



**Northeastern University**

**School of Law**

Legal Skills in Social Context

# Supported Decision-Making

*Fostering the Self-Determination of Individuals with Disabilities*

## **Law Office 3**

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## **EXECUTIVE SUMMARY**

In the United States, many individuals with cognitive disabilities, ranging from young adults to the elderly, are unjustly stripped of their autonomy and placed under the authority of court-appointed guardians. Injustice begins with mismanagement of the appointing process itself. When individuals with disabilities appear in court, state statutes empower judges to determine their legal capacity, assessing their ability to make sound health care, financial, and life decisions. For elderly individuals whose capacity is questioned by a doctor or family member, the petition process usually does not lend a fair assessment of their mental abilities. Some judges have reported they rubber-stamp guardianship petitions indiscriminately to clear their dockets with little discretion or choice given to the elder.

For adults with cognitive disabilities, guardianship usually begins at the age of majority. For members of this group, on their eighteenth birthdays, well-intentioned family members are advised by the school system and medical doctors to petition the court to retain legal authority over the individual. These petitions are, overwhelmingly, granted without a thorough assessment of the individual's capacity or potential for capacity for independence. While some seniors and adults with cognitive impairments have family members who are appointed their guardians, others are placed under the care of a case manager overburdened with guardianship duties from dozens of other cases as well. Guardian abuse from family members and case managers alike is widely reported including theft, physical abuse, neglect, and other exploitations. Once an adult is placed under guardianship, the judge may not ever see them again for an update. Many states give guardians power that overwhelms and overtakes the adult's liberty and autonomy.

Disability activists throughout the nation and the world call for a less restrictive alternative to guardianship. One solution that has gained international backing is supported decision-making

(SDM). Unlike guardianship, SDM is a model under which the individual retains full legal autonomy, while the exercise of that autonomy through decision-making is aided by chosen supporters who assist in informing the individual of their options and communicating their decisions to others.

Article 12 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) represents a paradigm shift in disability law which has given rise to legislative movements to adopt SDM agreements around the world. Article 12 demands equality before the law for persons with intellectual impairments and calls for an end to discrimination on the basis of mental disability. Canada was the first country to enact an SDM statute, though it maintained some components of court-appointed guardianship in a hybrid mix of supported and substitute decision-making. Sweden was the second country to adopt SDM in its national framework. The drafting of their law was informed by a series of pilot programs centered on maintaining individual autonomy, and the law more closely reflected the spirit of self-determination of Article 12.

Studies show that individuals across the spectrum of cognitive ability were benefited in their physical and mental well-being when they were delegated opportunities to exercise meaningful choice and a sense of control in their daily lives, such as in SDM. For the elderly and individuals with cognitive disabilities alike, self-determination is a foundational aspect for increasing the individual's ability to decide and act in a manner in line with their goals and needs. This, in turn, fosters increased independence and a person's satisfaction in their quality of life. Unlike guardianship, SDM maintains an individual's autonomy, or, the exercise of free will, and the important mental functions paramount to self-determination through a model of independence that is buttressed by external supports. SDM requires a two-step process of (1) repealing guardianship and other barriers to an individual's exercise of decision-making power, and (2) the

provision of support systems that are tailored according to an individual's cognitive needs. The role of the supporter is to present information necessary to facilitate an individual's decision in a manner that does not unduly influence the supported person. An individual is best served by a flexible system of supporters that have an established, trusting relationship with the person.

In 2015, Texas became the first jurisdiction in the United States to enact a statute for SDM, with others following. Four general categories have emerged in legislation addressing this issue: (1) states that have no reference to SDM or to a less restrictive alternative to the guardianship statute; (2) states that reference less or least restrictive alternatives in their guardianship statute; (3) states that explicitly reference SDM in their guardianship statute, and; (4) states that have SDM statutes separate from the guardianship statute. The first category of states that do not provide a reference to SDM or other alternatives does not necessarily preclude it as an option altogether. In addition, while a less restrictive alternative as stated in the second category does not necessarily mean SDM, it represents a trend towards offering alternatives to guardianship that is slowly gaining traction throughout the United States.

Within states of the first category - including Connecticut, Idaho, Wyoming and Indiana - there is variety in the form of guardianship emphasized, with Connecticut identifying plenary guardianship as the norm while Idaho and Wyoming prefer limited guardianship as a means of protecting the autonomy and self-determination of the individual. Indiana, while having a guardianship statute that lacks consideration of alternatives, appears to be in the early stages of implementing SDM legislation, with the 2017 Senate Committee on Judiciary unanimously passing a resolution urging the legislative council to explore SDM as an alternative. Despite the spectrum within the category, it is apparent that legislatures are embracing methods of preserving individual freedoms to the utmost extent, the same freedoms SDM seeks to protect.

In the second category of state statutes, twenty-three states - including Virginia, New York, and Florida, among others - have least or less restrictive alternative language in guardianship statutes. Some states, such as Virginia, use the “best interest” standard, in which the court must impose the least restrictive alternative protecting the individual’s best interest. Others require courts to consider less restrictive alternatives before considering guardianship, emphasizing the autonomy of the individual and tailoring the support to the specific need. New Hampshire, for example, requires that the individual experience the “greatest amount of personal freedom” consonant with their capacity. Florida and California are two examples of states that fall somewhere between the “best interest” standard and emphasis on autonomy; this middle ground considers the welfare and security of the individual weighed against the least restrictive alternative. Massachusetts is in this second category of statutes at the moment, although an SDM bill was proposed earlier this year in both the Senate and House of Representatives.

Only five guardianship statutes reference SDM language in the statute, including those of Maine and Missouri, both of which approved SDM incorporation in their guardianship statutes in 2018. Often, SDM is referenced or utilized in the statutes in a limited capacity, such as for organ transplant decisions in Kansas, but these states still represent a trend towards SDM-focused legislation and a normalization of the practice over plenary guardianship practices. Following Texas’s example in 2015, Delaware, Alaska, Wisconsin, and the District of Columbia have codified SDM. These other states have utilized the Texas SDM statute as a model for the language and structure of the practice to emphasize freedom and self-determination of the individual. They offer standardized SDM agreements and explicitly explain the roles, duties, and limitations of the supporter. Tennessee, uniquely, does not have an explicit SDM statute due to push back from



legislators, but the guardianship statute now incorporates language allowing SDM to be a valid and accessible alternative, suggesting SDM is legally recognized here as well.

In many states that do not have SDM statutes, the court has become a valuable means of accessing SDM. Often these cases feature young adults with cognitive or behavior limitations who can live relatively independently. The Margaret “Jenny” Hatch’s case in Virginia in 2013 was the first to recognize an SDM agreement. Her case was supported through evidence that she could make sound decisions once properly informed and her guardianship was too limited for her needs. Other individuals in various states, such as New York, Massachusetts, and Indiana, petitioned the court in similar ways, arguing for SDM because guardianship was too restrictive and hurt their self-determination rights. Courts, such as New York’s Surrogate Court in Kings County, have granted the SDM requests, seeing it as necessary to protect individual freedoms, finding that guardianship does not protect the individual’s best interest, and acknowledging the individual can function relatively independently. These cases span over nine different jurisdictions, suggesting that this is a movement across the United States that is spreading.

This study also analyzes the pilot programs that various states have conducted in order to test or explore the viability of supported decision-making. Various states have piloted different kinds of programs to explore supported decision-making, raise awareness, conduct trainings throughout the community, or test the viability of supported decision-making in practice. The study identifies three stages of a pilot program: Design, Deploy, and Assess. Each stage of a program, not strictly applicable to all pilot programs, successfully transitions the program into clear and identifiable transition that builds off the previous step. The study also divides the different programs into three tiers: Tier I, Tier II, and Tier III. These tiers were used to categorize pilot programs throughout the nation. Factors in deciding the grouping included: initial goals set for the

program, resources allocated, and finalized results and findings. For example, the Massachusetts' pilot program, grouped into Tier III, involved court hearings which resulted in changing a disabled adult's guardianship to supported decision-making, whereas the South Carolina pilot program, categorized under Tier I, focused on increasing awareness instead of direct services. The Tier III pilot programs are recognized by some to be the most comprehensive. The Texas pilot program was among the first explorations of supported decision-making by a state. The other programs, along with the other Tier III programs (Massachusetts and New York) referenced Texas's lead.

Many pilot programs were joint efforts by various organizations located in each respective state. The Center for Public Representation, a non-profit organization in partnership with Nonotuck Resource Associates, Inc. and the Human Services Research Institute implemented the pilot program in Massachusetts. In Texas, the pilot program involved The Arc of San Angelo, Angelo State University, the Texas Council for Developmental Disabilities, and many more organizations and agencies. It's a collaboration of many, and that is reflected in supported decision-making's collective and concerted nature. It will take collaboration to further supported decision-making in the Massachusetts Legislature for the communities to access.

This paper begins with a discussion of the theoretical underpinnings of supported decision-making. It considers the concept of autonomy as a human rights, philosophical and psychological theory, and research directly focused on models and frameworks for supported decision-making, as well as empirical research. Second, it discusses the history of SDM and its development in the international community, the trends in the United States in legislation and case law, and pilot programs. Then, this paper considers critical perspectives on SDM and offers responses to it, as well as community responses. Finally, the paper includes recommendations and highlights the best

practices, especially related to statutes and pilot programs, based on community feedback and the research considered throughout this paper.

## INTRODUCTION

Supported decision-making (SDM) is a tool used by persons with disabilities that allows them to receive support from chosen supporters when they need assistance making life decisions. The person with a disability, or supported person, retains their decision-making capacity under SDM, as compared to more restrictive forms of intervention such as guardianship or conservatorship, which strip individuals of their legal rights and autonomy. SDM is something individuals with and without disabilities engage in every day. It is the process by which all of us seek advice from others to make decisions large and small, such as asking a mechanic what is wrong with one's car, talking to one's friends about the best route to get across town at rush hour, or talking with loved ones about end-of-life options.

By formalizing this process as SDM, the disability community seeks to harness this well-recognized approach as a means of retaining autonomy in the face of the current legal landscape that often strips individuals with disabilities of their civil and human rights. SDM has been gaining support both around the world and in the United States in recent years. In 2006, adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) indicated global recognition of the human right to equal recognition before the law for all persons regardless of disability.<sup>1</sup> The UNCRPD made SDM a human rights imperative as a means to promote autonomy and legal capacity for persons with disabilities.<sup>2</sup>

Within the United States, advocates in the disability community recognize guardianship as a violation of constitutional rights where one's legal personhood is removed and placed in a third party, usually called a guardian. Legal personhood, or being seen as a person before the law, is a

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<sup>1</sup> L. VANPUYMBROUCK, SUPPORTED DECISION MAKING IN THE UNITED STATES: A WHITE PAPER BY CQL | THE COUNCIL ON QUALITY AND LEADERSHIP 6 (2017).

<sup>2</sup> *Id.*

prerequisite for many rights and duties we consider fundamental to the human experience, such as the right to contract, hold property,<sup>3</sup> decide where to live, what to eat, and who to associate with,<sup>4</sup> among others. When legal personhood is removed through the process of guardianship, the authority to make all of the everyday decisions that we may take for granted is removed and placed in the guardian. Though guardianship may be limited in scope, a plenary guardian has the sole power to decide every aspect of life for the person under guardianship. The 1990 Americans with Disabilities Act (ADA) and the 2000 Developmental Disabilities Assistance and Bill of Rights Act (DD Act) mark the beginning of mainstream recognition in the United States that persons with disabilities should retain the right to their autonomy and independence to the greatest extent possible.

Starting from recognition of the human and civil rights violations inherent in guardianship and the potential for SDM to serve as a viable alternative to or even replacement for the current guardianship model, in this paper we will review and analyze existing trends within SDM, including: (1) the international development of SDM; (2) the domestic development of SDM, with a focus on various statutory schemes, court cases, pilot projects, and formal processes regarding SDM; and (3) the stated concerns and recommendations from within the Massachusetts disability community, incorporating feedback from self-advocates, family members, doctors, service providers, and others. The synthesis of this research will culminate in recommendations on how Massachusetts may move toward culturally sensitive SDM implementation that is responsive to both the needs and desires of those within and serving the disability community.

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<sup>3</sup> Alexis Dyschkant, *Legal Personhood: How We Are Getting It Wrong*, 2015 U. ILL. L. REV. 2076, 2076 (2015).

<sup>4</sup> *The Justice for Jenny Trial*, THE JENNY HATCH JUST. PROJECT, <http://jennyhatchjusticeproject.org/trial> (last visited Mar. 4, 2019).

## DEFINITIONS

**The Americans with Disabilities Act (ADA):** A civil rights law enacted in 1990 in the United States that prohibits discrimination of any kind against individuals with disabilities in areas of public life, and specifically in all places that are open to the general public. The law is designed to protect people with disabilities from unequal treatment and establish equal opportunities for all.<sup>5</sup>

**Capacity:** A person's ability to understand and make decisions about their life.<sup>6</sup> Determining legal capacity involves a judge assessing an individual's capacity as described above, sometimes as to specific areas, such as making medical or financial decisions. If a judge determines that an individual has legal capacity, that individual retains their right to make decisions for themselves.<sup>7</sup> If, however, a judge determines that an individual lacks capacity or is incapacitated, that individual loses the legal right to make decisions on their own behalf, and that right is given to a third party who is appointed by the court to serve as the individual's guardian.<sup>8</sup> Under the law in Massachusetts, an individual is presumed to have legal capacity unless and until a judge determines otherwise.<sup>9</sup>

**Conservatorship:** In Massachusetts, conservatorship is a legal relationship in which a person, known as a conservator, is appointed by a court to make decisions regarding property and finances on behalf of an individual who has been adjudicated to lack the legal capacity to make such decisions on their own behalf. The conservator does not have the power to make decisions beyond

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<sup>5</sup> *What is the American with Disabilities Act*, NAT'L NETWORK (Mar. 2019), <https://adata.org/learn-about-ada>.

<sup>6</sup> Alec Buchanan, *Mental Capacity, Legal Competence and Consent to Treatment*, 97(9) J. OF THE ROYAL SOC'Y OF MED. 415, 415 (2004).

<sup>7</sup> *Id.*

<sup>8</sup> *Id.*

<sup>9</sup> 104 MASS. CODE REGS. 28.10 (2019); 115 MASS. CODE REGS. 5.07 (2019).

that scope.<sup>10</sup> For example, a conservator does not have the power to decide where the individual under conservatorship will live.<sup>11</sup>

**Developmental Disabilities Assistance and Bill of Rights Act (DD Act):** A federal law enacted in 2000 that authorizes programs throughout the United States to provide services to individuals with developmental disabilities in a way that empowers, rather than disempowers, those individuals to participate in and remain as integrated as possible in the larger community.<sup>12</sup> The law's purpose is to "assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life."<sup>13</sup>

**Guardianship:** In Massachusetts, guardianship is a legal relationship in which a person, known as a guardian, is appointed by a court to make decisions on behalf of an individual who has been adjudicated by the court to lack the legal capacity to make those decisions for themselves.<sup>14</sup> Guardianships can be limited or plenary in nature. Under a limited guardianship, the guardian has the authority to make decisions only in certain areas, or only for a certain amount of time.<sup>15</sup> Under a plenary or full guardianship, the guardian has the right to make all life decisions on behalf of the individual under guardianship.<sup>16</sup>

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<sup>10</sup> MASS. GEN. LAWS ch. 190B, § 5A-102 (Westlaw through 2018 2nd Ann. Sess.).

<sup>11</sup> *Id.*

<sup>12</sup> *The Developmental Disabilities Assistance and Bill of Rights Act of 2000*, ADMIN. FOR COMMUNITY LIVING, <https://acl.gov/about-acl/authorizing-statutes/developmental-disabilities-assistance-and-bill-rights-act-2000> (last updated Apr. 26, 2017).

<sup>13</sup> Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. § 15001 (2012).

<sup>14</sup> MASS. GEN. LAWS ch. 190B, § 5A-102 (Westlaw through 2018 2nd Ann. Sess.).

<sup>15</sup> ELEANOR CROSBY LANIER, LIMITED GUARDIANSHIP OF THE PERSON AND PROPERTY (2017).

<sup>16</sup> Neha Patel, *The Homeless Mentally Ill and Guardianship: An Assessment of Current Issues in Guardianship and Possible Application to Homeless Mentally Ill Persons*, 11 GEO. J. ON POVERTY L. & POL'Y 495, 503 (2004).

**Health Care Proxy:** Massachusetts law defines a health care proxy as a document pursuant to which an individual gives another person, known as the health care agent, the right to make medical decisions on their behalf in the event that they are not able to do so.<sup>17</sup>

**Intellectual/Developmental Disability (I/DD):** “A severe and chronic disability attributed to a mental/cognitive or physical impairment, or combination of mental and physical impairments, diagnosed or that become obvious before the age of 22. The condition is likely to continue indefinitely and limits the individual in 3 or more of the following areas: (1) self-care, (2) receptive and expressive language, (3) learning, (4) mobility, (5) self-direction, (6) capacity for independent living, [and] (7) economic self-sufficiency.”<sup>18</sup>

**Incapacitated Person:** Under current Massachusetts law, an incapacitated person is defined as someone who, for reasons unrelated to age, “has a clinically diagnosed condition that results in an inability to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care, even with appropriate technological assistance.”<sup>19</sup>

**Individualized Education Program (IEP):** A document required by the Individuals with Disabilities Education Act for each public-school child who receives special education services.<sup>20</sup> Parents, teachers, school staff, and the student work together to identify the student’s needs and what services are required in order to allow the student to receive a quality education and participate in the general curriculum.<sup>21</sup>

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<sup>17</sup> MASS. GEN. LAWS ch. 201D, § 1 (Westlaw through 2018 2nd Ann. Sess.).

<sup>18</sup> *What is I/DD*, NORTH CAROLINA COUNCIL ON DEVELOPMENTAL DISABILITIES, <https://nccdd.org/welcome/what-is-i-dd.html> (last visited Mar. 11, 2019).

<sup>19</sup> MASS. GEN. LAWS ch. 190B, § 5-101 (Westlaw through 2018 2nd Ann. Sess.).

<sup>20</sup> *A Guide to the Individualized Education Program*, U.S. DEPARTMENT OF EDUCATION, <https://www2.ed.gov/parents/needs/spced/iepguide/index.html> (last visited Mar. 15, 2019).

<sup>21</sup> *Id.*



**Individuals with Disabilities Education Act (IDEA):** A United States federal law enacted in 1990 that promises appropriate accommodations in the public-school system, including special education services, to all children with eligible disabilities. “The IDEA governs how states and public agencies provide early intervention, special education, and related services to more than 6.5 million eligible infants, toddlers, children, and youth with disabilities.”<sup>22</sup>

**Least (or Less) Restrictive Alternatives:** Methods of meeting an individual with a disability’s needs that, “separately and in combination, are no more intrusive or restrictive of freedom than reasonably necessary to achieve a substantial therapeutic benefit.”<sup>23</sup> Least restrictive alternatives can include options such as supported decision-making or power of attorney.

**Person Centered Planning:** An informal process in which a team of people meets to brainstorm ideas, strategize, and resolve issues for a person with a disability. The planning process focuses on personal development of the person with a disability. Specifically, person centered planning outlines what the person with disabilities wishes to accomplish and identifies methods for becoming more self-sufficient. This approach is more of a way of thinking through a person’s major life choices than a uniform system of decision-making.<sup>24</sup>

**Power of Attorney:** A document under which an individual gives another person, known as the “attorney-in-fact,” the right to make decisions regarding their assets.<sup>25</sup>

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<sup>22</sup> *About IDEA, INDIVIDUALS WITH DISABILITIES ACT*, <https://sites.ed.gov/idea/about-idea/> (last visited Mar. 11, 2019).

<sup>23</sup> VA. CODE ANN. § 16.1-336 (West, Westlaw through 2018 Reg. Sess. and 2018 Spec. Sess. 1 and including 2019 Reg. Sess. chs. 17, 18, 164 and 225).

<sup>24</sup> *Person-Centered Planning*, PACER’S NAT’L PARENT CTR. ON TRANSITION AND EMP., <https://www.pacer.org/transition/learning-center/independent-community-living/person-centered.asp> (last visited Mar. 11, 2019).

<sup>25</sup> RUTH A. MATTSON AND REBECCA TUNNEY, ESTATE PLANNING FOR THE AGING OR INCAPACITATED CLIENT IN MASSACHUSETTS § 3.2.2 (2018).

**Principal:** A person with a disability who has executed a supported decision-making agreement in order to obtain decision-making support from their chosen network of supporters.<sup>26</sup> Also referred to as the supported person or the adopter.

**Substituted Decision-Making:** A framework in which the right to make one's own decisions is removed and placed in another, where the decision-maker substitutes their judgment for that of the individual on whose behalf the decision-maker is acting.<sup>27</sup> Examples include guardianship and conservatorship.<sup>28</sup>

**Supported Decision-Making (SDM):** A system for people with all forms of disabilities to foster the individual right of decision-making. A person with a disability selects supporters who agree to offer their guidance to the person in any area of life the person chooses. Supporters can come in many forms, including family members, friends, medical practitioners, or community advisors. The supporters advise the person with a disability and ensure that they understand their options and the potential consequences, but do not make decisions for them. Supporters can help a person with a disability make decisions by explaining decisional outcomes and even communicating their decisions to service providers if the person is unable to do so.<sup>29</sup>

**Supported Decision-Making Agreement:** An agreement a person with a disability enters into with one or more supporters to obtain decision-making support, which can be customized based on the areas in which the person needs support and how many supporters they want to have.<sup>30</sup>

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<sup>26</sup> H.R. 172, 191st Gen. Court, 2019-2020 Sess. § (Mass. 2019).

<sup>27</sup> Eilionóir Flynn & Anna Arstein-Kerslake, *The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?* 32 BERKELEY J. INT'L. L. 124, 125 (2014).

<sup>28</sup> Kristin Booth Glen, *Introducing a "New" Human Right: Learning From Others, Bringing Legal Capacity Home*, 49 COLUM. HUM. RTS. L. REV. 1, 2 (2018).

<sup>29</sup> *FAQs About Supported Decision-Making*, ACLU, <https://www.aclu.org/other/faqs-about-supported-decision-making> (last visited Mar. 11, 2019).

[https://www.aclu.org/sites/default/files/field\\_document/faq\\_about\\_supported\\_decision\\_making.pdf](https://www.aclu.org/sites/default/files/field_document/faq_about_supported_decision_making.pdf) (2015)

<sup>30</sup> H.R. 172, 191st Gen. Court, 2019-2020 Sess. § 1 (Mass. 2019).

**Supporter:** The person in a supported decision-making agreement who provides decision-making advice to the intellectually or developmentally disabled person.

The above terms and concepts are used throughout this paper as we discuss and analyze supported decision-making (SDM). However, these terms do not represent an exhaustive list of the terms used to discuss SDM. For example, the supported person under SDM has been referred to in various parts of the country as the person with a disability, the incapacitated person, the person with a functional impairment, the supported person, the adopter, or the principal. We chose the above terms to define as they were the ones used most widely throughout the existing research we reviewed and that we found to be most accessible to the greatest number of people. Although the words may change, the meaning behind them does not. In every U.S. jurisdiction that has implemented SDM in some manner, there is language to describe: (1) an individual with a disability requiring a formalized process for receiving decision-making support; (2) an individual or set of individuals who provide decision-making support; (3) the contract or agreement under which the supported decision-making process is formalized for the individuals involved and, often, for the court as well; and (4) more restrictive means of assistance that involve substituted, rather than supported, decision-making.

# THEORETICAL UNDERPINNINGS OF SUPPORTED DECISION-MAKING

Supported Decision-Making (SDM) represents a shift in thinking from a paternalistic perspective about how to best protect individuals with intellectual disabilities, cognitive impairments and/or mental health challenges to one focused on promoting the autonomy, independence, dignity, and self-determination of such persons. This change in thinking has theoretical underpinnings in the disciplines of law, philosophy, and psychology.

## I. AUTONOMY AS A HUMAN RIGHT

As discussed below, Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) transformed SDM from a guardianship alternative to a “human-rights imperative” by calling on governments to provide support for all persons to exercise legal capacity.<sup>31</sup> The general principles of the UNCRPD include “respect for inherent dignity; individual autonomy, including the freedom to make one’s own choices, and independence of persons; full and effective participation and inclusion in society; and accessibility.”<sup>32</sup>

By acknowledging the right of persons with disabilities to recognition as persons before the law and invoking the duty of governments to take measures to provide support for disabled individuals to exercise legal capacity, Article 12 represents a radical paradigm-shift from *substituted* to *supported* decision-making.<sup>33</sup> Through SDM, supported persons are able to retain

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<sup>31</sup> Anna Arstein-Kerslake, *Future Directions in Supported Decision-Making*, 37 DISABILITY STUD. Q. (2017), <http://dsq-sds.org/article/view/5070/4549>.

<sup>32</sup> Kristin B. Glen, *Supported Decision-Making and the Human Right of Legal Capacity*, 3 INCLUSION 2, 5 (2015).

<sup>33</sup> Robert D. Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making*, 19 HUM. RTS. BRIEF 8, 8 (2012).

their right to decide instead of ceding it to a guardian. By accentuating the legal rights of individuals with intellectual disabilities on an international stage, the UN's adoption of Article 12 has catalyzed a fundamental shift in how society views such persons.<sup>34</sup>

Throughout the paper we discuss the case law, legislation, and international trends reflecting this fundamental shift in the recognition of legal rights of individuals with disabilities; however, awareness of the rights-based arguments for SDM is important to contextualize an understanding of the philosophical and psychological theory behind this movement.

## II. PHILOSOPHICAL THEORY: AUTONOMY AND PERSONHOOD

Autonomy has long been central to political theory and rights-based arguments; however, the roots of deference to individual autonomy are found in earlier philosophical explorations of the self.

### *a. Philosophy of Government: Moral and Political Autonomy*

Philosophers Immanuel Kant and John Stuart Mill clearly articulated the importance of autonomy.<sup>35</sup> Kant's theory centered on the concept of autonomy as freedom of will to exercise choices based on independent moral reasoning uninhibited by external factors.<sup>36</sup> He suggested that this might be achieved by not only permitting, but also *encouraging* others to exercise their capacity for free will and decision-making in choices that involved or impacted them.<sup>37</sup> Echoing and expanding upon Kant's theories, Mill considered autonomy in the socio-political sphere; he conceptualized liberty as the freedom to act on one's opinions and hypothesized that this freedom

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<sup>34</sup> Glen, *supra* note 32, at 2.

<sup>35</sup> Candace Cummins Gauthier, *Philosophical Foundations of Respect for Autonomy*, 3 KENNEDY INST. ETHICS J. 21, 23 (1993).

<sup>36</sup> *Id.*

<sup>37</sup> *Id.* at 24.

was not only necessary for the development of individuality and happiness of persons, but was also essential to the promotion of general welfare in society as a whole.<sup>38</sup> This sentiment is at the core of modern promotion of self-determination in SDM.

*b. Autonomy as Personhood: Shifting the Conception of Self*

By grounding their theories of respect for autonomy in rational agency, Kant and Mills reserve the application of these principals to those with the capacity to exercise reasoning, foresight, and discerning judgment.<sup>39</sup> The Kantian theory of autonomy as responsiveness to reasoning, predicated on the presumption of rationality, inherently excludes cognitively disabled persons as autonomous agents.<sup>40</sup> Since these moral and political theories deny the capacity for individual autonomy among intellectually disabled persons,<sup>41</sup> a departure from traditional notions of autonomy is necessary to recognize the dignity of all persons in a manner consistent with Article 12's acknowledgement of the legal personhood of disabled individuals.<sup>42</sup>

One manner of achieving this is to invert the concept of autonomy as *independence* from external factors in decision-making to a model of *relational* autonomy based on support, advocacy, and enablement.<sup>43</sup> In such a model, the focus shifts from the *absence* of certain factors typically predictive of autonomy to the *presence* of factors that facilitate and validate the expression of an individual.<sup>44</sup> These factors may be external, such as supporters and other social and structural resources available to the disabled individual.<sup>45</sup> Removing the requirement that decision-making

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<sup>38</sup> *Id.* at 25.

<sup>39</sup> *Id.* at 26.

<sup>40</sup> Laura Davy, *Philosophical Inclusive Design: Intellectual Disability and the Limits of Individual Autonomy in Moral and Political Theory*, 30 HYPATIA 132, 135 (2015).

<sup>41</sup> *Id.* at 132.

<sup>42</sup> Dinerstein, *supra* note 33, at 9.

<sup>43</sup> Davy, *supra* note 40, at 144.

<sup>44</sup> *Id.*

<sup>45</sup> *Id.*

be entirely independent of external guidance allows for acknowledgement of and respect for the autonomy of supported persons in SDM arrangements.<sup>46</sup>

### **III. PSYCHOLOGICAL THEORY: EVIDENCE-BASED METHODS AND EMPIRICAL SUPPORT**

#### *a. Psychological Theory*

In 1976, a study of nursing home residents with varying degrees of cognitive and physical disabilities found that providing choices and responsibility for simple, yet meaningful tasks with readily available visual feedback had a marked influence on the subjective and objective well-being of participants.<sup>47</sup> Residents that were afforded choices and delegated responsibilities were happier, more alert, more active, and more engaged in the community than the control group.<sup>48</sup> Additionally, they had better health metrics than the control group over the course of the next six months.<sup>49</sup> Most significantly, they had a death rate over the following eighteen months reduced by half as compared to the control group.<sup>50</sup> From this seminal study, as well as its replication and corroboration, psychologists concluded that altering institutional environments to augment the sense of control and degree of personal responsibility that residents or patients experience is one of the most effective ways to increase engagement, energy, and happiness.<sup>51</sup>

#### **1. Self-Determination Research**

Self-determination is the ability to act as a causal agent in one's life by controlling decisions impacting one's environment and actions taken toward meeting present and future self-

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<sup>46</sup> *Id.*

<sup>47</sup> Ellen J. Langer & Judith Rodin, *The Effects of Choice and Personal Responsibility for the Aged: A Field Experiment in an Institutional Setting*, 34 J. OF PERSONALITY AND SOC. PSYCHOL. 191, 197 (1967).

<sup>48</sup> *Id.* at 195.

<sup>49</sup> Judith Rodin & Ellen J. Langer, *Long-Term Effects of a Control-Relevant Intervention with the Institutionalized Aged*, 35 J. OF PERSONALITY AND SOC. PSYCHOL. 897, 898 (1977).

<sup>50</sup> *Id.* at 899-900.

<sup>51</sup> Johnathan Haidt & Judith Rodin, *Control and Efficacy as Interdisciplinary Bridges*, 3 REV. OF GEN. PSYCHOL. 317-37 (1999).

conceived goals.<sup>52</sup> Although research on SDM remains in its nascent stage, research concerning self-determination – one of the central theoretical tenets on which SDM is conceptually founded – furnishes robust empirical support for the advancement of autonomy and decision-making participation.

Self-determination is a critical component of wellbeing; it correlates highly with life satisfaction and quality of life.<sup>53</sup> Deprivation of self-determination creates a self-perpetuating downward spiral, as feelings of perceived incompetence lead to increased reliance on others for care-giving and substituted decision-making.<sup>54</sup> Fortunately, the converse is also true; reinstating agency creates a positive feedback loop in which individuals with intellectual disabilities become *more* self-determined when afforded the opportunity to assume a greater degree of control over their lives.<sup>55</sup>

The core elements of self-determination include self-awareness, self-advocacy, goal setting, and goal attainment, which hinges on problem-solving abilities and decision-making skills.<sup>56</sup> An extensive review of the literature indicates that people with intellectual and developmental disabilities who exercise greater self-determination have increased independence and integration in their communities, improved problem-solving abilities, better employment opportunities, better physical health, and a heightened ability to recognize and resist abuse.<sup>57</sup> Moreover, research suggests that enhancing perceived agency and autonomy through augmented

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<sup>52</sup> SHOGREN ET AL., SUPPORTED DECISION-MAKING: THEORY, RESEARCH, AND PRACTICE TO ENHANCE SELF-DETERMINATION AND QUALITY OF LIFE 95-96 (2018).

<sup>53</sup> Yves Lachapelle et al., *The Relationship Between Quality of Life and Self-Determination: An International Study*, 49 J. OF INTELL. DISABILITY RES. 740, 741 (2005).

<sup>54</sup> Bruce J. Winick, *The Side Effects of Incompetency Labeling and the Implications for Mental Health Law*, 1 PSYCHOL., PUB. POL'Y, AND L. 6, 15-21 (1995).

<sup>55</sup> Karrie A. Shogren et al., *Effect of Intervention with the Self-Determined Learning Model of Instruction on Access and Goal Attainment*, 33 REMEDIAL AND SPECIAL EDUC. 320, 326-27 (2012).

<sup>56</sup> Karrie A. Shogren & Michael L. Wehmeyer, *A Framework for Research and Intervention Design in Supported Decision-Making*, 3 INCLUSION 17, 20 (2015).

<sup>57</sup> NAT'L COUNCIL ON DISABILITY, BEYOND GUARDIANSHIP: TOWARD ALTERNATIVES THAT PROMOTE GREATER SELF-DETERMINATION FOR PEOPLE WITH DISABILITIES LITERATURE REVIEW 41 (2018).



self-determination may improve psychological health and resilience, such as adjustment to the increasing care needs inevitable in aging.<sup>58</sup>

#### i. Impact of Guardianship vs. Supported Decision-Making on Self-Determination

Institutionalization and substituted decision-making models like guardianship undermine and diminish self-determination,<sup>59</sup> creating a negative impact that pervades physical and mental health.<sup>60</sup> On the other hand, SDM has the potential to facilitate greater self-determination among persons with disabilities by providing the support needed to comprehend the choices they face while ensuring that they still retain ultimate decision-making authority.<sup>61</sup> In addition to promoting greater self-determination, some researchers have predicted that SDM will improve quality of life outcomes.<sup>62</sup> Preliminary research suggests that SDM may actually assist individuals with intellectual and developmental disabilities in *expanding* their capacity, as decision-making and self-determination are skills that can be learned with education and practice.<sup>63</sup> Enhanced self-determination is only one of many positive outcomes likely to be conferred when SDM is used in lieu of guardianship; for example, older adults with progressive dementia and cognitive decline are more likely to retain cognitive function when their cognitive skills are engaged and employed.<sup>64</sup>

## **2. Implications from Positive Psychology**

More recently, researchers have begun to focus on the application of positive psychology principles in SDM practice. The field of positive psychology centers on the belief that subjective well-being is inherently linked to certain factors, which may be leveraged to augment life

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<sup>58</sup> Brian P. O'Connor & Robert J. Vallerand, *The Relative Effects of Actual and Experienced Autonomy on Motivation in Nursing Home Residents*, 13 CANADIAN J. ON AGING 528, 536 (1994).

<sup>59</sup> Peter Blanck & Johnathan G. Martinis, "The Right to Make Choices": *The National Resource Center for Supported Decision-Making* 3 INCLUSION 24, 25 (2015).

<sup>60</sup> Arstein-Kerslake, *supra* note 31.

<sup>61</sup> NAT'L COUNCIL ON DISABILITY, *supra* note 57.

<sup>62</sup> Blanck & Martinis, *supra* note 59, at 31.

<sup>63</sup> *Id.* at 42.

<sup>64</sup> *Id.*

satisfaction. Researchers posit that by respecting and incorporating personal preferences, experiences, and values, SDM may more effectively promote well-being and happiness in supported individuals.<sup>65</sup>

*b. Supported Decision Making Research*

**1. Conceptual Frameworks for the Provision of Support**

Although the detrimental impact of guardianship on self-determination is clear, removing barriers to autonomy – such as those imposed by substituted decision-makers – represents only half of the equation; substantive equality pursuant to the UNCRPD Article 12 mandate requires not only the removal of restraints on autonomy, but also the provision of adequate support structures to facilitate meaningful empowerment of persons with cognitive disabilities.<sup>66</sup> This approach is consistent with the contemporary recognition of disability as a mere misalignment of an individual’s particular strengths and abilities with environmental demands (including social, environmental, and decisional contexts), which has replaced the previously dominant medical model.<sup>67</sup>

Researchers have proposed an integrated social-ecological framework for assessing personal, environmental, and social factors to determine support needed by individuals with varying cognitive impairments.<sup>68</sup> The authors emphasize that assessment of abilities and environmental demands is a highly personalized process that should be responsive to changes throughout the life course in both individual and environmental factors.<sup>69</sup> In recognizing the

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<sup>65</sup> Lisa A. Woudzia, *Supported Decision-Making and Positive Psychology*, 4 RES. AND PRAC. IN INTELL. AND DEV. DISABILITIES 61, 67 (2016).

