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A Call to Society for Supported Decision-Making: Theoretical and Legal Reasoning

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Abstract

We call attention to the need for supported decision-making (SDM) in place of substituted decision-making (e.g., guardianship). SDM allows individuals with intellectual and/or developmental disabilities to make their own life choices with self-appointed supporters. Whereas there is a growing recognition that SDM is a needed practice, America's deep-rooted paternalistic culture makes it difficult to fully embrace SDM models. Recent court rulings portray an evolution of decision making towards SDM as an option for individuals with intellectual and/or developmental disabilities. These court rulings along with widely accepted theories and emerging research supporting SDM have an increasingly critical influence on policymakers in further advancing the rights of persons with disabilities.

Keywords Supported decision-making · Alternative decision-making · Intellectual disability · Developmental disabilities

Historically, disability has been a justification for unequal treatment and oppression (Baynton 2013; Wolbring 2008). Ableism, prejudice or discrimination toward an individual with physical, mental, or emotional disabilities that society deems as needing "fixing" (Castañeda and Peters 2000), has made it difficult for people with disabilities to be fully integrated into a society that restricts and excludes them from mainstream activities. Ableism has been evident in the taking away of the rights of individuals with disabilities to make their own decisions about their own lives (Meyer 2014). Although individuals with disabilities are entitled to the same rights as the general population under the Constitution of the United States (1776), substituted decision-making has been utilized with individuals who have a diminished capacity to make decisions on their own. For example, guardianship, a form of substituted decision-making, has been widely used when a court authorizes another person(s) to make important decisions on behalf of the individual with a disability (Salzman 2010).

Guardianship is appointed by the court and is difficult to reverse (Andreasian et al. 2014). It is an assignment made for life, regardless if the individual with a disability wants the person to be their guardian or even wants to have a guardian in general (Andreasin et al. 2014). If an individual under the guardianship wishes to terminate the arrangement, they must go to court. Guardianship marginalizes and limits the decision-making rights of the individual (Salzman 2010) by granting the guardian the right to overrule decisions made by the individual with a disability (Annino 2013). It segregates a person from social, economic, and civic life (Salzman 2010), and violates Title II of the American Disabilities Act requiring "the states [to] provide services, activities, and programs in the most integrated and least restrictive setting appropriate to the needs of qualified persons with disabilities" (Salzman 2010, p. 160). Furthermore, guardianship can result in abuses by the guardian (e.g., neglect) because reports from the guardian only need to be filed annually (Andreasin et al. 2014; Payne-Christiansen and Sitlington 2008). According to a 2010 report by the U.S. Government Accountability Office (GAO), there have been hundreds of allegations of physical

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abuse, neglect, and financial exploitation by guardians from 1990 to 2010, alone.

As society has progressed and ideas about disability have changed from disability being situated in the individual (i.e., medical model of disability) to disability being a social construct (i.e., social model of disability), models of decision-making pertaining to people with disabilities have changed, too. To support individuals with disabilities to exercise their right toward independence and community living, there is a need to implement supported decision-making (SDM). SDM is built around the idea of person-centered planning and the concept of self-determination (Campanella 2015; Deci and Ryan 1985; Wehmeyer 2006). It also aligns with the goals of the social model of disability (Oliver 1981), which provides a framework for societal institutions to be more inclusive to individuals with disabilities, and draws attention to the societal responsibility to assist this community to fit in and be successful, and promotes the empowerment and inclusion of people with disabilities in the least restrictive manner (Barnes 2012).

SDM is about giving individuals with disabilities back their voice and the right to exercise their legal capacities. It is defined as a decision-making process in which individuals have control over the final decisions that pertain to their lives with the support and/or advice from their supporters who are personally appointed by the individual with a disability. SDM allows individuals with disabilities to receive help in making decisions while retaining control over who helps them (Jameson et al. 2015), and SDM supports them to be fully included into the community (Shogren and Whemeyer 2015).

The United Nations Committee on the Rights of Persons with Disabilities notes that SDM can take on several forms depending on the extent of support the individual with intellectual disability needs, but the purpose of the support person(s) is to enable the individual to exercise their legal capacity to the best of their ability (Andreasian et al. 2014). SDM is about working with the individual with intellectual and/or developmental disability (IDD; Campanella 2015) and figuring out the optimal support for that individual. This alternative decision-making process relies on a "we" approach, such that it is not solely one individual making the decision, but rather, one or more individuals supporting the individual with a disability in understanding the options and providing resources and assistance to the individual with a disability who makes the final decision.

