporters and those receiving support, and contextual factors such as timing and readiness of initiating the intervention. One limitation of this report was that many of the adopters had no social network or individuals they felt they could trust and rely upon to build a SDM team.

Virginia

In the case of Jenny Hatch, which took place in Virginia, the practice of SDM was presented as a rational, ethical, and most healthy psychological approach for assisting people with IDD to be as autonomous as possible (Commonwealth of Virginia H.J. Res. 190 Reg. Sess., 2014). Despite the court finding in favor of Jenny Hatch and establishing judicial precedent, no formal position on the use of SDM exists in Virginia at this time. Recommendations by the court were to initiate exploration of a method for measuring decision-making capacity of an individual as a first step toward developing a program to support SDM at the state level (Commonwealth of Virginia H.J. Res. 190 Reg. Sess., 2014).

Wisconsin

As another of the five NRC-SDM grant award states, Wisconsin has partnered with Minnesota on working to expand the Center for Excellence in Supported Decision Making (CESDM). A fact sheet distributed throughout the State and on the Internet directs interested individuals to social workers who are available to provide assessments regarding guardianship and alternatives. Legal and technical advice, as well as an introduction to SDM agreements (based on documents from Texas law) and other concerns on guardianship, is also provided (Center for Excellence in Supported Decision Making, n.d.).

DISCUSSION

While individual opinions may vary or be neutral when asked about SDM, among the loudest voices that emerge from this review are two distinct groups with a clear divide between: those that support SDM, including individuals, families and advocates of the community of IDD; and those that oppose, including lawyers, businesses and professionals that have some interest in maintaining the status quo of established guardianship laws. Both groups point to the obvious gaps that exist in evidence and the absence of guidelines for processes in establishing SDM as well as monitoring to avoid abuses and risk (Kohn & Blumenthal, 2014). Although evidence gaps and monitoring for risks and abuses in SDM are major concerns for opponents of SDM, the literature recognizes that in fact formalized guardianship approaches have poorly established evidence and a history of recorded abuses (Kohn et al., 2012) as well as higher incidence of institutionalization (Lachs et al., 2002). However, the conclusions each side makes are substantially different. Those that support SDM critically evaluate the paucity of literature and are exploring methods to strengthen the evidence and establish guidelines. Suggestions that come from the academic literature include furthering the depth and breadth of research and investigating multiple aspects of SDM to improve its effectiveness for autonomy in decision making, developing guidelines and mechanisms for processes, as well as monitoring, with a recognition of the need to maintain individualism and flexibility (Gooding, 2013). The legislative decisions and pilot interventions echo these recommendations as essential elements of a successful SDM contract. The proponents of SDM do not appear to be deterred by the challenges and, in fact, appear to welcome suggestions for future research as a pathway to building credibility of SDM as the necessary first choice when guardianship options are being considered (Kohn & Blumenthal, 2014; Pathare & Shields, 2012).

Those that criticize SDM are convinced that revising and improving monitoring of guardianship laws is the better path, and argue that guardianship is too entrenched in our system for attitudes and behaviors to change (Coleman, 2015). Guardianship however, is so “deeply rooted in a culture of paternalistic practices toward people with disabilities” (Johns, 2012, p. 3) that it extends beyond determining legal capacity to make decisions, but permeates every context a person with IDD might encounter when making those choices. History shows that norms and cultural attitudes “can either promote equal status and positive attitudes or unequal status and negative attitudes” toward minority groups including people with disabilities (Yuker, 1988, p. 273). The voices that claim that guardianship over SDM is for the individual with disabilities’ “own safety” or in their “best interest” is an old debate the disability community and advocacy groups have much experience with (Perske, 1972). Understanding that people with disabilities are entitled to rights as citizens, including the notion that least restrictive supports and services, should be used demands a re-evaluation of established practices.

Of significance are the reports of challenges and obstacles from the pilot studies and NRC-SDM grant funded projects. There are significant similarities in the reported barriers across studies in implementation of SDM. One of the most significant of these barriers appears to be a limited knowledge of the processes and impact of guardianship itself, and limited understanding of the differences between SDM and guardianship. Some of these outcomes were also found as incidental factors within the academic literature and potential factors of poor satisfaction with SDM (Jamieson et al., 2016; Werner & Chabany, 2016). It may be that best practices for implementing SDM models in practice begin with exploring the culture and readiness for change (Wensing, Bosch & Grol, 2013) by those that must buy into this approach, versus guardianship.