<sup>66</sup> Anna Arstein-Kerslake, *Restoring Voice to People: Realizing the Right to Equal Recognition Before the Law of People with Cognitive Disabilities* (July 2014) (Doctoral Thesis in Law, National University of Ireland, Galway) (on file with the library, National University of Ireland, Galway), <http://hdl.handle.net/10379/5106>.

<sup>67</sup> Arstein-Kerslake, *supra* note 60.

<sup>68</sup> Shogren & Wehmeyer, *supra* note 56, at 19.

<sup>69</sup> *Id.*

fluidity of support needs, this framework acknowledges that “disability is not a static condition inherent to the person, but results from the interaction of personal characteristics and environmental demands.”<sup>70</sup> Three key domains must be considered to effectively design a support system that enables an individual to be successful within their environment; these are: (1) the individual’s decision-making ability; (2) the context in which decision-making will occur; and (3) specific support needs for enabling decision making.<sup>71,72</sup>

Within these broad domains of the social-ecological framework, researchers have further examined interactions of intellectual disabilities, mental health, and aging to identify specific factors that are most relevant in effective SDM design.<sup>73</sup> Significant personal factors include: age, gender, race, ethnicity, language, and communication preferences.<sup>74</sup> Culture may heavily influence communication preference, and more research is needed to elucidate culturally competent communication strategies.<sup>75</sup> Other personal factors of import include severity of mental health needs and presence of self-harming thoughts or delusions.<sup>76</sup>

Researchers acknowledged that the rate of aging’s impact on cognitive decline must be considered, and that physical impairments associated with aging – such as changes in sensory perception – also play a role in affecting decision-making abilities.<sup>77</sup> Intelligence quotient (IQ) matters in considering the needs of those with intellectual disabilities, as does the comparative level of impairment relevant to functioning.<sup>78</sup> Moreover, co-morbid conditions dramatically

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<sup>70</sup> Karrie A. Shogren et al., *Supported Decision Making: A Synthesis of the Literature Across Intellectual Disability, Mental Health, and Aging*, 52 EDUC. AND TRAINING IN AUTISM AND DEV. DISABILITIES 144, 145 (2017).

<sup>71</sup> Shogren & Wehmeyer, *supra* note 56, at 17.

<sup>72</sup> Karrie A. Shogren et al., *Development of the Supported Decision-Making Inventory System*, 55 INTELL. AND DEV. DISABILITIES 432, 435-38 (2017).

<sup>73</sup> Shogren, et al., *supra* note 70.

<sup>74</sup> *Id.* at 150.

<sup>75</sup> *Id.* at 151.

<sup>76</sup> *Id.* at 150.

<sup>77</sup> *Id.*

<sup>78</sup> *Id.*

change support needs, particularly with respect to the complexity of health decisions that needed to be made.<sup>79</sup> Researchers highlighted that management of pain-related symptoms of illness or injury often necessitates medications with side effects that drastically impair cognitive functioning.<sup>80</sup>

Critical environmental factors that play a role in mediating decision-making include existing social and institutional supports, living arrangements, family attitudes towards the individual with a disability and their ability to make decisions, opportunities to engage in decision-making, and complexity of the decisions to be made.<sup>81</sup> The context of the decision – whether urgent or long-term in nature – is one of the most significant factors.<sup>82</sup> The perceived degree of impact of the decision is likewise an important factor; medical and financial decisions, as well as those concerning driving, tend to be the “highest stakes” decisions.<sup>83</sup> Accessibility of information and manner of communication also play a key role.<sup>84</sup> These findings were consistent with those of a previous study, which found that the way in which medical information is framed and communicated had tangible outcomes in swaying the decisions of mentally ill individuals.<sup>85</sup>

## **2. Choice Structure and Engagement in Decisions**

Some environments simply afford individuals the chance to make more choices on a daily basis.<sup>86</sup> When meaningful choice opportunities and appropriate support systems are provided to individuals with disabilities, such as deciding where to work and live and with whom to interact,

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<sup>79</sup> *Id.*

<sup>80</sup> *Id.*

<sup>81</sup> *Id.* at 148-152.

<sup>82</sup> *Id.* at 151.

<sup>83</sup> *Id.* at 152.

<sup>84</sup> *Id.* at 148.

<sup>85</sup> Paul M. Salkovskis, *Experimental Investigation of Factors Involved in the Decision to Undertake Genetic Testing for Schizophrenia*, 19 J. OF MENTAL HEALTH 202, 210 (2010).

<sup>86</sup> Michael Wehmeyer & Nancy Bolding, *Self-Determination Across Living and Working Environments: A Matched-Samples Study of Adults with Mental Retardation*, 37 Mental Retardation 353, 360-63 (1999); *See also* Michael Wehmeyer & Nancy Bolding, *Enhanced Self-Determination of Adults with Intellectual Disability as an Outcome of Moving to Community-Based Work or Living Environments*, 45 J. OF INTELL. DISABILITY RES. 371, 379 (2001).

research shows that they hone decision-making skills, which positively affects community integration and life outcomes.<sup>87</sup> However, research suggests that for individuals with impaired decision-making abilities, providing options alone – without a support structure – is not enough.<sup>88</sup> Selective presentation of only the most salient information has been shown to increase the likelihood that individuals with mental illness and/or cognitive impairment will participate actively in the decision-making process.<sup>89</sup> This is the critical role of the supporter(s): to present the available options and relevant information in a manner that does not unduly influence the decision of the supported person.

Researchers have found that peer support is one effective method to promote engagement in a neutral manner, as is training in self-advocacy, communication, and problem solving. Utilization of visual decision-making aids such as graphic presentation of information and color-coding, as well as culturally competent communication specifically tailored to level of impairment, were also found to increase participation in decision-making, while negative attitudes of family and staff towards decision-making reduced the efficacy of these aids.<sup>90</sup> Decision-making support was found to be most effective when provided by one or more individuals who already had a trusting relationship with the person with a disability, as well as knowledge of their history and experience with decision-making (including previous decisions and outcomes), their goals, the nature of their impairment, and their degree of functioning.<sup>91</sup> Researchers have found that flexible

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<sup>87</sup> SHOGREN, *supra* note 52, at 183-199.

<sup>88</sup> J.G. Wong et al., *Capacity to Make Health Care Decisions: Its Importance in Clinical Practice*, 29 PSYCHOL. MED. 437 (1999).

<sup>89</sup> Shogren, *supra* note 70, at 151.

<sup>90</sup> *Id.*

<sup>91</sup> Jacinta Douglas et al., *Factors that Underpin the Delivery of Effective Decision-Making Support for People with Cognitive Disability*, 2 RES. AND PRAC. IN INTELL. AND DEV. DISABILITIES 37, 40 (2015).

and collaborative styles of assistance were the most effective, noting that using multiple strategies to provide customized support was optimal.<sup>92</sup>

In summary, psychological literature provides a conceptual framework of best practices for SDM. The literature suggests that individualized support tailored to align with a supported person's identified needs, values, goals, and abilities as contextualized by environmental factors is the SDM approach most likely to succeed.

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<sup>92</sup> *Id.*

## EMPIRICAL RESEARCH

Although systematic research is naturally limited by the recency of supported decision-making's (SDM) use as a viable alternative to guardianship, a small number of studies have been conducted. Moreover, systematic research is presently underway to generate empirical data on the efficacy and impact of SDM, as well as ground theoretical predictors of success and metrics of evaluation in real-world practice and pilot programs.

### I. EMPIRICAL RESEARCH ON SUPPORTED DECISION-MAKING

To fill the current research gap, the National Resources Center on Supported Decision-Making (NRC-SDM) made SDM a National Research Priority,<sup>93</sup> and is conducting various qualitative and quantitative studies to document the nature, use, barriers to, and outcomes of SDM by older adults and persons with intellectual and developmental disabilities. The results of the first study to be completed by the NRC-SDM suggest that the majority of participants with intellectual or developmental disabilities reported that “SDM brought greater confidence, the ability to do more things, and greater happiness.”<sup>94</sup> This empirical research corroborates the theory linking SDM with improved quality of life and life satisfaction outcomes through its effect on facilitating self-determination.<sup>95</sup> Another study on SDM, based in Australia, revealed that participants experienced greater community inclusion, improved decision-making skills, increased social

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<sup>93</sup> National Institute on Disability, Independent Living, and Rehabilitation Research—Rehabilitation Research and Training Centers, 80 Fed. Reg. 10099 (proposed Feb. 25, 2015) (proposing a priority for an RRTC on Employer Practices Leading to Successful Employment Outcomes for Individuals with Disabilities), <https://www.govinfo.gov/content/pkg/FR-2015-02-25/pdf/2015-03877.pdf>; National Institute on Disability, Independent Living, and Rehabilitation Research—Rehabilitation Research and Training Centers, 80 Fed. Reg. 10106 (proposed Feb. 25, 2015) (proposing a priority for an RRTC on Self-Directed Care to Promote Recovery, Health, and Wellness for Individuals with Serious Mental Illness), <https://www.govinfo.gov/content/pkg/FR-2015-02-25/pdf/2015-03880.pdf>.

<sup>94</sup> NAT'L COUNCIL ON DISABILITY, *supra* note 57, AT 43.

<sup>95</sup> Nina A. Kohn et al., *Supported Decision-Making: A Viable Alternative to Guardianship?* 117 PENN. STATE L. REV. 1111, 1138 (2013).

networks, and higher self-confidence; however, the authors concluded that models of SDM are many and varied, and there is need for more systematic investigation of specific models and their outcomes.<sup>96</sup>

Another study examined the viability of SDM for adults with serious mental illness (SMI).<sup>97</sup> Results were promising, indicating that SDM may enhance feelings of self-empowerment and improve functional outcomes for persons with SMI, as has been shown in studies involving individuals with cognitive disabilities.<sup>98</sup> Communication methods that were found to be particularly helpful in facilitating decision-making in this population were repeated presentation of information in multimedia formatting.<sup>99</sup> Reporting results of a study in Ireland on the efficacy of SDM in this population, the author highlighted that decision-making support was most needed during periods of acute emotional distress and was most effectively provided by clarifying available options and affirming self-efficacy.<sup>100</sup>

Randomized control trials – the “gold standard” of research design – are rare in this relatively new area, and most are limited to the highly specific subset of health decision-making support. However, within this narrow context, results of decision-support systems are promising and can likely be extrapolated to the larger context of SDM.<sup>101</sup>

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<sup>96</sup> Christine Bigby et al., *Supporting People with Cognitive Disabilities in Decision Making: Processes and Dilemmas*, LIVING WITH DISABILITY RES. CTR., [https://www.asid.asn.au/files/639\\_46\\_m\\_whiteside\\_c\\_bigby\\_j\\_douglas.pdf](https://www.asid.asn.au/files/639_46_m_whiteside_c_bigby_j_douglas.pdf) (last visited Mar. 12, 2019) (referencing slides 43-51).

<sup>97</sup> Dilip V. Jeste et al., *Supported Decision Making in Serious Mental Illness*, 81 PSYCHIATRY 28 (2018).

<sup>98</sup> *Id.* at 35.

<sup>99</sup> *Id.* at 30.

<sup>100</sup> *Id.* at 35.

<sup>101</sup> Leanne Brown et al., *A Randomized Controlled Trial Protocol Testing a Decision Support Intervention for Older Patients with Advanced Kidney Disease*, 72 J. OF ADVANCED NURSING 1191, 1200 (2016).



## II. FUTURE RESEARCH AND DIRECTIONS

More research is needed to determine the extent to which SDM achieves its goals, its limitations, and the conditions under which it is most likely to succeed.<sup>102</sup> Some scholars have posited that the greatest barrier to widespread implementation of SDM is the lack of valid and reliable data demonstrating its impact on life outcomes.<sup>103</sup> In response to this need, the NRC-SDM is spearheading a research initiative to evaluate the effect of SDM on quality of life.<sup>104</sup> The first study to be funded is descriptive and aims to quantify the extent to which the use of SDM is associated with demographic and individual factors such as age, gender, disability type and severity, and socioeconomic status, as well as environmental factors such as use of technology.<sup>105</sup> A second outcome of this study is to examine the impact of these variables on actual and perceived self-determination, daily choice in life activities, integration in community living, and overall satisfaction with and quality of life.<sup>106</sup>

A second study called for at the 2013 NRC-SDM symposium is experimental and geared towards evaluating the efficacy of supported decision-making interventions using the Self-Determined Decision-Making Model (SDDMM).<sup>107</sup> Using a randomized control trial design, this study will explore the degree to which disabled individuals may be enabled to engage in self-regulated problem-solving as well as setting and achieving goals relevant to life decisions.<sup>108</sup> A smaller descriptive study led by investigators at Syracuse University is focusing on identifying

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<sup>102</sup> Kohn, *supra* note 95, at 1157.

<sup>103</sup> *Id.* at 1128-1129.

<sup>104</sup> Arstein-Kerslake, *supra* note 31.

<sup>105</sup> *Id.*

<sup>106</sup> *Id.*

<sup>107</sup> *Id.*

<sup>108</sup> *Id.*

decision-making methods that promote community integration and demographic variables associated with success of these methods.<sup>109</sup>

One key takeaway from a recent publication on the future of SDM is that it simply needs to be discussed more as an option for individuals with intellectual and cognitive impairments; it is currently mentioned far less frequently than guardianship.<sup>110</sup> In order to gain more traction, broad awareness and education about what SDM is and how it works must be made accessible to those most likely to benefit from it,<sup>111</sup> and perhaps even framed as an optimal default when appropriate.

Researchers caution that as SDM becomes increasingly implemented, safeguards must be employed to ensure that the desires and opinions of supported individuals continue to inform the design and practice of SDM arrangements and research.<sup>112</sup> The National Council on Disability warns that, without proper training and safeguards to prevent over-regulation, supporters may misunderstand their role and substitute their decisions for the person with a disability or unintentionally lead the person to a pre-determined outcome “through issue-framing, inaccurate assessment of [the person’s] preferences, or simple conversations” in which the person may give deference to his or her supporters.<sup>113</sup> In order to avoid such pitfalls, researchers recommended educating family members and other supporters on the fundamental philosophy behind SDM, as well as training supporters in how to effectively use communication and conflict resolution strategies while mitigating the risk of undue influence from power differentials.<sup>114</sup> Training

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<sup>109</sup> *Community Living and Supported Decision-Making: Understanding and Increasing Supported Decision-Making’s Positive Impact on Community Living and Participation Outcomes*, BURTON BLATT INST. SYRACUSE U., [http://bbi.syr.edu/projects/Community\\_Living\\_DRRP/index.html](http://bbi.syr.edu/projects/Community_Living_DRRP/index.html) (last visited March 14, 2019).

<sup>110</sup> John M. Jameson et al., *Guardianship and the Potential of Supported Decision Making for Individuals with Disabilities*, 40 RES. AND PRAC. FOR PERSONS WITH SEVERE DISABILITIES 36, 43-46 (2015).

<sup>111</sup> *Id.* at 48-49.

<sup>112</sup> Arstein-Kerslake, *supra* note 31.

<sup>113</sup> NAT’L COUNCIL ON DISABILITY, *supra* note 57, at 49-50.

<sup>114</sup> Bigby, *supra* note 96 (referencing slides 44-46).

supporters in how to balance enabling rights with minimizing risk and how to collaborate with other supporters was also recommended.<sup>115</sup>

Researchers in this field also caution against leaving behind those with the most challenging impairments, acknowledging that the majority of pilot programs have been dominated by individuals with mild cognitive disabilities.<sup>116</sup> Some practitioners and scholars contend that SDM is not appropriate for more severely disabled individuals, raising arguments that often center on the inability of people with profound cognitive disabilities to “understand and process information rationally, engage in purposive behavior, or communicate preference intentionally.”<sup>117</sup> However, such individuals are not excluded from the human rights imperative of Article 12 of the UNCRPD. Instead, researchers emphasize the need to determine how best to support people with serious intellectual disabilities in a manner that allows their will and preferences to inform decisions made *with* them, rather than *for* them in their perceived “best interest.”<sup>118</sup>

Although meeting the needs of the most vulnerable disabled populations will undoubtedly be challenging, it is essential to reframe how we think of autonomy and disability in a way that shifts focus from internal factors to externalized context and available supports.<sup>119</sup> Researchers suggest that leveraging a multimedia toolkit of integrated technology may help to meet the needs of individuals with severe mental illness.<sup>120</sup> Nevertheless, there is a small group of persons – estimated by the National Council on Disability to hover around 5% – for whom none of the current models of SDM are predicted to be viable.<sup>121</sup> In those situations, “facilitated communication,” based on what the supporter “believes to be the individual’s true wishes,” rather than “best

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<sup>115</sup> *Id.*

<sup>116</sup> Arstein-Kerslake, *supra* note 31.

<sup>117</sup> *Id.*

<sup>118</sup> *Id.*

<sup>119</sup> *Id.*

<sup>120</sup> Jeste, *supra* note 97, at 37-38.

<sup>121</sup> NAT’L COUNCIL ON DISABILITY, *supra* note 57, at 52.

interests,” should be used for the shortest time possible and subject to independent and impartial review to prevent abuse.<sup>122</sup> As one scholar commented on the inclusion of individuals with high-support needs:

The starting point is not a test of capacity, but the presumption that every human being is communicating all the time and that this communication will include preferences. Preferences can be built up into expressions of choice and these into formal decisions. From this perspective, where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices.<sup>123</sup>

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<sup>122</sup> *Id.*

<sup>123</sup> STEPHANIE BEAMER & MARK BROOKES, MAKING DECISIONS: BEST PRACTICE AND NEW IDEAS FOR SUPPORTING PEOPLE WITH HIGH SUPPORT NEEDS TO MAKE DECISIONS 4 (2001).

# **HISTORY AND DEVELOPMENT OF SUPPORTED DECISION-MAKING**

## **I. INTERNATIONAL TRENDS**

Various countries have considered supported decision-making (SDM) as a replacement to court-appointed guardianship for over twenty years. In 1996, the Canadian province of British Columbia implemented measures to restore autonomy to people with disabilities in regard to medical, financial, and other life affairs by passing the Representation Agreement Act. Sweden soon followed suit, but took a different approach by offering trained professionals in lieu of more informal supporters. This system allows individuals who do not have family or friends who can act as supporters to retain access to SDM as an alternative to guardianship. In 2007, the United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD included an article that human rights groups and disabilities activists have interpreted as calling for an end to the practice of court-appointed guardianship in favor of SDM. The following section outlines the chronological evolution of SDM around the world, both leading up to the adoption of the UNCRPD and how foreign governmental bodies have responded to its guarantee of the rights of persons with disabilities.

The discussion begins with British Columbia's Representation Agreement Act of 1996 and Sweden's Personal Ombudsmen system. The Canadian act was the first SDM statute and still included some elements of substituted decision-making, whereas Sweden took a different approach by first implementing a series of pilot programs and ultimately adopting a model with more focus on autonomy and avoiding substituted decision-making frameworks such as guardianship. The discussion then moves on to the UNCRPD, which emphasized the rights of individuals with disabilities to enjoy equal treatment before the law, autonomy, and access to support. Finally, the section analyzes SDM pilot programs in Australia and Israel that have been implemented since the adoption of the UNCRPD. Both Australia and Israel have signed and ratified the UNCRPD, in 2008 and 2012 respectively.

*a. Canada - British Columbia*

Canada was the first country to codify SDM with the passage of the Representation Agreement Act of 1996 in British Columbia.<sup>124</sup> The purpose of an agreement under the statute is to make advance decisions regarding health care, personal care, financial affairs, and other matters in order to avoid court-appointed substituted decision making in the event that the individual later becomes incapacitated.<sup>125</sup> The act allows for a mix of supported and substituted decision-making, stating that the supporter may be given authority to help make decisions or make decisions on behalf of the adult, potentially including authority to admit the adult to a family care home, group home for the mentally handicapped, or a mental health boarding home. The scope of decisions covered under an agreement can include routine management of financial affairs such as paying bills or making purchases, healthcare, legal services including instructions to counsel, and personal care, which encompasses “(a) the shelter, employment, diet and dress of an adult, (b) participation by an adult in social, educational, vocational and other activities, (c) contact or association by an adult with other persons, and (d) licenses, permits, approvals or other authorizations of an adult to do something.”<sup>126</sup>

Under the act, a supporter may not generally be authorized to refuse life-saving healthcare; to physically restrain, move, or manage the adult if the adult objects; or to refuse consent for certain mental health decisions.<sup>127</sup> Parties must enter representation agreements voluntarily and a representation agreement cannot be made mandatory as a condition for receiving a good or service.<sup>128</sup> A principal may appoint multiple supporters under the same agreement to either have

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<sup>124</sup> See VANPUYMBROUCK, *supra* note 1, at 6.

<sup>125</sup> R.S.B.C. 1996, c. 405 (Can., Westlaw through B.C. Reg. 238/2018).

<sup>126</sup> *Id.*

<sup>127</sup> *Id.*

<sup>128</sup> *Id.*

different areas of authority or to share all or part of the same area of authority.<sup>129</sup> Supporters who share the same area of authority must act unanimously.<sup>130</sup> The act emphasizes autonomy and self-determination in that all adults are presumed to be capable of making decisions and representation agreements until it is proven that they are not, meaning that they cannot understand the nature or consequences of the proposed agreement. Additionally, adults may enter into a representation agreement even if they are not capable of making a contract or of independently managing their own healthcare, personal care, legal matters, or finances.<sup>131</sup> Relevant factors in determining that the adult is capable of entering into the agreement are the adult's desire to have a representative; the adult's choices, preferences, and ability to express approval or disapproval; the adult's awareness of the nature of the agreement; and the relationship between the adult and representative, which must be one of trust.<sup>132</sup>

*b. Sweden*

Sweden followed Canada's lead by implementing an SDM system in 2000, though the system differs in several key respects. The system began with a series of pilot programs from 1995 through 1998 before its permanent expansion in 2000 and securing permanent funding as part of the welfare system in 2013.<sup>133</sup> Although individuals can use family or friends as their supporters, Sweden also offers a Personal Ombudsmen (PO) service.<sup>134</sup> The aim of the PO program is to prevent guardianship for individuals with severe mental or psychosocial disabilities through the use of trained supporters who conduct outreach and provide supported decision-making assistance to those in need; they help facilitate decisions and control over one's own affairs, but do not have

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<sup>129</sup> *Id.*

<sup>130</sup> *Id.*

<sup>131</sup> *Id.*

<sup>132</sup> *Id.*

<sup>133</sup> *Sweden: Personal Ombudsmen*, ZERO PROJECT, <https://zeroproject.org/policy/sweden-2/> (last visited Mar. 12, 2019).

<sup>134</sup> *Id.*

medical responsibility and are not allowed to engage in substituted decision-making.<sup>135</sup> Per a report by the Zero Project, the program has demonstrated positive outcomes in the lives of disabled individuals through empowerment and is significantly less costly than the services offered previously.<sup>136</sup> Local government officials throughout the country consider the PO system to be “a natural part of the services that are expected to be offered in a municipality.”<sup>137</sup> The model has also been adopted in Oslo, Norway; Helsinki, Finland; and the Czech Republic.<sup>138</sup>

*c. United Nations Convention on the Rights of Persons with Disabilities*

SDM agreements in the campaign for disability rights drew international attention after the United Nations adopted the Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007. Article 12 of the UNCRPD demanded equal recognition before the law for all persons with disabilities, whereas guardianship and other restrictive intervention practices frequently denied legal equality on the basis of mental disability.<sup>139</sup>

The European Commissioner for Human Rights interpreted the UNCRPD to be an enumeration of existing fundamental rights common to all persons but adapted to the unique identity of persons with disabilities.<sup>140</sup> Particularly, Article 12 highlighted inequality in the courtroom where individuals with disabilities were systemically stripped of their legal autonomy, and further labeled this deprivation as a human rights violation.<sup>141</sup> The UNCRPD offered directions in section 3 of Article 12 for how international community may achieve legal equality

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<sup>135</sup> *Id.*

<sup>136</sup> *Id.*

<sup>137</sup> *Id.*

<sup>138</sup> *Id.*

<sup>139</sup> G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities (Jan. 24, 2007).

<sup>140</sup> EUR. PARL. ASS., EQUALITY AND INCLUSION FOR PEOPLE WITH DISABILITIES (2014), <http://assembly.coe.int/nw/xml/XRef/Xref-DocDetails-EN.asp?FileID=21339&lang=EN>.

<sup>141</sup> Comm. on the Rights of Persons with Disabilities, General Comment No. 1 (2014): Article 12: Equal Recognition Before the Law (May 19, 2014), <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>.



for persons with disabilities through domestic changes, requiring those countries that ratified the convention to provide people with disabilities “access... to the support they may require in exercising their legal capacity.”<sup>142</sup> The words “support” and “legal capacity” that appeared in Article 12 are the theoretical foundation to the international movement for SDM agreements.<sup>143</sup>

The European Commissioner for Human Rights clarified what the UNCRPD meant by legal capacity. “Legal capacity,” he wrote, “is the capacity to acquire a right.”<sup>144</sup> Human rights conventions, such as the UNCRPD, branch into two intertwining arms: legal capacity – the function of having rights – and the capacity to exercise those rights. The Commissioner states that “legal capacity is an inherent right of all persons.”<sup>145</sup> The human being is the vessel to which rights are attached and this attachment of fundamental, inalienable rights guaranteed to all cannot justifiably be compromised in any fashion, regardless of the limitations of the individual’s mental functioning.

Nonetheless, court-appointed guardianship substitutes the guardian’s judgement for that of the individual who has been deemed incapacitated, which effectively transfers that person’s rights to another.<sup>146</sup> When a person with a disability may no longer exercise their right to make decisions because a third party executes decisions on their behalf, this constitutes a denial of legal capacity.<sup>147</sup> With their legal capacity stripped, it is impossible for a person with a disability to enjoy the full scope of their human rights. This is because the guarantee of their right to autonomy,

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<sup>142</sup> G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities (Jan. 24, 2007).

<sup>143</sup> Dinerstein, *supra* note 33.

<sup>144</sup> EUR. PARL. ASS., EQUALITY AND INCLUSION FOR PEOPLE WITH DISABILITIES (2014), <http://assembly.coe.int/nw/xml/XRef/Xref-DocDetails-EN.asp?FileID=21339&lang=EN>.

<sup>145</sup> *Id.*

<sup>146</sup> Dinerstein, *supra* note 33.

<sup>147</sup> EUR. PARL. ASS., EQUALITY AND INCLUSION FOR PEOPLE WITH DISABILITIES (2014), <http://assembly.coe.int/nw/xml/XRef/Xref-DocDetails-EN.asp?FileID=21339&lang=EN>.

freedom of movement, or even their right to marry, crumbles when their right to make decisions is vested in another.<sup>148</sup>

Article 12, section 3 of the UNCRPD stated that the remedy for a compromised or revoked form of legal capacity is “support.”<sup>149</sup> A report to the Committee on Equality and Non-Discrimination of the Parliamentary Assembly of the Council of Europe stated, “legal capacity is an inherent right of all persons, and... it needs to be distinguished from the capacity to exercise rights, for which support may be offered when necessary, in accordance with Article 12 of the [UNCRPD].”<sup>150</sup> While the UNCRPD requires that all persons be on equal footing before the law with a full, protected recognition of their legal capacity, the framework for exercising those fundamental rights can be unique to the individual.<sup>151</sup> SDM represents a “paradigm shift in international and national law” because it is intended to replace court-appointed guardianship systems which result in the partial or total legal incapacitation of persons with disabilities.<sup>152</sup> In contrast to guardianship, SDM leaves the legal capacity of individuals with disabilities intact while providing the necessary supports for the exercise of their fundamental liberties.

A handful of countries, possibly in response to successful statutes and the UNCRPD, have responded by implementing robust pilot programs to test SDM in their respective countries. While this list is limited, it has provided SDM proponents with valued best practices on how to appropriately execute such programs. In order to best illustrate successes and challenges from international pilot programs, this analysis will focus on two robust case studies from Australia and Israel, both of which have ratified the UNCRPD.

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<sup>148</sup> Arstein-Kerslake, *supra* note 31.

<sup>149</sup> Dinerstein, *supra* note 33.

<sup>150</sup> EUR. PARL. ASS., EQUALITY AND INCLUSION FOR PEOPLE WITH DISABILITIES (2014), <http://assembly.coe.int/nw/xml/XRef/Xref-DocDetails-EN.asp?FileID=21339&lang=EN>.

<sup>151</sup> Robert Dinerstein, *Emerging International Trends and Practices in Guardianship Law for People with Disabilities*, 22 ILSA J. OF INT’L AND COMP. L. 436 (2016).

<sup>152</sup> EUR. PARL. ASS., *supra* note 150.

*d. Australia*

Absent legislation, Australia has worked to develop pilot programs to bring awareness and provide care for those seeking a less restrictive model than guardianship. The participants of the pilot programs were primarily individuals with mild intellectual disabilities.<sup>153</sup> Despite the adoption of SDM legislation in Sweden and Canada, there is very little empirical data about the results of those laws. Reports have focused on theoretical methodologies rather than actual application. While SDM has legal status in both Sweden and Canada, in Australia the focus has been on pilot programs needed to make such an undertaking successful.<sup>154</sup>

Between 2010 and 2015, six pilot programs were run in Australia.<sup>155</sup> Two programs were conducted in South Australia and one each in Victoria, New South Wales, Australian Capital Territory, and Western Australia.<sup>156</sup> The programs were limited in the number of participants. Some programs had as few as six pairs of supported persons and their supporters while others had as many as thirty-six.<sup>157</sup> The programs were funded by government grants or short-term grants from industry and philanthropic bodies.<sup>158</sup> Since all programs were non-statutory, the person with the disability always had the ultimate decision-making power rather than that power being shared with the supporter.<sup>159</sup>

The core of each program focused on the relationship between the supporter and the supported person. The first step in one of the programs was referred to as *decision readiness* where the program staff worked to help the person with a cognitive disability develop decision-making

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<sup>153</sup> Christine Bigby et al., *Delivering Decision Making Support to People with Cognitive Disability – What Has Been Learned from the Pilot Programs in Australia from 2010 to 2015*, 52 AUSTL. J. OF SOC. ISSUES 222, 231 (2017).

<sup>154</sup> *Id.* at 222-40.

<sup>155</sup> *Id.* at 224.

<sup>156</sup> *Id.*

<sup>157</sup> *Id.* at 226.

<sup>158</sup> *Id.*

<sup>159</sup> *Id.* at 222-40.

skills, preceding the recruitment of supporters and the formation of the SDM agreement. Some of the programs helped persons with disabilities identify supporters they already knew, including family members and friends. One of the programs had unpaid volunteers, and another other had a mix of paid staff, unpaid family members, and friends.<sup>160</sup> Supporters had to meet basic requirements including respect for the rights, values, goals, and experiences of each person; good interpersonal skills; and an ability to recognize conflicts of interest.<sup>161</sup> All programs had training documents and staff to guide and assist the supporters.<sup>162</sup>

Upon review of the programs, the team identified some key successes and areas for improvement. The biggest success highlighted through all the programs was the increased confidence in making decisions by the individual with a disability.<sup>163</sup> One issue they discussed, however, was a potential need for filling in the gap between making a decision and acting on that decision.<sup>164</sup> They suggested including formal decision-making agreements to increase accountability.<sup>165</sup> The biggest challenge faced by the majority of the programs was “tension associated with the role of decision supporter and consequent conflict with others involved in the decision maker’s life.”<sup>166</sup> One program in particular highlighted the difficulty in recruiting and identifying people as decision-making supporters.<sup>167</sup>

The Australian pilot program study suggested that one of the biggest issues plaguing the success of SDM is the lack of awareness that such a possibility exists for individuals with

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<sup>160</sup> *Id.* at 226.

<sup>161</sup> *Id.* at 230

<sup>162</sup> *Id.* at 222-40.

<sup>163</sup> *Id.* at 231.

<sup>164</sup> Christine Bigby, Jacinta Douglas, Terry Carney, Shih-Ning, Then Ilan Wiesel, & Elizabeth Smith, *Delivering Id.* at 234.

<sup>165</sup> *Id.* at 235.

<sup>166</sup> *Id.* at 236.

<sup>167</sup> *Id.* at 234.

disabilities.<sup>168</sup> The authors also offered the lack of statutory authority and poorly defined supporter roles as an explanation to the challenges faced by the supporters.<sup>169</sup> Supporters would more likely have to rely on personal relationships with the supported person and the community as opposed to having a clearly defined role and responsibilities decreed by law.<sup>170</sup> Overall, the need for a long term and comprehensive program seems to be evident. In the absence of statutory law, a need to establish comprehensive training and methodology is paramount for the success of SDM as a less restrictive alternative to guardianship.<sup>171</sup>

*e. Israel*

In August of 2014, Israel launched its own pilot program to study the effects that SDM would have on the lives of persons with disabilities. Bizchut, the Israel Human Rights Center for People with Disabilities, commenced its Article 12 Pilot Project to test Israel's SDM model. This was part of an effort funded by a European Union grant and included collaboration between various organizations on the ground such as the Beit Issie Shapiro as well as the Jerusalem Municipality Welfare Department.<sup>172</sup> The pilot program took place in Jerusalem and was overseen by an advisory committee composed of representatives from the government and civil society, as well as persons with disabilities and their family members.<sup>173</sup> The program concluded with a conference hosted by the Office of the Commissioner for Equal Rights for Persons with Disabilities, where

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<sup>168</sup> *Id.* at 237.

<sup>169</sup> *Id.* at 235.

<sup>170</sup> *Id.* at 222-40.

<sup>171</sup> *Id.*

<sup>172</sup> *Supported Decision-Making Service for Persons with Disabilities*, THE ISRAEL HUMAN RIGHTS CENTER FOR PEOPLE WITH DISABILITIES 33 (2015), <http://bizchut.org.il/he/wpcontent/uploads/2017/06/Support-system-Model-Bizchut.pdf>.

<sup>173</sup> *Id.*

all advisory members were invited to present the results of the pilot.<sup>174</sup> The program had three goals, which are stated in the report as follows:

- (1) Developing and formulating a “supported decision making” model.<sup>175</sup>
- (2) Running a pilot for twenty people, currently under guardianship in the Jerusalem area.<sup>176</sup>
- (3) Disseminating the model among persons with disabilities, family members, professionals and policy makers in the field.<sup>177</sup>

In order to properly execute the goals of the program they divided the pilot into stages, focusing on recruitment of supporters; training of supporters; recruitment of partnerships for the program; establishment of the advisory committee; study design and implementation; recruitment of participants; and reporting.<sup>178</sup> Though these are not all the stages included in the pilot, for the purposes of this analysis, these are the most relevant.

The program administrators were particularly diligent in their recruitment of participants. Their method involved interviewing the individual and those in their close social circles.<sup>179</sup> If someone chose to participate in the program, they would have an in-depth introductory interview and would then be matched with a specific supporter according to their needs.<sup>180</sup> This stage of the program lasted several months and resulted in the recruitment of a total of twenty-two participants, although by the end of the program three of the participants had chosen to discontinue their participation.<sup>181</sup> This program was not only aimed at providing alternative services to those

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<sup>174</sup> *Supported Decision-Making Service for Persons with Disabilities*, THE ISRAEL HUMAN RIGHTS CENTER FOR PEOPLE WITH DISABILITIES (2015).

<sup>175</sup> *Id.* at 33.

<sup>176</sup> *Id.*

<sup>177</sup> *Id.*

<sup>178</sup> *Id.* at 34-37.

<sup>179</sup> *Id.* at 35.

<sup>180</sup> *Id.*

<sup>181</sup> *Id.*

currently under guardianship, but it was also a way to educate the community on available alternatives.<sup>182</sup>

Although the program was described as an overall success, there were some noteworthy dilemmas, particularly those that arose in the relationship between the supporter and the supported person. The report pointed to issues in establishing and maintaining contact between the pair; at times the supported individual would forget or not attend meetings and sometimes be unresponsive to the supporter.<sup>183</sup> They also pointed to difficulties in the supporter communicating or understanding the wishes of the supported individual, as well as difficulties establishing boundaries within the support process.<sup>184</sup> In identifying the amount of support required, the program raised more questions than answers. Due to the specific and unique nature of each individual's disability, it was often difficult to gauge not only the amount of support needed, but how active or proactive a role the supporter should take.<sup>185</sup> The report pointed to tension between the supporter and those in the social circle of the supported individual, arising out of objections to decisions and lack of trust.<sup>186</sup>

Overall, the pilot pointed to the model's effectiveness. Most participants showed signs of increased awareness and decision-making skills.<sup>187</sup> Because the program was conducted with only participants that were already under a guardianship, the limitations which required the approval of the guardian for all decisions aided by the supporter is highlighted as a potential problem in the

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<sup>182</sup> *Supported Decision-Making Service for Persons with Disabilities*, THE ISRAEL HUMAN RIGHTS CENTER FOR PEOPLE WITH DISABILITIES (2015).