One of the largest obstacles individuals with IDD encounter is that people in society either do not perceive them as capable of making sound decisions or hold a very individualistic view of the issue (i.e., people perceive that it is the individual's responsibility to fit into society). However, there are many success stories of individuals with IDD prospering at jobs (see: Real People, Real Jobs) with the assistance of their families, a university program, or other supporters. Under a different guardian or supporter, they may not have received the same opportunities. Therefore, there needs to be a movement ending the restrictive substituted-decision making rulings for individuals with intellectual disability. SDM offers unique characteristics and advantages that allow for individual development and a voice in decisions: (a) it is a moldable model such that it is adaptable to individuals depending on their level of support needs (Campenella 2015); (b) the individual with a disability represents themselves and makes the final decisions (Andreasian et al. 2014); (c) the supporter(s) are chosen by the individual and are as active in the individual's life as the individual needs them to be; (d) the SDM agreement can be terminated at the will of the individual with a disability (Andreasian et al. 2014); and (e) the SDM agreement does not require court involvement, but it does need to be notarized.

Without the advocacy for SDM at the federal and state level, SDM may be overlooked and people may be placed in a detrimental guardianship. There is a responsibility of organizations and societal institutions to reduce barriers against people with disabilities (Burchardt 2004), and the form of decision-making for an individual can make a significant impact. When a person with a disability is assigned to guardianship, this status often restricts full participation in the community. SDM, however, retains the ability of individuals with IDD to participate in society and aligns more with the human rights a person has in our society. Therefore, it is important to implement SDM for individuals with IDD.

SDM is a relatively novel concept; thus, there is little research in this area. The purpose of our paper is to inform the research community and practitioners about the empirical research, government rulings, and current applications of SDM in order to demonstrate the need to implement SDM into additional communities and into the lives of people with IDD who do not yet practice SDM. We argue that the various agencies and entities at levels of decision-making need to create policies and advocate for SDM. We first explain key theories supporting SDM and summarize meta-analysis studies targeting the general population that support each theory and demonstrate the impact each theory has in people's lives. Next, we provide information on how the U.S. government has demonstrated support directly and indirectly for SDM through various historical rulings and policies in favor of SDM. We also describe how the state of Texas paved the road in passing major policies implementing SDM as an official option for individuals with IDD. These policies and court rulings demonstrate the need for our society to combat ableism and

Table 1 Definitions of key constructs within SDM

Theory/Key Concept	Author(s)	Definition
Self-determination	Niemiec and Ryan (2009)	A macro-theory of human motivation, emotion, and development that takes interest in factors that either facilitate or forestall the assimilative and growth-oriented processes in people
Autonomy	Parker et al. (2001); Niemiec and Ryan (2009)	Degree of discretion someone has over important decisions in their life, experiencing behaviors as volitional and reflectively self-endorsed
Empowerment	Spreitzer (1992); Thomas and Velthouse (1990)	Motivational construct manifested in four cognitions: meaning, competence, self-determination, and impact
Intrinsic Motivation	Ryan and Deci (2000a, 2000b)	Doing something because it is inherently interesting or enjoyable

further implement SDM into the community of individuals with IDD. Finally, we discuss the implications of SDM for promoting inclusion of individuals with disabilities.

Theoretical Basis for SDM

Researchers have explored the basic framework of SDM through the theory of self-determination, which is the primary theory behind SDM. Several other key constructs have also provided support for the implementation of SDM with individuals with disabilities. Though this may not be an exhaustive list of theories that support SDM, these constructs are vital to understand how implementing SDM would affect the individual with IDD and the individual's community, and these theories create a basis for the importance of SDM. They are not novel theories, but rather have been researched extensively and are found to be important in the lives of people, in general. These constructs include empowerment, intrinsic motivation, and autonomy. Table 1 describes the basic definitions of the supporting self-determination theory and other constructs.

Several meta-analyses have been conducted on the impact these theories have in the lives of the general population. Typically, individuals with IDD are forced into the individualistic model, making them solely responsibility for fitting into society (Brett 2002). However, by applying the social model of disability (Oliver 1981), the responsibility of people with disabilities to fit into society incorporates society's organizations and institutions (Barnes 2012); thus, creating a framework for professionals to incorporate into their workplaces and make their organizations more supportive for people with disabilities (Oliver 2013). Table 2 summarizes meta-analyses supporting these theories and the impact they have on the general population. If incorporating these theoretical models into the general population is beneficial and important, then it should also be important to incorporate them into the lives of people with IDD.

