

**REPORT ON LEGISLATION BY THE  
MENTAL HEALTH LAW COMMITTEE AND  
THE DISABILITY LAW COMMITTEE**

**S.7107**

**Sen. Mannion**

AN ACT to amend the mental hygiene law, in relation to supported decision-making by people with intellectual, developmental, cognitive and psycho-social disabilities. (Office for People with Developmental Disabilities (Internal # 3 - 2021))

**THIS BILL IS APPROVED WITH MODIFICATION**

Supported decision-making (SDM) is an emerging practice by which persons with intellectual, developmental, cognitive and psychosocial disabilities can make their own decisions with the support of trusted persons in their lives. SDM can take many forms, from entirely informal to a more formal process resulting in a signed supported decision-making agreement (SDMA) between the person with a disability, often referred to as the “Decision-Maker,” and their supporters. SDM is now widely recognized as a constitutionally required “less restrictive alternative to guardianship;<sup>1</sup> the Uniform Law Commission has explicitly included SDM as such

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<sup>1</sup> Supported decision-making has been recognized as a “less restrictive alternative” to guardianship by, *e.g.*, the American Bar Association, the National Guardianship Association, the Arc of the U.S., the National Council on Disability, *see* COMM’N ON DISABILITY RIGHTS, ABA, REPORT TO THE HOUSE OF DELEGATES: RES. NO. 113 (2017), [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/supported-decision-making-resolution-final.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/supported-decision-making-resolution-final.pdf); NATIONAL GUARDIANSHIP ASSOCIATION, POSITION STATEMENT ON GUARDIANSHIP, SURROGATE DECISION-MAKING AND SUPPORTED DECISION-MAKING (2017), [https://www.guardianship.org/wp-content/uploads/2018/09/SupportedDecision\\_Making\\_PositionStatement.pdf](https://www.guardianship.org/wp-content/uploads/2018/09/SupportedDecision_Making_PositionStatement.pdf); THE ARC, POSITION STATEMENTS, AUTONOMY, DECISION-MAKING SUPPORTS AND GUARDIANSHIP (2017) (joint statement with American Association for Intellectual and Developmental Disabilities), <https://thearc.org/wp-content/uploads/2021/05/Autonomy-Decision-Making-Supports-and-Guardianship.pdf>; NATIONAL COUNCIL ON DISABILITY: NATIONAL COUNCIL ON DISABILITY, BEYOND GUARDIANSHIP: TOWARD ALTERNATIVES THAT PROMOTE GREATER SELF-DETERMINATION, 130-138 (2018), [https://ncd.gov/sites/default/files/NCD\\_Guardianship\\_Report\\_Accessible.pdf](https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf). Most recently, The Fourth National Guardianship Summit, also recognized supported decision-making as a “less restrictive alternative” to guardianship. *See* note 29, *infra*. The constitutional imperative of least restrictive alternative derives from *O’Connor v. Donaldson*, 422 U.S. 563 (1975) and has been embraced by New York courts. *See, e.g., Kesselbrenner v. Anonymous* 33 N.Y. 2d 161,165 (1973); *Manhattan Psychiatric Center v. Anonymous*, 285 A.D. 2d 189, 197-98 (1st Dept. 2001). (All sites last visited June 30, 2021).

**About the Association**

*The mission of the New York City Bar Association, which was founded in 1870 and has 25,000 members, is to equip and mobilize a diverse legal profession to practice with excellence, promote reform of the law, and uphold the rule of law and access to justice in support of a fair society and the public interest in our community, our nation, and throughout the world.*

in its recently revised Uniform Guardianship, Conservatorship and Other Protective Proceedings Act,<sup>2</sup> and several states have followed suit.<sup>3</sup>

At the same time, a growing number of U.S. states—ten as of this writing—and the District of Columbia, have adopted legislation to legally recognize decisions made pursuant to supported decision-making agreements (SDMAs).<sup>4</sup> SDMA statutes have a number of purposes, including encouraging and incentivizing the use of SDM and SDMAs, empowering people with disabilities to become more self-determined and autonomous, and ending unwarranted discrimination against persons with disabilities whose decisions are often questioned or disregarded because third parties believe that they “lack capacity.” SDMA statutes, like the instant bill, draw on the non-discrimination principles of the Americans with Disabilities Act to require equal treatment of persons with disabilities who make decisions pursuant to a legislatively recognized SDMA by requiring third parties to accept those decisions and, in return, conferring immunity for their good faith acceptance.<sup>5</sup> As the Legal Director for the Autism Self-Advocacy Network has written, “It is critical that states adopt legislation through which people with significant decision-making support needs can make legally enforceable decisions with the assistance of a chosen support network.”<sup>6</sup>