<sup>183</sup> *Id.* at 39.

<sup>184</sup> *Id.*

<sup>185</sup> *Id.*

<sup>186</sup> *Supported Decision-Making Service for Persons with Disabilities*, THE ISRAEL HUMAN RIGHTS CENTER FOR PEOPLE WITH DISABILITIES (2015).

<sup>187</sup> *Id.* at 40.

analysis.<sup>188</sup> This created a disadvantage and “a low ‘glass ceiling’ for support.”<sup>189</sup> The overall conclusion of the advisory committee was that “decision making support services should be provided as an alternative to guardianship, rather than as a concomitant service.”<sup>190</sup>

Though many pilot programs in the international community, including this one, are goal-oriented, the Israeli pilot emphasizes that this does not have to be a requirement of an SDM model. The data indicates that a pilot program’s focus could be substantive rather than qualitative in its emphasis on tailored trainings.<sup>191</sup> The final analysis of the Israeli pilot program emphasized the importance of proper training as well as having paid personnel as supporters.<sup>192</sup> The analysts also emphasized the value perceived by those acting as supporters.<sup>193</sup> If a supporter is paid and therefore sees the relationship as an employed service, there might be a greater incentive not only to have proper training but to objectively aid the supported person.<sup>194</sup>

Generally, the international community has been moving in the direction of adopting SDM models with increasing frequency. This was evident in early SDM legislation, as well as in the adoption of the UNCRPD and its ratification by countries such as Australia and Israel. Though the implementation of SDM is difficult to quantify, national statutes and pilot programs suggest a growing trend towards its adoption. Although it is not clear whether international attention to SDM is a direct response to the UNCRPD, the Convention certainly provided compelling arguments and bases for implementing SDM. It might be that a growing interest in SDM led to the statements in Article 12 encouraging less restrictive alternatives to guardianship. What is evident, however, is

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<sup>188</sup> *Id.* at 44.

<sup>189</sup> *Id.* at 40.

<sup>190</sup> *Id.*

<sup>191</sup> *Id.* at 29.

<sup>192</sup> *Id.* at 41.

<sup>193</sup> *Id.*

<sup>194</sup> *Supported Decision-Making Service for Persons with Disabilities*, THE ISRAEL HUMAN RIGHTS CENTER FOR PEOPLE WITH DISABILITIES (2015).



that the international community is looking for solutions that will protect each individual's right to personhood. SDM statutes in Canada and Sweden and pilot programs in countries like Australia and Israel are moving in that direction. It is important to note, however, that while the international community seems to be moving at a relatively active pace, the United States has been somewhat slower in its adoption of SDM. Although there is no federal SDM statute in the United States, several other federal statutes promote the rights and individual liberties of persons with disabilities, which lay the groundwork for the implementation of SDM. Additionally, a handful of states have adopted SDM statutes, while others emphasize the need for SDM or other least restrictive alternatives within their guardianship statutes.

## **II. TRENDS IN THE UNITED STATES**

The Americans with Disabilities Act, Individuals with Disabilities Education Act, American Bar Association Report, and the Developmental Disabilities Assistance and Bill of Rights Act are all federal laws and reports that touch on certain foundational concepts that have been integral to the origins of the SDM movement in the United States. Some of these concepts include: the right to make decisions, the right to be protected from abuse, and the importance of community integration for persons with physical and developmental disabilities. The following section discusses each of the aforementioned laws and other persuasive materials that reinforce trends recognized internationally to be vital to protect individual autonomy, community integration, and the right to make decisions. Pilot programs and state legislation rely heavily on the fundamental values and ideas detailed in these reports. This area of the discussion is important to outline where individual rights and values are emphasized, but also where national efforts need to be continued. While not a comprehensive list of laws that seek to protect individuals with

disabilities, each selected example highlights elements underlying the goals of SDM in particular, and helps to create an enforceable set of tools in support of equality in the workplace, schools, and in the community overall.

*a. The Americans with Disabilities Act*

As protective civil rights legislation, the Americans with Disabilities Act (ADA) covers both cognitive and physical disabilities. The act defines “disability” with respect to an individual as “a physical or mental impairment that substantially limits one or more major life activities of such individual.”<sup>195</sup> The ADA requires that accommodations be available for individuals with disabilities to access services – both the services necessary for life such as food and housing, and the services that make life enjoyable such as entertainment and recreation.<sup>196</sup> While the ADA requires the service providers to offer accommodations, the ADA also respects an individual’s right to refuse accommodations if they so desire. Title II, for example, mandates that “state and local governments may not require a disabled individual to accept a special accommodation or benefit if he or she does not want to accept it.”<sup>197</sup> Guardianship is an accommodation of sorts—albeit not as defined by the ADA—but, taken at face value, guardianship exists to facilitate decision-making for someone who has been deemed incapable of making their own decisions. In principle, the courts foisting guardianship on an individual with a disability against their will is against the spirit of the ADA. Absent specific SDM legislation, judges may find arguments rooted in the ADA persuasive when deciding whether to allow SDM agreements to supersede guardianship orders, though we found no cases yet exploring that theory.

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<sup>195</sup> 42 U.S.C. § 12102 (2012).

<sup>196</sup> 42 U.S.C. § 12182 (2012).

<sup>197</sup> MARGARET C. JASPER, LEGAL ALMANAC: THE AMERICANS WITH DISABILITIES ACT § 3:8 (2012).

*b. The Individuals with Disabilities Education Act*

The Individuals with Disabilities Education Act (IDEA) is a federal law that ensures free appropriate public special education and related services to more than 6.5 million eligible children with disabilities.<sup>198</sup> IDEA authorizes formula grants to states to support special education, early intervention, and related services.<sup>199</sup> IDEA also authorizes discretionary grants to state educational agencies, institutions of higher education, and other nonprofit organizations to support “research, demonstrations, technical assistance and dissemination, technology development, personnel preparation and development, and parent-training and information centers.”<sup>200</sup>

The stated purpose of IDEA recognizes that disability does not diminish the rights of individuals to participate in or contribute to society and posits that improving educational results for children with disabilities “is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency” for individuals with disabilities.<sup>201</sup> The Act discusses how, before the enactment of the Education for All Handicapped Children Act of 1975 (Public Law 94-142), now known as IDEA, the educational needs of children with disabilities were not being fully met because, among other things, the children did not receive appropriate educational services.<sup>202</sup> Once this law was enacted, it guaranteed access to free and appropriate public education in “the least restrictive environment” for every child with a disability.<sup>203</sup>

The intent to ultimately increase the autonomy of individuals with disabilities via independent living and economic self-sufficiency by providing appropriate resources and services

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<sup>198</sup> *About IDEA*, *supra* note 22.

<sup>199</sup> *Id.*

<sup>200</sup> *Id.*

<sup>201</sup> 20 U.S.C. § 1400(c)(1) (2012).

<sup>202</sup> *Id.* § 1400(c)(2)(a).

<sup>203</sup> *About IDEA*, *supra* note 22.

in a least restrictive environment parallels the goal of SDM to maintain or increase individual autonomy through the appropriate application of support services. The creation and continued implementation of IDEA indicates a national prerogative to promote equality for individuals with disabilities by meeting their individual needs through the services provided.

*c. The American Bar Association Report*

The American Bar Association's (ABA) Report to the House of Delegates was developed as a reference to the Commission on Disability Rights Section of Civil Rights and Social Justice Section of Real Property, Trust, and Estate Law Commission on Law and Aging. The opening "urges state, territorial, and tribal legislatures to amend their guardianship statutes to require that decision-making supports that would meet the individual's needs be identified and fully considered" to terminate guardianship and restore rights.<sup>204</sup>

Overall, the ABA report includes a background on the implementation, expansion, and benefits of supported decision-making agreements. Through sequencing the history of supported decision-making, the report outlines how this approach moved from a traditional and informal concept to a more formal and legally accepted practice. This movement includes non-governmental organizations and advocacy group sponsorship and is slowly being recognized in administrative agency recommendations, legislative statutes, and case law.<sup>205</sup> While supported decision-making is the recommended goal, the report does not exclude the possibility of using other less restrictive alternatives to guardianship that promote autonomy and foundational human rights such as the freedom to make life decisions. The report notes the historical institutionalization

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<sup>204</sup> AMERICAN BAR ASSOCIATION, REPORT TO THE HOUSE OF DELEGATES (2017), [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2017\\_SDM\\_%20Resolution\\_Final.authcheckdam.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/2017_SDM_%20Resolution_Final.authcheckdam.pdf).

<sup>205</sup> *Id.*

of guardianship and recognizes that society has advanced beyond the extremes of complete lack of autonomy or total independence in cases where assistance more appropriate.<sup>206</sup>

Two key concepts in this report resonate with the broader discussions surrounding SDM implementation: (1) how oversight is to be administered; and (2) the lack of in-depth analysis of the impact of such agreements.

First, a key reason guardianship may be considered inappropriate is the court system's lack of capacity to comprehensively oversee each case coupled with the possibility of abuse of a vulnerable population. This emphasizes the relevance and importance of the SDM structure, which allows the person with a disability to be the ultimate decision-maker in their own life. We also must understand the gaps in the current system so we may offer appropriate recommendations to address them.

Second, record-keeping has not traditionally been a priority and therefore there is generally not reliable, comprehensive data on the impact of guardianship on those in the system. Along the same lines, current data does not yet offer a longitudinal view of improving quality of life and other possible metrics through the SDM framework. Therefore, the movement must come from the persuasiveness of advocates, persons with disabilities, and the volition of those in power to make the changes. The ABA report offers a brief review on authorities leading the charge, and how their wisdom may be implemented.

*d. Developmental Disabilities Assistance and Bill of Rights Act*

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) is a federal law that was enacted in 2000 based on Congressional findings about the lives and rights of individuals with disabilities. The act brought into focus many issues that individuals with

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<sup>206</sup> *Id.*

disabilities faced at the turn of the century and continue to face today. Individuals with disabilities continue to face problems related to the high risk of “abuse, neglect, financial and sexual exploitation, and the violation of their legal and human rights.”<sup>207</sup> The law emphasized that individuals with developmental disabilities have the right to be protected from these acts just like everyone else. It also brought attention to the need for persons without disabilities to become involved and “aware of the capabilities and competencies of individuals with developmental disabilities.”<sup>208</sup> This is an important point for SDM – society’s basic lack of knowledge about the developmentally disabled community casts a shadow of misunderstanding over all persons with disabilities.

One of the stated goals of the DD Act is to provide “individuals with developmental disabilities with the information, skills, opportunities, and support to” make informed decisions about their own lives; live in homes where they can exercise their rights and responsibilities as citizens; have and pursue meaningful and productive lives; and live free of violations of their human rights.<sup>209</sup> The purpose and policy sections of the DD law go into further detail about how it should be put into action in each state and what the intent of the law is, but the overarching theme is that states should find ways to promote self-determination, productivity, and integration of individuals with developmental disabilities.

Overall, the aforementioned laws and report reflect the recognition that autonomy, independence, and self-determination are essential rights to be protected; these rights are also central to the theory and practice of SDM. Further, the impact of retaining one’s own decision-making ability is critical to growth, empowerment, and improvement in persons with disabilities.

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<sup>207</sup> 42 U.S.C. § 15001(a)(5) (2012).

<sup>208</sup> *Id.* § 15001(a)(13).

<sup>209</sup> *Id.* § 15001(a)(16)(A)-(G).

## **CURRENT STATE OF THE LAW**

Currently in the U.S. only four states and the District of Columbia have statutes codifying supported decision-making (SDM), although two other states have pending SDM legislation and the majority of states do reference least restrictive alternatives or SDM in their guardianship statutes. However, this overall lack of statutory recognition of SDM does not preclude the practice of SDM; pilot programs have been implemented in various states to study SDM and several courts have implemented SDM agreements in denying petitions for guardianship and in terminating pre-existing guardianships. The interaction between statutes, cases, and pilot programs does not always occur in the same way, although pilot programs are often a precursor to legislation.

This section begins with an analysis of guardianship and SDM statutes. The language in these statutes varies between states, and some statutory language provides a much stronger basis for advocates to make successful arguments in favor of SDM agreements. The discussion then turns to case law and examines 15 cases where individuals had their guardianships vacated and replaced with SDM agreements. None of these cases were brought in states with SDM statutes in place, although one occurred in a state with approved SDM legislation that will go into effect later this year and another occurred in a jurisdiction that subsequently passed SDM legislation. Finally, the section concludes with an analysis of different types of pilot programs that have been implemented across the U.S. We discuss the goals of the different types of programs and specific examples of each, including their program design, outcomes, strengths, and weaknesses.

### **I. STATUTES**

Although some states have begun to SDM statutes in recent years, starting with Texas in 2015, the majority of states still do not explicitly address SDM or other alternatives to

guardianship. There are four broad categories identifiable among legislation in this area: (1) states that have no reference to SDM or less restrictive alternatives in their guardianship statute; (2) states that reference less or least restrictive alternatives in their guardianship statute; (3) states that explicitly reference SDM in their guardianship statute, and; (4) states that have separate SDM statutes. While there are outlier states that do not fit neatly into any one category, such as states that employ SDM in the limited context of certain medical decisions, the above categories offer an overview of the spectrum of SDM and guardianship legislation.

It is important to note that, within the first category, the lack of statutory language regarding less restrictive alternatives does not necessarily preclude the use of SDM. For instance, Indiana has no statutory language regarding SDM; however, in 2018, a young woman who had been under guardianship for nearly a decade had her guardianship order vacated and replaced with an SDM agreement.<sup>210</sup> In the second category, which encapsulates states that mention less or least restrictive alternatives to guardianship, the phrase “less restrictive alternatives” includes any method of meeting the needs of a person with disabilities while restricting as few liberties as possible. This may include SDM, but also encompasses a host of other options including durable power of attorney, medical power of attorney, healthcare proxy, or representative payees.<sup>211</sup> The third category includes states that expressly mention SDM in their guardianship statutes either by listing it as a possible alternative to consider, or specifically requiring that the court examine SDM as an option.

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<sup>210</sup> Marilyn Odendahl, *Indiana Woman Makes Judicial History by Seeking Supported Decision-Making Agreement*, THE INDIANA LAWYER (June 12, 2018), <https://www.theindianalawyer.com/articles/47278-indiana-woman-makes-judicial-history-by-seeking-supported-decision-making-agreement>.

<sup>211</sup> IOWA DEP’T. OF ELDER AFFAIRS, ALTERNATIVES TO GUARDIANSHIP AND CONSERVATORSHIP FOR ADULTS IN IOWA 6-7 (2001), <http://publications.iowa.gov/3372/1/AlternativesGuardianshipConservatorship.pdf>; *supra* at 12.



The final category includes states that codify SDM in separate statutes. The statutes that specifically delineate SDM include in their definition sections a set of core terms essential to SDM. Most of these definition sections begin by defining SDM. For example, Texas’ statute defines SDM as “a process of supporting and accommodating an adult with a disability to enable the adult to make life decisions, including decisions related to where the adult wants to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live with, and where the adult wants to work, without impeding the self-determination of the adult.”<sup>212</sup> Wisconsin’s statute uses the same language but replaces the term “disability” with “functional impairment.”<sup>213</sup> The definition sections of such statutes usually define an SDM agreement simply as the arrangement entered into by the person seeking SDM and their supporter(s). Often, the person seeking SDM is described as a “principal.”<sup>214</sup> Across multiple jurisdictions, several other relevant terms are often included and defined, including “educational records,” “life decisions,” “medical records,” and “affairs.”<sup>215</sup> These statutes set out the role of supporters, who may be a supporter, and the scope of authority that a supporter may be given. Many SDM statutes also include sample agreement forms that can be customized; this may be a helpful starting point for individuals who seek to enter into an SDM agreement. Most importantly, consistent across each SDM statute is the tenet that a supporter is not permitted to make decisions on behalf of the principal, only to help the principal gather information, comprehend the information, and understand their options as well as the implications of each possible option.<sup>216</sup> The core of SDM is that the decision is always ultimately left to the principal.

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<sup>212</sup> TEX. EST. CODE ANN. § 1357.002(3) (West, Westlaw through 2017 Reg. Sess.).

<sup>213</sup> WIS. STAT. ANN. § 52.01(6) (West, Westlaw through 2017 Act 370).

<sup>214</sup> DEL. CODE ANN. tit. 16, § 9403a(8) (West, Westlaw through 82 Laws 2019, ch. 4).

<sup>215</sup> D.C. CODE ANN. § 7-2131 (West, Westlaw through Feb. 22, 2019); H.R. 7992, 2018 Gen. Assemb., January Sess. § 15.3-3 (R.I. 2018).

<sup>216</sup> *See, e.g.*, TEX. EST. CODE ANN. § 1357 (West, Westlaw through 2017 Reg. Sess.).

*a. No Supported Decision-Making or Least Restrictive Alternative Language*

Seventeen states do not contain any reference within their guardianship statutes to either SDM specifically, or more generally, to less restrictive alternatives. Although these states do not explicitly require consideration of alternatives to guardianship, several do require that the least restrictive form of guardianship be imposed or, in lieu of such language, emphasize maximum self-reliance under guardianship. At least one such state, Indiana, appears to be in the beginning stages of adopting an SDM statute.<sup>217</sup>

Under Connecticut's guardianship statute, plenary guardianship appears to be the default.<sup>218</sup> What makes it unique, however, is that it includes an option for a limited guardianship, albeit with an extremely high standard of proof. It states:

If the court finds *by clear and convincing evidence* that the respondent is able to do some, but not all, of the tasks necessary to meet essential requirements for the respondent's physical health or safety or that the respondent is able to make some, but not all, informed decisions about matters related to the respondent's care, the court shall appoint a limited guardian or limited co-guardians.<sup>219</sup>

The standard of evidence is high, such that it is more difficult to be assigned a limited guardianship than to be appointed a plenary guardianship.<sup>220</sup> Despite this obstacle, the option for a less restrictive option in the form of a limited guardianship is nevertheless present and distinguished from a plenary guardianship; the statute even includes a separate section delineating the powers and duties of a limited guardian.<sup>221</sup>

Idaho's statute, in contrast, encourages limited guardianship. Although Idaho's statute does not explicitly require courts to consider alternatives before imposing guardianship, it does state

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<sup>217</sup> S. Res. 44, 120th Gen. Assemb., 1st Reg. Sess. (Ind. 2017).

<sup>218</sup> CONN. GEN. STAT. ANN. § 45a-676 (West, Westlaw through Revision of 1958, Revised to Jan. 1, 2019).

<sup>219</sup> *Id.* (emphasis added).

<sup>220</sup> *Id.*

<sup>221</sup> *Id.*

that courts should impose “the least restrictive form of guardianship” that minimally interferes with legal capacity in order to allow “incapacitated persons to participate as fully as possible in all decisions affecting them...”<sup>222</sup> Similar to an SDM framework, this statute requires limited guardianship in accordance with the individual’s needs and capacity. Limitations on guardianship may signify either a limit on the scope of decision-making authority or a time limit following which the court will generally reevaluate the need for guardianship. The inclusion of this provision demonstrates that complete guardianship is disfavored in cases where individuals have retained at least some capacity; moreover, it evinces a certain amount of deference to the right of self-determination of incapacitated individuals.

Echoing this deference to the rights of autonomy and self-determination, Wyoming’s statute includes a similar requirement to impose the least restrictive form of guardianship. The Wyoming statute expressly includes a rights-based reasoning, articulating that “[the individual] under any guardianship or conservatorship shall have *the right* to... [t]he least restrictive and most appropriate guardianship or conservatorship suitable to [their] circumstances...” (emphasis added).<sup>223</sup>

Similar to Idaho and Wyoming, Utah’s guardianship statute also shows a legislative preference for limited guardianships as opposed to plenary guardianships. The Utah guardianship statute provides that “[t]he court shall prefer a limited guardianship and may only grant a full guardianship if no other alternative exists.”<sup>224</sup> However, Utah’s statute takes the preference even further than does Idaho by requiring the court to specifically find a full guardianship to be absolutely necessary in order to impose it: “If the court does not grant a limited guardianship, a

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<sup>222</sup> IDAHO CODE ANN. § 15-5-303 (West, Westlaw through ch. 1 to 67 of the 2019 1st Reg. Sess. of the 65th Idaho Leg.).

<sup>223</sup> WYO. STAT. ANN. § 3-1-206 (West, Westlaw through chapters effective Mar. 6 of the 2019 Gen. Sess.).

<sup>224</sup> UTAH CODE ANN. § 75-5-304(2)(a) (West, Westlaw through 2018 3rd Spec. Sess.).

specific finding shall be made that nothing less than a full guardianship is adequate.”<sup>225</sup> Such a guardianship still employs a substituted decision-making framework, but the presence of a court-required finding makes the imposition of plenary guardianship more difficult in Utah.

Alabama’s guardianship statute emphasizes maximum self-reliance for individuals under guardianship. Within Alabama’s guardianship statute, the following is expressed:

The court shall exercise the authority conferred in this division so as to encourage the development of maximum self-reliance and independence of the incapacitated person and make appointive and other orders only to the extent necessitated by the incapacitated person’s mental and adaptive limitations or other conditions warranting the procedure.<sup>226</sup>

While Alabama is a state that has not adopted SDM language or procedure and does not utilize the common “least restrictive alternative” phrasing, it does emphasize the importance of upholding every individual’s self-reliance and independence through a cautionary warning to only limit these freedoms if necessary.<sup>227</sup>

Despite the fact that SDM and explicit reference to less restrictive alternatives to guardianship are not present in the abovementioned states, the ideal of autonomy to the greatest extent possible is often nevertheless promoted through other legislative or judicial strategies, such as Utah’s “specific finding” requirement for full guardianship.<sup>228</sup> This is consistent with the emerging trend among state legislatures to embrace methods of supporting individuals in ways that preserve their freedoms as much as possible.

As something of an outlier in this category, Indiana appears to be in the beginning stages of implementing SDM for incapacitated individuals despite its present lack of statutory language

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<sup>225</sup> *Id.*

<sup>226</sup> ALA. CODE § 26-2A-105(a) (Westlaw through Act 2018-579).

<sup>227</sup> *Id.*

<sup>228</sup> UTAH CODE ANN. § 75-5-304(2)(a) (West, Westlaw through 2018 3rd Spec. Sess.).

requiring consideration of alternatives prior to ordering guardianship. In 2017, the Senate Committee on Judiciary unanimously passed a resolution strongly urging the legislative council to explore and consider codifying SDM as an alternative to guardianship for adults with intellectual and developmental disabilities (I/DD).<sup>229</sup> The main concerns cited in the resolution are that guardianship constitutes a complete deprivation of control, and that it is frequently very difficult to terminate a guardianship once it is ordered.<sup>230</sup> Another motivating issue is that guardianship is currently the default for adults with I/DD in Indiana, and schools are required to tell parents of children with I/DD who have individualized education programs (IEPs) that they must petition for guardianship before their child turns 18 in order to continue to be involved in the child's IEP.<sup>231</sup> As a result, many young adults are consigned to full guardianship when less restrictive means, such as SDM, would likely be adequate to meet their needs. The Senate Committee's resolution recommended collaborating with service organizations to explore a model of SDM that uses trained advisors to help individuals make life decisions in an effort to facilitate skills development and improve the quality of life for adults with IDD.<sup>232</sup> There is currently an SDM pilot program operating in Indiana, which is discussed beginning at page 99 *infra*. Additionally, since passage of the Senate resolution there has already been a case in which guardianship was vacated in favor of an SDM agreement, discussed at page 90 *infra*. Taken together, these steps indicate that Indiana is moving toward embracing SDM even though their current guardianship statute makes no mention of less restrictive alternatives nor SDM; importantly, this also proves that SDM can still be a viable alternative even if it is not expressly authorized by statute.

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<sup>229</sup> S. Res. 44, 120th Gen. Assemb., 1st Reg. Sess. (Ind. 2017).

<sup>230</sup> *Id.*

<sup>231</sup> *Id.*

<sup>232</sup> *Id.*

*b. Least or Less Restrictive Alternatives Language*

Twenty-three states, while not explicitly mentioning SDM, do require courts to consider the viability of less restrictive alternatives before ordering guardianship. Although this may include SDM, it may also indicate a host of other alternatives such as durable power of attorney or a representative payee.<sup>233</sup> Many alternatives limit the deprivation of liberty by only granting substituted decision-making authority to a third party within a very narrow scope; for instance, if a person only needs assistance with finances, a representative payee can be appointed who only has authority over finances. With SDM, all decision-making authority remains with the principal, but it is still included under the broad umbrella of least restrictive alternatives since it necessarily imposes far fewer restrictions on liberty than even a limited guardianship.

Several of the states in this category use a “best interest” standard, requiring that the court impose the least restrictive alternative that is in the individual’s best interest.<sup>234</sup> Since the best interest determination is made by the court, this standard reflects a paternalistic conception that individuals with disabilities need protection as well as a presumption that they are incapable of determining what is in their own best interest – concepts which are antithetical to the underlying assumptions on which SDM is predicated.

Other statutes in this category that require courts to consider less restrictive alternatives before imposing guardianship<sup>235</sup> show much more deference to the autonomy of individuals by requiring a more specific finding of capacity and the tailoring of a remedy to the individual’s precise needs.<sup>236</sup> These statutes provide greater protection of liberty by requiring the court to make

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<sup>233</sup> IOWA DEP’T. OF ELDER AFFAIRS, ALTERNATIVES TO GUARDIANSHIP AND CONSERVATORSHIP FOR ADULTS IN IOWA 6-7, 12 (2001), <http://publications.iowa.gov/3372/1/AlternativesGuardianshipConservatorship.pdf>.

<sup>234</sup> See, e.g., VA. CODE ANN. § 64.2-2007 (West, Westlaw through 2018 Reg. Sess. and 2018 Spec. Sess. 1 and including 2019 Reg. Sess. chs. 17, 18, 164 and 225).

<sup>235</sup> WASH. REV. CODE ANN. § 11.88.120 (West, Westlaw through ch. 3 of the 2019 Reg. Sess.).

<sup>236</sup> See, e.g., ARIZ. REV. STAT. ANN. § 14-5304(B) (Westlaw through legislation effective Feb. 20, 2019 of the 1st Reg. Sess. of the 54th Leg.).

a specific determination that there are no viable alternatives that would meet the individual's needs while restricting fewer rights.

One state which requires consideration of the best interests of the individual is Virginia. Virginia's guardianship statute lists a series of factors to be considered when making a determination of whether guardianship or conservatorship is required for a respondent. Among the factors listed are "(i) the limitations of the respondent; ... (iii) the availability of less restrictive alternatives, including advance directives and durable powers of attorney; (iv) the extent to which it is necessary to protect the respondent from neglect, exploitation, or abuse; ... and (vii) the best interests of the respondent."<sup>237</sup>

Despite Virginia's use of the "best interest" standard, there has been at least one case, discussed beginning at page 78 *infra*, in which an individual had her guardianship order vacated and replaced with an SDM agreement. This shows that even in states using this standard, which appears to presume a certain level of incapacity, SDM may still be considered by the court as a viable alternative to guardianship. This is promising, as it strongly emphasizes individual autonomy.

Like Virginia, New York also uses a "best interest" standard; however, New York is unique in that it has two guardianship statutes, both of which have been interpreted by the courts as requiring consideration of least restrictive alternatives and have been used as a basis for implementing SDM.<sup>238</sup> The earlier of these statutes is Article 17-A of the Surrogate's Court Procedure Act. According to this statute, guardianship of persons with intellectual disabilities must be supported by evidence that the guardianship is both necessary and in the best interest of the

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<sup>237</sup> VA. CODE ANN. § 64.2-2007 (West, Westlaw through 2018 Reg. Sess. and 2018 Spec. Sess. 1 and including 2019 Reg. Sess. chs. 17, 18, 164 and 225).

<sup>238</sup> *In re Dameris L.*, 956 N.Y.S.2d 848, 853 (Sur. Ct. 2012).

person with a disability.<sup>239</sup> The more recent statute is Article 81 of the Mental Hygiene Law. In describing its purpose, Article 81 states that it is “desirable for and beneficial to persons with incapacities to make available to them the least restrictive form of intervention.”<sup>240</sup> This is implemented in two distinct ways. First, when a guardianship is being considered by the court, the sufficiency and reliability of “available resources” to provide for personal needs without the appointment of a guardian must be taken into account.<sup>241</sup> The available resources include such things as powers of attorney, health care proxies, supportive friends and family, and residential care facilities.<sup>242</sup> Second, if a guardianship is determined to be necessary, the least restrictive form of guardianship is used “with powers limited to those which the court has found necessary” to assist the individual.<sup>243</sup>

Other statutes, including Florida and California, represent a middle ground between those using the best interest standard and those that primarily emphasize autonomy due to their dual emphases on the individuals’ capacity as well as the need for protection. Florida’s guardianship statute asks for the “least restrictive appropriate alternative” and requires the court appoint a guardian consistent with the need for welfare and safety.<sup>244</sup> It also requires that the guardianship “must reserve to the incapacitated person the right to make decisions in all matters commensurate with the person’s ability to do so.”<sup>245</sup> Although it incorporates this element, the Florida statute emphasizes that this form of guardianship may nevertheless be too limiting to the individual’s liberty and that if it is not the “least restrictive” option, it should not be utilized.<sup>246</sup>

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<sup>239</sup> N.Y. SURR. CT. PROC. ACT LAW § 1750 (McKinney, Westlaw through L.2019, chs. 1 to 19).

<sup>240</sup> N.Y. MENTAL HYG. LAW § 81.01 (McKinney, Westlaw through L.2019, chs. 1 to 19).

<sup>241</sup> *Id.* § 81.02(a)(2).

<sup>242</sup> *Id.* § 81.03(e).

<sup>243</sup> *Id.* § 81.16.

<sup>244</sup> FLA. STAT. ANN. § 744.2005(3) (West, Westlaw through 2018 2nd Reg. Sess. of the 25th Leg.).

<sup>245</sup> *Id.*

<sup>246</sup> *Id.* § 744.2005.



California uses “conservatorship” terminology to talk about guardianship of an incapacitated adult.<sup>247</sup> Guardianship statutes in the state of California refer only to minors. Paralleling Florida’s language, California conservatorship law require the court to expressly find that a conservator is the “least restrictive alternative”<sup>248</sup> and emphasizes the need to protect the individual.<sup>249</sup> “Protection” is defined with reference to typical welfare necessities such as health, psychosocial needs, shelter, and food.<sup>250</sup> However, this statute does emphasize the importance of protecting individual rights.<sup>251</sup> Its purpose section states such objectives as “[p]rotect[ing] the rights of persons who are placed under conservatorship,” and requiring “that community-based services are used to the greatest extent in order to allow the conservatee to remain as independent and in the least restrictive setting as possible.”<sup>252</sup> While California does not have SDM, its legislative intent and statutory language convey a favorable disposition toward and concern for preserving the independence and rights of individuals under conservatorship.<sup>253</sup>

California is also an outlier in this category. In January 2018, a statute for a limited version of SDM was proposed in California but it failed to pass. It would have prohibited conservators from communicating information concerning the conservatee (including those within a limited conservatorship) to first responders if doing so was against the expressly communicated wishes of the conservatee.<sup>254</sup> This was motivated by a legislative effort to protect persons with disabilities and the elderly from unwanted interaction with first responders, and the associated violation of privacy.<sup>255</sup>

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<sup>247</sup> CAL. PROB. CODE, § 1801 (West, Westlaw through urgency legis. through ch. 2 of the 2019 Reg. Sess.).

<sup>248</sup> *Id.* § 1800.3(b).

<sup>249</sup> *Id.*

<sup>250</sup> *Id.*

<sup>251</sup> *Id.*

<sup>252</sup> *Id.*

<sup>253</sup> *Id.*

<sup>254</sup> Assemb. 437, 2017-2018 Leg., Reg. Sess. (Cal. 2017).

<sup>255</sup> *Id.*

Finally, some statutes within this category that call for considering less restrictive alternatives place a much more candid emphasis on the individual's autonomy and right of self-determination. Since this emphasis is congruent with the underlying rationale for and assumptions incorporated into SDM, it is possible that these jurisdictions might be more amenable to frequent referral to SDM as opposed to other alternatives. One such state is New Hampshire, which defines within its guardianship statute a "[l]east restrictive form of intervention," which means that the guardianship or alternative imposed on the ward must contain only those limitations necessary to provide the incapacitated adult with needed care and rehabilitative services.<sup>256</sup> Furthermore, the New Hampshire statute indicates "that the ward shall enjoy the greatest amount of personal freedom and civil liberties consistent with his or her mental and physical limitations."<sup>257</sup>

Another example of statutory language that openly prioritizes an individual's autonomy and right of self-determination is Georgia's guardianship statute, which requires that the court must first determine that "less restrictive alternatives are not available or appropriate" prior to ordering a guardianship, whether limited or plenary.<sup>258</sup> Even when guardianship is imposed, the statute stipulates that guardianship orders shall be limited as much as possible given the adult's capabilities and limits, and that guardians should encourage self-reliance and independence.<sup>259</sup> These requirements suggest that the ultimate goal is to assist persons under guardianship in developing their capabilities to a level where guardianship may no longer be necessary, or perhaps to a degree where a less restrictive form of guardianship might suffice. Importantly, Georgia's approach emphasizes the individual's capacity, rather than a need for protection, which empowers persons with disabilities by acknowledging their legal capacity.

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<sup>256</sup> N.H. REV. STAT. ANN. § 464-A:9 (Westlaw through ch. 379 of the 2018 Reg. Sess. and C.A.C.R. 15 and 16).

<sup>257</sup> *Id.*

<sup>258</sup> GA. CODE ANN. § 29-4-1(f) (West, Westlaw through Act 1 of the 2019 Legis. Sess.).

<sup>259</sup> *Id.*

Similar to Georgia, Arizona and Colorado both have guardianship statutes containing language suggesting that guardianship should be utilized only if an alternative option applicable to the circumstances is not available.<sup>260</sup> For example, Arizona’s statute says: “The court may appoint a general or limited guardian as requested if the court finds by clear and convincing evidence that [...] [t]he person’s needs cannot be met by less restrictive means.”<sup>261</sup> The standard of clear and convincing evidence indicates that there must be strong support showing that nothing but a guardianship will be appropriate for an incapacitated individual. Colorado’s statute also permits the appointment of a guardian “only [if the court finds] clear and convincing evidence” that no other option that is “less restrictive” is available and applicable to the case.<sup>262</sup> Colorado recognizes that guardianship is not the best option available for many individuals and requires that each individual is given the opportunity to bring forward alternative methods and models, potentially including SDM.<sup>263</sup> By explicitly specifying this high burden of proof that must be met for plenary guardianship to be ordered, Arizona and Colorado afford an even higher degree of protection of liberty than Georgia.

Also noteworthy is Rhode Island’s statute, which requires a more in-depth inquiry into an individual’s decision-making capacity before guardianship is imposed, providing an additional procedural safeguard for individuals who do not require plenary guardianship.<sup>264</sup> Rhode Island’s guardianship statute requires that a person petitioning for guardianship determine, based on the use of a “decision making assessment tool,” the level of decision-making ability of the person for

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<sup>260</sup> ARIZ. REV. STAT. ANN. § 14-5304(B) (Westlaw through legis. Effective Feb. 20, 2019 of the 1st Reg. Sess. of the 54th Leg.); COLO. REV. STAT. ANN. § 15-14-311 (West, Westlaw through emergency legis. through ch. 7 of the 1st Reg. Sess. of the 72nd Gen. Assemb.).

<sup>261</sup> ARIZ. REV. STAT. ANN. § 14-5304(B) (Westlaw through legis. Effective Feb. 20, 2019 of the 1st Reg. Sess. of the 54th Leg.).

<sup>262</sup> COLO. REV. STAT. ANN. § 15-14-311 (West, Westlaw through emergency legis. through ch. 7 of the 1st Reg. Sess. of the 72nd Gen. Assemb.).

<sup>263</sup> *Id.*

<sup>264</sup> *See* Tit. 33 R.I. GEN. LAWS ANN. §§ 33-15-1 to -47 (West, Westlaw through ch. 353 of the Jan. 2018 Sess.).

whom guardianship is sought.<sup>265</sup> Based on the assessment result, the petitioner must choose either a limited guardianship or a full guardianship.<sup>266</sup> A subsequent requirement is that the petitioner state the steps that have been taken to utilize least restrictive alternatives to guardianship, although no specific alternatives are mentioned.<sup>267</sup> This multistep process within the guardianship statute suggests that an individual's decision-making ability is a prominent concern for Rhode Island legislators and that such legislators want to have only the most appropriate measures in place for individuals with reduced decision-making capacity.