The umbrella theory that embodies the key concepts/theories described as supporting SDM is self-determination theory (SDT). Deci and Ryan (1985) define self-determination as the capacity to make decisions and to have those decisions determine actions. They state that self-determination is a fundamental need in people. An important component of SDT is the personal control of choices of daily and future life plans (Stancliffe et al. 2000). When individuals are self-determined, they operate from an autonomy-orientation, striving towards self-actualization (Wehmeyer 1992). Individuals are able to choose their own course of action and gain a better idea of their own potential in life. Furthermore, by having the ability to make their own choices, the individual has a greater perception of control (Wehmeyer 1992). Hagger and Chatzisarantis (2009) conducted a meta-analysis analyzing how self-determination affected the health outcomes of planned behavior. They found that self-determined motivation was linked to proximal antecedents of intentional behavior and had a significant effect on proximal predictors of intention, especially for attitudes and planned behavioral control. Another meta-analysis found that components of self-determination (e.g., autonomy, competence, and relatedness) were related to physical and mental health (Ng et al. 2012). The perception of control has positive impacts on the individual, whereas perceptions of a lack of control have detrimental effects (Wehmeyer 1992). Individuals with IDD under substituted decision-making lack control over decisions made in their lives, and research suggests this is not beneficial for any individual with a disability or not. Incorporating all aspects of SDT into people's lives is important. In further support of this, meta-analyses regarding key concepts of SDM (i.e., autonomy, empowerment, and intrinsic motivation) also indicate the importance of integrating these ideas into people's lives (as shown in Table 2).

Autonomy theory emphasizes the idea that autonomous behaviors derive from an integrated sense of self or an internal locus of control (Deci and Ryan 1985). Behaviors that are autonomous are performed out of personal interest; these behaviors are internally regulated (Black and Deci 2000). In Black and Deci's study of students taking an introductory organic chemistry course at a university, they

Table 2 Meta-analyses of self-determination theory and other constructs that support SDM

Theory/Key Concept	Citation	Inclusion/Exclusion Criteria	Relevant Key Findings
Self-determination theory (SDT)	Ng et al. (2012)	Exclusion: Focus on competitive sport, school physical education, work motivation, career choices for medical students	• Following SDT, autonomy supportive health care climate was positively correlated with measures of positive mental and physical health, and negatively correlated with negative mental health • Basic psychological needs and autonomy were positively correlated with indices of positive mental and physical health, and negatively related to indicators of negative mental and physical health
	Hagger and Chatzisarantis (2009)	Inclusion: Studies 2008 and prior; empirical test of effect size of construct of SDT and theory of planned behavior statistical information	• Self-determined motivation is linked to proximal antecedents of intentional behavior and has a significant effect on proximal predictors of intention • This research supports that self-determined motives regarding health behavior is related to perceptions of control
	Chatzisarantis et al. (2003)	Inclusion: Self-determination theory, organismic-integration theory, perceived locus of causality, self-determination continuum, autonomy continuum, physical exercise, sport, athletics, physical education classes, school, and classroom Exclusion: No statistical data; not use measures of perceived locus of control (PLOC) not use at least two dimensions of PLOC	• The pattern of correlations between external regulation, introjection, and identification conform to a simple ordered structure, thus supporting assumptions of self-determination theory concerning the independence of internalization and intrinsically motivated processes • There is support for self-determination continuum from external regulation to identification via introjection • Self-determination continuum is independent from motivation and intrinsic motivation; thus, internalization, intrinsic motivation, and amotivation are distinct processes • Introjection and intrinsic motivation mediate the effects of perceived competence on physical activity thereby, resulting in physical competence not being sufficient condition for developing strong intentions and an internal PLOC
Empowerment Theory	Kar et al. (1999)	Inclusion: Written case; analyzed both rich and poor nations; domains; sustainable; successful; women-led Domain: Human rights, equal rights, economic development and health. Overall analyzed 40 case studies	• Even the most deprived women and mothers could lead successful social action movements that are self-empowering. • Seven areas used to enhance empowerment: (1) empowerment training; (2) media use; (3) public educations; (4) partnerships (e.g., unions); (5) job training to enhance autonomy; (6) assistance for essential opportunities; (7) rights protection (e.g., victim protection) • Involvement in social action movements had strong empowering effects • Social context affects empowerment movement and outcomes; context can either present barriers or support to social action movements
	Seibert et al. (2011)	Inclusion: Articles report statistical information to calculate correlations among variables; at least on relationship between psychological empowerment and its contextual antecedents or consequences at the individual or team level; adult participants; conducted in an organizational field setting	• Psychological empowerment is related to contextual constructs of high-performance managerial practices, socio-political support, leadership, work characteristics, and positive self-evaluation traits • Psychological empowerment results in increased job satisfaction, organizational commitment, task and contextual performance; and