In fact, service provider, family and legal ‘buy-in’ appear to be a major contributor to successful implementation of SDM approaches for pilot projects with the community of individuals with IDD. Acceptance by these communities, through exposure to the background and philosophy of SDM as well as education on how it functions as an alternative to guardianship, was identified in the majority of the literature as a critical component to implementing SDM for individual cases (Dameris, 2012; The Jenny Hatch Justice Project, n.d.) as well as in pilot studies (ASAN, Maine, North Carolina). Best practice approaches that emerged from these pilot studies and that were used as evidence to influence individual court cases include:

- An established record of trained/known supporters and their roles;
- A documented history of informal supported decision making by the people with disabilities;
- Formalization through use of legal SDM agreements;
- Documentation of mechanisms for how SDM would occur while simultaneously providing for flexibility; and
- Customization of SDM agreements to individual needs.

According to academic research, there is another major determinant in the court cases. Werner and Chabany (2015) emphasized the perceptions of parents or caregivers of individuals with IDD’s capacity to participate in SDM. Individuals with IDD and their families had strong beliefs that guardianship was the best and only option. The researchers proposed that children with IDD may internalize others’ beliefs that they are incapable of making autonomous decisions based on years of low expectations from families and professionals (Werner & Chabany, 2015). Jameson et al.’s (2015) national survey on guardianship and people with IDD posits that the impact of guardianship has long lasting effects that directly influences the persons’ capacity for autonomy or self-determined decision-making. More importantly, they found that the IEP process, based on their responders, appeared to cultivate the person toward choosing guardianship as a first option. In examining the court documents of Dameris L. (2012) and Ross v. Hatch (2013) it is clear that each of these individuals had been offered opportunities to explore and learn from supported decision-making experiences over time. It is also evident that this documented history of “learning SDM” was important to the court decision to terminate guardianship in these cases. The current pilot project that the state of Indiana is pursuing, implementing SDM into IEPs, may provide a future model of IEPs as a method for supporting and enhancing long-term positive outcomes in community living by nurturing self-determined decision-makers from an early age.

Lastly, when weighing guardianship and SDM, two states - New York and Michigan - are approaching SDM cases from the perspective of community advocacy efforts that emphasize SDM versus guardianship as a civil rights issue. Legislation from the ADA, specifically Title II regulations, requires that public entities “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities” (ADA, 1990, n.p.; Pub. L. No. 101-336). Guardianship is recognized by the American Bar Association as well as the disability community as the most restrictive form of providing necessary supports and decision making for people with IDD (Jameson et al., 2015). SDM attends to Title II to provide autonomy and the least restrictions to people with IDD and allows for maintenance of legal capacity as well as personhood.

CONCLUSION

Using a social justice lens, SDM provides for a much greater pragmatic approach to legal determinations concerning an individual's personhood, legal and human rights. However, opponents of SDM (as well as advocates, and people with IDD) voice serious concerns that without formalized mechanisms this approach has the potential to be abused in many of the same ways as reported in guardianship appointments. While SDM may benefit from Model Laws and evidence for best practice, for it to stay true to its foundation in autonomy and self-determination, each community and every individual must be provided with the opportunity to maintain flexibility in determining when, and in what manner, supports are identified, provided, and modified.

To support the commitment of deinstitutionalization and success of living in the community requires personalization of services and supports - as no two people, including people with IDD are the same - and therefore individualization of supports is needed (McConkey & Keogh, 2016). The academic literature that does exist identifies that SDM lacks the necessary evidence vital for advocates to argue for its adoption as an alternative to guardianship. There is a dearth of evidence in every respect of the approach including issues related to the supporter, guidelines, and mechanisms for process, and of monitoring outcomes. Lastly, SDM is recognized conceptually as a 'good-thing' but implementation can present a challenge. This challenge, in part, is due to the entrenched stigmas surrounding people with IDD as well as a system where guardianship is the default. The advocacy, state wide legislative policy, and grey literature describe that SDM can be, and should be, used to uphold the constitutional laws and human rights of people with IDD, and that elements of the ADA can be used to do so. Pilot projects and studies report common frustrations and challenges with a lack of 'buy-in' and adoption by communities, such as the projects in Maine and North Carolina. However, evidence of successful model projects, such as the two-year pilot from HSRI, the Center for Public Representation, and Nonotuck Resources, and the ASAN Model Law, can serve as frameworks to guide others. The ASAN Model Law and the advocacy efforts of ASAN have assisted two states to implement SDM into law. Other states are hoping to take the lessons learned from these early initiatives, and incorporate them into their activities. Concerns from across the literature echo a history of the conundrum courts face in determining what is best for a person with IDD when faced with balancing between concerns of safety and supervision versus allowing individuals to maintain control over their own decision-making and their own legal capacity. This is primarily because people with IDD fall outside of the normative cognitive parameters society identifies as having the capacity for sound decision-making. However, SDM upholds a philosophic view that all people are interdependent when making decisions; SDM also honors the disability communities' call for equality, autonomy, and self-determination to make decisions – and at times take risks – as a part of full personhood.

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