Consistent with the legislative intent of the above-discussed provisions of the guardianship statute, Rhode Island has an SDM statute that is currently pending before the legislature.<sup>268</sup> The purpose section of the proposed statute gives supporters “legal status to be with the adult and participate in discussions with others when the adult is making decisions or attempting to obtain information,” and establishes SDM as a legally codified alternative to guardianship.<sup>269</sup> The statute is guided by the principles that “(1) [a]ll adults should be able to choose to live in the manner they wish and to accept or refuse support, assistance, or protection; (2) [a]ll adults should be able to be informed about and participate in the management of their affairs, and; (3) [t]he values, beliefs, wishes, cultural norms, and traditions that adults hold should be respected in supported adults to manage their affairs.”<sup>270</sup> The statute includes a section regarding the presumption of capacity for managing one's own affairs as well as a section delineating the form and requirements of an SDM agreement.<sup>271</sup>

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<sup>265</sup> Tit. 33, § 33-15-2(2).

<sup>266</sup> *Id.* § 33-15-2(2)(i)-(ii).

<sup>267</sup> *Id.* § 33-15-2(4).

<sup>268</sup> H.R. 7992, 2018 Gen. Assemb., Jan. Sess. (R.I. 2018).

<sup>269</sup> *Id.* § 33-15.3-2(2).

<sup>270</sup> *Id.* §§ 33-15.3-2(b)(1)-(3).

<sup>271</sup> *Id.* §§ 33-15.3-4, -11.

As a final example, in Massachusetts, the guardianship statute requires that courts make specific findings before imposing guardianship, including that the guardianship is necessary and that “the person’s needs cannot be met by less restrictive means....”<sup>272</sup> The statute also specifies that all court appointments under the statute should encourage independence and self-reliance, and should be tailored to the individual’s capacity and limitations.<sup>273</sup> Although the Massachusetts statute does not mandate the same high standard of proof for these findings as do those of Arizona and Colorado, it is clear that the statute gives deference to the capacity and autonomy of individuals.

Similar to the parallel efforts of the Rhode Island legislature discussed above, in which a focus on autonomy is integrated into the guardianship statute with simultaneous SDM legislation pending, in Massachusetts, an SDM bill was recently proposed in both the Senate and the House.<sup>274</sup> Senator Joan Lovely, backed by a large coalition including the Center for Public Representation (CPR) who administered Massachusetts’s SDM pilot program, is sponsoring the addition of SDM in a proposal to amend chapter 190B of the Massachusetts General Laws. The proposal would add a new section following section 5-507, which discusses durable power of attorney, that would provide for SDM agreements.<sup>275</sup> The proposed bill defines the model and enumerates the range of associated decisions:

Supported decision-making means the process of supporting, without impeding the self-determination of the decision-maker, and accommodating the decision-maker in making life decisions, including decisions related to where the decision-maker wants to live; the services, supports, financial decisions, and medical care the decision-maker wants to receive; whom the decision-maker wants to live with; and where the decision-maker wants to work.<sup>276</sup>

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<sup>272</sup> MASS. GEN. LAWS ch. 190B, § 5-306 (Westlaw through 2018 2nd Ann. Sess.).

<sup>273</sup> *Id.*

<sup>274</sup> H.R. 172, 191st Gen. Court, 2019-2020 Sess. § 1 (Mass. 2019).

<sup>275</sup> S. 64, 191st Gen. Court, 2019-2020 Sess. (Mass. 2019).

<sup>276</sup> *Id.*

The bill incorporates a template SDM agreement.<sup>277</sup> The template includes basic details on the role of the decision-maker as well as that of the supporter(s). The agreement form also has an optional section which details the decision-maker's requests for support with regard to daily activities such as obtaining food, managing health and/or financial affairs, and accessing and using public services.<sup>278</sup> Additionally, the form highlights decisions in which the supporter may *not* participate in providing support. The intent of the model form is to facilitate and streamline an SDM agreement between the supported person and the supporter.<sup>279</sup>

An additional proposal within the Massachusetts bill is the amendment of section 3 of chapter 71B of the General Laws. The bill stipulates that any IEP team would be required to inform the student and family at the earliest possible meeting of the availability of SDM alternatives to guardianship, which is in stark contrast to the current practice.<sup>280</sup> The goal is to increase education as to the availability of an SDM option to the young adults with IEPs who are nearing emancipation, as these individuals so often are shunted into guardianship by default yet would benefit from the availability of a less-restrictive option. The IEP team is responsible for assisting the child and their family in drafting the SDM agreement and planning its implementation.<sup>281</sup> Unlike most of the other statutes, the Massachusetts bill also emphasizes training materials. The bill outlines the importance of training material availability for both the supported person and their supporter(s).

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<sup>277</sup> Mass. H.R. 172. § 1.

<sup>278</sup> *Id.*

<sup>279</sup> Mass. S. 64.

<sup>280</sup> *Id.*

<sup>281</sup> *Id.*

*c. Supported Decision-Making in Guardianship or Other Statutes*

Only five states expressly mention SDM within a guardianship or other statute. Several of these states mention SDM within their guardianship statutes, but other states employ SDM in more limited contexts.<sup>282</sup> Although this shows that these states have yet to fully embrace SDM as an alternative to guardianship, it does demonstrate an awareness of and willingness to consider it. Such minimal use of SDM for individuals with disabilities in particular, narrow contexts might lead to broader implementation of SDM as states become more familiar and comfortable with the idea and have the opportunity to assess its functioning. Maine and Missouri both approved bills in 2018 that will incorporate SDM formally into their guardianship statutes, demonstrating that the movement toward SDM may be gaining traction – or at least more attention – within legislatures.

Maine represents one of the most significant recent shifts toward SDM, since the legislature conducted an in-depth examination of alternatives over several years and ultimately re-wrote much of the state’s Probate Code, explicitly incorporating SDM.<sup>283</sup> In 2015, Maine’s legislature issued a resolution that required the Probate and Trust Law Advisory Commission (PATLAC) to examine SDM as an alternative to guardianship as part of a broader directive to recodify and revise the Probate Code.<sup>284</sup> Specifically, PATLAC was instructed to “examine the concept of supported decision-making, consult with interested parties, and make recommendations concerning inclusion of supported decision-making in the Probate Code, including any proposed legislation...”<sup>285</sup> During 2016 and 2017, PATLAC met with Probate Court judges and representatives of various interested groups throughout the state, held a public forum, and reviewed the Uniform Law

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<sup>282</sup> See, e.g., H.R. 123, 128th Leg., 2nd Reg. Sess. (Me. 2018); but see, e.g., KAN. STAT. ANN. § 65-3276 (West, Westlaw through Jul. 1, 2018 of the 2018 Reg. Sess.).

<sup>283</sup> H.R. 1322, 127th Leg., 2nd Reg. Sess. (Me. 2016).

<sup>284</sup> *Id.*

<sup>285</sup> ME. PROB. AND TR. LAW ADVISORY COMM’N, REPORT TO JOINT STANDING COMMITTEE ON JUDICIARY: RESOLVE, DIRECTING THE PROBATE AND TRUST LAW ADVISORY COMMISSION TO STUDY AND MAKE RECOMMENDATIONS REGARDING SUPPORTED DECISION-MAKING, Leg. 128-2015, 1st Sess., at 1 (Me. 2017).

Commission’s latest revisions to the Uniform Guardianship and Protective Proceedings Act.<sup>286</sup> PATLAC ultimately recommended adopting the Uniform Law Commission’s revisions, which were drafted with significant participation by the disability rights community, and also specifically recommended adopting SDM.<sup>287</sup> As a result, in 2018, the Maine legislature enacted a bill that thoroughly revised and replaced Maine’s Probate Code.<sup>288</sup> The approved legislation will become effective as of July 1, 2019, and will include definitions both of less restrictive alternatives as well as of SDM.<sup>289</sup> “Supported decision-making” is defined in the Code as “assistance from one or more persons of an individual’s choosing...[i]n understanding the nature and consequences of potential personal and financial decisions that enables the individual to make the decisions; and...[w]hen consistent with the individual’s wishes, in communicating a decision once it is made.”<sup>290</sup> This definition is congruent with the legislative intent and content of separate SDM statutes, as discussed below, and encourages optimal self-determination and independence while minimizing the deprivation of rights that guardianship inherently involves.

Another bill incorporating SDM into a guardianship statute that was passed in 2018 was that of Missouri. In the bill, Missouri explicitly indicated that a court should seek alternatives that are less restrictive prior to appointing guardians:

Before appointing a guardian or conservator, the court shall consider whether the respondent's needs may be met without the necessity of the appointment of a guardian or conservator, or both, by a less restrictive alternative including, but not limited to, the following: supported decision-making agreements or the provision of protective or supportive services or arrangements provided by individuals or public or private services or agencies.<sup>291</sup>

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<sup>286</sup> *Id.* at 1-2.

<sup>287</sup> *Id.* at 2-3.

<sup>288</sup> H.R. 123, 128th Leg., 2nd Reg. Sess. (Me. 2018).

<sup>289</sup> *Id.* § 5-102.

<sup>290</sup> *Id.* § 5-102(32).

<sup>291</sup> S. 806, 99th Gen. Assemb., 2nd Reg. Sess. (Mo. 2018).



In addition to guardianship statutes incorporating SDM, some states use SDM for incapacitated individuals in the limited context of medical decisions. For example, Maryland enacted an SDM statute in the spring of 2015 that implemented SDM only in the narrow context of medical decisions – more specifically, solely concerning organ transplants and anatomical gifts.<sup>292</sup> Much like Maryland, Kansas has employed SDM in the context of organ transplants despite the lack of any explicit mention of SDM in the state’s guardianship statute.<sup>293</sup>

In 2017, Kansas’s House and Senate unanimously passed a bill regarding nondiscrimination in organ transplantation in response to disability-based discrimination in health care services, particularly organ transplants, that violated the Americans with Disabilities Act.<sup>294</sup> The statute, which became effective on July 1, 2018, prohibits doctors and healthcare entities from taking disability into account when recommending and providing transplants provided that supports are in place to ensure compliance with postoperative medical requirements.<sup>295</sup> Although the statute only refers to SDM in the narrow context of organ transplant decisions, the functionality of SDM as described is quite similar to its role in broader statutes. The purpose of SDM under the statute is to help the person with disabilities make decisions by communicating information in a manner that is understandable and accessible, ascertaining wishes, and assisting in the expression of the principal’s decisions.<sup>296</sup> The statute requires that medical information be provided to the supporter in order to facilitate their role.<sup>297</sup> Notably, the statute requires that the person with disabilities be involved in the making of their own medical decisions and that all decisions comport with the individual’s wishes, even when the person has a court-appointed guardian responsible for

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<sup>292</sup> S. 792, 435th Gen. Assemb., 2015 Reg. Sess. (Md. 2015).

<sup>293</sup> KAN. STAT. ANN. § 65-3276 (West, Westlaw through Jul. 1, 2018 of the 2018 Reg. Sess.).

<sup>294</sup> H.R. 2343, 87th Leg., 2018 Reg. Sess. (Kan. 2018).

<sup>295</sup> KAN. STAT. ANN. § 65-3276(c)(2) (West, Westlaw through Jul. 1, 2018 of the 2018 Reg. Sess.).

<sup>296</sup> *Id.* §§ 65-3276(h)(2)(C)(i), (iv).

<sup>297</sup> *Id.* § 65-3276.

making medical decisions.<sup>298</sup> These examples of limited applications of SDM demonstrate recognition of SDM as a useful and effective tool for individuals with disabilities, and one that could be expanded to serve a broader role in the future.

*d. Supported decision-making statutes*

Finally, four states and the District of Columbia have separate statutes codifying SDM for use as an alternative to guardianship. Additionally, Tennessee attempted to pass a robust SDM statute, but legislative concessions led to the state's ultimate passage of a much more limited version. Within this category, Texas was the pioneer, passing an SDM statute in 2015; other states that have SDM statutes have largely followed the same model and utilized similar or even identical statutory language.

Texas began its journey into statutorily-backed SDM in 2009, when the legislature passed a bill authorizing a pilot program.<sup>299</sup> The pilot program was intended to explore the viability of an SDM model in Texas, and the Texas Council for Developmental Disabilities was delegated the responsibility of implementing and managing the program, as well as evaluating its success.<sup>300</sup> In 2011, the Council chose The Arc of San Angelo to pilot the project.<sup>301</sup> During the three-year pilot program, the Arc identified that the largest barrier to effective SDM agreements was the lack of legal recognition by medical and support services.<sup>302</sup> Prompted by these findings, the Texas legislature passed a series of bills officially recognizing SDM agreements. The state also reformed its guardianship laws in 2015, empowering a ward to petition to lift their guardianship and execute

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<sup>298</sup> *Id.* § 65-3276(h)(2)(C)(iii).

<sup>299</sup> H.R. 1454, 81st Leg., Reg. Sess., 2009 Tex. Sess. Law Serv. ch. 72 (West).

<sup>300</sup> *Id.*

<sup>301</sup> *Programs*, THE ARC OF SAN ANGELO, <https://www.thearcofsanangelo.org/programs#supported-decision-making> (last visited Jan. 24, 2019).

<sup>302</sup> *Id.*

a replacement SDM agreement.<sup>303</sup> This legislation also established a bill of rights for those under guardianship.<sup>304</sup> Reform efforts continued in 2016, culminating in a series of reform bills, passed in 2017, that (1) placed a fiduciary duty upon supporters, even those who did not use the official state forms; (2) modernized the Texas Education Code to include recognition of SDM agreements for individuals who come of age while under special education arrangements (such as IEPs), whereas previously only parents and legal guardians were recognized, and; (3) likewise modified schools' dyslexia testing requirements to require the consent of individuals at the age of majority, consistent with their SDM agreements, whereas previously parental or guardian consent on behalf of the student was sufficient.<sup>305</sup>

The Definitions section of the Texas Estates Code includes definitions of “adult,” “disability,” “supported decision-making,” “supported decision-making agreement,” and “supporter.”<sup>306</sup> “Less restrictive alternative” language is referenced in the Purpose section, in which the legislation provides that “[t]he purpose of this chapter is to recognize a less restrictive alternative to guardianship for adults with disabilities who need assistance with decisions regarding daily living but who are not considered incapacitated persons for purposes of establishing a guardianship under this title.”<sup>307</sup> The Scope section of the statute stipulates the parameters of the supporter’s role, including the necessity of accessing relevant protected information which may otherwise be confidential, assisting the supported individual with understanding that information, and facilitating communication between the supported individual

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<sup>303</sup> TEX. EST. CODE ANN. § 1357.001 (West, Westlaw through 2017 Reg. Sess.). *See also* H.B. 39, 86th Leg., Reg. Sess., 2019 Tex. Sess. Law Serv. ch. 214.

<sup>304</sup> TEX. EST. CODE ANN. § 1151.351 (West, Westlaw through 2017 Reg. Sess.).

<sup>305</sup> TEX. EST. CODE ANN. § 1357.052 (West, Westlaw through 2017 Reg. Sess.). *See also* TEX. EDUC. CODE ANN. § 29.011 (West, Westlaw through 2017 Reg. Sess.).

<sup>306</sup> TEX. EST. CODE ANN. § 1357.002 (West, Westlaw through 2017 Reg. Sess.).

<sup>307</sup> *Id.* § 1357.003.

and appropriate persons as needed to execute the supported person's decision.<sup>308</sup> Texas's SDM statute was the first of its kind in the United States, and as such it set the tone for the other SDM statutes that followed; in some cases, the Texas SDM statute has not only been used as a model for other state legislatures, but has actually been copied nearly verbatim.<sup>309</sup>

The Delaware SDM statute was passed soon after Texas's. It created the option of SDM agreements for "incapacitated adults" and established a codified model form.<sup>310</sup> It lists the following as its purposes: (1) to assist the incapacitated individual in making and communicating informed decisions, and (2) to bestow upon the supporter(s) legal status to participate in confidential or privileged discussions, as is often necessary for successful use of an SDM agreement.<sup>311</sup> The emphasis of this bill rests heavily on articulating the supporters' duties, limitations, and responsibilities. It also establishes the fundamental principles that should be fulfilled by the SDM statute, which include protecting, as much as possible, the individual's freedom of decision-making; ensuring informed decision-making; respecting cultures, beliefs, and norms of the individual, and; providing the least restrictive but most effective form of assistance possible.<sup>312</sup>

Alaska's statute on SDM was passed by the state's Senate in 2018. It emphasizes the mutual agreement between the supporter(s) and the "incapacitated adult," requiring informed consent on both sides.<sup>313</sup> Moreover, it outlines the requirements and duties of a supporter; what the agreement must include; what makes an agreement valid, such as a signature in the presence of witnesses;

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<sup>308</sup> *Id.* § 1357.051.

<sup>309</sup> WIS. STAT. ANN. § 52.01 (West, Westlaw through 2017 Act 370).

<sup>310</sup> S. 230, 148th Gen. Assemb., 2015-2016 Sess. (Del. 2016).

<sup>311</sup> *Id.*

<sup>312</sup> *Id.*

<sup>313</sup> H.R. 336, 30th Leg., 2nd Sess. (Alaska 2018).

and what makes it void.<sup>314</sup> Like Texas, Alaska includes a sample agreement in the text of the bill.<sup>315</sup> Uniquely, the Alaska statute is distinguished by its emphasis on highly particularized procedural concerns, with the formal creation and standardization of an SDM agreement emerging as the core priority of the legislation.<sup>316</sup>

The District of Columbia’s SDM statute went into effect in May of 2018. It is similar to other SDM statutes, such as that of Delaware, in that it underscores the mutual agreement between the supporter and the “incapacitated individual”; like the other SDM statutes discussed above, the D.C. statute includes a codified SDM form.<sup>317</sup> It also provides useful information illustrating what roles supporters may take on in SDM agreements, such as communicating the supported person’s decisions to others or obtaining information necessary to an evaluation of options and prediction of outcomes.<sup>318</sup> It allows some flexibility, providing that the SDM model may be modified to best fit the needs of the incapacitated adult.<sup>319</sup> In its definition section, the D.C. statute also expresses what “life decision[s]” a supporter may assist with, including routine decisions in domains such as housing, medical care, and employment.<sup>320</sup> By expressly articulating the expectations and limitations of the supporter, this section of the statute clarifies and restricts the scope to which a supporter is constrained, protecting the incapacitated adult’s decisions beyond this scope. By providing areas in which an incapacitated individual may contend that they are independent, this statute also empowers individuals currently under guardianship with the first step – identification of capacity – to transition out of guardianship and into an SDM agreement. Finally, the D.C. SDM statute acknowledges and emphasizes that agreements “shall” be relied upon by any persons or

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<sup>314</sup> *Id.*

<sup>315</sup> *Id.*

<sup>316</sup> *Id.*

<sup>317</sup> Council 22-0154, 22nd Council Period, Reg. Legis. Meeting, 65 D.C. Reg. 5747 (May 25, 2018).

<sup>318</sup> *Id.*

<sup>319</sup> *Id.*

<sup>320</sup> *Id.*

agencies who receive them, unless there is “substantial cause” suggesting the adult needs protection from the supporter.<sup>321</sup>

Around the same time, Wisconsin passed also an SDM bill.<sup>322</sup> The bill allows adults with a “functional impairment” to create an SDM agreement with one or more supporters.<sup>323</sup> The “supporter” is another person who may assist the adult in the decision-making process by providing assistance with one or all of the following: (1) understanding available options; (2) accessing information and data relevant for life decisions such as medical, educational, and financial records; (3) comprehending the information from the records once it is obtained, and/or; (4) communicating the decisions that the adult makes.<sup>324</sup> The supporter does not have power of attorney rights under the bill, but rather has solely the extent of authority granted by the adult with a functional impairment to assist in making decisions when the such help is sought.<sup>325</sup>

One recent outlier to these SDM statutes is Tennessee. Initially, Tennessee senators introduced a bill quite similar to Texas’s current SDM statute in January 2017. It included substantially the same definitions and scope sections as the Texas law, although it imposed a fiduciary duty on supporters with respect to the principals.<sup>326</sup> The proposed bill also included a model SDM agreement.<sup>327</sup> However, after being sent between the Judiciary committee and a summer study for nearly a full year, the bill received sharp pushback from legislators anticipating complications.<sup>328</sup> The concerns focused around a number of perceived issues, including (1) that

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<sup>321</sup> *Id.*

<sup>322</sup> WIS. LEGIS. COUNCIL, ACT MEMO (Supported Decision-Making Agreements) (Apr. 30, 2018), <https://docs.legis.wisconsin.gov/2017/related/lcactmemo/act345>.

<sup>323</sup> *Id.*

<sup>324</sup> *Id.*

<sup>325</sup> *Id.*

<sup>326</sup> S. 264, 110th Gen. Assemb., Reg. Sess. (Tenn. 2017).

<sup>327</sup> *Id.*

<sup>328</sup> Supported Decision-Making Agreement Act – Amends TCA Title 34: Hearing on SB 264 by Massey (HB 0941 by \*Carter) before Senate Judiciary Committee, 110th Gen. Assemb., Reg. Sess. (Tenn. 2018) (video recording of hearing on Jan. 30, 2018); Supported Decision-Making Agreement Act – Amends TCA Title 34: Hearing on SB 264

the proposed form was too “prescriptive” and inflexible for the supported person to be in control; (2) that by adding “least restrictive alternatives” to the existing power of attorney structure, the supported person would be able to tailor the support to their needs in a way that would have legal recognition without having to explain SDM anew; and (3) that by not including template agreements, people would not have false, but perceived, choice between the one style of agreement and full conservatorship.<sup>329</sup> The final version of the bill adopted and signed into law was much shorter than and essentially unrecognizable from the version initially introduced. The final text read as follows:

AN ACT to amend Tennessee Code Annotated, Title 34, relative to supported decision-making agreements. BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF TENNESSEE: SECTION 1. Tennessee Code Annotated, Section 34-1-101, is amended by adding the following as a new subdivision: "Least restrictive alternatives" means techniques and processes that preserve as many decision-making rights as practical under the particular circumstances for the person with a disability. SECTION 2. This act shall take effect upon becoming a law, the public welfare requiring it.<sup>330</sup>

Though Tennessee would now appear to be in the category of “least restrictive alternatives” as explored in part b above, we chose to include it here because the initial legislation was aimed at comprehensive SDM recognition. The Tennessee statute’s adopters argued that by adding this definition for “least restrictive alternatives” and acknowledging SDM as one such alternative in the bill’s name, the language would facilitate such agreements with greater flexibility.<sup>331</sup>

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by Massey (HB 0941 by \*Carter) before Senate Judiciary Committee, 110th Gen. Assemb., Reg. Sess. (Tenn. 2018) (video recording of hearing on Feb. 6, 2018).

<sup>329</sup> Supported Decision-Making Agreement Act – Amends TCA Title 34: Hearing on SB 264 by Massey (HB 0941 by \*Carter) before Senate Judiciary Committee, 110th Gen. Assemb., Reg. Sess. (Tenn. 2017) (video recording of hearing on Sept. 11, 2017).

<sup>330</sup> S. 264, 110th Gen. Assemb., Reg. Sess. (Tenn. 2017).

<sup>331</sup> Supported Decision-Making Agreement Act – Amends TCA Title 34: Hearing on SB 264 by Massey (HB 0941 by \*Carter) before Senate Judiciary Committee, 110th Gen. Assemb., Reg. Sess. (Tenn. 2017) (video recording of hearing on Sept. 11, 2017).

Elsewhere in the definitions section we see that such language has legal force as it pertains to conservatorship: “(4)[...](B) ‘Conservatorship’ is a proceeding in which a court removes the decision-making powers and duties, in whole or in part, in a least restrictive manner, from a person with a disability who lacks capacity to make decisions in one or more important areas and places responsibility for one or more of those decisions in a conservator or co-conservators.”<sup>332</sup> Taken in tandem with the new language in Title 34 and its colorful legislative history, as well as the inclusion of SDM in the final legislation’s title, there is a strong indication that SDM agreements should now have full legal recognition in Tennessee.<sup>333</sup>

*e. Statutory Analysis Conclusion*

Those states that by statute neither reference the general concept of least restrictive alternatives nor SDM specifically, still leave open the possibility of SDM finding recognition in the courts, as cases in Indiana and Kentucky have aptly demonstrated (see discussion below). Furthermore, although there is no explicit mention of less or least restrictive alternatives, most states still place statutory emphasis on limited guardianships and conservatorships over full or plenary guardianships. Some states, such as Wyoming and Utah, mandate that full guardianships be used only as a last resort.<sup>334</sup> However, these states are the exception, not the rule, and limited guardianships are nevertheless a substituted decision-making arrangement that strips individuals of basic liberties and rights.

Those states that, by statute, explicitly require courts to consider less or least restrictive alternatives to guardianship provide a clear foundation for SDM agreements to find purchase in the courts. This open door to SDM has been utilized successfully in Virginia and New York, among

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<sup>332</sup> TENN. CODE ANN. § 34-1-101 (West, Westlaw through 2018 2nd Reg. Sess.).

<sup>333</sup> *Id.*

<sup>334</sup> See generally UTAH CODE ANN. § 75-5-304 (West, Westlaw through 2018 3rd Spec. Sess.); WYO. STAT. ANN. § 3-1-206 (West, Westlaw through chapters effective Mar. 6 of the 2019 Gen. Sess.).



other states, as is examined in the case law discussion below.<sup>335</sup> While some states in this legislative category have implemented least restrictive alternatives in conjunction with the paternalistic “best interest” standard that presumes incapacity and the need for protection, others promisingly show a far greater degree of deference to individual autonomy and the right of self-determination. Despite this distinction, SDM remains viable even in jurisdictions that emphasize protection over autonomy, such as Virginia.

The five states that expressly mention SDM within their guardianship statutes yet stop short of a full and separate codification of SDM demonstrate that legislatures are taking note of SDM as a concept, albeit tentatively. Although these states have been hesitant to create full and complex statutes as did Texas, they do represent a trend towards recognition of SDM, as evidenced by both Maine and Missouri’s adoption of this language in 2018.

With the exception of Delaware, all states that have passed comprehensive SDM statutes devoted considerable space to inclusion of a template agreement. Though the statutes note that the forms are merely examples, an agreement must take substantially the same form in order to have legal recognition in the respective states. Thus, the forms have a non-negligible impact on how SDM develops in these states – a conclusion that some have criticized, as evidenced in the Tennessee pushback discussed above. The majority of the comprehensive statutes also include strong Purpose sections, which provide reaffirming language on the importance of autonomy and self-determination. Moreover, these statutes afford legal recognition to SDM agreements, which facilitates supporters’ access to medical and financial records – an essential component of providing support from an informed perspective. Though Texas was the first state to adopt such a

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<sup>335</sup> Order, *Ross v. Hatch*, No. CWF-120000-426-DP (Va. Cir. Ct. Aug. 2, 2013). *See also, e.g.*, *Guardian for A.E.*, 2015 N.Y.L.J. 4377 (Sur. Ct. 2015).

statute, the subsequent states that have passed and are currently passing similar legislation show that it will not be the last.

## **II. CASES**

In addition to enacting statutes that promote SDM agreements, courts have begun to increasingly favor SDM models in lieu of traditional guardianship models. In petitioning for guardianship, the petitioner bears the burden of proving, to the satisfaction of the court, that the appointment of a guardian is necessary and in the best interest of the person with a disability. Currently, fifteen cases across nine different jurisdictions have been decided in favor of SDM as opposed to guardianship. All of the cases discussed below were adjudicated in jurisdictions without official SDM statutes in place, including Virginia, New York, Nevada, Kentucky, Indiana, and Massachusetts; one state, Maine, had passed legislation incorporating SDM that is not yet in effect, and one jurisdiction, D.C., subsequently passed SDM legislation.

Most of the cases involved young adults with cognitive or behavioral limitations who nevertheless lead relatively independent lives; frequently, such individuals are subjected to guardianship by default, and litigation is precipitated by their explicit requests for increased self-determination and autonomy. Often, petitioners who prevail in such cases are those who have shown both the ability and desire to be accountable for their own decisions and are benefited by a supportive environment in which they may seek assistance when necessary.

The case of Margaret “Jenny” Hatch, decided in Virginia, was a landmark case for SDM, as it was the first case to recognize an SDM agreement as a viable alternative to guardianship. Notably, it was decided in 2013, prior to the passage of legislation by Texas in which full statutory recognition of SDM was granted for the first time in the United States. At the time of her petition,

Ms. Hatch was twenty-nine years old; despite having Down syndrome, she had a job, her own apartment, and a vibrant social life.<sup>336</sup> She was also an active participant in her church community and in local politics.<sup>337</sup> Prior to bringing the case, Ms. Hatch was practicing an informal version of SDM in which she relied on the support of friends, employers, and professionals to help her understand the complexities of choices she faced.<sup>338</sup>

One day, Ms. Hatch was hit by a car while riding her bicycle, and it was during her hospitalization for injuries sustained in this accident that her parents initiated guardianship proceedings against her.<sup>339</sup> The judge found that, given her diagnosis of Down syndrome, she was “incapacitated” as defined by VA Code section 64.2-2000 such that she required a guardian.<sup>340</sup> This definition required a court finding that she was “incapable of evaluating information effectively or responding to people, events, or environments to such an extent that the individual lacks the capacity to [meet their health and safety needs or manage their property and financial affairs without a guardian or conservator respectively].”<sup>341</sup> Ms. Hatch was forced into a group home, where she felt unsafe, was segregated from her friends and church community, and was required to do menial, repetitive labor.<sup>342</sup> Recounting the experience in her own words, Ms. Hatch said: “I wanted my life back, but they told me to forget about my old life ... I cried every night at the group home.”<sup>343</sup>

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<sup>336</sup> Margaret Hatch et al., *Unjustified Isolation is Discrimination: The Olmstead Case Against Overbroad and Undue Organizational and Public Guardianship*, 3 INCLUSION 65 (2015).

<sup>337</sup> *Id.*

<sup>338</sup> Order, Ross v. Hatch, No. CWF-120000-426-DP.

<sup>339</sup> Hatch, *supra* note 336.

<sup>340</sup> Order, Ross v. Hatch, No. CWF-120000-426-DP.

<sup>341</sup> VA. CODE ANN. § 64.2-2000 (West, Westlaw through 2018 Reg. Sess. and 2018 Spec. Sess. 1 and including 2019 Reg. Sess. chs. 17, 18, 164 and 225).

<sup>342</sup> Hatch, *supra* note 336.

<sup>343</sup> *Id.*

Ms. Hatch contested the guardianship. Based on her own testimony combined with that of psychological professionals who attested to her ability to make choices once properly informed, she successfully persuaded the court to recognize that the guardianship was more restrictive than her needs required.<sup>344</sup> Concluding that she would eventually be able to fully conduct her own affairs if afforded the benefit of an SDM agreement, the judge appointed two of Ms. Hatch's friends and supporters as limited guardians (confined to the purview of health and safety) in an order set to expire in one year.<sup>345</sup> The court also tasked them with guiding Ms. Hatch to fully implement an SDM arrangement that would ease her transition from the limited guardianship and provide ongoing help following its termination.<sup>346</sup> "At the end, it is the Court's opinion that [Ms. Hatch] will be able to assist and work with staff provided by the Medicaid Waiver [and her friends], who will be providing the supportive decision-making [sic] skills and increased self-reliance that will allow her to adapt and succeed independently."<sup>347</sup>

This case constituted a watershed decision for a number of reasons. Most significantly, it took place prior to any SDM legislation. At the time the case was decided, only one state was actively exploring the possibility of SDM – Texas had launched a pilot program to evaluate the viability and impact of SDM in 2009.<sup>348</sup> Thus, this case indicates that courts may recognize and respond to the potential of SDM even absent statutory authority. Furthermore, this case demonstrates that the transition and implementation of SDM agreements for those currently under plenary guardianship may be a gradual one, in which the support of guardians is leveraged to assist the person under guardianship in developing the skills required to fully transition into making their

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<sup>344</sup> Order, *Ross v. Hatch*, No. CWF-120000-426-DP.

<sup>345</sup> *Id.*

<sup>346</sup> *Id.*

<sup>347</sup> *Id.*

<sup>348</sup> H.R. 1454, 81st Leg., Reg. Sess., 2009 Tex. Sess. Law Serv. ch. 72 (West).

own decisions at a self-determined pace. Finally, the case indicates that courts may recognize that SDM is a viable and less restrictive alternative to traditional guardianship, thus altering the calculus of satisfying the burden imposed in many states to consider all such alternatives prior to imposing guardianship.

In the wake of the widely publicized Hatch case, courts in other jurisdictions soon began ruling in favor of SDM agreements despite an absence of statutory authority. One noteworthy case was that of 24-year-old Cory Carlotto, as Mr. Carlotto was also a participant in the Nonotuck pilot program discussed below. Mr. Carlotto was diagnosed with autism, cognitive limitations, obsessive compulsive disorder, and anxiety, all of which impacted his decision-making abilities.<sup>349</sup> Mr. Carlotto had been under his mother's guardianship since he was eighteen because his cognitive ability was approximately five years behind his actual age and his parents felt he still needed assistance, though they always wanted to transition him to a less restrictive alternative.<sup>350</sup> That opportunity came when Mr. Carlotto joined the Nonotuck pilot program, and on November 17, 2015, Mr. Carlotto's guardianship was terminated and replaced with an SDM agreement under which his mother, father, and sister are serving as his supporters.<sup>351</sup>

By early 2019, New York has decided six cases in favor of SDM, with incredibly compelling dicta regarding SDM written into a preceding seventh. Prior to the decision of the Hatch case in Virginia, Justice Glen of the New York County Surrogate's Court adjudicated a New York case in which the petitioner sought a less restrictive method of support for his wife, Dameris, a twenty-nine-year-old woman with mild to moderate intellectual disability who was at that time

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<sup>349</sup> *Cory, Pilot Project Participant*, SUPPORTED DECISION-MAKING, <http://supporteddecisions.org/cory/> (last visited March 12, 2019).

<sup>350</sup> *Id.*

<sup>351</sup> *Id.*

under the co-guardianship of her husband (petitioner) and her mother.<sup>352</sup> In its decision regarding the requested termination of the guardianship, the court found that it no longer had jurisdiction over the case, given that the petitioner and Dameris had permanently moved out of state.<sup>353</sup> However, the court went on to write that if it *had* retained jurisdiction over the case, based on an in-depth assessment of the facts, guardianship was no longer warranted.<sup>354</sup> In reaching this conclusion, the court considered evidence that the steady presence of supportive family members and neighbors in Dameris’s life established a “system of supported decision-making [...] that constitute[d] a less restrictive alternative to the Draconian loss of liberty entailed [in guardianship].”<sup>355</sup> Expanding on this, the court further stated that, under binding New York precedent, courts had recognized that the least restrictive alternative is a “Constitutional imperative.”<sup>356</sup> Although this case lacked jurisdiction, and thus its discussion of SDM comprises non-binding dicta, it laid an important foundation for the following cases by interpreting the New York guardianship statute in light of state and national constitutional concerns as well as the human rights mandate in Article 12 of the UNCRPD.<sup>357</sup>

Justice Margarita López Torres of Kings County, New York, has decided six cases in which petitions for guardianship were dismissed in favor of SDM as an alternative model of intervention.<sup>358</sup> In each of these opinions, Justice López writes that if there exist less restrictive alternatives that are sufficient and reliable to meet the needs of the person in need of support,

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<sup>352</sup> *In re Dameris L.*, 956 N.Y.S.2d 848 (Sur. Ct. 2012).

<sup>353</sup> *Id.*

<sup>354</sup> *Id.* at 853.

<sup>355</sup> *Id.*

<sup>356</sup> *Id.* at 854.

<sup>357</sup> *Id.* at 853.