Table 2 (continued)

Theory/Key Concept	Citation	Inclusion/Exclusion Criteria	Relevant Key Findings
	Burke et al. (2006)	Exclusion: Dissertations; clinical and adolescent populations; measure only team leader traits, rather than behaviors; limited to measurement of affective or cognitive team performance outcomes, rather than behavioral performance outcomes; assess leadership structure only; collectives and groups characterized by a complete lack of task interdependence; no usable test statistic reported	a decrease in employee turnover intentions. • Team empowerment is related to team performances • Overall, empowerment behaviors (i.e., coaching, monitoring, feedback, etc.) accounted for 31% of the variance in team learning • Empowerment was significantly positively related to perceived team effectiveness • Empowerment accounted for 10% of the variance in team productivity • Boundary spanning and behaviors related to empowerment explain moderate to large amounts of variance in team performance outcomes
Intrinsic Motivation	Patall et al. (2008)	Inclusion: Manipulation of choice; measure of intrinsic motivation; experimental; participants make a choice between specified and unspecified options; conducted in US and Canada with "normal" populations; information to calculate an estimate of the effect of choice on outcome Exclusion: Self-regulatory strength depletion literature; experiments with implied choices but no choice was clear; one-group posttest or one group pretest-posttest designs; non-random assignments; post-hoc statistical procedures to equate choice and no choice groups; single group cross-sectional studies using multivariate statistics or simple bivariate correlations to describe the choice and motivation relationship	• Providing choice enhances intrinsic motivation, effort, task performance, and perceived competence Effects of choice on intrinsic motivation was stronger, or more effective, when: there were instructionally irrelevant choices; two to four successive choices were given; rewards were not given; for children compared to adults; for experiments conducted in a laboratory embedded in a natural setting
	Cerasoli et al. (2014)	Inclusion: Report effect size for relation between intrinsic motivation and performance; some defensible measure/instrument of both intrinsic motivation and performance Exclusion: Non-English studies	• Intrinsic motivation is a medium to strong predictor of performance • Incentive saliency influenced predictive validity of intrinsic motivation for performance, such that incentives undermined intrinsic motivation when directly tied with performance • Intrinsic motivation was the better predictor for quality of performance and incentives were a better predictor of quantity of performance
Autonomy	Zangaro and Soeken (2007)	Inclusion: Studies conducted from 1991 to 2003; references cited in articles found from initial computerized search; quantitative analysis of empirical data; sample included registered staff nurses; reported sample sizes; sufficient statistical data to compute effect sizes of relationships between job satisfaction and another variable of interest; published in English	• Autonomy had a moderately positive correlation with job satisfaction • Having autonomy and good collaboration between nurses and physicians as well as reduced job stress increases job satisfaction
	Spector (1986)	Inclusion: Autonomous or participative decision making measure; measured at least one employee outcome variable shared by at least four other studies; data reported correlation form or a statistic transformable into a correlation	• Perceived control, or autonomy, was related to higher levels of job satisfaction, commitment, involvement, performance and motivation • Perceived control was related to lower levels of physical and emotional symptoms, role stress, turnover intentions, and turnover

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Theory/Key Concept	Citation	Inclusion/Exclusion Criteria	Relevant Key Findings
	Fischer and Boer (2011)	Inclusion: Studies that had the GHQ and/or STAI measures and their references; within the period of 1972 and December 2005 for GHQ, within 1970 and 2006 for STAI, and within 1981 and 2007 for MBI; non-Western samples included; nonclinical adult samples; sufficient statistical information Exclusion: Populations with health problems or participants who were caretakers of chronically sick individuals	• Increased levels of autonomy were related to lower levels negative psychological symptoms • In individualistic societies, individualism, or autonomy, was significantly associated with better well-being, overall; however, in collectivistic societies, increases in individualism tended to increase levels of negative well-being • Greater levels of individualism, or autonomy, were associated with reduced state and trait anxiety, as well as emotional exhaustion • Individualism mediated the effects of wealth, such that when there were higher levels of individualism, more wealth was associated with lower levels of state and trait anxiety and emotional exhaustion

Table 2 (continued)

found that students who took the course due to autonomous motivation had more positive experiences, higher perceived competence and interest, and lower anxiety. Autonomous motivation was also related to drop-out rates in that students who were more autonomously motivated at the beginning of the course were more likely to remain in the course. Meta-analyses on autonomy (as seen in Table 2) indicate its important effect on an individual's job satisfaction, commitment, involvement, and well-being (Fischer and Boer 2011; Spector 1986; Zangaro and Soeken 2007). Therefore, a lack of control is deleterious to an individual, and this applies to individuals with IDD, too.

Another theory that incorporates this idea of control is empowerment theory. Empowerment is a means to choose and to have control; a person has the ability to make a choice and to have control over their lives (as in as much control someone can actually have over what happens; Morris 1997). Psychological empowerment includes a combination of personal beliefs of control, involvement in activities to utilize personal control, and awareness of the environment (Zimmerman 2000). Empowerment is an enabling process in which individuals feel their behavior is self-determined and they can perform assigned tasks well and see meaning in their work (Fulford and Enz 1995). Seibert et al. (2011) conducted a meta-analysis on the effects of empowerment in the organizational setting and found that empowerment was related to leadership, work performance, and occupational well-being (e.g., job satisfaction, organizational commitment). Increasing an individual's sense of empowerment leads to positive outcomes, even for the affected community (e.g., the organization).

The quality of experience and performance drastically varies when someone is behaving intrinsically versus behaving extrinsically (Ryan and Deci 2000a). Intrinsic motivation refers to the engagement in something because it is inherently interesting or satisfying (Ryan and Deci 2000a). Cerasoli et al. (2014) found in their meta-analysis that intrinsic motivation was a better predictor for *quality* of performance. Table 2 further shows the effect that intrinsic motivation has on someone's outcomes. Ensuring an individual's motivation to do something is because of some intrinsic reasoning is important to incorporate and is a concept SDM encompasses. When an individual makes a decision and the final decision is what the individual wants inherently, the motivation behind the decision was intrinsic.

Overall, implementing these theoretical elements into people's lives have had positive impacts. For example, Wehmeyer and Palmer (2003) conducted research with high school seniors with IDD, followed up at one- and three-years post-school. They found that those who had higher self-determination skills during high school had greater capability to make their own decisions, fared better across several life categories (e.g., employment, financial

independence, and independent living) than freshman students with IDD who scored lower in self-determination skills. Incorporating a sense of control into individuals with IDD is important. SDM allows for these individuals to make their own decisions.

However, in order to apply these theories, individuals with IDD need to be given the resources. SDM relies on the strength of the individual and their available resources. An appointed person by the individual with a disability may help explain the choices and/or issues, but the ultimate and final choice is that of the person in which the decision affects and not someone else. Stancliffe et al. (2000) analyzed levels of personal control in 76 adults with IDD and found that people who were not assigned a guardian had higher levels of personal control than people who were assigned a guardian. The theories explored earlier are about the individual making their own decisions based on their own desires, wants, and needs, which is emphasized as key components in SDM. These theories demonstrate that society has been promoting the right to make one's own decisions for decades; thus, now is the time to expand this right to all people.

Indications of Support for SDM in Court Rulings

Historically, individuals with disabilities have been presumed as incompetent and unable to make decisions for themselves (Blanck and Martinis 2015; Rood et al. 2015). Under this mode of thinking, guardianship has served as a form of "surrogate decision-making," failing to recognize that individuals with disabilities have varying capacities to make decisions for themselves (Dinerstein 2012, p. 9). However, concerns over legal capacity and the use of guardians led to the formation of a presidential commission to address due process rights in 1978. Specifically, the Task Panel on Legal and Ethical Issues of the President's Commission on Mental Health (1978) recommended state guardianship laws include (a) expanded procedural protections (e.g., written and oral notice, the right to be present at proceedings, appointment of counsel, the burden of proof, a comprehensive evaluation of functional abilities, and a judicial hearing employing standards used in civil actions), (b) a clear definition of incompetency tied to functional abilities, (c) a limitation of guardians' powers to ensure the right to least restrictive setting, and (d) a system of limited guardianships in which rights are removed and supervision provided only for those activities an individual is incapable of acting independently.