<sup>358</sup> *Guardian for A.E.*, 2015 N.Y.L.J. 4377 (Sur. Ct. 2015); *In re D.D.*, 19 N.Y.S.3d 867 (Sur. Ct. 2015); *In re Hytham M.G.*, 41 N.Y.S.3d 719 (Sur. Ct. 2016); *In re Michelle M.*, 41 N.Y.S.3d 719 (Sur. Ct. 2016); *Estate of Hilton*, 2017 N.Y.L.J. 284 (Sur. Ct. 2017); *Estate of Albert J.*, 2017 N.Y.L.J. 475 (Sur. Ct. 2017).

guardianship is not warranted; further, she refers to guardianship as an “extreme remedy.”<sup>359</sup> Moreover, López writes that in order to identify the least restrictive alternative to guardianship that satisfies New York’s goal of protecting persons with intellectual disabilities from harm, an inquiry into the availability of resources to assist the individual – including a support network of family, friends, and professional services – is required.<sup>360</sup>

The first of the cases decided by Justice López was *Guardian for A. E.*, decided in 2015 in the Kings County Surrogate Court.<sup>361</sup> The petitioner for guardianship was the mother of A., a nineteen-year-old young woman with a mild intellectual disability and several serious health conditions.<sup>362</sup> Justice López, in considering the petition, noted that appointing a guardian to an individual entails “a vesting in the guardian of ‘virtually complete power over’ such individual, which ‘clearly and dramatically infringes on [the individual’s] liberty interests.’”<sup>363</sup> The judge further looked to the guardianship statute and its mandate that guardianship “may be granted only if it is the least restrictive alternative to achieve the goal of protecting a person with a mental disability.”<sup>364</sup> Ultimately, the judge determined that A.’s mother failed to show sufficient proof that guardianship was both necessary and in A.’s best interest; the evidence and testimony produced did not demonstrate that A. was incapable of managing herself and her affairs due to her intellectual disability.<sup>365</sup> Although A. herself conceded that she struggled with money management and budgeting, she was able to clearly articulate her mental and physical health conditions and needs, attend school, plan for the future, commute, feed herself, care for her living quarters

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<sup>359</sup> See, e.g., *In re Michelle M.*, 41 N.Y.S.3d 719 (Sur. Ct. 2016).

<sup>360</sup> *In re Michelle M.*, 41 N.Y.S.3d 719.

<sup>361</sup> *Guardian for A.E.*, 2015 N.Y.L.J. 4377.

<sup>362</sup> *Id.*

<sup>363</sup> *Id.* at 2 (quoting *In re Mark C.H.*, 906 N.Y.S.2d 419, 427 (Sur. Ct. 2010)).

<sup>364</sup> *Id.*

<sup>365</sup> *Guardian for A.E.*, 2015 N.Y.L.J. 4377.

independently, and maintain a strong social network.<sup>366</sup> Justice López described A. as a high-functioning, engaging, “socially sophisticated” young woman capable of exercising SDM and denied the petition for plenary guardianship.<sup>367</sup>

Just two months later, Justice López reached a similar decision in *In re D.D.*<sup>368</sup> D.D. was a twenty-nine-year-old man diagnosed with Down syndrome and low to mild intellectual disability whose brother and mother petitioned to be his co-guardians.<sup>369</sup> In her opinion, Justice López wrote that she found D.D. to be a “capable, thoughtful, and engaging adult with mild intellectual disability who is high functioning, well integrated socially, able to work, to travel independently, [and] to exercise self-care and management.”<sup>370</sup> A guardian ad litem for D.D. presented evidence that he was capable of making his own decisions concerning his life affairs – including his health and wellness – with the consultation of his family, those close to him, and supportive services; predicated on this system of support, D.D.’s guardian ad litem concluded that D.D. did not need a guardian and instead recommended alternatives.<sup>371</sup> Since plenary guardianship, under New York law, must only be instituted only when less restrictive alternatives have been deemed inapplicable, Justice López decided that D.D.’s brother and mother failed to sufficiently demonstrate the necessity of a guardian for D.D.<sup>372</sup> She poignantly commented that “the standard here is not whether the petitioners can make better decisions than D.D., it is whether or not D.D. has the capacity to make decisions for himself with the support that he abundantly has.”<sup>373</sup>

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<sup>366</sup> *Id.*

<sup>367</sup> *Id.*

<sup>368</sup> *In re D.D.*, 19 N.Y.S.3d 867 (Sur. Ct. 2015).

<sup>369</sup> *Id.*

<sup>370</sup> *Id.* at 874.

<sup>371</sup> *In re D.D.*, 19 N.Y.S.3d 867.

<sup>372</sup> *Id.*

<sup>373</sup> *Id.* at 875.



In the case *In re Hytham M.G.*, the third New York case decided by Justice López, Hytham was a twenty-three-year-old man with an IQ of 71 which placed “him in the ‘borderline delayed’ range of cognitive functioning in accordance with the Stanford-Binet Intelligence Scales: Fifth Edition.”<sup>374</sup> Despite this diagnosis, the court concluded that the documentary evidence presented indicated that Hytham was a highly functional individual capable of all activities of daily living.<sup>375</sup> Hytham was also capable of and motivated to work.<sup>376</sup> Relying on language from *In re D.D.*, Justice López reaffirmed that the relevant legal standard for consideration is not whether a guardian can make better decisions than Hytham, it is whether or not Hytham has the capacity to make decisions for himself with the support that he abundantly has.<sup>377</sup> Concluding that the loving and supportive environment in which Hytham was presently enveloped “has enabled him to thrive despite his limitations,” Justice López determined that plenary guardianship was not appropriate at the time, and denied the petition.<sup>378</sup>

Yet another case decided by Justice López in Kings County, New York, is that of Michelle M., a thirty-four-year old woman diagnosed with Down syndrome and an intellectual disability.<sup>379</sup> Michelle lived independently with her roommates, held a part-time job for over six years, and did her own cooking and shopping.<sup>380</sup> She was also able to travel independently, utilizing public transportation to get to work, run errands, and meet her friends and boyfriend.<sup>381</sup> The record demonstrated not only Michelle’s responsible management of her health and finances, but also that in her day to day life, she was capable of making decisions about her employment, interpersonal

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<sup>374</sup> *In re Hytham M.G.*, 41 N.Y.S.3d 719 (Sur. Ct. 2016).

<sup>375</sup> *Id.*

<sup>376</sup> *Id.*

<sup>377</sup> *Id.*

<sup>378</sup> *Id.*

<sup>379</sup> *In re Michelle M.*, 41 N.Y.S.3d 719 (Sur. Ct. 2016).

<sup>380</sup> *Id.*

<sup>381</sup> *Id.*

relationships, personal safety, and place of residence; she also regularly participated in vocational and recreational activities at a day habilitation program for individuals with developmental disabilities.<sup>382</sup> Upon application of the relevant statutory analysis under New York law, as discussed above, her parents' petition for guardianship was dismissed due to lack of evidence showing that guardianship was both necessary and in Michelle's best interest.<sup>383</sup> The court ruled that allowing Michelle to retain her legal right to make decisions about her own affairs, while providing her with any necessary assistance to make or communicate those decisions within an SDM framework – essentially mirroring that which she already had in place – was ultimately in her best interest.<sup>384</sup>

*Estate of Hilton* uses almost identical language and arguments for dismissing a guardianship petition because the individual for whom petitioners sought guardianship had the ability to function relatively independently.<sup>385</sup> Once again, petitioners were the parents of the individual for whom guardianship was sought; in light of their advancing age, petitioners sought guardianship for their son, who was diagnosed with a mild intellectual disability, short-term memory problems, and impaired peripheral vision in one eye.<sup>386</sup> Justice López found that the petitioners had failed to satisfy their burden of proving that Hilton was in need of a guardian, as well as that such an appointment would be in his best interest.<sup>387</sup> Elaborating on this point, Justice López wrote “it is not in the best interest of a person who has the capacity to make decisions to have that decision-making authority wholly removed through an Article 17-A guardianship, regardless of good intentions.”<sup>388</sup> Accordingly, the court found that it was ultimately in Hilton's

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<sup>382</sup> *Id.*

<sup>383</sup> *Id.*

<sup>384</sup> *Id.*

<sup>385</sup> *Estate of Hilton*, 2017 N.Y.L.J. 284 (Sur. Ct. 2017).

<sup>386</sup> *Id.*

<sup>387</sup> *Id.*

<sup>388</sup> *Id.*

best interest to allow him to retain his legal right to make decisions about his own life while providing him support in doing so as necessary through the SDM framework Hilton had already informally established.<sup>389</sup>

In *Estate of Albert J.*, the most recent López decision issued in the Kings County Surrogate Court of New York, Justice López once again dismissed a parental petition for guardianship in favor of setting up an SDM framework.<sup>390</sup> In her opinion, Justice López emphasized the legal right to freedom and the necessity of preserving that autonomy; the right to due process when limiting freedoms of choice, and; the need to prioritize what is in the best interest of the individual.<sup>391</sup> She emphasized that the petitioner has not met the requisite burden of proof to show the guardianship is needed and in Albert J.’s best interest.<sup>392</sup> Justice López continued on to emphasize that New York’s guardianship statute, Article 17-A, is an “entirely plenary guardianship” that does not afford authority to the court to customize or limit the “scope of guardianship of the person to address the individual’s specific areas of need.”<sup>393</sup> As a result, the best decision for this individual’s best interest and autonomy, according to the Court, was the flexible and highly tailored approach afforded by an SDM arrangement.<sup>394</sup>

In addition to the abovementioned cases denying petitions for guardianship in favor of SDM, there have also been various cases wherein courts have vacated existing guardianships in favor of SDM. In 2016, Ryan Herbert King, Jr. petitioned a District of Columbia court to remove his guardianship and replace it with an SDM model.<sup>395</sup> The court found that King did not fit the

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<sup>389</sup> *Id.*

<sup>390</sup> *Estate of Albert J.*, 2017 N.Y.L.J. 475 (Sur. Ct. 2017).

<sup>391</sup> *Id.*

<sup>392</sup> *Id.*

<sup>393</sup> *Id.*

<sup>394</sup> *Id.*

<sup>395</sup> Order, *In re Ryan Herbert King, Jr.*, No. 2003 INT 249 (D.C. Super. Ct. 2003).

definition of an incapacitated individual as defined in the D.C. Code section 21-2011(11).<sup>396</sup> He could make and communicate decisions, receive and evaluate information, manage his own finances, meet his health, safety, and habilitation needs, and successfully direct his own life with the support of his family.<sup>397</sup> Given this evidence, the court granted the petition to terminate his guardianship and use an SDM agreement.<sup>398</sup> Notably, this case was adjudicated before the District of Columbia passed its SDM bill in 2018.<sup>399</sup>

In *In re A Protected Person*, a guardianship that had been in place since 2003 was successfully vacated in 2017.<sup>400</sup> The petitioner was the protected person’s guardian, who based the petition for termination on the protected person’s self-sufficiency and connection with supportive service providers.<sup>401</sup> In the proceedings, the protected person confirmed her desire to terminate the guardianship.<sup>402</sup> In the absence of its own binding jurisprudence, the Nevada court looked to persuasive precedent from other states, such as the cases of *In the Matter of the Guardianship of Dameris L., Ross v. Hatch*, and *In re Ryan Herbert King Jr.*<sup>403</sup> Ultimately, the court held that in analyzing the necessity of ongoing guardianship, it should fully examine whether there is an alternative “system of supported decision making in place that constitutes a less restrictive alternative to ... a plenary ... guardianship.”<sup>404</sup>

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<sup>396</sup> *Id.*

<sup>397</sup> *Id.*

<sup>398</sup> *Id.*

<sup>399</sup> *Id.*

<sup>400</sup> Order After September 5, 2017 Hearing; Order Terminating Guardianship; Decree of Discharge, *In re A Protected Person*, No. PRO3-00264 (Nev. Jud. Dist. Ct. 2017).

<sup>401</sup> *Id.*

<sup>402</sup> *Id.*

<sup>403</sup> *Id.*

<sup>404</sup> *Id.*

Kentucky represents yet another jurisdiction with case law in favor of SDM despite the absence of statutory authority.<sup>405</sup> In 2017, a woman diagnosed with a mild intellectual disability became the first in the state to have her guardianship terminated in favor of an SDM agreement.<sup>406</sup> The twenty-two-year-old woman, Suzanne “Suzie” Heck, been under guardianship since the age of eighteen.<sup>407</sup> Ms. Heck lived with housemates and utilized adult training services.<sup>408</sup> She and her supporters, including both friends and paid service providers, approached Kentucky Protection & Advocacy (KPA) for help terminating her guardianship, believing her to be capable of making her own decisions with assistance.<sup>409</sup> Both Ms. Heck’s guardian and a psychologist with KPA agreed that Ms. Heck had a solid support network in place and was capable of using it to make her own decisions.<sup>410</sup> Despite the county attorney’s uneasiness with the arrangement, the court terminated Ms. Heck’s guardianship in favor of SDM in consideration of her use of training services and help from trusted supporters in making decisions.<sup>411</sup> In this case, as in several of the New York cases discussed above, Ms. Heck already had a sufficient support network in place that the court deemed to be adequate to meet her needs in conjunction with her capacity.

Although documentation of the case is unavailable, there was also a 2017 case in Vermont in which an individual’s guardianship was vacated and replaced with an SDM agreement.<sup>412</sup> This individual was a participant in Vermont’s SDM pilot program, discussed below.<sup>413</sup>

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<sup>405</sup> *Freed from Guardianship a Kentucky First: Suzie Wins Her Rights in Court Using SDM*, NATIONAL RESOURCE CENTER FOR SUPPORTED DECISION MAKING (2017), <http://www.supporteddecisionmaking.org/impact-stories/freed-guardianship-kentucky-first-suzie-wins-her-rights-court-using-sdm>.

<sup>406</sup> *Id.*

<sup>407</sup> *Id.*

<sup>408</sup> *Id.*

<sup>409</sup> *Id.*

<sup>410</sup> *Id.*

<sup>411</sup> *Id.*

<sup>412</sup> *DD Services Division – Supported Decision Making*, 2017 DAIL ANNUAL REPORT (Dec. 2017), [https://dail.vermont.gov/sites/dail/files/documents/DDSD\\_Supported\\_Decision\\_Making.pdf](https://dail.vermont.gov/sites/dail/files/documents/DDSD_Supported_Decision_Making.pdf).

<sup>413</sup> *Id.*

In June 2018, an Indiana resident named Jamie Beck had her guardianship terminated in favor of an SDM agreement.<sup>414</sup> Ms. Beck was diagnosed with a mild intellectual disability and attention deficit hyperactivity disorder (ADHD), and following the death of her parents when she was nineteen, she was placed under guardianship and moved into a nursing home.<sup>415</sup> Over the next eight years, Ms. Beck participated in a pilot program, moved from the nursing home to a supported-living home, and eventually gained full-time employment at Ball Memorial Hospital.<sup>416</sup> Ms. Beck’s petition to terminate her guardianship acknowledged that she would still need to use formal and informal support services, but contended that she was no longer incapacitated within the meaning of Indiana’s guardianship statute.<sup>417</sup> In agreement, the court terminated Ms. Beck’s guardianship and noted that her informal supports would be formalized in an SDM agreement; moreover, the order provided that the court would retain limited jurisdiction in order to monitor the agreement.<sup>418</sup> Ms. Beck’s guardian fully and enthusiastically supported the switch to Ms. Beck’s use of SDM, acknowledging that Ms. Beck had worked very hard to regain capacity.<sup>419</sup>

Decided the same month (June 2018) as the Indiana court’s termination of Ms. Beck’s guardianship, petitioner Joshua Strong prevailed in a similar case in Maine.<sup>420</sup> In cognizance of the recently passed revision of the Maine Probate Code that requires consideration of less restrictive alternatives to guardianship and makes explicit mention of SDM, the court terminated Mr. Strong’s guardianship on the grounds that he was “utilizing Supported Decision-Making and

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<sup>414</sup> Marilyn Odendahl, *Indiana Court Pilot Project Helps Woman Gain Independence*, THE INDIANA LAWYER (June 18, 2018), <https://www.theindianalawyer.com/articles/47328-indiana-court-pilot-project-helps-woman-gain-independence>.

<sup>415</sup> *Id.*

<sup>416</sup> *Id.*

<sup>417</sup> *Id.*

<sup>418</sup> Order to Terminate Guardianship, *In re Beck*, No. 89D02-1805-GU-000044 (Ind. Super. Ct. June 13, 2018), <http://media.ibj.com/Lawyer/websites/opinions/index.php?pdf=2018/june/Beck-termination.pdf>.

<sup>419</sup> Odendahl, *supra* note 210.

<sup>420</sup> Order of Termination of Guardianship, *In re Strong*, No. 2002-0082 (Me. Prob. Ct. June 6, 2018), <http://supporteddecisionmaking.org/sites/default/files/Strong-Order-of-Termination-of-Guardianship.pdf>.

[was] therefore no longer incapacitated.”<sup>421</sup> Mr. Strong had been under guardianship for over 15 years, since April 2002; he had recently had graduated from a pilot program that incorporated SDM and had been hoping to transition from guardianship to an SDM model for four years.<sup>422</sup> Following termination of his guardianship, Mr. Strong stated that he was excited to no longer have to ask permission for everything, and to be able to exercise his best judgment.<sup>423</sup> Recognizing that this case signified the first instance of guardianship termination in favor of SDM in Maine, Mr. Strong’s attorney stated that the case “creates a new and broader narrative about civil rights and liberties, which expands the ability for all Mainers to have access to the accommodations and support they need to ensure legal capacity before the law.”<sup>424</sup>

Consistent with the emerging legislative trend, the case law analyzed above adduces a shift in judicial preference towards SDM in favor of guardianship, often in explicit deference to individual rights. The fifteen cases discussed above, in which the court has either denied a petition for guardianship or petitioners have prevailed in terminating an existing guardianship, span nine different jurisdictions. In many cases where guardianship was terminated, the individual’s guardian was in support of terminating the guardianship and the individual already had an extensive support network in place. Given the persuasive reasoning of this case law, as well as the broader context of jurisprudential trends in the United States and global recognition of autonomous decision-making and legal capacity as a human right catalyzed by Article 12 of the UNCRPD, it is likely that more will follow.

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<sup>421</sup> *Id.*

<sup>422</sup> Nell Brimmer, *Guardianship Terminated in Favor of Supported Decision-Making for the First Time in Maine*, DISABILITY RIGHTS MAINE (June 13, 2018), <https://drme.org/news/2018/guardianship-terminated-in-favor-of-sdm-1st-time-in-maine>.

<sup>423</sup> *Id.*

<sup>424</sup> *Id.*

### III. PILOT PROGRAMS

While the movement toward SDM makes progress in the legislative and judicial realms, it is worth noting that on-the-ground efforts to implement this practice have been gaining traction within the states. In some instances, pilot programs have been instituted prior to legislative acts codifying SDM practices through these programs. State agencies, non-profit organizations, advocates, and other community members are building awareness, training target audiences, and tailoring services to develop a structure of SDM in the absence of legislative or judicial authority. This section aims to highlight the pilot programs most relevant to SDM, including the details of program design, scope of activities, and current findings. Overall, the goal of this outline is to provide a guide of recommendations based on the successes and challenges from ongoing pilot programs.

#### *a. Pilot Program Implementation Phases*

There are three identifiable Phases to pilot program implementation: Design, Deploy, and Assess. To build a successful program, each phase must address key questions, available resources, and next steps. While aspects of the phases may overlap, it is important to develop an outline of program objectives, needs, and potential challenges early in the process to continue to think critically about the effectiveness of the program as whole. This section identifies some of the key questions and considerations for each phase as a program is implemented in practice.

A number of important factors play into setting up a pilot program in the Design Phase, including resource availability, creation of partnerships, and the short-term and long-term goals of the program. Outlining the strengths and weaknesses in these areas is important for setting up a focused and feasible pilot. A state does not have to have an SDM statute in place to conduct a pilot program. Alternatively, the successes of pilot programs may stand as an incentive to encourage



SDM legislation. Therefore, whether or not a state statute exists could be considered a factor in designing an SDM pilot program, but the lack of a statute is not an inherent barrier.

Pilot programs may be funded and implemented by state or federal agencies, through partnerships between inter-state organizations, or any combination thereof. The Working Interdisciplinary Network of Guardianship Stakeholders (WINGS) is an example of a multi-stakeholder collaboration that partners with intra-state agencies, federal resources, and other advocacy groups to lead pilot program activities within states.<sup>425</sup> Other pilot programs do not create an independent agency to run the program and delegate services, instead relying on partnerships with identified and interested groups.

Programs receiving funding from state or federal agencies likely need to apply for the grant or award with details of the program's design and goals; it is therefore critical to have these elements clarified in the Design Phase. The initial design, successes, and findings from early programs in Texas, Massachusetts, and New York, have been looked to as successful and effective examples to develop similar platforms in other states. The goals of the pilot programs, when expressly provided, tend to be qualitative in nature and identify the need to disseminate information, train advocates, or provide direct services based on the type of program implemented. Quantitative analyses comparing program effectiveness and impact are not readily available due to the individualized nature of the programs. However, it is arguable that this kind of research would be beneficial and is likely to be utilized as the sample size of programs increases. As pilot programs continue to be established in the states, therefore, it may be compelling from a funding perspective to outline both qualitative and quantitative goals for analysis and the assessment of the program's impact.

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<sup>425</sup> *State WINGS*, AMERICAN BAR ASSOCIATION (Feb. 12, 2019), [https://www.americanbar.org/groups/law\\_aging/resources/wings-court-stakeholder-partnerships0/state-wings/](https://www.americanbar.org/groups/law_aging/resources/wings-court-stakeholder-partnerships0/state-wings/).

Another element of the Design Phase is to outline who may be necessary to include in a particular phase of implementation or in the program as a whole. Some programs convened committees or workgroups to assist in designing the program, including but not limited to: adults with disabilities, parents and caregivers of the adults, social workers, and other advocates. Available reports on successful program design point to the need to include diverse perspectives throughout the process, such as disabled adults, parents, caregivers, policymakers, and others. The stakeholders involved in the up-front design may depend on the audience the program is targeting, but reports highlight that a diverse panel of perspectives may be most effective.

With a comprehensive outline developed in the Design Phase, the Deploy Phase encompasses the preliminary activities and ongoing efforts necessary to implement the objectives of the program. The length of pilot programs will depend on the frequency and source of funding. Identified programs have lasted anywhere between one to five years, but in many states the pilot programs are funded on an annual basis.<sup>426</sup> Since awareness, advocacy, and services are needed on an ongoing basis, the determinative goal of this phase should be to establish a program that can be permanent.

Since funding from public sources for an ongoing project may be inconsistent over time, it may be challenging to determine in the Design Phase the availability of budget for commissioning staff and volunteers, technological capabilities, developing high-quality materials, and other administrative and operational needs. Another practical concern is the oversight of program implementation, especially programs providing services directly to individuals in need of assistance. Programs engaging adults with disabilities and their families to develop SDM networks

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<sup>426</sup> Morgan Whitlatch, *Supported Decision-Making: From Theory to Practice*, NATIONAL RESOURCE CENTER FOR SUPPORTED DECISION-MAKING (Oct. 4, 2017), [http://supporteddecisionmaking.org/sites/default/files/event\\_files/QT%20DC%20ARDC%20Presentation%20%282017.10.pdf](http://supporteddecisionmaking.org/sites/default/files/event_files/QT%20DC%20ARDC%20Presentation%20%282017.10.pdf) at 47.

and agreements need an added level of oversight to prevent manipulation, ill treatment, and mistakes. It may be challenging in the early stages of a new program to define what this oversight entails and what resources are needed to support it.

Additionally, it is important in the Deploy Phase to identify and communicate with current and potential partners. Developing partnerships is key to expanding the program's reach in the community, and may lead to other long-term collaboration opportunities. Overall, the Design Phase should be focused on implementing and maintaining a successful program, with a critical eye to the future.

While measuring effectiveness should be an ongoing process overlapping with the implementation of the program, it is important that there is an Assessment Phase composed of milestones at which a thorough analysis takes place. Unfortunately, many programs do not have annual or other timely reports with comprehensive metrics compiled and available to the public. Securing additional funding to continue or grow the program may require an impact analysis. Therefore, it is a significant advantage to have clearly established goals at the outset and reporting periods throughout the program.

Further, other states looking to implement a program look to the successes of prior or ongoing programs as a model. Without clear and quantifiable goals and a large sample size, it is difficult to compare the effectiveness of one type of pilot or effort over another. This may inhibit programs trying to identify the most effective and important next steps for the program within the state. Some critical questions that may be used to determine impact include:

- Has the target audience been reached? If so, quantify.
- What resources have been developed for the audience or the community in general?  
Are they targeted to specific audiences or are they general?

- Has feedback been collected from a variety of stakeholders throughout and following the program?
- What are some key learnings following the program?
- What went well and where are the areas for improvement?
- Does feedback highlight possible next steps?
- Is there an ability to expand the scope or reach of the program?
- Are there identifiable and quantifiable goals for a subsequent program to compare to the initial pilot?

*b. Pilot Program Categories and Examples*

Research on the current state pilot programs aimed at facilitating SDM awareness and services shows that there is no single, widely-adopted approach. There are three identifiable levels, or Tiers, of pilot programs that encompass different types of scope, resources, and objectives. While the Tiers appear to build on each subsequent effort, there are examples of pilot programs initiating at each level without having started from a lower level. Further, there are interesting differences between even programs within the same type of pilot category. The following section contains a description and compilation of some of the pilot programs that exist in the states and further demonstrates the differences between the Tier categories. Key details and interesting distinctions of each program are provided to highlight the opportunities available in the variety of approaches used to pilot SDM programs.

**1. Tier I Pilot Programs**

The Tier I category consists of early-stage, education-based pilot programs. These pilot programs tend to focus on gathering information, insights, and feedback to create training materials and spread awareness about SDM and its usefulness. A variety of stakeholders may be included in

the initial program design to determine the target audience and method of gathering information, to consolidate learnings, and to disseminate awareness. Materials developed as part of a Tier I program tend to have a broad scope, targeting caregivers and other decision-makers in the community and pointing this audience toward state and federal resources for more information on options.

Arizona's pilot program, which was put into action on October 1, 2018, is aimed at educating and training doctors, nurses, social workers, teachers, and IEP workers on SDM as an alternative to guardianship. The program is run by the Arizona Center for Disability Law (ACDL) in partnership with The Arc of Arizona, and the Southwest Institute for Families and Children.<sup>427</sup> The pilot program, called the Supported-Decision-Making and Information and Training Pilot Project, is aimed at increasing awareness of the viability of SDM, promoting its practice, and increasing the number of individuals that choose SDM over guardianship.<sup>428</sup> Through a grant from Arizona's Developmental Disabilities Planning Council, which is federally funded, ACDL has received \$60,000 plus a twenty-five percent match, roughly \$75,000 total, to work specifically with individuals that have intellectual and developmental disabilities.<sup>429</sup>

Another Tier I example focused on exposure and awareness is in South Carolina. Similar to Arizona, the South Carolina Supported Decision Making Project is a collaboration between a number of the state's agencies and nonprofits, including the South Carolina Developmental Disabilities Council, The Arc of South Carolina, and ABLE South Carolina.<sup>430</sup> The project is

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<sup>427</sup> *ACDL to partner in Pilot Project for Supported Decision-Making Information and Training*, ARIZONA CENTER FOR DISABILITY LAW, <https://www.azdisabilitylaw.org/acdl-partner-pilot-project-supported-decision-making-information-training/> (last visited Mar. 11, 2019).

<sup>428</sup> *Id.*

<sup>429</sup> Telephone Interview with George Garcia, Exec. Dir. of Sw. Institute. for Families & Children (Feb. 8, 2019).

<sup>430</sup> *The SC Supported Decision-Making Project*, ABLE SOUTH CAROLINA, <https://www.able-sc.org/sdm/> (last visited Feb. 13, 2019).

funded by the South Carolina Developmental Disabilities Council.<sup>431</sup> As outlined on the public webpage, this project seeks to “increase awareness of Supported Decision Making in South Carolina and promote alternatives to guardianship that allow individuals with disabilities to retain control of their lives.”<sup>432</sup> While the Arizona project is attempting to train specific stakeholders and engage persons with disabilities, the South Carolina program is focused on providing resources to broader audiences. Instead of direct services, the South Carolina website includes a number of resources available to the public including a template SDM agreement, upcoming family and professional trainings, and a note that an SDM manual and video will be ‘coming soon.’<sup>433</sup> The agreement template is an eight-page example outlining areas where the individual would like assistance from mentioned supporters, and outlining how those decisions are to be supported with respect to the individual’s preferences.<sup>434</sup>

Tier I programs, overall, appear to be most compelling for early-stage and low-resource efforts. Identifying opportunities and challenges from collaborating and other research efforts may be a key starting point for groups interested in determining the most effective way to expand services and impact. Further, findings supported by qualitative and quantitative data may be persuasive to find sources of funding for a larger-scale program. A Tier I fact-finding effort may open the door to larger-scale and longer-term programs in the future.

## **2. Tier II Pilot Programs**

Tier II programs focus on grass-roots efforts to improve awareness, training, and support to community members. Rather than focusing solely on general education, the overall goal is to

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<sup>431</sup> *Id.*

<sup>432</sup> *Id.*

<sup>433</sup> *Id.*

<sup>434</sup> *Supported Decision-Making Agreement*, ABLE SOUTH CAROLINA, <https://able-sc.org/wp-content/uploads/2016/09/SDM-Representation-Agreement-Final.pdf> (last visited March 6, 2019).

increase the number of trained advocates and provide them with a broad range of resources. Some states, such as Oregon, have deployed statewide trainings to target audiences in order to build awareness of SDM and promote availability of local, state, and federal resources.<sup>435</sup>

Indiana has established the Volunteer Advocates for Services for Incapacitated Adults (VASIA) as a training program.<sup>436</sup> The main organization that is using the VASIA program is Achieva Resources in Wayne County Indiana. The VASIA program provides volunteers that visit individuals with mental illness or intellectual and developmental disabilities (I/DD).<sup>437</sup>

Achieva Resources' members work as both guardians and SDM advocates for persons with disabilities, mental illness, and elderly persons.<sup>438</sup> The VASIA program requires potential volunteers and trainees to complete an application, which includes having three written references, authorization for Achieva Resources to conduct a criminal background check, and a driving history.<sup>439</sup> After the person completes all the steps necessary to get approved to become a volunteer, they are trained by other volunteers and Achieva Resources employees.<sup>440</sup> Once the training process is complete, the organization connects the volunteer with clients.<sup>441</sup> In some cases, the organization has employees go with the volunteer to the first few meetings.<sup>442</sup> Volunteers visit clients who live in group homes and supported living homes in six counties in Indiana.<sup>443</sup> Volunteers generally help the participants in everyday life, completing tasks, and speaking to various authorities on their behalf.<sup>444</sup>

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<sup>435</sup> See *Supported Decision Making Train-the-Trainer Project*, THE ARC OREGON, <https://thearcoregon.org/2018/10/14/supported-decision-making-train-the-trainer-project/> (last visited Feb. 13, 2019).

<sup>436</sup> ACHIEVA RESOURCES, <http://www.achievaresources.org/> (last visited Mar. 9, 2019).

<sup>437</sup> *Id.*

<sup>438</sup> *Id.*

<sup>439</sup> *Id.*

<sup>440</sup> *Id.*

<sup>441</sup> *Id.*

<sup>442</sup> *Id.*

<sup>443</sup> *Id.*

<sup>444</sup> *Id.*

While overlap occurs between the categories, Indiana falls under Tier II because the extensive volunteer and training requirements are dedicated to helping persons by using a broader range of services, and are not specifically aimed only at SDM for incapacitated persons. Oregon has implemented another Tier II example, focused primarily on training advocates in SDM. The Arc Oregon advocates for the rights of children and adults with I/DD to fully participate in the community. Arc Oregon's Supported Decision-Making Train-the-Trainer Project is a "collaboration with community partners" to develop a training program for professionals, families, and the community.<sup>445</sup> The program aims to raise awareness of opportunities available to families and children with I/DD when they turn eighteen.<sup>446</sup> Through this awareness and training, Arc Oregon hopes to develop an expanded community of advocates to represent the successes of SDM.<sup>447</sup>

The more formal Guardianship, Advocacy and Planning Services (GAPS) program offers another service-oriented option for transitioning children or families struggling to support their child with I/DD.<sup>448</sup> In addition to SDM, the website notes that GAPS supports over 70 adults as legal guardian, health care representative, and/or advocate. The underlying principles of GAPS, however, remain the same as Arc Oregon's overall mission: to treat everyone with dignity and respect, and encourage self-reliance and independence to the greatest extent possible.<sup>449</sup> This means using "legal guardianship only as a last resort."<sup>450</sup>

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<sup>445</sup> See THE ARC OREGON, *supra* note 435.

<sup>446</sup> *Id.*

<sup>447</sup> *Id.*

<sup>448</sup> *Guardianship, Advocacy, and Planning Services*, THE ARC OREGON, <https://thearcoregon.org/what-we-do/programs/gaps/> (last visited Feb. 13, 2019).

<sup>449</sup> *Id.*

<sup>450</sup> *Id.*



Vermont is situated similarly to Oregon as a Tier II program because the state's pilot was established to create a culture of SDM throughout Vermont.<sup>451</sup> The program created a Task Force on Supported Decision-Making to oversee two subgroups tasked with accomplishing specific goals.<sup>452</sup> The first goal of establishing the program was achieved in collaboration with Upper Valley Services, public guardians, guardianship evaluators, attorneys and the Attorney General's Office.<sup>453</sup> Upper Valley Services is a nonprofit organization that is dedicated to serving those who are developmentally disabled in Vermont.<sup>454</sup> Public guardians and guardianship evaluators are part of Vermont's Office of Public Guardian, which is part of the larger Developmental Disabilities Services Division (DDSD).<sup>455</sup> This project

is designed to: (1) Identify 5-7 people currently under public guardianship who can direct their own lives with appropriate supports and services; (2) Convene a team for each person that will plan, create a written document that memorialize the supports and put those supports in place; (3) Conduct a new capacity evaluation for each person that reviews his/her functional ability to direct his/her own life with those supports; and (4) File a petition asking the Court to terminate the guardianship for each person for whom the evaluation shows that he/she can direct his/her own life.<sup>456</sup>

A second goal of the Task Force subgroups was completed in collaboration with the Disability Law Project (DLP) of Vermont Legal Aid which represents youth turning eighteen in probate court guardianship proceedings in the Northeast Kingdom of Vermont.<sup>457</sup> The Green Mountain Self Advocates (GMSA) is an advocacy group that aims for people with developmental

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<sup>451</sup> DAIL *supra* note 412, at 1.

<sup>452</sup> *Id.*

<sup>453</sup> *Id.*

<sup>454</sup> UPPER VALLEY SERVICES, <https://uvs-vt.org/> (last visited March 9, 2019).

<sup>455</sup> *Developmental Disabilities Services Division Office of Public Guardian*, VERMONT OFFICIAL STATE WEBSITE, <https://ddsd.vermont.gov/programs/public-guardian> (last visited March 9, 2019).

<sup>456</sup> DAIL *supra* note 412 at 1.

<sup>457</sup> *Id.*

disabilities to educate peers to take control of their lives.<sup>458</sup> Working with the DLP and GMSA, the Task Force sought to “develop standard supported decision-making agreements which will assure that youth with disabilities are empowered to make their own decisions affecting their lives, with the support they need to have the information necessary to make those decisions, including decisions concerning their education, employment and health care.”<sup>459</sup>

As a result of this program, in 2017, the Vermont Superior Court issued a court order vacating a guardianship in favor of a Supported Decision-Making Agreement which “detailed the type of decision-making support the individual needs and the people the individual chose for support.”<sup>460</sup>

There are clear future steps the Task Force aims for. First, the Task Force states that it will review the current Vermont Capacity Guidelines and seek to amend them appropriately to determine whether an individual should be placed under guardianship.<sup>461</sup> There are guidelines the Task Force itself brainstormed with the first coalition, involving the Upper Valley Services, guardians from the Office of Public Guardian, and attorneys from the Attorney General’s office. These guidelines will need to be renewed and adapted in accordance with each new finding from the pilot program.

The second future step the Task Force aims to accomplish is developing model procedures in conducting capacity evaluations.<sup>462</sup> This step would progress in answering the “what” and “how” questions: What do we use in assessing the guidelines? What elements, factors, interactions, if any, do we look for in determining capacity? How do we determine the different degrees of

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<sup>458</sup> *Mission of Green Mountain Self-Advocates*, GREEN MOUNTAIN SELF-ADVOCATES, <http://www.gmsavt.org/gmsa-mission/> (last visited March 9, 2019).

<sup>459</sup> DAIL *supra* note 412, at 1-2.

<sup>460</sup> *Id.* at 2.

<sup>461</sup> *Id.*

<sup>462</sup> *Id.*

capacity? How do we construct recommendations that reflect concerns from varied communities? This step is the substantive portion of the first step, to figure out how to implement new guidelines with real people and put the evaluations into practice. Given the individualized nature of SDM the first two steps are not concrete, but constantly evolving and shaping to the needs of the person with a disability.

Lastly, the Task Force will focus on promoting and spreading awareness of SDM. Grassroots support and involvement is imperative in the progress of the movement. As communities become aware of and advocate for SDM, partnerships will likely form and create advocacy groups along with strategic awareness campaigns, which will be vital in disseminating information on the benefits of an SDM approach.<sup>463</sup>

These examples show that Tier II programs play a key role in guiding many different communities. Whereas Tier I pilots generally allow for the community to guide the program, and Tier III provides services to a target group, Tier II programs have the distinct advantage of understanding the perspective of diverse stakeholders and training these members to improve their effectiveness in the SDM system as a whole. This is a challenging approach because opinions may vary significantly between audiences on how best to allocate resources and efforts within the system. However, Tier II programs must acknowledge and develop targeted training materials to support the range of existing perspectives. From this vantage point, Tier II programs play a critical role in the SDM advocacy movement.