In 2008, in an effort to move away from substituted decision-making, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) implemented Article 12 to "recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life" (United Nations 2008, p. 10). This paradigm shift embraces SDM by recognizing the individual, rather than the guardian, as the primary decision-maker (Dinerstein 2012). The United States, however, has not ratified the laws under CRPD; thus, in the absence of an equal recognition law in the US, courts and legislatures have stepped in to discuss the ethical and legal challenges related to the deprivation of legal capacities among individuals with disabilities (Flynn and Arstein-Kerslake 2014). Indeed, Salzman (2010) posits that challenges to guardianship squarely fall under Title II of the Americans with Disabilities Act that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." Further, in light of *Olmstead v. LC* (1999), Salzman (2010) argued that *Olmstead* can be used to challenge guardianship laws as a form of unlawful segregation. Specifically, "supported decision-making is less isolating than guardianship and provides greater opportunities for a person with a disability to interact with others-the principal goal of the integration mandate" (Salzman 2010, p.161).

The following court cases present a broad overview of cases illustrating an evolution of decision-making toward SDM as an option for individuals with IDD (Jameson et al. 2015). The list of court cases is not meant to be comprehensive; rather, it is intended to serve as a starting point for discussion and future research on SDM reform. For example, an early Supreme Court case upheld Kentucky's involuntary commitment procedures for individuals with intellectual disability (referred to as *retarded persons*, as was the convention at the time of the ruling), a ruling viewed as very restrictive toward the rights of individuals with IDD (*Heller v. Doe* 1993; Brown 1994). Specifically, a class action by involuntarily committed persons with intellectual disability challenged the constitutionality of the state's involuntary commitment procedures as the burden of proof to commit individuals to Kentucky institutions differed between those with mental illness, which was "beyond a reasonable doubt," and those with intellectual disability, which was "clear and convincing evidence" (p. 312). In *Heller v. Doe*, the Supreme Court ruled Kentucky's statutes did not violate the Fourteenth Amendment's Equal Protection Clause because a "commonsense distinction" existed between those with intellectual disability and those with mental illness (p. 326). The court determined a "reduced burden" for the commitment of individuals with intellectual disability was justified because intellectual disability is generally easier to diagnose, allows for a more accurate prediction of dangerousness as it is relatively static

condition with a documented record of behavior, and is less invasive to treat than mental illness (*Heller v. Doe*, supra, 509 U.S., pp. 321–328).

Analogous to involuntary civil commitment, in 1995, the Supreme Court of Iowa recognized the imposition of guardianship not only results in a forfeiture of substantial rights, but also in stigmatization as it conceptually labels the individual as incompetent. As a result, the court placed the burden of proof on the party who initiated guardianship, concluding that those seeking to attain guardianship had to establish clear and convincing evidence the proposed ward's decision-making capacity is impaired (*Hedin v. Gonzales* 1995). This case is important because it concluded that liberty interests at stake in adult guardianship are similar to liberty interests in involuntary commitment cases, necessitating comparable constitutional protections. In such cases an effort must be made to explore less restrictive and intrusive alternatives.

This orientation is evident in *Re Peery* (1999), as the Supreme Court of Pennsylvania recognized that a support circle could render guardianship unnecessary. The court reversed an order and upheld the trial court decision stating that Patricia Peery, a sixty-year-old woman with cognitive impairment, was not in need of guardianship because she had a personal support system assisting her. The trial court had noted that her low IQ did not result in her being incapable of taking care of herself, though she depended on others for health, welfare, safety, and medical-related needs. In addition, the court noted she was happy with her living arrangements, her caretakers were "devoted and reliable," and therefore her wishes should be honored as long as her decisions were "rational and result[ed] in no perceivable harm for her" (p. 130).

Similarly, in 2012, the New York County Surrogate's Court interpreted New York law as allowing SDM and stayed involved with the case for three years. Dameris could manage many of her daily needs, although the court found she needed assistance with financial and medical affairs. The court, though not required by New York law but in accordance with the United Nations CRPD Article 12, sought her consent before placing her under guardianship, encouraged the development of a support network, and appointed monitors related to family progress and Spanish translators. Eventually, the court terminated the guardianship, determining that Dameris was no longer in need of guardianship (*In Re Guardianship of Dameris L.* 2012; see also, Flynn and Arstein-Kerslake 2014). Further, the Circuit Court in Virginia ruled against permanent guardianship for another individual with IDD. Margaret "Jenny" Hatch, a 29-year-old woman with Down syndrome, challenged her mother's guardianship petition in favor of the successful SDM network she established. The court named the friends she chose as temporary limited guardians for a year with the intent of supporting her through the transition to SDM. This landmark case was the first case to order the use of SDM instead of permanent guardianship (*Ross et al. v. Hatch* 2013).

In summary, the selected cases provide a progression toward less restrictive arrangements (whether guardianship or institutionalization) in line with a cautious and deliberate approach to safeguard liberties and explore less intrusive arrangements. Indeed, most states require such an exploration of less restrictive options to ensure a maximum level of independence in guardianship rulings (see Arias 2013). Further, such orientation is in line with the aims of SDM and the United Nations CRPD Article 12 and has implications not only for those with disabilities, but also those with declining capacity associated with an ever-increasing aging society (e.g., in U.S., the population over sixty-five years of age is estimated to increase from 40 million in 2010 to 72 million by 2030; Arias 2013).

Alternative to Guardianship: A Deeper Look into Texas

In 2015, the state of Texas became the first state to officially recognize SDM as a substitute to guardianship. During the 84th Texas Legislative Session, legislators passed House Bill 39 and Senate Bill 1881, recognizing the rights of individuals with disabilities to make their own choices through SDM rather than substituted decision-making. House Bill 39 requires probate courts to consider whether supports and services and other alternatives to guardianship have been considered through clear and convincing evidence. The passage of Senate Bill 1881 facilitated the use of SDM for certain adults with disabilities through the Supported Decision-Making Agreement form. This form recognizes that individuals with disabilities are capable of making their own decisions, such as where and with whom they would like to live, what medical care they like to receive, how they would like to spend their money, and where they would want to work.

According to the Disability Rights Texas, under an SDM agreement, a supporter has no authority to make decisions for an individual with IDD (unless it is specified in the agreement); instead, the supporter can assist the individual by helping them "understand the options, responsibilities, and consequences of their decisions; obtain and understand information relevant to their decisions; and communicate their decisions to the appropriate people" (Disability Rights Texas 2016, p. 1). Any individual over the age of 18 who has a physical or mental impairment that substantially limits one or more major life activities can enter an SDM agreement. A person must have sufficient capacity to enter an agreement; however, the level of capacity remains

undefined (Tex. Est. Code § 1357.056). The level of physical or mental capacity an individual must have in order to enter such an agreement may need to be defined in the future, but currently, it is determined case-by-case and is beyond the scope of this article. Ultimately, unlike substituted decision-making, under the Support Decision-Making Act, the person in need of assistance may *choose* who they would like support from (Tex. Est. Code § 1357.055) and make their own decisions regarding their lives.

Under a full guardianship, an individual with a disability loses many rights; however, under an SDM agreement, the individual "voluntarily, without undue influence or coercion," agrees to be assisted by a supporter (The Arc of Texas 2015, n.p.). In the case a guardian must be appointed, the probate court must have enough evidence that indicates alternatives to this method have been sought but were not feasible. Additionally, S.B. 1882 amended the Estates Code on the rights of wards under guardianship, limiting the rights, benefits, responsibilities, and privileges of a ward under a court-ordered guardianship (Bill of Rights of Wards 2015).

Although Texas did not pass a series of SDM statutes until 2015, the state had previously examined SDM. Several incidents facilitated the creation of these statutes, in addition to the Jenny Hatch case. In 2009, State Senator Judith Zaffirini proposed a bill to launch a volunteer-supported-decision-making advocate pilot program for persons with IDD and persons with other cognitive disabilities who lived in the community (Texas HHSC and Texas Department of Aging and Disability Services 2010; Volunteer-Supported Decision-Making Advocate Pilot Program, Tex. Gov't Code Ann. § 531.02446 2009). The project prevented two unnecessary guardianships and ended another; it was last implemented in 2013. Additionally, the Guardianship Reform and Supported Decision-Making (GRSDM, n.d.) Workgroup also played a prominent role in moving legislation forward. In 2013, the GRSDM Workgroup proposed seven policy proposals to promote alternatives to guardianship, which were influenced by the 2009 pilot program (Texas GRSDM). During this same year, the Coalition of Texans with Disabilities (CTD) and other organizations also started to notice a growing problem among elders and individuals with IDD—many were losing control of their assets and living situation even under guardianship, which sparked further interests in SDM. In 2014, the Texas Judicial Council endorsed SDM proposals by assessing ways in which Texas courts could protect and improve the lives of those under guardianship (Texas Judicial Council 2014). The following year the SDM reform was passed in Texas. On September 1, 2015, the first person in Texas signed the Supported Decision-Making Agreement (NASW 2015). Since the passage of these reforms, CTD's Guardianship