### **3. Tier III Pilot Programs**

Finally, Tier III programs are likely to involve elements of Tier I and Tier II programs due to the fundamental importance of building awareness, training, and resources for advocates.

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<sup>463</sup> *Id.*

However, these programs are more comprehensive in that the scope includes providing services directly to individuals and families in need of SDM. These efforts are focused on establishing a substantive network of advocates and supporters to strengthen a viable SDM agreement for appropriate individuals.

Massachusetts, Texas, New York, and North Carolina are examples of Tier III pilot programs that successfully implemented and studied SDM. Efforts are being made to expand on the pilot programs' successes by implementing more programs, and to test SDM across different geographic areas of the states. The discussion below begins with Massachusetts, as the Massachusetts program was very robust because it built on the successes of some of the other programs.

Legal obstacles are often present when there is a systematic attempt to switch from a customary practice to something new and innovative. Courts, albeit sometimes justifiably, are often hesitant to take innovative practices seriously when no data is available to prove the effectiveness and the safety of an alternative solution. Guardianship has long been the customary form of intervention for people with I/DD, but less restrictive alternatives like SDM are highly promising.

In 2013, the overuse of guardianship was identified as an issue adversely affecting disability rights.<sup>464</sup> The Center for Public Representation (CPR), a nonprofit law firm focusing on disability rights in Massachusetts and around the country, and others recognized SDM as an appropriate response to these ongoing, systemic problems, and sought to prioritize a SDM pilot.<sup>465</sup> Accordingly, in 2015, CPR sought to implement a pilot program in order to gather data and

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<sup>464</sup> ELIZABETH PELL & VIRGINIA MULKERN, SUPPORTED DECISION MAKING PILOT: PILOT PROGRAM EVALUATION YEAR 1 REPORT 5 (2015).

<sup>465</sup> *Id.*

feedback on SDM.<sup>466</sup> CPR partnered with Nonotuck Resource Associates, Inc. (Nonotuck), to offer persons with I/DD living in western Massachusetts an opportunity to try SDM as a less restrictive alternative to guardianship.<sup>467</sup> CPR later contracted with a nonprofit research and consulting organization, the Human Services Research Institute (HSRI), to conduct an independent evaluation of the pilot and to report its findings.

HSRI issued two comprehensive reports on the pilot program. The Year One report focused on the steps to achieve pilot establishment, participant selection, SDM adoption, and outreach and awareness activities.<sup>468</sup> The report included thirty-three enumerated practice recommendations, which were intended as tips and guidelines for future SDM pilots.<sup>469</sup> The Year Two report followed the sequential stages of the pilot's development.<sup>470</sup> It presented SDM pilot findings as well as potential implementation challenges. Some of these challenges occurred while the pilot was taking place, while others were simply observations that HSRI flagged as potentially problematic in the future.<sup>471</sup> The report also took a deep dive into the experiences of each of the participants of the program, including adopters, supporters, and staff members.<sup>472</sup>

The pilot program consisted of nine adults, resulting in seven executed SDM arrangements.<sup>473</sup> The Year One report stated that "CPR and Nonotuck staff engaged in SDM conversations with nine adults . . . and executed SDM arrangements for seven;"<sup>474</sup> however, the

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<sup>466</sup> See ELIZABETH PELL & VIRGINIA MULKERN, SUPPORTED DECISION MAKING PILOT: PILOT PROGRAM EVALUATION YEAR 1 REPORT (2015).

<sup>467</sup> *Id.* at 5.

<sup>468</sup> See PELL & MULKERN, *supra* note 466.

<sup>469</sup> See *Id.*

<sup>470</sup> ELIZABETH PELL & VIRGINIA MULKERN, SUPPORTED DECISION MAKING PILOT: PILOT PROGRAM EVALUATION YEAR 2 REPORT 4 (2016).

<sup>471</sup> See ELIZABETH PELL & VIRGINIA MULKERN, SUPPORTED DECISION MAKING PILOT: PILOT PROGRAM EVALUATION YEAR 2 REPORT (2016).

<sup>472</sup> *Id.* at 15.

<sup>473</sup> PELL & MULKERN, *supra* note 464, at 15.

<sup>474</sup> *Id.*

report also stated that six females and two males were pilot participants.<sup>475</sup> One of the pilot participants was still considering entering into an SDM agreement when HSRI issued the Year One report.<sup>476</sup> The adopters differed in cognitive abilities and age.<sup>477</sup> The youngest participant was twenty-four years old, while the oldest was seventy-nine years old.<sup>478</sup> Most of the participants had moderate intellectual disabilities, while two had mild intellectual disabilities, and one had never been formally diagnosed with an intellectual disability.<sup>479</sup> Five adopters never lived in any kind of institution for persons with disabilities, two lived for decades in different Massachusetts state institutions, and one lived in residential schools between the ages of nine and twenty-two and subsequently lived in a group home until her late twenties.<sup>480</sup>

In the early stages of the pilot program, Nonotuck staff members met numerous times with each of the individuals previously identified as likely prospects for SDM adoption.<sup>481</sup> The report noted that multiple meetings were necessary during the educational phase of the pilot because sometimes it was difficult at times to gauge whether the prospective adopters understood SDM as a concept, and to ensure that they did before proceeding.<sup>482</sup> Most of these meetings were met with cordiality and enthusiasm. Only on one occasion was an insulting comment made by a family member.<sup>483</sup> CPR staff noted that any incredulity should be turned into a positive learning opportunity, as it could reasonably be assumed that any negative presumptions of SDM were probably due to a lack of general understanding of the concept as a whole.<sup>484</sup> Furthermore,

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<sup>475</sup> *Id.* at 20.

<sup>476</sup> *Id.* at 19.

<sup>477</sup> *Id.* at 1.

<sup>478</sup> *Id.* at 20.

<sup>479</sup> *Id.*

<sup>480</sup> *Id.*

<sup>481</sup> *Id.* at 29.

<sup>482</sup> *Id.* at 1.

<sup>483</sup> *Id.* at 17.

<sup>484</sup> *Id.*

directing conversation and questions to the prospective adopter was found to be more productive than engaging only with the caregiver or family member.<sup>485</sup>

After adopters were chosen for the pilot, they had to select supporters. The most common supporters were family members, though some participants also selected friends without disabilities, care managers, live-in caregivers, and other paid caregivers.<sup>486</sup> Perhaps most interesting was the number of supporters chosen by the participants. None of the participants selected only one supporter; five participants selected three or more supporters, and one participant chose ten supporters.<sup>487</sup> The adopters were encouraged to be independent in their selection process, but often times CPR staff needed to explain why one supporter rather than another would be better for the purpose of decision-making, particularly when financial or health matters were under consideration.<sup>488</sup>

The decision-making process itself was also an area of focus for all of the participants. Adopters and supporters engaged in extensive conversations regarding how decisions would be discussed and decided. Agreements were maintained and, in some cases, modified if the adopter changed their mind about the decision-making process.<sup>489</sup> The SDM documentation aimed to use plain language and to avoid legal jargon when possible.<sup>490</sup> CPR also put structural safeguards into place, including free legal assistance, the ability to withdraw from the pilot at any time, and monthly care manager monitoring.<sup>491</sup>

Dr. Michael J. Kendrick, an international disability rights advocate and a key voice on SDM, observed that “[e]veryone has the right to make the wrong decision, but if you don’t have

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<sup>485</sup> *Id.*

<sup>486</sup> *Id.* at 21.

<sup>487</sup> *Id.* at 23.

<sup>488</sup> *Id.* at 21.

<sup>489</sup> *Id.* at 25.

<sup>490</sup> *Id.* at 26.

<sup>491</sup> *Id.* at 31.

the right you can't make the right or wrong decision.”<sup>492</sup> He went further to suggest that guardianship really should be thought of as an alternative to SDM, rather than vice versa, as commonly understood.<sup>493</sup> This decision-making principle was observed and upheld during the second phase of the Massachusetts pilot program. From March of 2015 through July of 2016, the nine adopters made seventy-two SDM decisions.<sup>494</sup> These decisions covered a range of topics including health and dental care, finances, socialization and leisure, employment, intimate relationships, legal matters, living arrangements, mental and behavioral health, and even one SDM arrangement decision.<sup>495</sup>

Consistent with Dr. Kendrick's words, supporters understood that SDM adopters should be able to make “bad” decisions as well as “good” ones.<sup>496</sup> The supporters were cognizant that agreement with the adopter about the correctness of a decision was unnecessary.<sup>497</sup> Avoiding harmful consequences of a “bad” decision did occasionally shape the choices laid out by the supporter in order to keep an individual adopter safe, but the duty to uphold an adopter's decision-making autonomy was taken seriously by all of the supporters participating in this pilot.<sup>498</sup> Eight of the nine adopters stated that they were given the right and the ability to make decisions about their own lives.<sup>499</sup> Additionally, the supporters perceived that the adopters understood SDM to mean making decisions on their own, but also that it was meant to provide a mechanism in order to seek out decision-making help from one or more of the dependable relationships between parties.<sup>500</sup>

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<sup>492</sup> PELL & MULKERN, *supra* note 470, at 10.

<sup>493</sup> Interview with Dr. Michael Kendrick, Indep. Disability Rights Consultant, in Boston, Mass. (Feb. 6, 2019).

<sup>494</sup> PELL & MULKERN, *supra* note 470, at 4.

<sup>495</sup> *Id.* at 13.

<sup>496</sup> *Id.* at 10.

<sup>497</sup> *Id.* at 12.

<sup>498</sup> *Id.* at 16.

<sup>499</sup> *Id.* at 15.

<sup>500</sup> *Id.*



One potential SDM implementation challenge relates to the balance between decision-making autonomy and the concern for the adopter's safety. HSRI observed that "[w]here there are dual responsibilities for ensuring safety and offering opportunities for risk-taking, decision supporters may limit or restrict information without advising the SDM adopter that they have done so."<sup>501</sup> State standards in Massachusetts require care providers to promote an individual's self-determination and decision-making autonomy to the fullest extent possible.<sup>502</sup> Some of this autonomy inevitably lends itself to risk for an individual. However, Massachusetts also requires care providers to ensure that an individual's safety and well-being are not unreasonably jeopardized.<sup>503</sup> In this pilot, supporters aimed to balance these two interests; promoting autonomy, while ensuring the safety of the adopter was not unreasonably jeopardized.

The supporters who participated in this program were committed to its success. When there were multiple supporters, much of this success was due to the already established and ongoing communications between the parties.<sup>504</sup> CPR insisted that a supporter always be available to help an adopter as needed.<sup>505</sup> For example, all of the adopters had more than one supporter, and adopters utilized the supporters who were available if another was not for whatever reason.<sup>506</sup> There was ongoing cooperation across multiple supporters, which increased communication between adopters and supporters. CPR staff did point out that one potential problem could arise if the supporters communicated only with each other, discussing and making a decision, and only then presenting that decision to the adopter, but no evidence of such a problem was observed in this pilot even when more than two supporters were involved.<sup>507</sup>

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<sup>501</sup> *Id.* at 17.

<sup>502</sup> *Id.* at 17 n.16.

<sup>503</sup> *Id.* at 17.

<sup>504</sup> *Id.* at 19.

<sup>505</sup> *Id.* at 13.

<sup>506</sup> *Id.*

<sup>507</sup> *Id.* at 21.

In addition to internal success between adopters and supporters, there was great success between SDM participants and members of the community. Although most SDM decisions did not involve community members, the ones that did were accepted and acted upon without requests for documentation or proof of representation.<sup>508</sup> As a precautionary measure, it may be advisable to provide an “SDM participant license” or a copy of the SDM agreement to be carried by the adopter at all times, especially if a decision must be made in a doctor’s office or a financial institution.<sup>509</sup> No such problems occurred in this program, but that may have been due to the fact that a supporter was always present with an adopter when there was an interaction with a community member and thus was able to provide knowledge and assistance as needed. This may not always be the case in other pilots or with SDM in general, so it is important to provide adopters with tangible proof of SDM participation.<sup>510</sup>

Both adopters and supporters expressed satisfaction with SDM. Adopters were satisfied with their ability to make their own decisions, and supporters were satisfied with the decisions that they were a part of.<sup>511</sup> At times, adopters expressed varying levels of apathy with supporters, although this only occurred when a family member was a supporter.<sup>512</sup> This should not be alarming; it ought to be expected by most, if not all, family relationships. Additionally, more than one adopter elected to change his or her supporter.<sup>513</sup> This mechanism was intentionally built into the program as a way of satisfying the dynamic wants and needs of adopters, and also to reduce conflicts of interest.<sup>514</sup>

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<sup>508</sup> *Id.* at 23.

<sup>509</sup> *Id.*

<sup>510</sup> *Id.*

<sup>511</sup> *Id.* at 24.

<sup>512</sup> *Id.*

<sup>513</sup> *Id.*

<sup>514</sup> *Id.* at 25.

Most importantly, SDM adopters did not experience abuse, neglect or other forms of exploitation.<sup>515</sup> There was a general understanding by both parties that the elimination of all risk is impossible, and that strong relationships must be built on trust and mutual conversation.<sup>516</sup> Persons with intellectual disabilities are at extremely high risk for exploitation and abuse, but no such abuse occurred during this pilot and CPR staff maintains that this pilot did not increase the risk of abuse or neglect for any of the participants.<sup>517</sup> This being the case, SDM programs ought to require “periodic review of SDM-specific rights, values and principles with both adopters and decision supporters.”<sup>518</sup> Furthermore, “[a]lthough adopters and decision supporters were initially advised of their SDM-specific ‘rights,’ there was not a standardized list of rights or a protocol on the frequency or points in time . . . care managers or other pilot staff would remind adopters and decision supporters of SDM values and principles of SDM,” which could be helpful in ensuring that the adopter is not subjected to abuse or exploitation.<sup>519</sup>

The pilot program involved periodic monitoring and review.<sup>520</sup> Care managers visited adopters at least once a month to inquire as to the adopters’ satisfaction with SDM and to offer an opportunity to discuss any pressing concerns or current limitations.<sup>521</sup> In the future, an SDM-specific assessment or monitoring instrument should be developed and implemented as no formal oversight is currently available.<sup>522</sup> CPR proposed one such instrument whereby adopters and supporters can anonymously rank their satisfaction with various elements of SDM and then submit these rankings for review by some formal oversight body.<sup>523</sup>

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<sup>515</sup> *Id.*

<sup>516</sup> *Id.* at 26.

<sup>517</sup> *Id.*

<sup>518</sup> *See* PELL & MULKERN, *supra* note 471.

<sup>519</sup> *Id.* at 28-29.

<sup>520</sup> *Id.* at 26.

<sup>521</sup> *Id.* at 29.

<sup>522</sup> *Id.*

<sup>523</sup> *Id.* at 30.

SDM had a demonstrable impact on adopters' lives. Positive results included "increased pride, increased self-confidence, increased happiness, trying new experiences, taking more control of their own health care, and helping others more."<sup>524</sup> Additionally, for the families already utilizing SDM, formalizing the process was comforting to parents and relatives.<sup>525</sup> None of the adopters, supporters, or CPR staff expressed negative attitudes toward SDM or its impact on the lives of participants.<sup>526</sup> Although one supporter was unsure of the impact SDM had and was uncomfortable affirmatively stating that there had been positive improvements, the supporter did not express any negative views.<sup>527</sup>

After the completion of this pilot, the participants continued using SDM and legally-recognized decision-making authorities increased.<sup>528</sup> This pilot intentionally limited the scope of decision-making authority for logistical reasons, but the strong results suggest that authorities can and ought to be expanded to a wide variety of adopter experiences in banking, managing funds, and for people who are receiving publicly-funded services.<sup>529</sup>

The most vocal criticism of SDM alleges that SDM will be abused.<sup>530</sup> Robert Fleischner, a former attorney for CPR who helped draft the initial SDM legislation now under consideration in the Massachusetts legislature, has spoken extensively about the safeguards available to SDM participants.<sup>531</sup> One example of a safeguard is that supporters have the ability to report abuse to their support team, which is almost always made up of more than one person, and usually has between five and ten supporters.<sup>532</sup> Conversely, a person under guardianship is only appointed one

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<sup>524</sup> *Id.* at 31.

<sup>525</sup> PELL & MULKERN, *supra* note 464, at 17.

<sup>526</sup> PELL & MULKERN, *supra* note 470, at 31.

<sup>527</sup> *Id.* at 32.

<sup>528</sup> *Id.* at 7.

<sup>529</sup> *Id.* at 43.

<sup>530</sup> Telephone Interview with Robert Fleischner, Retired Partner, Center for Public Relations (Feb. 22, 2019).

<sup>531</sup> *Id.*

<sup>532</sup> *Id.*

guardian, who may be the person perpetuating the abuse. Unlike with guardianship where the guardian could be a stranger, supporters in an SDM arrangement are chosen by the adopter and many who participated in the pilot were case managers in shared living, which is defined as “people with disabilities sharing a home with people without disabilities who receive a stipend for providing care.”<sup>533</sup> Many were not case managers, but were nonetheless participants in shared living.<sup>534</sup> Shared living participants are often the people closest to the adopters, as they have had a long enough period of time together time to build a trusting relationship.<sup>535</sup>

Spreading the word about the success of the pilots is critical, as it provides evidentiary support to the notion that abuse and neglect are rare when SDM is used. However, Fleischner recommended being cautious about pushing SDM expansion too quickly, as right now there is simply too much demand for SDM in relation to the amount of resources available to use it correctly.<sup>536</sup> These are not agreements that can be routinely implemented in an attorney’s office in one afternoon, for instance. Rather, these agreements must be thoughtfully and carefully considered by all the relevant parties. In the CPR pilot, each participant took hours over the course of many meetings to work through and complete the SDM agreement form.<sup>537</sup>

SDM is still a relatively new practice, thus much of the current work should focus on outreach and awareness in the community. In this pilot, there was extensive outreach in the community across both years of the pilot, but as SDM is still a newly recognized way of thinking about an individual’s autonomy and decision-making authority, much more awareness and education are needed. Promotion and dissemination in the form of conference presentations,

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<sup>533</sup> PELL & MULKERN, *supra* note 464, at 1.

<sup>534</sup> Fleischner, *supra* note 530.

<sup>535</sup> *Id.*

<sup>536</sup> *Id.*

<sup>537</sup> *Id.*

consultations, webinars, publication and resource documents, continuing legal education, and so forth are vital to the continued success of SDM. Based on this pilot, there is no evidence that professionals within the community reject its practice as a whole, or that they would be unwilling to adhere to the decisions made by adopters, but any hesitation that does exist is probably due to a lack understanding and not because of a moral objection. This pilot provides great evidentiary weight to the assertion that SDM is a viable framework for individuals with disabilities. There is great potential to reduce the number of guardianship appointments because of the great success SDM has had so far. Nevertheless, there is still a presumption in society that guardians are informed and knowledgeable about the rights and the needs of the individuals they make decisions for, however wrong this presumption may be. SDM may not be a viable alternative for every person with a cognitive disability, but when it is a potential alternative it ought to be explored. For detailed findings and recommendations from the pilot program see Appendix V.

To date, the Massachusetts pilot program is the most comprehensive of the Tier III programs. This is in part because the designers had the successes of prior programs to build from. Texas, for instance, was the first state to pass an SDM statute in 2015, and was also the first state to run a pilot program beginning in 2009.<sup>538</sup> The Texas pilot is also a Tier III program, and several states looked to the success that Texas had with its pilot program as a model to form their own programs. In fact, many ideas even beyond the pilot program have been pulled by other states from the Texas model, including much of the Texas statute.<sup>539</sup>

The Texas legislature passed H.R. 1454 in 2009, which issued the pilot program.<sup>540</sup> The Texas Council for Developmental Disabilities (TCDD) and the Department of Aging and

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<sup>538</sup> H.R. 1454, 81st Leg., Reg. Sess. (Tex.2009); *see also* TEX. ESTATES CODE ANN. §§ 1357.001-1357.102 (West, Westlaw through 2017 Reg. Sess.).

<sup>539</sup> Fleischner, *supra* note 530.

<sup>540</sup> H.R. 1454, 81st Leg., Reg. Sess. (Tex. 2009).

Disability Services (DADS) took on this venture.<sup>541</sup> As Texas was the earliest to explore and integrate SDM into law, there are common and enduring themes that were present even in the 2009 bill. Some language from the bill stated that it was designed “to enable the person to make life decisions... without impeding the self-determination of the person.”<sup>542</sup> Some goals of H.R. 1454 included funding and creating a plan for a model of study. In creating and establishing these models, the Legislature at the time of enacting the bill also recognized the importance of environment and demographics.<sup>543</sup> For example, H.R. 1454 stated that “[t]he commission shall select at least one rural community and at least one urban community in which to implement the program.”<sup>544</sup> The urban communities and rural communities of Texas are vastly different; some key differences involve transportation, hospitals, emergency services, vast economic differences, and geography.<sup>545</sup> Next, the bill aimed to evaluate and analyze the findings from the pilot program which explicitly included analyzing hands on experiences. The legislature explicitly indicated that “[t]he commission shall ensure that the pilot program provides supported decision-making services to persons living in the community.”<sup>546</sup> Lastly, H.R. 1454 aimed to have The Arc of San Angelo, as administrator of the pilot program, report its findings back to the Legislature.<sup>547</sup>

Volunteer supporters underwent mandatory training before they could participate in the program. This training included learning what constitutes “Informed Consent,” “Substituted Judgment,” and “Best Interest.”<sup>548</sup> The curriculum also involved analyzing the risks and benefits

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<sup>541</sup> *Id.*

<sup>542</sup> *Id.* § 531.02446(5)(a).

<sup>543</sup> H.R. 1454, 81st Leg., Reg. Sess. (Tex. 2009).

<sup>544</sup> *Id.* § 531.02446(5)(b)

<sup>545</sup> Sydney Murphy, Opinion, *In Texas, rural and urban must unite against a common threat*, HOUSTON CHRONICLE (Jan. 9, 2019), <https://www.houstonchronicle.com/opinion/outlook/article/In-Texas-rural-and-urban-must-unite-against-a-13518952.php>.

<sup>546</sup> H.R. 1454, 81st Leg., Reg. Sess. § 531.02446(5)(e) (Tex. 2009).

<sup>547</sup> *Id.* § 531.02446(5)(g)

<sup>548</sup> THE ARC OF SAN ANGELO, ALTERNATIVES TO GUARDIANSHIP: VOLUNTEER-SUPPORTED DECISION-MAKING PILOT 2 (2012) (available for download at <https://sdmny.org/download/arc-of-san-angelo-evaluation-supplemental-report-ii-2012/>).

of both SDM and guardianship. The staff was partly comprised of social work interns from a partnership with Arizona State University, along with other scouted volunteers.<sup>549</sup>

Participants were mostly referred to the program by family members and county courts.<sup>550</sup> Program directors met with participants to see whether the initial goals set out for the study would align with the participants' goals and benefit the participants.<sup>551</sup> Individuals that were deemed to be at immediate risk of guardianship in the absence of intervention took priority.<sup>552</sup> The participants also underwent training, but the trainings were varied and specifically tailored to their disabilities and challenges.<sup>553</sup> Action plans were developed based on individual needs; nineteen people worked on the design of the project, three of whom had developmental disabilities.<sup>554</sup> More importantly, as the program progressed, roughly 350 people attended trainings through networking, interactive educational sessions, and a specific, more comprehensive five-day training called the Leadership Academy PLUS training session.<sup>555</sup> (See chart in Appendix VI). Program accomplishments in the 2012 report included the following:<sup>556</sup>

- Restoration of rights to one individual.
- Provided info and assisted four individuals who eventually avoided guardianships.
- Assisted in establishing Advance Directives thru Medical Power of Attorney for ten individuals, preventing unwarranted guardianship restrictions (Found that in Texas, Medical Power of Attorney ultimately springs from the doctor).

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<sup>549</sup> *Id.* at 2.

<sup>550</sup> *Id.*

<sup>551</sup> *Id.*

<sup>552</sup> *Id.*

<sup>553</sup> *Id.*

<sup>554</sup> *Id.*

<sup>555</sup> *Id.*

<sup>556</sup> *Id.* at 2-3



- Diverted *two* individuals in the investigative stage for guardianship, to this study as the least restrictive alternative.
- Provided guidance and general assistance to fifteen individuals and their families.

Active volunteers led training sessions for future volunteers and participants and also worked directly with individuals.<sup>557</sup> However, there were many tedious tasks and time-consuming processes; pairing volunteers and participants, the trainings themselves, and building trust over time were factors to consider in allocating resources.<sup>558</sup> Despite the numerous benefits of the program, the “one-on-one factor” was definitely costly.<sup>559</sup>

Matching a client with a volunteer was a very time-consuming and individualized process. Some specific barriers that arose were scheduling conflicts and time constraints.<sup>560</sup> The staff who oversaw the program were overloaded with administration of the program including recruiting, training, matching, and paperwork, all while working directly with the clients as supporters.<sup>561</sup>

There was also some potential conflict with the existing state law in Texas. The Texas Probate Code contained an immunity clause protecting the guardianship program from any civil liability.<sup>562</sup> This pilot program provided direct services to people who were possibly eligible for either guardianship<sup>563</sup> or SDM.<sup>564</sup> However, the presence in the clause of the words “to a ward” cast doubt regarding the protection of the pilot program, since the term generally is only applied to individuals under guardianship.<sup>565</sup> Legal research and consultation later determined that the

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<sup>557</sup> *Id.* at 2.

<sup>558</sup> *Id.*

<sup>559</sup> *Id.* at 3.

<sup>560</sup> *Id.* at 2.

<sup>561</sup> *Id.* at 3.

<sup>562</sup> TEX. PROB. CODE ANN. §674 (West, Westlaw through 2017 Reg. Sess.)

<sup>563</sup> *Id.*

<sup>564</sup> THE ARC OF SAN ANGELO, *supra* note 548, at 2.

<sup>565</sup> TEX. PROB. CODE ANN. §674 (West, Westlaw through 2017 Reg. Sess.)

liability was not a concern.<sup>566</sup> Chapter 84 of the Charitable Immunity and Liability of the Texas Practice and Remedies Code says that volunteers acting on behalf of charitable organizations are not to be held liable, assuming that all actions were within the scope of the pilot program.<sup>567, 568</sup>

A priority for the program, which proved beneficial, was training all participants about the medical power of attorney in Texas.<sup>569</sup> The concept of informed consent means that the patient fully understands the procedure. This understanding was essential to each individual's contributions to the project in the bigger picture. It was important that this grassroots movement was well guided, with clear goals to induce change in the community.

In addition to the robust pilot programs in Texas and in Massachusetts, New York implemented a similar Tier III program. New York's pilot program, SDMNY, encompasses a broad scope of activities and goals including educational campaigns, facilitation programs, and advocacy efforts. SDMNY offers a variety of educational resources through its website and through in-person trainings to educate a variety of stakeholders who may be involved in the SDM process.<sup>570</sup> This includes resources, materials and trainings focused toward supported persons, supporters, parents, attorneys, professionals, and other advocates.

The SDMNY facilitation model incorporates a provided facilitator to work with the person with intellectual or developmental disabilities (I/DD), who is called the "Decision-Maker" (DM), through three phases of identifying supporters and negotiating a Supported Decision-Making Agreement (SDMA).<sup>571</sup> "Facilitators" are trained or experienced persons recruited from areas such

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<sup>566</sup> THE ARC OF SAN ANGELO, *supra* note 548, at 2.

<sup>567</sup> *Id.* at 4.

<sup>568</sup> Texas law provides that a volunteer of a charitable organization is immune from civil liability as long as the act or omission does not arise from the operation or use of a motor vehicle including airplanes. TEX. CIV. PRAC. & REM. CODE ANN. §84.004(d) (West, Westlaw through 2017 Reg. Sess.).

<sup>569</sup> THE ARC OF SAN ANGELO, *supra* note 548, at 4.

<sup>570</sup> SUPPORTED DECISION-MAKING NEW YORK, <https://sdmny.org> (last visited Feb. 13, 2019).

<sup>571</sup> *What We Do*, SUPPORTED DECISION-MAKING NEW YORK, <https://sdmny.org/about-sdmny/> (last visited Feb. 13, 2019).

as social work programs and occupational therapy programs.<sup>572</sup> They receive a two-day intensive training and ongoing supervision from “mentors.”<sup>573</sup> Once an SDMA is signed, the “facilitator” or “mentor” will check in with the DM and supporters on a monthly basis and continue to be available for 6 months after.<sup>574</sup>

New York outlines recommended steps for SDM viability, implementation, and enforcement:<sup>575</sup>

- (1) Educate stakeholders, including persons with I/DD, parents and family members, providers, the educational system, judges, lawyers, and the court system, healthcare providers, and financial institutions. Pilot programs may be effective in this respect.
- (2) Acceptance of SDMA by governmental agencies with which persons with I/DD and their families interact
- (3) Court and attorney recognition of SDM as a constitutionally-required less restrictive alternative to guardianship, or to restore rights to persons currently subject to guardianship
- (4) Incorporate SDM in educational transition planning and teach decision-making skills as part of the curriculum
- (5) Pass legislation so that private third parties can accept SDMA without fear of potential liability, and are required to do so as a matter of law
- (6) Ensure sustainability through Medicaid funding

The New York model is undoubtedly one of the most comprehensive and successful examples of SDM in action. In collaboration with the Cooke School and Institute, the SDMNY

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<sup>572</sup> *Id.*

<sup>573</sup> *Id.*

<sup>574</sup> *Id.*

<sup>575</sup> *An Agenda for Change in NYS, SUPPORTED DECISION-MAKING NEW YORK*, <https://sdmny.org/for-advocates/> (last visited Feb. 13, 2019).

program will have two students to be the first young adults to sign agreements “outlining their wishes for how they want to make decisions in the future.”<sup>576</sup> Two additional students are in the process of drafting their agreements as part of the project.<sup>577</sup>

In addition to New York, Massachusetts, and Texas, North Carolina implemented a Tier III program to pilot SDM. Currently, there is not a report detailing the specifics of the program, but it is comprehensive enough in its size and scope to render it a Tier III program.

The First in Families of North Carolina (FIFNC) Program received funding from the National Resource Center for Supported Decision-Making’s State Grant Program to pilot SDM for individuals with developmental disabilities and older adults.<sup>578</sup> Specifically, FIFNC has a subset initiative called Lifetime Connections that is focused on offering support and planning services to people with all types of disabilities and their families.<sup>579</sup> Their membership-based services are tailored to the needs of the individual or family. Lifetime Connections first aims to educate families about the options available to individuals with disabilities, including SDM, as it provides support to vulnerable individuals while “protecting their autonomy and dignity.”<sup>580</sup>

Further, FIFNC works to identify and train individuals with developmental disabilities, their families, and other members in the community. Workshops and services conducted focus on future planning with such topics as wills & estates planning and letters of intent.<sup>581</sup> Core to these

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<sup>576</sup> Renée Nicholson, *Young Adults at SKILLS First to Sign NYS Supported Decision-Making Agreements*, COOKE SCHOOL AND INSTITUTE (Sept. 24, 2018), <https://cookeschool.org/2018/09/27/sdm/>.

<sup>577</sup> *Id.*

<sup>578</sup> Debby Torres, *First in Families of North Carolina Receives Grant*, FIRST IN FAMILIES OF NORTH CAROLINA (Jun. 29, 2015), <http://fifnc.org/programs/PRAboutSupportedDecisionMaking.pdf>.

<sup>579</sup> *Lifetime Connections*, FIRST IN FAMILIES OF NORTH CAROLINA, <http://fifnc.org/programs/connections.html> (last visited Feb. 13, 2019).

<sup>580</sup> *Id.*

<sup>581</sup> *Id.*

services is FIFNC's "Personal Network" assistance, which is a group of volunteers who provide advocacy and assist a disabled individual in meeting life goals.<sup>582</sup>

Overall, the process outlined by Lifetime Connections aims to create an agreement as a written document that "ensures the individual's choices are protected but is also mindful of areas of vulnerability."<sup>583</sup> The materials available on the site point to a broad goal of strengthening existing relationships and involving others as needed to protect individual moral authority.<sup>584</sup> The site notes that this process may also be effective to petition for partial guardianship.<sup>585</sup>

All of the Tier III pilot programs have achieved high levels of success. The Massachusetts pilot is the gold standard thus far, but other states continue to experiment with SDM both as a way to better understand logistically how SDM can happen, and to study the effect on decision-making autonomy and self-determination. While these effects have been extremely positive, expansion of SDM must be achieved slowly but comprehensively in order to ensure that resources are available to administer the program appropriately. For example, in Massachusetts, the pilots enacted only reached the western part of the state. The cultural and ideological differences geographically may have an effect on the success of SDM. One of the most important things the pilots can teach us is that understanding of SDM is nuanced depending on who is involved with it. Advocates of SDM must be conscious of these nuances to further its goals and principles.

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<sup>582</sup> *Lifetime Connections: Personal Network*, FIRST IN FAMILIES OF NORTH CAROLINA, [http://fifnc.org/programs/personal\\_networks.html](http://fifnc.org/programs/personal_networks.html) (last visited Feb. 13, 2019).

<sup>583</sup> FIRST IN FAMILIES OF NORTH CAROLINA, ABOUT SUPPORTED DECISION-MAKING AGREEMENTS (2015), <http://fifnc.org/programs/aboutsdmafif63015.pdf>.

<sup>584</sup> *Id.*

<sup>585</sup> *Id.*

## **CRITICAL PERSPECTIVES AND RESPONSES**

Numerous benefits of supported decision-making (SDM) have been detailed above. Nothing is more important or more intrinsic to human life than the right to choose. The human rights of impaired and developmentally disabled adults are the biggest issues to consider when discussing SDM. There are numerous policymakers, scholars, and advocates who do well in distinguishing the fundamental rights gained by implementing SDM over guardianship. However, there are few who do this while still recognizing the potential inadequacies and drawbacks of a formal SDM structure. The voices of opposition, often proponents of guardianship, have called into question various issues surrounding the efficacy and implementation of SDM. These critical responses must be weighed in order to properly define the scope, benefits, and limitations of SDM on a larger scale. Below, we will explore some of the perspectives challenging SDM in an effort to both discern possible responses to the critiques and also to offer a wider picture of SDM reform.

### **I. CRITICAL PERSPECTIVES**

In this section, we will explore some of the potential drawbacks to SDM in order to afford a more holistic view of the practice. Consequences of implementing SDM on the legal, social, criminal, financial, and health care systems are discussed, as well as issues with guardianship that still loom with the advent of SDM. In the section that follows, we will explore ideas to combat these various concerns.

The primary issue often presented while discussing the implementation and expansion of SDM is the scarcity of statistical data. This concern manifests itself in various considerations. Some use it to define the relatively new ground where SDM has been executed, while others use the lack of analysis on SDM's effects as a red light to halt reform. A Pennsylvania State Law

Review article entitled *Supported Decision-Making: A Viable Alternative to Guardianship*, discussed the lack of statistical studies historically and presently that examine SDM.<sup>586</sup> The authors explored the reason why statistical data is important, noting that “this lack of evidence is unfortunate not only because it means that we do not know whether supported decision-making is achieving its goals, but also because it makes it difficult to develop and support effective evidence-based supported decision-making practices.”<sup>587</sup> The article reasoned that many of the existing SDM studies have issues with sample size and the representative nature of the data collection.<sup>588</sup> Many adversaries of SDM believe that this poses a significant issue because policymakers base decisions on the statistical likelihood of effectiveness.<sup>589</sup> The article concluded that “significant research is needed to guide policy in this area if policymakers are to actually design and implement practices which effectively empower persons with disabilities.”<sup>590</sup>

Another point often posed by SDM critics is the relative nature of disability and mental illness and the possibility that SDM will not be effective in all cases. Many worry that there is a level of incapability not appropriate for SDM. Most proponents of this idea regard the lack of corresponding data as a leading cause for this issue. An article from *Psychiatry* titled *Supported Decision Making in Serious Mental Illness* explored this issue in detail. The article, written by medical doctors, looked at patients diagnosed with serious mental illness. This review of medical and legal literature depicts the useful nature of SDM.<sup>591</sup> The article ultimately concludes, however, that SDM needs to be researched in a broader and more comprehensive manner, stating that “[f]urther empirical research is needed to clarify candidates for SDM, decisions in need of support,

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<sup>586</sup> Kohn, *supra* note 95, at 1128.