Action Group, in partnership with the GRSDM Workgroup, has been preparing for the 85th Legislature in 2017 to propose changes to the current laws: changing the term "ward" to "person under guardianship" in policies and documents and establishing duties of guardians to improve protections for individuals committed to institutional settings. Since Texas' guardianship reform, other states (Virginia, Maryland, Massachusetts, North Carolina, New York, and Washington, D.C.) have started to examine or implement SDM at varying levels (Arc of Indiana 2016). The above court cases and legal rulings demonstrate that the legal system is supporting ideas that are in line with SDM.

The Use of Supported Decision-Making to Promote Inclusion

In order for individuals with IDD to live, learn, work, and socialize in the community of their choice, they need to live in inclusive communities and interact with existing systems (Christensen and Byrne 2014). SDM reform assumes individuals are to some extent capable of making decisions about their lives and living in inclusive communities with the help of a supporter. Hence, SDM is an excellent way to help these individuals achieve inclusion in the community. Although SDM may not be for appropriate for everyone, one should not be denied SDM simply based on their disability label. A person-centered approach can be used with some individuals to facilitate the decision-making process, if the decision involves multiple parties. After all, the individual's desires must be considered. A support system needs to be in place where legislative, judicial, educational, and other entities work together to support the implementation of SDM.

Because SDM reform is relatively new, spreading awareness is vital. Schools and teachers need to be informed of laws, regulations, and best practices about SDM because schools are an important entity to prepare students for living an inclusive life in the community. Teaching students the advantages and disadvantages of SDM versus guardianship and how to obtain SDM agreement is essential to prepare them for living in the community. In states like Texas where there is an SDM law, schools need to include it as one of the choices when students reach the age of majority. Schools can help educate students with disabilities and their families about options other than guardianship that can play a major role in parents supporting a young adult with a disability to live in the community.

Similarly, many legal professionals have minimal information about and understanding of values associated with SDM. It is essential for these professionals to receive training and education about SDM and its role in people's lives. Their understanding and full support of the
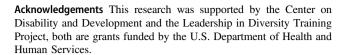
implementation of SDM are critical for those with IDD to be included in the community. Because a supported decision-making agreement creates a confidential relationship between the supporter and a person with a disability, the supporter may be held liable for the breach of the confidential relationship (Enax v. Noack 2000) and could leave supporters vulnerable to legal liability over decision-making. Thus, such conflicts must be mitigated or further discussed with families, friends, and selected supporters. Finally, there is a need for state level legislative initiatives that reflect recommendations by the Task Panel on Legal and Ethical Issues of the President's Commission on Mental Health (1978), the United Nations CRPD Article 12, as well as recent case law supporting SDM as a viable option for those with IDD (see *In Re Guardianship of Dameris L.* 2012, and *Ross et al. v. Hatch* 2013).

Similarly, there is a need for additional research to determine and substantiate the benefits of SDM. Such research should focus on the nature and extent of supports necessary to enable the individual with a disability to make decisions when appropriate as well examine the benefits of such decisions. Of particular interest may be the examination of "qualities/attributes" of individuals best suited to provide support. Sound qualitative research designs will further enrich our understanding of how individuals with disabilities, families, and other interested parties not only support the individual's right to make the final decision but also ensure the quality of such decisions.

At the core of SDM are the principles of individual autonomy, trust, and support. SDM acknowledges an individual's right to make his or her own decisions when capable of doing so. Whereas there is a growing recognition that SDM is a needed practice for people with disabilities, the movement toward SDM reform has been slow (Boundy and Fleischer 2013). America's deep-rooted culture of paternalism and ableism makes it hard for the nation to fully embrace SDM models (Johns 2012). To challenge this perspective, society will have to shift its view of individuals with disabilities from the medical model to the social model of disabilities in which the structures within society—that is, the attitudes, environment, and organization—are seen as the problem rather than the individuals with disabilities (Mental Disability Advocacy Center, 2006). The movement to empower individuals with disabilities through SDM has been slow, but several court rulings and the passage of various statutes have led states and policymakers to recognize the importance of SDM and how other practices, such as permanent guardianship, can defy a person's rights to think and act for themselves.

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