<sup>587</sup> *Id.* at 1129.

<sup>588</sup> *Id.* at 1131.

<sup>589</sup> *Id.* at 1113-1114.

<sup>590</sup> *Id.* at 1155.

<sup>591</sup> Jeste, *supra* note 97.

selection of supporters, guidelines for the SDM process, integration of SDM with emerging technological platforms, and outcomes of SDM.”<sup>592</sup> The authors insisted that more must be determined before unified adoption of SDM over guardianship.<sup>593</sup> There is a critical distinction drawn between intellectually disabled persons and those with serious mental illness. The application of this distinction to SDM is founded in the arguments for more research but also persuasive to the arguments against completely replacing guardianship with SDM.

As discussed earlier, guardianship is often the default method of intervention for persons who need help making decisions because of their intellectual disabilities. The need for a guardian is determined by the court system, usually with guidance from health care experts. The article from *Psychology* articulated that there are no distinguishing levels of impairment with SDM as with guardianship, and why that is problematic.<sup>594</sup> While individuals under guardianship have little to no control over their decisions, some believe that moving persons to SDM would give decision-making power to those who are unfit for it.<sup>595</sup> The article argues that, without limits and established safeguards based on the free decision-making capacity of persons with intellectual disabilities, there could be confusion and unfortunate mistakes.<sup>596</sup>

The authors of the *Psychiatry* article found further issues of shifting to SDM persons with varying degrees of incapacity throughout life. They noted that, “[m]oreover, for persons with serious mental illness, symptoms tend to fluctuate over time, which may limit their ability to engage with and arrive at appropriate decisions through SDM.”<sup>597</sup> SDM fully recognizes the decision-making rights of those with intellectual disabilities, but it is argued that SDM doesn’t

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<sup>592</sup> *Id.* at 28.

<sup>593</sup> *Id.* at 29.

<sup>594</sup> *Id.* at 39.

<sup>595</sup> *Id.*

<sup>596</sup> *Id.* at 36.

<sup>597</sup> *Id.* at 39.



account for the inevitable degradation of those decision-making capacities as a person ages.<sup>598</sup> To this point, the article expounded that “research is needed to examine scenarios for when the choice for making decisions with the help of supports may be lessened or even restricted, and will be critical for developing standards and best practices in regard to use of SDM in such contexts.”<sup>599</sup> This evinces the idea that SDM may not be applicable in all contexts and it is integral to define how to measure those areas. This critique is connected to a lack of empirical data but also stands on its own as a predictive thought that exists when establishing a new system of care.

Thomas F. Coleman, the Legal Director of the Disability and Abuse Project of the Spectrum Institute in Northridge, California, stands as an outspoken voice on this issue of establishing SDM in place of guardianship.<sup>600</sup> Coleman has authored numerous articles for the Spectrum Institute on the critiques of SDM. He also leads many letter-writing campaigns to legislators on the efficacy of SDM and often consults on guardianship reforms and best practices to create effective change. As an advocate with a legal background writing numerous critiques of SDM, it is interesting to note that Coleman fully supports the basic reasoning behind SDM and its intended impact on disability rights.<sup>601</sup> Where Coleman differs from the most passionate supporters of SDM is in his belief that SDM has numerous drawbacks that stand at odds with guardianship.

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<sup>598</sup> *Id.*

<sup>599</sup> *Id.*

<sup>600</sup> See generally THOMAS COLEMAN, A REVIEW OF “MODEL LEGISLATION” FOR SUPPORTED MEDICAL DECISION-MAKING AGREEMENTS: THE DEFECTS ARE IN THE DETAILS 2 (2014), <http://disabilityandabuse.org/sdm-model-legislation.pdf>.

<sup>601</sup> THOMAS COLEMAN, SUPPORTED DECISION MAKING IS A RIGHT THAT NEEDS TO BECOME A REALITY (2018), <http://disabilityandabuse.org/sdm/sdm-right-into-reality.pdf>.

Coleman primarily believes that SDM is too de-regulative.<sup>602</sup> He fears the same abuse and restriction of liberties that occur with guardianship will occur with SDM because there is not enough form in its function.<sup>603</sup> He argues that “[b]ecause supported decision-making arrangements generally occur outside of the judicial system, they do not have the type of monitoring mechanisms that are built into guardianship proceedings.”<sup>604</sup> In one of his articles, Coleman argued that SDM is essentially privatizing guardianship.<sup>605</sup> This privatization argument centers on the idea that guardianship offers court-monitored safeguards against injustice while SDM will become a person-to-person network. Coleman worries that there may be a movement away from traditional court determination,<sup>606</sup> and he advocates instead for continued observation, stating that “[t]he exploration of SDM during a legal proceeding minimizes risks to the respondent and may eliminate potential liability to everyone involved if the SDM arrangement receives the approval of the court. In contrast, establishing a supported decision-making arrangement outside of a court proceeding increases the risk of abuse or exploitation of the adult in question.”<sup>607</sup>

Alongside his broad assumptions of potential risk, Coleman makes moving arguments regarding the capacity to contract, informed medical consent, conflicts of interest, and criminal law cases that could occur with SDM.<sup>608</sup> First, the capacity to contract could be an issue in an SDM framework. Coleman argues that if the capacity of the adult is ultimately determined to be questionable – meaning that the signee did not have informed consent at time of signing – any

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<sup>602</sup> See THOMAS COLEMAN, SUPPORTED DECISION-MAKING: A CRITICAL ANALYSIS, WHAT PUBLIC OFFICIALS, PROFESSIONALS, ADVOCATES, AND FAMILIES NEED TO KNOW Overview (2016), <http://spectruminstitute.org/sdm/sdm-report.pdf>.<http://spectruminstitute.org/sdm/sdm-report.pdf>

<sup>603</sup> *Id.*

<sup>604</sup> *Id.*

<sup>605</sup> *Id.* at 1.

<sup>606</sup> *Id.* at 2

<sup>607</sup> *Id.* at 3.

<sup>608</sup> *Id.*

contract they signed as their own decision under SDM could be questioned or even invalidated.<sup>609</sup> This same issue of informed consent arises with medical decisions. A physician is vulnerable to liability due to the fact that consent is required to perform treatment. If that consent is determined to be invalid by the incapacity to make such a decision, Coleman argues that a slippery slope could occur where medical providers are confused about consent with persons with I/DD under SDM.<sup>610</sup> Coleman believes that this problem is fostered by SDM and that “an order of guardianship, even a guardianship limited solely to the issue of medical decisions, would avoid this problem.”<sup>611</sup>

Coleman further points to potential conflicts of interest that may arise out of SDM agreements. Coleman uses the example of a person with I/DD presenting to an attorney with their supporter present; however, the lawyer is unable to represent both parties due to ethical concerns, especially in proceedings about an issue between the supported person and supporter.<sup>612</sup> Another particularly concerning legal consequence could emerge in criminal rape trials where the determination of informed consent depends on a measure of mental capacity in the victim. Coleman argues that guardianship addresses the ability of the ward to consent to sexual relationships, but under SDM this legal determination would be all but gone.<sup>613</sup> Coleman opines that this would lead to complications and injustices in the court system and leave individuals with disabilities incapable of consenting to sexual relations in a more vulnerable spot than under guardianship.<sup>614</sup>

Coleman’s arguments are founded on years of experience as a civil rights advocate. Coleman expressly believes in curtailing the oppressions under guardianship, but is also wary of

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<sup>609</sup> *Id.*

<sup>610</sup> *Id.* at 4.

<sup>611</sup> *Id.*

<sup>612</sup> *Id.*

<sup>613</sup> *Id.* at 5.

<sup>614</sup> *Id.*

the impacts of SDM.<sup>615</sup> As someone who has been entrenched in the guardianship system for years, Coleman brings a valuable point of view and offers a wealth of personal knowledge on the good and bad elements of guardianship. He also demonstrates the struggle of changing such an established system such as guardianship. This contention is also seen in a response to the National Council on Disability's report on SDM by the VOR (Voice of Reason), an advocacy organization for individuals with I/DD. As already discussed, the NCD's report, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities*, argued for the implementation of SDM over continued guardianship.<sup>616</sup> VOR rebuffed this idea, explaining that alternatives to court appointed guardianship might not be appropriate for many of the people they work with.<sup>617</sup> They contend that "[t]here must be recognition that ending guardianship for some people may be fraught with unintended and harmful consequences."<sup>618</sup>

Similar to the considerations presented in the *Psychology* article, VOR is worried that SDM may not be applicable to all disabled adults. VOR argues that their advocacy populations are often not representative of the populations discussed in the NCD's report.<sup>619</sup> They also believe that the current guardianship system is not broken but instead needs to be reformed to work more effectively.<sup>620</sup> VOR believes that the rights of those with severe disabilities might even be taken away by moving to SDM; "VOR maintains that problems with guardianship can be avoided through strong enforcement and monitoring and better access to information on guardianship. To eliminate guardianship or make it more difficult for family members and friends to become

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<sup>615</sup> THOMAS COLEMAN, SHOULD THE LIMITED CONSERVATORSHIP SYSTEM BE IMPROVED OR BE ELIMINATED ALTOGETHER 2 (2014), <http://disabilityandabuse.org/sdm/sdm-report.pdf>.

<sup>616</sup> HUGO DWYER, RE: NCD REPORT, MARCH 22, 2018, "BEYOND GUARDIANSHIP: TOWARD ALTERNATIVES THAT PROMOTE GREATER SELF- DETERMINATION FOR PEOPLE WITH DISABILITIES" 1 (2018), <https://www.vor.net/images/stories/2018-2019/NCD-Cover-Letter-and-Comments-on-Findings.pdf>.

<sup>617</sup> *Id.*

<sup>618</sup> *Id.* at 3.

<sup>619</sup> *Id.* at 4-5.

<sup>620</sup> *Id.* at 4.

guardians will leave people with I/DD more vulnerable to the abuse, exploitation, and neglect that guardianship is designed to prevent.”<sup>621</sup> VOR’s position is informational and stands as a real-world example alongside Coleman’s and others’ issues with SDM replacing guardianship. VOR argues that SDM, while an important approach to the least restrictive alternative idea, needs to be further explored at a macro level before national adoption.

Groups critical of SDM, like VOR, stand more in opposition to broad SDM implementation than they do in favor of keeping guardianship as it currently performs. The belief and hopefulness of reforming the guardianship system is not discussed nearly as much as the issues these groups have with SDM. Just as arguments of advocates of SDM often seem one-sided, so are the opposing arguments. In summation, SDM critiques, although few and far between, do offer helpful insight. These perspectives help SDM proponents formulate important responses and more importantly, activate further research into how to effectively implement SDM alongside guardianship.

The critiques highlighted above do not stand unopposed. The next section explores various perspectives in response to SDM adversaries. These responses come from broad and varied areas of study and exemplify the fundamental values incorporated in SDM.

## **II. RESPONSES TO CRITICAL PERSPECTIVES**

A fundamental American value is that all people have “certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness.”<sup>622</sup> To protect these unalienable rights, the U.S. Constitution mandates that no State shall “deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of

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<sup>621</sup> *Id.* at 5.

<sup>622</sup> THE DECLARATION OF INDEPENDENCE para. 2 (U.S. 1776).

the laws.”<sup>623</sup> The constitutional right to liberty, of which personal autonomy is a large part, is being denied to more than one million people in the United States today by guardianship.<sup>624</sup>

The United States Constitution is “the supreme law of the land.”<sup>625</sup> Therefore, while there are many valid concerns and critiques regarding SDM, it is a violation of the Constitution to use those concerns as a justification for denying persons their constitutional liberties. We will discuss in more detail how SDM proponents may address the concerns of detractors; however, we must first explore why SDM as an alternative to guardianship is a constitutional imperative, and how concerns may be resolved without abandoning the use and continued implementation of SDM in the United States.

For individuals living under guardianship, the State has declared them legally incapacitated such that their legal personhood and all its attendant rights have been placed in a third party appointed as their guardian.<sup>626</sup> Under guardianship, an individual loses the right to control almost every area of their own life: the right to marry, vote, drive, seek employment, contract with others, go to court when one’s rights have been violated, apply for government benefits, manage one’s own finances, choose where to live, consent to or refuse medical treatment, choose friends and associates, and choose what to eat are all determined by the guardian.<sup>627</sup> Disability advocates have referred to the removal of these fundamental decision-making rights as a form of “civil death,” because while still technically living, the individual under guardianship is deprived of all autonomy and self-determination.<sup>628</sup> As early as 1987, U.S. Congressman Claude Pepper, a member of the Select Committee on Aging, observed that guardianship is “the most punitive civil

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<sup>623</sup> U.S. CONST. amend. XIV, § 1.

<sup>624</sup> NATIONAL COUNCIL ON DISABILITY (NCD), BEYOND GUARDIANSHIP: TOWARD ALTERNATIVES THAT PROMOTE GREATER SELF-DETERMINATION 17 (2018).

<sup>625</sup> U.S. CONST. art. VI, cl. 2.

<sup>626</sup> VANPUYMBROUCK, *supra* note 1 at 5.

<sup>627</sup> NATIONAL COUNCIL ON DISABILITY, *supra* note 624 at 29.

<sup>628</sup> *Id.* at 17.

penalty that can be levied against an American citizen, with the exception, of course, of the death penalty.”<sup>629</sup>

Further, the stripping of rights that occurs when an individual is placed under guardianship usually occurs through a process that falls far short of the “due process of law” required by the Fourteenth Amendment.<sup>630</sup> While theoretically the court process is viewed as an important safeguard to ensure only those who truly need guardianship are placed under its restrictions, the reality is that many courts are so deferential to anyone petitioning to have someone placed under guardianship that the process is nothing more than an empty formality. A Boston Globe Spotlight investigation in 2008 found that elders were frequently being placed under guardianship after hospitalization for physical ailments such as a broken ankle or hip.<sup>631</sup> The article highlighted the broken process by showing that the medical certifications required to be provided to the court as justification for placing the elders under guardianship had a median length of 83 words, with two cases studied having a medical certification of a mere six or seven words.<sup>632</sup> The entire proceeding in which the judge would review a guardianship case to determine whether he or she could justifiably strip the elder of all autonomy was often cursory at best, with some hearings lasting as little as two minutes.<sup>633</sup> In these two minutes, a person is entirely stripped of their fundamental decision-making capacity in the eyes of the law.

Domestic and international law has begun to recognize the violation of rights inherent under guardianship, with the passage of the Americans with Disabilities Act (ADA) in 1990, the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) in 2000, and the United

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<sup>629</sup> SHOGREN, *supra* note 52 at 8.

<sup>630</sup> See Jeff Kelly et al., *Courts Strip Elders of their Independence*, BOSTON GLOBE, Jan. 13, 2008.

<sup>631</sup> *Id.*

<sup>632</sup> *Id.*

<sup>633</sup> Lynn Gerhard, *Old, Sick, and Unbefriended*, BOSTON GLOBE, Jan. 18, 2008.

Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007.<sup>634</sup> What the ADA and DD Act share is the express recognition of the rights of individuals with disabilities to participate in their own self-determination, and to live within their community in an integrated way to the greatest extent possible.<sup>635</sup> In enacting these statutory schemes, Congress has definitively stated that disability does not “diminish a person’s right to fully participate in all aspects of society.”<sup>636</sup> The UNCRPD is an international human rights declaration similarly recognizing that people with disabilities are entitled to legal status equal to all other individuals.<sup>637</sup> The U.S. is a signatory but has not ratified the convention; states that have ratified the UNCRPD must “recognize that people with disabilities enjoy legal capacity on an equal basis with others in all aspects of life,” and must provide necessary support to ensure individuals with disabilities may fully exercise that legal capacity.<sup>638</sup> SDM is an option that allows individuals with disabilities to exercise the rights to which they are entitled under laws and treaties such as the DD Act, the ADA, and the UNCRPD. Under an SDM agreement, an individual with a disability receives information and guidance from trusted advisors, called supporters, to enable them to make major and minor life decisions, while maintaining that the individual with a disability has the sole right to make the final decision for themselves.<sup>639</sup>

Guardianship takes a paternalistic view of promoting the best interests of the individual with a disability, as determined by a third party, especially when the guardian is a medical professional.<sup>640</sup> More often than not, parents petition for guardianship when their child approaches the age of eighteen because educators, doctors, and others have presented it as the only option to

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<sup>634</sup> VANPUYMBROUCK, *supra* note 1, at 5-6; NATIONAL COUNCIL ON DISABILITY, *supra* note 624, at 47.

<sup>635</sup> See 42 U.S.C. §§ 12101, 15001 (2012).

<sup>636</sup> 42 U.S.C. § 12101(a)(1) (2012).

<sup>637</sup> VANPUYMBROUCK, *supra* note 1, at 5-6.

<sup>638</sup> *Id.*

<sup>639</sup> *Id.* at 3.

<sup>640</sup> NATIONAL COUNCIL ON DISABILITY, *supra* note 624, at 80.



support the child.<sup>641</sup> As an increasing number of jurisdictions recognize the extreme nature of guardianship, disability advocates seek to establish SDM as the first option, and to use guardianship as a last resort to be considered only after less restrictive alternatives have been explored and deemed inappropriate or insufficient.<sup>642</sup> This model of considering the least-restrictive alternatives first is premised on the idea that SDM supplements the list of tools used to assist those with cognitive disabilities and is not founded on the complete and total abolition of guardianship.

In considering SDM as a viable option for preserving the constitutional and civil rights of persons with disabilities, some broad concerns must be addressed first. As discussed previously, a common refrain among opponents is that there is a lack of data on SDM because it is a new and emerging practice, and therefore the structure lacks assurances that participants will not be subject to abuse or exploitation.<sup>643</sup> This critique fails to note that the same objection could be raised to guardianship, which not only suffers from a lack of data on success, but also comes with a documented history of abuses and inadequate oversight mechanisms to prevent and stop abuses when they occur.<sup>644</sup> For example, a 2018 Senate report drafted by the Special Committee on Aging noted that a comprehensive survey of courts completed in 2014 indicated that: “64 percent of courts took action related to misconduct against at least one guardian in the prior three years.”<sup>645</sup>

Conversely, research by the National Council on Disability has determined that individuals who are supported in growing and utilizing skills to foster their autonomy through approaches like SDM “have better life outcomes and quality of life, including being more independent, more

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<sup>641</sup> Dustin Rynders, *Supporting Adults with Disabilities to Avoid Unnecessary Guardianship*, 55 HOUSTON LAW. 26, 27 (2018).

<sup>642</sup> Kohn et al., *supra* note 95, at 1125-6.

<sup>643</sup> VANPUYMBROUCK, *supra* note 1, at 16.

<sup>644</sup> *Id.*; NATIONAL COUNCIL ON DISABILITY, *supra* note 624, at 67-70.

<sup>645</sup> STAFF OF S. SPECIAL COMM. ON AGING, 115TH CONG., 2D SESS., ENSURING TRUST: STRENGTHENING STATE EFFORTS TO OVERHAUL THE GUARDIANSHIP PROCESS AND PROTECT OLDER AMERICANS 15 (2018).

integrated into their communities, better problem-solvers, better employed, healthier, and better able to recognize and resist abuse.”<sup>646</sup> Although the risk of abuse in SDM may not be completely eliminated, it seems to follow that the risk is lower under a framework teaching individuals the necessary skills to better recognize, resist, and report such abuse. Further, far from allowing SDM to become an essentially privatized version of guardianship, states could empower an agency or official to oversee SDM and investigate alleged abuses.<sup>647</sup> Concerns regarding funding for such oversight can be mitigated by pointing out that successful implementation of an SDM approach may lead to lower rates of individuals needing government benefits because greater self-determination has been shown to lead to increased independence, employment, and even employment in higher paying positions.<sup>648</sup> There is, therefore, an argument for broad implementation of SDM to promote financial savings to the state that may outweigh additional funding needed to create a position or division of an agency to oversee SDM.

It is well established that decision-making is a basic skill that persons without disabilities are taught throughout childhood and adolescence by being afforded opportunities to make increasingly important decisions so that, by age eighteen, society recognizes most individuals have had enough decision-making practice to be awarded full autonomy.<sup>649</sup> However, children with disabilities are often not afforded the same opportunities growing up to learn the skill of decision-making.<sup>650</sup> Upon approaching eighteen, guardianship is urgently recommended to parents of children with disabilities as the necessary and only option.<sup>651</sup> For SDM to be truly viable as an alternative to guardianship, children with disabilities must be taught decision-making skills

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<sup>646</sup> NATIONAL COUNCIL ON DISABILITY, *supra* note 624, at 131.

<sup>647</sup> *Id.* at 138.

<sup>648</sup> SHOGREN, *supra* note 52, at 9.

<sup>649</sup> *Id.* at 102-103.

<sup>650</sup> *Id.* at 103.

<sup>651</sup> *Id.* at 102-103; NATIONAL COUNCIL ON DISABILITY, *supra* note 624, at 92.

throughout childhood, just as their peers without disabilities are, so that they will be prepared to enter SDM agreements when they reach adulthood.<sup>652</sup> Additionally, educators and parents must be informed about SDM as a viable alternative to guardianship so they may foster such learning both at home and in the classroom to prepare children with disabilities to make full use of SDM as adults and thereby retain maximum independence, self-determination, and autonomy.<sup>653</sup>

Another concern cited by opponents of SDM is that supporters in an SDM agreement may unduly influence the supported person such that the relationship appears closer to the substituted decision-making model of guardianship than the ideal of SDM with the supported person as the final decision-maker.<sup>654</sup> As a general approach to guard against this, supporters will need training on how to provide information and guidance without substituting their judgment for that of the supported person or improperly influencing the decision of the supported person.<sup>655</sup> Additionally, individuals with disabilities should receive self-advocacy training so they may understand what a successful SDM model looks like and recognize when it is working or not.<sup>656</sup> The Autistic Self Advocacy Network (ASAN) has determined that having multiple supporters, as opposed to a single supporter, provides a safeguard for supporters to serve as a check on the others to prevent any of them from inadvertently or purposefully engaging in substituted decision-making.<sup>657</sup>

The concerns of opponents to SDM appear to be rooted in the paternalistic approach to disability that led to the rise of the guardianship system in the first place, which the U.S. and international communities have recognized as violative of the rights inherent in all people. As an emerging and adapting trend, there is inevitably a certain amount we cannot know about SDM's

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<sup>652</sup> SHOGREN, *supra* note 52, at 102-103.

<sup>653</sup> *Id.* at 102-103; VANPUYMBROUCK, *supra* note 1, at 17.

<sup>654</sup> NATIONAL COUNCIL ON DISABILITY, *supra* note 624, at 137.

<sup>655</sup> *Id.*

<sup>656</sup> *Id.* at 138.

<sup>657</sup> Kelly Israel, *Supported Decision Making and Deinstitutionalization: Lessons Learned from the Autistic Self Advocacy Network's Invitational Summit*, in 42 TASHCONNECTIONS Fall 2017 at 9, 10.

viability and outcomes. However, SDM at least places individuals with disabilities in the driver's seat of their own lives and affords them "the dignity of risk," which has been denied to them for far too long.<sup>658</sup> It is past time we abandon the antiquated view of disability as abnormal and something to be controlled, and embrace the approach of respecting that disability is but one element of a whole person who should be provided with reasonable supports to live and participate in society as fully as possible.<sup>659</sup>

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<sup>658</sup> NATIONAL COUNCIL ON DISABILITY, *supra* note 624, at 47.

<sup>659</sup> SHOGREN, *supra* note 52, at 30-34.

# **COMMUNITY FEEDBACK, RECOMMENDATIONS & BEST PRACTICES**

In addition to reviewing and analyzing sources of law and scholarly work on supported decision-making (SDM), we completed extensive field research to better understand the views and concerns of the local community involved in SDM. We begin this section with a summary of the common themes discovered through that research, followed by recommendations for implementing SDM in Massachusetts based on both our field and scholarly research. One prevalent theme throughout this section is that Massachusetts must be responsive to the concerns and needs of the community to ensure a successful statewide implementation of SDM as a viable alternative to guardianship.

## **I. COMMUNITY FEEDBACK & RECOMMENDATIONS**

From discussions with and review of published posts by Massachusetts community members, including supported persons, supporters, family members, doctors, attorneys, and advocacy organizations, the common thread has emerged that SDM is a viable option and should be made readily available as one tool of support for individuals with disabilities.<sup>660</sup> Families considering what the most appropriate form of support may be for a family member with a cognitive disability deserve to have a range of options to consider, ranging from guardianship where basic physical well-being may be more protected but personal autonomy is sacrificed, to SDM where personal autonomy is protected but basic physical well-being may be less so.<sup>661</sup> The

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<sup>660</sup> Fleischner, *supra* note 530; Telephone Interview with Paul Lanzikos, Exec. Dir., N. Shore Elder Services, John Ford, Attorney, Nw. Justice Ctr. & Cheryl Krisko, Chief Program Officer, N. Shore Elder Services (Feb. 27, 2019); *see* David Kassel, *Supported Decision Making Bill Needs Clarity and Safeguards*, COFAR BLOG (Feb. 21, 2019), <https://cofarblog.wordpress.com/2019/02/21/supported-decision-making-bill-needs-clarity-and-safeguards/>.

<sup>661</sup> Fleischner, *supra* note 530.

appropriateness of either option and of options in between such as limited guardianship, power of attorney, and health care proxy, depends on the values of the family and individual as well as practical considerations of the individual's capacity to understand, make, and communicate their own decisions.<sup>662</sup>

As mentioned in the prior discussion, opponents of SDM believe that SDM may be less protective of the physical well-being of the supported person than a limited or full guardianship. This concern was echoed in discussing the pending Massachusetts legislation on SDM, arguing that it lacks even a basic plan or structure for implementation, and especially that it fails to set up a framework that includes oversight or formal mechanisms to safeguard against abuses.<sup>663</sup> While there appears to be consensus that some form of oversight is necessary, there is some disagreement on who should provide that oversight. Particularly, various stakeholders debate whether government oversight would be an effective safeguard against abuse or an impediment to responding efficiently to abuses if and when they occur.<sup>664</sup> While there have been successful pilot programs in Massachusetts and elsewhere,<sup>665</sup> one major drawback is that the pilot programs have largely been led by those who, before the pilot programs began, were already avid SDM proponents.<sup>666</sup> Having SDM proponents lead studies and pilot programs exploring SDM's viability and efficacy is inherently problematic because it subjects any findings that might result to a cloud of confirmation bias,<sup>667</sup> which casts doubt on the legitimacy of those findings.<sup>668</sup> Other

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<sup>662</sup> *Id.*; see generally Kassel, *supra* note 660.

<sup>663</sup> Lanzikos, Ford, & Krisko, *supra* note 660; Kassel, *supra* note 660.

<sup>664</sup> Fleischner, *supra* note 530.

<sup>665</sup> PELL & MULKERN, *supra* note 464, at 31; PELL & MULKERN, *supra* note 470, at n.17; FIRST IN FAMILIES OF NORTH CAROLINA, *supra* note 579; THE ARC OF SAN ANGELO, *supra* note 548.

<sup>666</sup> David Kassel, *Movement to Replace Guardianship Appears Based on Little Research*, COFAR BLOG (Nov. 7, 2018), <https://cofarblog.wordpress.com/2018/11/07/movement-to-replace-guardianship-appears-based-on-little-research/>.

<sup>667</sup> Confirmation bias is a tendency to evaluate information in a way "that is consistent with one's existing beliefs." Bettina J. Casad, *Confirmation Bias*, ENCYCLOPEDIA BRITANNICA, <https://www.britannica.com/science/confirmation-bias> (last visited Feb. 28, 2019).

<sup>668</sup> Kassel, *supra* note 666.

pilot programs need to be completed by objective teams so that those spearheading the SDM movement in Massachusetts and elsewhere may analyze an unbiased report comparing varied frameworks for SDM. Ultimately, this will enable groups to create a viable, sustainable plan for SDM implementation that ensures the best possible outcomes for the supported individuals while safeguarding, to the greatest extent possible, both their personal autonomy and security.<sup>669</sup>

Another barrier to thoughtful statewide implementation of SDM in Massachusetts is lack of widespread knowledge of and education about SDM.<sup>670</sup> If more people understood what an SDM arrangement is supposed to look like, it would seem to logically follow that they would be better able to recognize when an SDM arrangement deviated from that ideal in a way that may place a supported person at risk of abuse. Additionally, parents and individualized education program (IEP) teams need to be aware that SDM is a viable option for children with disabilities who are nearing the age of majority, so that they are not denied the opportunity to weigh the advantages of SDM instead of guardianship and can make fully informed decisions about which approach to take.<sup>671</sup> Therefore, the availability of training and educational materials for educators and family members early in the life of individuals with disabilities serves two separate functions: (1) it meaningfully identifies SDM as an option for families with children with cognitive disabilities, and (2) it provides a safeguard against abuse by educating families on what a functioning SDM arrangement should look like so they may recognize if abuse is occurring.

Going forward, if Massachusetts is to implement SDM in a way that makes it a truly viable and sustainable option for individuals with disabilities, those responsible for implementation must

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<sup>669</sup> *Id.*

<sup>670</sup> Interview with Rep. Paul Tucker, Mass. House of Representatives in Boston, Mass. (Feb. 5, 2019); Interview with Dr. Michael Kendrick, Indep. Disability Rights Consultant & SDM Participants, in Boston, Mass. (Feb. 6, 2019); Fleischner, *supra* note 530.

<sup>671</sup> Kendrick & SDM Participants, *supra* note 670.

heed the concerns of those who will be most affected. At the very least, an objectively appropriate plan must be developed for widespread implementation that will be ready to execute in the event the SDM bill becomes law, and that plan must include (1) a system for oversight and reporting of abuse, and (2) a campaign to bring SDM into the mainstream consciousness and educate and train educators, doctors, social workers, family members and others to consider SDM as an option prior to full guardianship at a time when a greater level of personal autonomy may be both feasible and desirable. Below we discuss specific recommendations for drafting and passing SDM legislation and conducting pilot programs.

## **II. STATUTES**

There is a broad diversity of style and length among the states that have passed comprehensive SDM legislation. The District of Columbia's statute, for example, includes only four sections and leaves the role of implementing the chapter to the mayor.<sup>672</sup> Alaska, in contrast, has twenty sections covering specific requirements for validity, the duties of a supporter, services to provide, confidentiality, and more.<sup>673</sup> A state seeking to implement its own form of comprehensive SDM legislation would do well to start with the District of Columbia's example. Looking to this statute as an example, a comprehensive SDM statute requires: (1) definitions of new terms and references to terms applicable from other statutes, especially rules governing educational, financial, and medical records and their release; (2) requirements about who may and may not enter into such an agreement, with a focus on preventing a conflict of interest and/or abuse of power (for example, people already providing behavioral healthcare services to the supported person or people who have abused or exploited the supported person in the past may not be

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<sup>672</sup> D.C. CODE ANN. §§ 7-2131 to -2134 (West, Westlaw through Feb. 22, 2019).

<sup>673</sup> ALASKA STAT. ANN. §§ 13.56.010–.195 (West, Westlaw through 2018 2nd Reg. Sess.).



supporters); (3) how an SDM agreement is to be executed, who must witness it, and whether it must be notarized; (4) what the supported person may authorize supporters to do; (5) to what degree government and private organizations are to rely on the agreement; and (6) a method for reporting possible abuse, neglect, or exploitation by the supporter.

Furthermore, some of the more comprehensive SDM statutes passed to date have included a template agreement both to inform supporters, supported persons, and the people they will be communicating with what these agreements look like, as well as to highlight what kind of decisions the agreement covers.<sup>674</sup> The District of Columbia requires SDM agreements to be “substantially [the same form]” as the sample agreement provided in the code, as do Texas, Wisconsin, and Alaska.<sup>675</sup> Delaware is the clear outlier, neither providing a sample agreement in its statute nor specifying that agreements must substantially follow a particular form. Instead, Delaware leaves it to the Department of Health and Social Services to develop forms and promulgate regulations.<sup>676</sup> Although this could leave more room for individualization and customization of agreements, it could also leave people without the guidance necessary to enter into an effective agreement.

Of course, states looking to enact similar legislation can opt to have more detail than the District of Columbia. Wisconsin’s statute is largely modeled off of Texas’s example, and Alaska’s specific attention to such considerations as liabilities, duties, and confidentiality would also be good reading for drafters. Given how much has already been enacted, there is little reason to reinvent the wheel. Therefore, apart from the mentioned elements that appear to play a prominent role in SDM statutes, it is meaningful to review the structure, content, and history of existing

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<sup>674</sup> See D.C. CODE ANN. § 7-2132 (West, Westlaw through Feb. 22, 2019). See also TEX. EST. CODE ANN. § 1357.056 (West, Westlaw through 2017 Reg. Sess.); WIS. STAT. § 52.20 (Westlaw through 2017 Act 370); ALASKA STAT. ANN. § 13.56.180 (West, Westlaw through 2018 2nd Reg. Sess.).

<sup>675</sup> See D.C. CODE ANN. § 7-2132 (West, Westlaw through Feb. 22, 2019). See also TEX. EST. CODE ANN. § 1357.056 (West, Westlaw through 2017 Reg. Sess.); WIS. STAT. § 52.20 (Westlaw through 2017 Act 370); ALASKA STAT. ANN. § 13.56.180 (West, Westlaw through 2018 2nd Reg. Sess.).

<sup>676</sup> DEL. CODE ANN. tit. 16, § 9410A (West, Westlaw through 82 Laws 2019, ch. 4).

legislation to determine which pieces may be relevant to new legislation in a state. While a number of states have passed and are in the process of passing legislation on SDM,<sup>677</sup> it may not be the chosen starting point for some. Elsewhere, states without SDM legislation have implemented pilot programs, and some courts have recognized SDM in denying guardianship petitions or vacating guardianships. For this reason, we relay recommendations on implementing a pilot program as a separate option for developing and expanding access to SDM in the state.

### III. PILOT PROGRAMS

Implementing a pilot program is one path that advocates may seek to pursue as an alternative to, in conjunction with, or as a precursor to efforts to pass state legislation on SDM. However, because the objectives of passing legislation and implementing a pilot program may not be one in the same, it is important to view the opportunities and challenges of an SDM pilot program on its own.

States just starting to explore SDM this may consider an early-stage program aimed at collecting information, building awareness in the community, and developing partnerships. Tier I programs may achieve this objective by disseminating basic “training” materials, which share information on options available around guardianship and improving self-advocacy, among other things.<sup>678</sup> It is cogent to establish a Tier I program with a long-term vision of building on services provided, community involvement, and statewide recognition. A program at this level is a basic information-collecting process to determine where additional services or knowledge would be most effective, and how to implement these goals.

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<sup>677</sup> *In Your State*, NATIONAL RESOURCE CENTER FOR SUPPORTED DECISION-MAKING, [www.supporteddecisionmaking.org/states](http://www.supporteddecisionmaking.org/states) (last visited Feb. 28, 2019).

<sup>678</sup> See *ACDL to Partner in Pilot Project for Supported Decision-Making Information and Training*, *supra* note 427. See also *The SC Supported Decision-Making Project*, *supra* note 430.

Further, a Tier I program may expand its impact by having findings, fact sheets, brochures and other resources developed throughout the program available to the public on a website. It would be easy to measure the number of visitors and downloads to determine which materials may be important to add to and keep updated. Quantitative measures such as these may provide important evidentiary support in the development of a Tier II or Tier III program in the future.

Tier II programs may be most appropriate in states that have already established specific agencies, partnerships, or programs aimed at expanding SDM awareness and services. A Tier II pilot program should focus on spreading awareness to various stakeholders through more formal means of training and offering direct assistance to the community to support these goals.<sup>679</sup> Tier II programs have developed materials, presentations, and other tools available as resources to target audiences and to the public in general.<sup>680</sup>

More involved than Tier I programs but less service-oriented than Tier III programs, Tier II programs target communities involved in the SDM process to train engaged members in their role, options, and resources.<sup>681</sup> Further, these programs may engage with the community directly to determine where services through other programs or agencies may be able to provide assistance.<sup>682</sup> An effective measure of Tier II programs would be both quantitative and qualitative in nature. It would be helpful to provide reports on the number of trainings, in-person or online attendees, and downloads of training materials. Further, Tier II programs are positioned in a way

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<sup>679</sup> See *Supported Decision Making Train-the-Trainer Project*, *supra* note 435. See also *Guardianship, Advocacy, and Planning Services*, *supra* note 448; *Resources*, VERMONT OFFICIAL STATE WEBSITE, <https://ddsd.vermont.gov/resources> (last visited Feb. 28, 2019).

<sup>680</sup> See *Supported Decision Making Train-the-Trainer Project*, *supra* note 435. See also *Services Provided by Achieva Resources*, ACHIEVA RESOURCES, <http://www.achievaresources.org/services.html> (last visited Feb. 28, 2019); *Resources*, *supra* note 679.

<sup>681</sup> See *Supported Decision Making Train-the-Trainer Project*, *supra* note 435. See also *Services Provided by Achieva Resources*, *supra* note 680; *Resources*, *supra* note 679.

<sup>682</sup> See *Supported Decision Making Train-the-Trainer Project*, *supra* note 435. See also *Guardianship, Advocacy, and Planning Services*, *supra* note 448; *Resources*, *supra* note 679.

to provide the most current updates about SDM to broad audiences. Incorporating feedback, updating materials, and improving availability of resources must be a continuous process in order for the materials of these programs to be effective and impactful.

Tier III programs are most directly involved with those engaging in SDM. The ideal Tier III program would have dedicated resources, partnerships, and long-term funding to administer services and support on a continuous basis. As the most comprehensive level, Tier III programs include elements from Tier I and Tier II, such as training resources, advocacy materials, and reports available to the public.<sup>683</sup>

Tier III programs may work with the supported person and their families in a number of ways, from developing a tailored approach to meet life goals, to constructing and executing an SDM agreement that meets the needs of the individual and their network.<sup>684</sup> While these programs can be more costly because of the one-on-one services provided,<sup>685</sup> the continued stories of success as seen in current Tier III programs are nonetheless compelling to continue supporting this level of pilot implementation.<sup>686</sup>

Further, Tier III programs should conduct periodic interviews with supporters, adopters, and other participants as a way to measure impact throughout the program. Comprehensive reports, findings, and statistics are critical to review and adjust the program, and also to guide other states looking to implement similar efforts.<sup>687</sup> As Tier III programs involve direct consultation and services affecting the lives of community members, it is important that there are instruments in

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<sup>683</sup> See SUPPORTED DECISION-MAKING NEW YORK, *supra* note 570. See also *Resource Library*, SUPPORTED DECISION-MAKING, <http://supporteddecisions.org/document-library/> (last visited Feb. 28, 2019).

<sup>684</sup> *Lifetime Connections*, *supra* note 579. See THE ARC OF SAN ANGELO, *supra* note 548, at 2.

<sup>685</sup> See THE ARC OF SAN ANGELO, *supra* note 548, at 2.

<sup>686</sup> See PELL & MULKERN, *supra* note 470, at 28-29. See also *Cory, Pilot Project Participant*, *supra* note 349; Nicholson, *supra* note 576.

<sup>687</sup> See, e.g., PELL & MULKERN, *supra* note 470, at 28-29. See also H.B. 1454, 81st Leg., Reg. Sess., 2009 Tex. Sess. Law Serv. ch. 72 (West).

place that provide an opportunity to give anonymous feedback, especially for adopters. This recommendation concerns balancing an individual's decision-making autonomy with the supporter's safety concerns. State standards in Massachusetts, for example, "require providers to promote an individual's self-determination and freedom of choice to the individual's fullest capability, and for individuals to undergo typical developmental experiences, even though such experiences may entail an element of risk."<sup>688</sup>

In summary, implementation of a successful pilot program in general would ultimately require the previously presented tiered components of (1) gathering information and training audiences, (2) spreading awareness, and (3) providing direct services and consultation to develop SDM agreements in practice. Based on the research it is likely that any pilot program would face challenges in funding, oversight, and administration, and would require the aid of or partnership with local and state organizations and agencies to support the program. While brochures, information, and training sessions are crucial components of an SDM program, it is important to remember that the disability community is diverse and each individual requires a tailored approach. It is clear from both conversations with the Massachusetts pilot program participants and research of other program materials that not all disabilities are the same, and that therefore not all individuals with disabilities can be supported using the same approach. The ultimate goal in developing a successful pilot program that leads to a statewide or nationally recognized practice would require sufficient resources to tailor trainings and services based on needs of the target audience, including supporters, supported persons, educators, health practitioners, judges, and lawyers, among others. Implementation is possible, but success depends upon the awareness that the individuals with disabilities must be engaged in the construction of the program.

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<sup>688</sup> See PELL & MULKERN, *supra* note 470, at 17.



## CONCLUSION

Supported decision-making (SDM) is a model that seeks to retain the autonomy of persons with disabilities where traditional methods, such as guardianship, have severely limited or removed an individual's freedom of choice. Currently, the Commonwealth of Massachusetts does not have a statute or formalized means of executing SDM, although a bill has been introduced in the state legislature this year.<sup>689</sup> Despite not having a statute, Massachusetts has had exposure to SDM through some cases, such as Cory Carlotto in Berkshire Probate Court, and through a pilot program administered by the Center for Public Representation.<sup>690</sup> The development of SDM in Massachusetts is not isolated, but rather part of a greater movement throughout the United States and the world to safeguard the rights of individuals with disabilities. In the U.S., this is approached in a number of ways: some states have started to implement SDM statutes or adjust the scope of guardianship statutes,<sup>691</sup> while others have implemented various pilot programs to promote local and state awareness of SDM and expand its use.<sup>692</sup> On an international scale, the SDM trend is evidence in countries like Sweden, Canada, Israel, and Australia have adopted SDM legislation or have implemented pilot programs to explore the viability of SDM in their countries.<sup>693</sup>

The progression of SDM can be attributed to its nature and practice. Proponents of SDM contend that every person utilizes SDM or its approach in daily life, and it should therefore be no different for persons with disabilities. SDM is based on the ideas of respect, advice, partnership,

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<sup>689</sup> SD.843, 191st General Court, (2019).

<sup>690</sup> *Cory, Pilot Project Participant*, *supra* note 349.

<sup>691</sup> *See* TEX. EST. CODE ANN. § 1357.002(3) (West, Westlaw through 2017 Reg. Sess.). *See also* WIS. STAT. ANN. §52.01(6) (West, Westlaw through 2017 Act 370); DEL. CODE ANN. tit. 16, § 9403a(8) (West, Westlaw through 82 Laws 2019, ch. 4); D.C. CODE ANN. §7-2131 (West, Westlaw through Feb. 22, 2019); H.R. 7992, 2018 Gen. Assemb., Jan. Sess. § 15.3-3 (R.I. 2018).

<sup>692</sup> *See The SC Supported Decision Making Project*, *supra* note 430. *Lifetime Connections*, *supra* note 579; SUPPORTED DECISION-MAKING NEW YORK, *supra* note 570.

<sup>693</sup> *See* R.S.B.C. 1996, c. 405 (Can., Westlaw through B.C. Reg. 238/2018). *See also* Sweden: *Personal Ombudsmen*, *supra* note 133; Bigby, *supra* note 153, at 222-240.

and the inherent rights of autonomy and self-determination of *all* persons. SDM provides a means for individuals with disabilities to receive guidance in chosen areas, such as financial management or medical decisions, while maintaining independence and decision-making authority. SDM preserves individual liberty and autonomy, affirming values we have held since the founding of the United States. In fact, SDM has been implemented in the U.S. based on fundamental rights found in the Constitution.

Thus far, SDM has been explored in pockets around the nation and is gaining traction in legislatures, courts, and communities. Activists and proponents are spreading awareness through school systems, pilot programs, media, and local and national politics. Within Massachusetts and elsewhere, the growth towards SDM as a formalized process presents a possibility for changes in the way we perceive and empower people with disabilities, opening the door for a future in which supported decision-making is the standard for these individuals and guardianship is the exception.



## APPENDICES

### Appendix I. CHARTING THE DIFFERENCES BETWEEN SDM AND OTHER FORMS OF

“SUPPORT”<sup>694</sup>

	Who appoints the agent/supporter?	How does this affect legal capacity?	How does this affect your rights?
<b>SDM</b>	Supported person chooses supporter(s)	Does not affect legal capacity determination	The supported person retains all rights to make important life decisions for him or herself.
<b>Guardianship</b>	Court appointed	Generally, includes a determination of broad legal incapacity	The guardian has the right to make decisions on behalf of the person with a mental disability, exclusive of the person with a mental disability.
<b>Conservatorship</b>	Court appointed	Generally, includes a determination of legal incapacity to manage one's assets	The conservator has the right to make decisions on behalf of the person with a mental disability.
<b>Health Care Proxy</b>	Supported person chooses agent	Does not affect legal capacity determination	The health care agent has the right to make medical decisions on behalf of the principal in the event that the principal is unable to make or communicate such decisions for him or herself.
<b>Power of Attorney</b>	Supported person chooses agent	Does not affect legal capacity determination	The attorney-in-fact has the right to make financial and property decisions on behalf of the principal, concurrent with the right of the principal to make such decisions for him or herself until he or she is deemed to lack the capacity to make such decisions.

The critical difference that sets SDM apart from guardianship, conservatorship, health care proxy, and power of attorney is that, under a SDM agreement, the individual with a disability retains the exclusive legal right to make important life decisions for oneself, including where to live, with whom to associate, and how to manage one's own finances. Under the other forms of

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<sup>694</sup> MATTSON AND TUNNEY, *supra* note 25.

support, the supported person must give up some or even all of their legal rights. Another major distinction is that in the case of SDM, powers of attorney, and health care proxies, there is no legal determination of incapacity for the supported person, whereas under guardianship and conservatorship, a court will generally adjudicate that the supported person lacks the legal capacity to make certain (or all) decisions for oneself.

## Appendix II. SDM RESOURCES

Title	Author	Type of Resource	Target Audience	Synopsis/Description	URL
Beyond Guardianship: Supported Decision-Making by Individuals with Intellectual Disabilities	2011 Guardianship Summit	Briefing paper	Lawyers and service providers	Briefing paper on SDM agreements for roundtable discussion at the 2011 Guardianship Summit.	<a href="http://www.supporteddecisionmaking.org/sites/default/files/beyond_guardianship.pdf">http://www.supporteddecisionmaking.org/sites/default/files/beyond_guardianship.pdf</a>
Building a Bridge: A Resource Manual for High School Students	Connecticut Transition Task Force	Resource manual	Students with disabilities and family members	Handbook to help young persons and their families prepare for life after high school	<a href="http://www.supporteddecisionmaking.org/sites/default/files/building_bridge_resource_manual_high_school_students.pdf">http://www.supporteddecisionmaking.org/sites/default/files/building_bridge_resource_manual_high_school_students.pdf</a>
D.C. Public Schools Supported Decision Making Form	D.C. Public Schools Office of Specialized Instruction	Model agreement	Students in Washington, D.C.	Agreement form for students to implement SDM regarding education decisions, specifically IEPs	<a href="http://www.supporteddecisionmaking.org/sites/default/files/dcps_supported_decision_making_form_0.pdf">http://www.supporteddecisionmaking.org/sites/default/files/dcps_supported_decision_making_form_0.pdf</a>
Delaware Supported Decision-Making Agreement Form	DE Legislature	Model agreement	Supported person, supporters, service providers, and family members	Template agreement that can be customized based on the supported person's needs	<a href="http://supporteddecisionmaking.org/sites/default/files/delaware-sdm-agreement.pdf">http://supporteddecisionmaking.org/sites/default/files/delaware-sdm-agreement.pdf</a>
Equality and inclusion for people with disabilities	Council of Europe: Parliamentary Assembly	Recommendation guide	Member States	Contains policy recommendations stating that member states should adopt SDM instead of institutionalization and should develop new policies in partnership with individuals with disabilities	<a href="https://www.refworld.org/cgi-bin/texis/vtx/rwmain?page=search&amp;docid=55b255374&amp;skip=0&amp;query=supported%20decision%20making">https://www.refworld.org/cgi-bin/texis/vtx/rwmain?page=search&amp;docid=55b255374&amp;skip=0&amp;query=supported%20decision%20making</a>
Facts About Law and the Elderly	American Bar Association	Guidebook	Aging adults	Includes definitions and descriptions of capacity, guardianship, how to determine if guardianship is the right option, alternatives to guardianship, and reporting requirements of elder abuse.	<a href="http://www.supporteddecisionmaking.org/sites/default/files/aba_facts_about_law_and_the_elderly_0.pdf">http://www.supporteddecisionmaking.org/sites/default/files/aba_facts_about_law_and_the_elderly_0.pdf</a>
Factsheet: Parents with Intellectual Disability	The Arc	Factsheet	Supported persons and family members	Describes supports that parents with I/DD may find helpful to allow them to parent successfully and retain their parental rights	<a href="https://www.thearc.org/what-we-do/resources/factsheets/parents-with-idd">https://www.thearc.org/what-we-do/resources/factsheets/parents-with-idd</a>

Future Directions in Supported Decision-Making	Disability Studies Quarterly	Journal article	Disability studies/Academic	Synopsis of supported decision making, international trends, and U.S. trends	<a href="http://dsq-sds.org/article/view/5070/4549">http://dsq-sds.org/article/view/5070/4549</a>
Guardianship of the Elderly: Protecting the Rights and Welfare of Seniors with Reduced Capacity	Senator Gordon H. Smith and Senator Herb Kohl	Report	Legislature	Discusses guardianship, alternatives to guardianship, guardianship issues, improvements in guardianship practice, and proposals for change	<a href="http://www.supporteddecisionmaking.org/sites/default/files/guardianship_report_elderly_senate_0.pdf">http://www.supporteddecisionmaking.org/sites/default/files/guardianship_report_elderly_senate_0.pdf</a>
PRACTICAL Tool for Lawyers: Steps in Supporting Decision-Making	American Bar Association	Toolkit	Lawyers	Manual for attorneys to help identify clients who would benefit from SDM and help them form SDM agreements	<a href="https://www.americanbar.org/content/dam/aba/administrative/law_aging/PRACTICALTool.pdf">https://www.americanbar.org/content/dam/aba/administrative/law_aging/PRACTICALTool.pdf</a>
Sample Supported Decision-Making Agreement	American Civil Liberties Union, Quality Trust	Model agreement	Supported person and supporters	Template agreement that can be customized based on the supported person's needs	<a href="http://supporteddecisionmaking.org/sites/default/files/aclu-qt-sdm-agreement.pdf">http://supporteddecisionmaking.org/sites/default/files/aclu-qt-sdm-agreement.pdf</a>
Sample Supported Decision-Making Agreement	Disability Rights Texas	Model agreement	Supported person, supporters, service providers, and family members	Template agreement that can be customized based on the supported person's needs	<a href="http://supporteddecisionmaking.org/sites/default/files/texas-sdm-agreement.pdf">http://supporteddecisionmaking.org/sites/default/files/texas-sdm-agreement.pdf</a>
Self-Determination and People with Intellectual and Developmental Disabilities: What Does the Research Tell Us?	National Gateway to Self-Determination	Slideshow	Supporters, family members, and service providers	Summary of research regarding individuals with intellectual/developmental disabilities having less self-determination than their non-disabled peers, factors contributing to self-determination, self-determination and adult outcomes, and importance of self-determination to adults with disabilities	<a href="http://www.aucd.org/docs/Self-Determination-WhatDoWeKnow.pdf">http://www.aucd.org/docs/Self-Determination-WhatDoWeKnow.pdf</a>
Supported Decision Making Information & Resources	Tennessee Council on Developmental Disabilities	Resource guide	Persons with disabilities, family members, and service providers	Collection of resources to inform TN residents about the SDM practices in the state	<a href="https://www.tn.gov/cdd/public-policy/supported-decision-making.html">https://www.tn.gov/cdd/public-policy/supported-decision-making.html</a>
Supported Decision Making Video	UC Davis MIND Institute	Video	Family members	Short, 20-minute overview of the importance of SDM by a leading national expert	<a href="https://www.youtube.com/watch?v=Q8Na88Wz90I&amp;feature=youtu.be">https://www.youtube.com/watch?v=Q8Na88Wz90I&amp;feature=youtu.be</a>
Supported Decision Making Webcast featuring Jonathan Martinis	Tennessee Council on Developmental Disabilities	Webcast	Family members	Short video providing a brief legal overview of alternatives to conservatorship, including	<a href="https://vimeo.com/241774157">https://vimeo.com/241774157</a>

Supported decision making: A review of the international literature	Davidson, et al.	Journal article	Policymakers	Reviews international evidence relating to SDM to discuss development of the practice within mental health services	<a href="https://www.sciencedirect.com/science/article/pii/S0160252715000096?via%3Dihub">https://www.sciencedirect.com/science/article/pii/S0160252715000096?via%3Dihub</a>
Supported Decision Making: Frequently Asked Questions	American Civil Liberties Union	Factsheet	Everyone	Brief overview of what SDM is, how it differs from alternatives, and where to get more information	<a href="https://www.aclu.org/sites/default/files/field_document/faq_about_supported_decision_making.pdf">https://www.aclu.org/sites/default/files/field_document/faq_about_supported_decision_making.pdf</a>
Supported Decision-Making Agreement	Center for Public Representation, Nonotuck Resource Associates	Model agreement	Supported persons, supporters, service providers, and family members	Template agreement that can be customized based on the supported person's needs	<a href="http://supporteddecisionmaking.org/sites/default/files/nonotuck-sdm-agreement.pdf">http://supporteddecisionmaking.org/sites/default/files/nonotuck-sdm-agreement.pdf</a>
Supported Decision-Making and Positive Psychology	Lisa A. Woudzia	Journal article	Supporters and policymakers	Describes how to integrate the principles of positive psychology to promote wellbeing in the context of SDM	<a href="https://www.tandfonline.com/doi/pdf/10.1080/23297018.2016.1188412?needAccess=true">https://www.tandfonline.com/doi/pdf/10.1080/23297018.2016.1188412?needAccess=true</a>
Supported Decision-Making Teams: Setting the Wheels in Motion	Suzanne M. Francisco and Jonathan G. Martinis	Guidebook	Supported persons and supporters	Step-by-step guide for self-advocates and their supporters, including write-in tools and an appendix of more resources	<a href="http://supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf">http://supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf</a>
Supported Health Care Decision-Making Agreement	Autistic Self Advocacy Network	Model agreement	Supported person, supporters, service providers, and family members	Template SDM agreement for healthcare decisions	<a href="http://supporteddecisionmaking.org/sites/default/files/asan-sdm-agreement.pdf">http://supporteddecisionmaking.org/sites/default/files/asan-sdm-agreement.pdf</a>
Ten Tips for Transitioning	Pacer Center: Champions for Children with Disabilities	Tip sheet	Family members	Tips for preparing children with disabilities to transition to adulthood, including the use of support networks	<a href="https://www.pacer.org/parent/php/PHP-c107.pdf">https://www.pacer.org/parent/php/PHP-c107.pdf</a>
The Right to Make Choices: International Laws and Decision Making by People with Disabilities	Autistic Self Advocacy Network	Guidebook	Supported persons	Explains how SDM works, the steps involved in the process, and tips and examples for individuals entering into SDM agreements	<a href="http://autisticadvocacy.org/wp-content/uploads/2016/02/Easy-Read-OSF-2-Supported-Decision-Making-v3.pdf">http://autisticadvocacy.org/wp-content/uploads/2016/02/Easy-Read-OSF-2-Supported-Decision-Making-v3.pdf</a>
Transition to Adulthood: A Health Care Guide	Autistic Self Advocacy Network	Toolkit	Supported persons and family members	Discusses how to use SDM in the healthcare context for young people with disabilities as they become adults	<a href="http://www.supporteddecisionmaking.org/sites/default/files/asan_healthcare_toolkit_0.pdf">http://www.supporteddecisionmaking.org/sites/default/files/asan_healthcare_toolkit_0.pdf</a>

for Youth and Families					
Webcast 06: Supported Decision Making: An Alternative to Conservatorship	Tennessee Council on Developmental Disabilities	Webcast	Family members and supporters	Hour-long webinar explaining how to be a supporter within an SDM framework	<a href="https://vimeo.com/277298319">https://vimeo.com/277298319</a>
When Do I Want Support? Supported Decision-Making Self -Assessment Tool	American Civil Liberties Union	Toolkit/Guidebook	Supported person and family members	Overview of SDM, steps to enter into an agreement, and applicable worksheets and information sheets to guide the process	<a href="https://www.aclu.org/other/when-do-i-want-support-supported-decision-making-self-assessment-tool">https://www.aclu.org/other/when-do-i-want-support-supported-decision-making-self-assessment-tool</a>

### Appendix III. SDM STATUTE CATEGORY LIST

No SDM or Least Restrictive Alternative Language	Least or Less Restrictive Alternative Language	SDM Language in Guardianship/Other Statutes	SDM Statutes
Alabama Arkansas Connecticut Hawaii Idaho Illinois Indiana Iowa Kentucky Louisiana Minnesota Mississippi Montana New Jersey Nebraska Utah Wyoming	Arizona California Colorado Florida Georgia Massachusetts* Michigan Nevada New Hampshire New York North Carolina North Dakota Oklahoma Oregon Ohio Pennsylvania Rhode Island* South Carolina South Dakota Vermont Virginia Washington West Virginia	Kansas Maine Maryland Missouri New Mexico	Alaska Delaware Tennessee Texas Washington, D.C. Wisconsin

\* Indicates that SDM statutes are pending in the legislature.

#### **Appendix IV. SAMPLE MASSACHUSETTS SDM AGREEMENT**

*This agreement was copied from the pending Massachusetts legislation, Senate Bill No. 64, with some of the section numbers and signature lines added for clarity.*

##### **Appointment of Supporter**

(1) I, [insert your name] [address] [date of birth], make this agreement of my own free will. It is my intention that I be the decision maker.

(2) [If there is more than one supporter, provide the following for each supporter] As the decision-maker, I choose as my supporter(s) the following person (people):

Full Name:

Address:

Phone Number:

E-mail Address:

My supporter, [name of supporter], may help me with making everyday life decisions relating to the following areas of my life: [describe here]

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[Optional section:]

As the decision-maker I would like assistance from, [name of supporter] with making decisions about:

Y/N obtaining food, clothing, and shelter.

Y/N taking care of my health, including helping me make large and small health care decisions.



Y/N managing my financial affairs.

Y/N accessing and using public supports and services.

Y/N taking care of myself, including managing the people who work with me, making decisions about my diet, safety and other day to day activities.

Y/N making legal decisions, including retaining a lawyer if I need one and working with the lawyer.

I do not want assistance from my supporter, (name of supporter), with decision making about the following areas of my life: [describe here]

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[Repeat section (2) for each additional supporter if there are any.]

(3) My supporter(s) is (are) NOT allowed to make decisions for me. I am the decision-maker.

(4) To help me with my decisions, my supporter(s) may:

1. Request information or records that are relevant to a decision, including medical, psychological, financial, educational, or treatment records;
2. Help me understand my options so I can make an informed decision by discussing with me the good things and bad things (pros and cons) of a decision
3. Give me information in a way that I can understand; or
4. Help me communicate my decision to appropriate persons.

Y/N A release allowing my supporter to see protected health information under the Health Insurance Portability and Accountability Act of 1996 (Pub. L. No. 104-191) is attached.

Y/N A release allowing my supporter to see educational records under the Family Educational Rights and Privacy Act of 1974 (20 U.S.C. Section 1232g) is attached.

(5) Effective Date of Supported Decision-Making Agreement

This supported decision-making agreement is effective immediately and will continue until  
(insert date) or until the agreement is terminated by my supporter or me or by operation of law.

Signed this \_\_\_ day of, 20\_\_\_.

(6) Consent of Supporter

I, (name of supporter), consent to act as a supporter under this agreement. I understand that as  
\_\_\_\_\_’s supporter my job is to honor and present his/her wishes and in the  
event I cannot perform my duties I will withdraw from this agreement.

(7) Signatures

\_\_\_\_\_

(my signature)

(my printed name)

\_\_\_\_\_

(signature of supporter) (printed name of supporter)

\_\_\_\_\_

(witness 1 signature) (printed name of witness 1)

\_\_\_\_\_

(witness 2 signature) (printed name of witness 2)

Commonwealth of Massachusetts

County of \_\_\_\_\_

This document was acknowledged before me on \_\_\_\_\_ (date) by \_\_\_\_\_

(name of adult with a disability) and \_\_\_\_\_ (name of supporter).

\_\_\_\_\_ (signature of notarial officer)

(Seal, if any, of notary)

\_\_\_\_\_ (Printed name)

My commission expires: \_\_\_\_\_

(8) WARNING:

IF A PERSON WHO RECEIVES A COPY OF THIS AGREEMENT OR IS AWARE OF THE EXISTENCE OF THIS AGREEMENT HAS CAUSE TO BELIEVE THAT THE DECISION-MAKER, THAT IS THE ADULT WITH A DISABILITY, IS BEING ABUSED, NEGLECTED, OR EXPLOITED BY A SUPPORTER OR SUPPORTERS, THE PERSON SHALL REPORT THE ALLEGED ABUSE, NEGLECT, OR EXPLOITATION TO THE DISABLED PERSONS PROTECTION COMMISSION BY CALLING THE ABUSE HOTLINE AT 1-800-426-9009 OR 1-888-822-0350 (TTY) OR, IF THE DECISION-MAKER, THAT IS THE PERSON WITH A DISABILITY, IS AGE 60 OR OLDER TO THE ELDER ABUSE PREVENTION HOTLINE AT 1-800-922-2275.

## **Appendix V. HUMAN SERVICES RESEARCH INSTITUTE PILOT PROGRAM FINDINGS**

*The following pilot findings, recommendations, and challenges are copied directly from the Human Services Research Institute Year 1 and Year 2 reports on the Massachusetts SDM pilot program administered by the Center for Public Representation and Nonotuck Resource Associates, Inc. For purposes of clarity, no edits apart from stylistic changes were made.*

### **Year 1 Report Findings and Recommendations:<sup>695</sup>**

#### Practice Recommendations

1. Educate project staff about the legal and social foundation and constructs for SDM.
2. Set aside time to discuss SDM initiative framework, resources needed and foreseeable implementation issues.
3. Create a shared vision of pilot and goals. Include why retaining decision making rights matters to people with disabilities and our society.
4. Establish a clear pilot project team and clarify roles
5. Schedule regular in person meetings with agendas to update one another and jointly plan next steps.
6. Clarify how problems will be solved.
7. Establish an Advisory Council to provide multiple perspectives on implementation.
8. Early pilot initiatives should establish an independent evaluation to safeguard SDM adopters with external review of implementation and to share lessons learned.

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<sup>695</sup> PELL AND MULKERN, *supra* note 466.

9. Prior to meeting with putative SDM adopters, prepare plain language educational materials. Include a brief explanation of what SDM is, why it is an important rights issue, and what the practical impact is expected to be if adopted.
10. Where legal staff do not have regular communications with people with I/DD, consider utilizing an expert to role model SDM introductory conversations. Review interview guidance for conversations with people with I/DD such as disability etiquette.
11. Prior to meeting with a person with I/DD, find out about a person's life and communication style.
12. Allow extra time for individuals with I/DD and their family members and caregivers to get comfortable so they can freely express reservations and ask questions.
13. Expect to meet more than once with individuals with I/DD to present and discuss SDM
14. Create a script for pilot staff to guide SDM conversations.
15. Establish a protocol with frequency and a responsible entity to periodically communicate to individuals their freedom to choose to withdraw from pilot without repercussion.
16. Provide opportunity for staff participating in selection discussions to debrief following sessions to insure consistency with respect to assurance of individual's choices and how any persuasion or disagreements might best be handled.
17. Shared living offered participants a community member as a potential decision supporter they trusted.
18. Even when individuals and service providers are well-known to one another, SDM conversations can lead service providers to learn something new about people they support
19. Participants were inclusive when nominating decision supporters.

20. When more than one decision supporter is chosen, describe in the SDM Agreement how multiple supporter consultation is to work.
21. Take precaution so that individuals with I/DD understand they can specify which types of decisions they want to use support from designated people, and which types of decisions they want to make on their own. Legal staff should minimize the influence of others (family, guardian, staff, etc.) by meeting with individuals without others present when possible.
22. Institute procedures to periodically remind SDM participants and decision supporters of the ability to change decision supporters, as well as change areas for decision assistance.
23. Institute procedures to examine a complaint concerning a decision supporter. Institute procedures to refer investigation of complaints that rise to the level of abuse, neglect or financial exploitation.
24. Create plain language SDM agreements. Avoid legal language where possible.
25. Require decision supporters to sign SDM Agreements to ensure they understand the commitment, freely consent, and know the agreement is flexible and can be changed as people's lives change.
26. Notarize SDM Agreements to convey a formal document with legal stature.
27. Mark SDM adoption as a celebratory event.
28. When a representative payee and SDM are both in place for financial decision support, periodically examine the need for the representative payee
29. Even when uncontested, discharging a guardianship is complicated and time consuming. Allow sufficient time to insure that all requirements can be met.

30. Incorporate safeguards into SDM initiatives such as no cost, voluntary adoption, free legal assistance, withdrawal from the pilot at any time for any reason, and care manager monthly monitoring.
31. Prepare for and budget to share information that an alternative to guardianship exists and to disseminate information on the pilot experience.
32. Prioritize audiences for outreach activities.
33. Prepare for and budget generously for additional staff time to carry out SDM activities, coordinate activities, and share pilot experience.

## **Year 2 Report Findings and Recommendations:<sup>696</sup>**

### Findings

1. SDM decisions ranged from everyday choices to very important decisions. With decision assistance, adopters made decisions regarding their health care, dental care, mental and behavioral health care, finances, legal matters, living arrangements, work and day supports, social and leisure activities, relationships, and an SDM-arrangement decision to change a supporter.
2. All SDM adopters articulated their understanding that SDM means they make decisions about their lives and have assistance from others. Regardless of age, diagnoses, or life histories, these SDM adopters understand that SDM means making their own decisions and

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<sup>696</sup> PELL AND MULKERN, *supra* note 471.

receiving decision help when they want help. All adopters reported that SDM is a positive experience.

3. Decision supporters understood and were able to uphold their duties to assist an individual with disabilities to understand options, help the person express preferences, and honor the person's preferences and decisions.
4. Decision supporters tailored decision aids and assistance to the person's needs. They did so by knowing a person well.
5. Even experienced decision supporters would appreciate peer support and opportunities to share experiences with other decision supporters. Establishing learning communities of decision supporters, locally and nationally, could provide for greater decision supporter awareness of issues that arise for supporters, and more comfort that SDM is a sustainable alternative to guardianship.
6. Multiple decision supporters worked well in this pilot--to a great extent because supporters were already committed to, and had established arrangements for, regular and ongoing communications.
7. In this pilot, adopters utilized supporters who were available.
8. Most SDM decisions did not involve general community members. Where community members were involved, the preferences and decisions of adopters were accepted and acted upon without reviewing documentation of SDM arrangement or decision supporter's role.
9. Community members acted on the expressed preferences of SDM adopters without documentation of decisional capacity or decision supporter's role.
10. SDM adopters were satisfied with making their own decisions, with the decision assistance provided, and with the outcomes of their decisions.



11. Decision supporters were satisfied with the SDM decisions in which they were involved, and reported they had not experienced any constraint or dilemma in exercising the role and responsibilities of supporter.
12. SDM adopters did not experience abuse, neglect or financial exploitation through use of SDM. Many pilot participants stated their belief that the structure of SDM, selecting people one trusts to help with decisions, and having more than one decision supporter, reduces risk of abuse.
13. Where SDM is in place, require review of SDM-specific rights, values and principles with both adopters and decision supporters.
14. Where SDM is in place for people with disabilities receiving services, include periodic SDM-specific monitoring in service quality reviews.
15. A lack of resources was not a barrier to adopting SDM for either adopters or decision supporters.
16. This pilot demonstrated that positive changes occurred for individuals with I/DD and other disabilities who exercised their decision-making rights utilizing tailored decision assistance from trusted decision supporters. Positive impacts included increased pride, increased self-confidence, increased happiness, trying new experiences, taking more control of their own health care, and helping others more.
17. Using SDM made a positive difference in decision supporters too, particularly for family members.
18. Decision supporters, care managers and CPR staff believe this intentional SDM pilot demonstrated that SDM is a viable means to provide people with I/DD and other disabilities customized decision-making assistance that allows people to keep their decision-making

rights, has a positive impact on their self-respect, gives people a voice in decisions about their lives, and can reduce society's use of guardianship.

19. Pilot participants believe SDM would be useful for other populations whose decision-making rights often removed, particularly for older adults with early stage dementias, adults with psychiatric disabilities, and youth with I/DD who become legally recognized adults at age 18 when many families are counseled to secure guardianship.
20. SDM outreach and awareness activity was extensive across both years of the pilot. SDM outreach and awareness activity in future can include the pilot experience and impact findings from this evaluation.

#### Potential Implementation Challenges

1. For both family and paid service providers serving as decision supporters, a concern with safety may occasionally limit an individual's choices. For decision supporters who are paid to provide supports to SDM adopters, state standards for service providers may influence their consideration of safety when providing decision assistance. Balancing support for some risk-taking with safety is not a new challenge for service providers. In Massachusetts, state standards require providers to promote an individual's self-determination and freedom of choice to the individual's fullest capability, and for individuals to undergo typical developmental experiences, even though such experiences may entail an element of risk. However, state standards also require that providers to ensure that an individual's safety and well-being are not unreasonably jeopardized. Where there are dual responsibilities for ensuring safety and offering opportunities for risk-taking, decision

supporters may limit or restrict information without advising the SDM adopter that they have done so.

2. This pilot showed a high level of cooperation across multiple decision supporters, but such cooperation may not always be the reality. In this pilot, where decision supporters were almost all given authority to assist an adopter in all decision areas, going to a supporter on hand worked. Future SDM pilots where there is more discrimination of supporters and areas of assistance may experience added complications when using multiple supporters.
3. With multiple supporters, CPR staff raised a concern that a decision-making process could result in the supporters discussing and making a decision and then presenting that decision to the adopter. While a risk, this evaluation did not find evidence of that kind of process.
4. In this pilot supporters were present with adopters for interactions with community members and were able to provide instruction to enhance communication where needed. In some instances, had adopter interactions with community members not included decision supporters, the experiences and outcomes may not have been as favorable.
5. Several adopters in the pilot advised HSRI staff that they did not have a copy of their Agreement. If copy was needed, adopters and decision supporters stated they would call a care manager, and care managers noted they would contact their Nonotuck supervisor or CPR staff. It may be useful to periodically check, such as annually, that adopters, supporters, and service providers have copies of the most current SDM Representation Agreement.
6. Decision supporters do at times exert influence on an adopter's decisions. Providing unbiased pros and cons of options can be challenging at times for decision supporters who want adopters to both enjoy new experiences but also reduce potential stigma.

7. Although adopters and decision supporters were initially advised of their SDM-specific “rights”, there was not a standardized list of rights or a protocol on the frequency or points in time (e.g., entrance into services, service plan review, quarterly care manager monitoring visit, etc.) care managers or other pilot staff would remind adopters and decision supporters of SDM values and principles of SDM. In Massachusetts, the annual service planning meeting includes a review of human rights for individuals with I/DD receiving publicly-funded services. SDM-specific principles and expectations could be incorporated into state regulation and a standardized SDM rights form.
8. Thus far, there is not an SDM-specific assessment or monitoring instrument in use. If care managers note a problem, they stated they would explore and follow up just as they would other concerns. During the course of this pilot, no untoward problems or risks were discerned by care managers. Thus, it is not clear if the typical path for problem resolution would be sufficient or require some SDM-specific adjustment.
9. Where SDM is in place, decision assistance and emotional support could be drawn upon to expand adopter experiences in banking, managing funds, and for those receiving publicly-funded services, to self-direct their services. The Year 1 Evaluation Report noted a less broad Practice Recommendation. When a representative payee and SDM are both in place for financial decision support, periodically examine the need for the representative payee. However, with the substantial changes demonstrated in adopters, and in decision supporters, self-directing services should also be considered.

## Appendix VI. THE ARC OF SAN ANGELO PILOT PROGRAM STATISTICS

*This table and its description are from the pilot program report from The Arc of San Angelo in Texas.*<sup>697</sup>

A total of nineteen (19) people (3 individuals with developmental disabilities, 2 family members and 14 others) facilitated the design of the project through face-to-face meetings. The project has identified seven (7) others for participation in the pilot program. Of those, three (3) have cognitive disabilities and meet the federal DD definition and four (4) have cognitive disabilities onset after the age of 22.

	Individuals with DD	Family Members	Others
CS01: Individuals received formal/informal community supports			
• Provided assistance which lead to Guardianship avoidance	4		
• Facilitated Restoration of Rights	1		
• Assisted establishment of Advance Directives through Medical Power of Attorney*	10		
• Diverted guardianships in the investigation stage	2		
CS04: People facilitated formal/informal community supports.			
• Facilitated project design	3	2	14
• Provided guidance, training, and help accessing services	15		
CS05: People trained in formal/informal community supports			
• Five-day Leadership Academy PLUS training session			12
• Networking event and interactive educational session			350**

\*\*Figure is approximate based on attendance rosters; breakdown is unknown

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<sup>697</sup> *Programs, supra* note 301.