The New York City Bar Association (“City Bar”) was founded in 1870 and is a private, non-profit organization of more than 25,000 attorneys, judges and law professors. The City Bar has long supported the vigorous and fair enforcement of civil rights laws. In January 2016, the City Bar’s Mental Health Law Committee and Disability Law Committee issued a report, *Revisiting S.C.P.A. 17-A: Guardianship for People with Intellectual Disabilities*, which addressed how, if at all, the state should provide substituted decision-making for this vulnerable population, and specifically noted the emergence of SDM as “a new model of autonomy and self-

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<sup>2</sup> NAT’L CONFERENCE OF COMMISSIONERS ON UNIF. STATE LAWS, UNIFORM GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT (UNIF. L. COMM’N 2017), <https://www.uniformlaws.org/HigherLogic/System/DownloadDocumentFile.ashx?DocumentFileKey=de9bae9e-0b4e-0781-12b5-f5305569bf19&forceDialog=0>.

<sup>3</sup> See, e.g., Maine Revised Probate Code, 18-C M.R.S. Sec. 5-401.

<sup>4</sup> TEX. EST. CODE ANN. §§ 1357.001 - 1357.102 (West 2019); WIS. STAT. ANN. §§ 52.01-52.32 (West 2018); ALASKA STAT. ANN. §§ 13.56.010-13.56.195 (West 2018); DEL. CODE ANN. tit. 16, §§ 9401A-9410A (West 2016); D.C. CODE ANN. §§ 7-2131 - 7-2134 (West 2018); IND. CODE ANN. §§ 29-3-14-1 - 29-3-14-13 (West 2019); N.D. CENT. CODE ANN. §§ 30.1-36-01 - 30.1-36-08 (West 2019); 42 R.I. GEN. LAWS ANN. §§ 42-66.13-1 - 42-66.13-10 (West 2020); NEV. REV. STAT. ANN. §§ 162C.010 - 162C.330 (West 2020); WASH. REV. CODE ANN. §§ 11.130.700 et. seq. (West 2020) (effective Jan. 1 2022); 2020 Wash. Legis. Serv. Ch. 312 (S.S.B. 6287) Part VI § 601-612 (West 2020); LA. STAT. ANN. § 13:4261.101- 13:4261.302 (West 2020).

<sup>5</sup> Americans with Disabilities Act, 42 U.S.C. Sec. 12101 *et seq.* As one commentator has written, “Just as we recognize that the law—and common principles of human decency—generally require that we build a ramp so that an individual with a physical impairment can enter a building without being carried up the steps, we should also recognize a legal obligation to provide decision-making support to an individual with limitations in mental capabilities rather than assign a guardian to make decisions *for* that person.” Rachel Mattingly Phillips, *Note: Model Language for Supported Decision-Making Statutes*, 98 Wash. U. L. Rev 615, 624 (2020).

<sup>6</sup> Samantha Alexandra Crane, *Is Guardianship Reform Enough? Next Steps in Policy Reforms to Promote Self-Determination Among People with Disabilities*, 8 J. Compar. & Int’l Aging L. & Pol’y 177, 180 (2015).

determination.”<sup>7</sup> The Mental Health Law Committee respectfully urges the Legislature to consider the adoption of S.7107 (“the bill”), with the modification proposed, in order to ensure that the rights of people with intellectual, developmental, cognitive and psychosocial disabilities are properly protected.

## **I. THE BILL IS THE CONSEQUENCE OF SIGNIFICANT INVOLVEMENT AND INVESTMENT BY THE STATE**

New York has played a significant and thoughtful role in the formulation and development of SDM and SMDAs in theory and in practice. In 2012, the American Bar Association Commissions on Law and Aging and Disability Rights convened the first national, interdisciplinary roundtable to explore SDM in New York City.<sup>8</sup> The convening received funding from the New York Community Trust and support from the federal government’s Administration for Community Living.<sup>9</sup> Three years later, as efforts to enact SDMA legislation grew around the country, the New York State Developmental Disability Planning Council (DDPC), awarded a \$1.5 million, five-year grant to Supported Decision-Making New York (SDMNY) to educate stakeholders about SDM, to develop and pilot a model utilizing SDM to divert persons at risk of guardianship or restore rights to persons currently under guardianship, and to develop an evidentiary base for prospective SDMA legislation in New York.<sup>10</sup> Over the last five years, SDMNY has enrolled more than 140 Decision-Makers, developed a three-phase model that facilitates Decision-Makers and their supporters in making an agreement reflecting the process by which the Decision-Maker will make decisions and the supporters will provide support going forward.<sup>11</sup>

Unlike the other jurisdictions that have enacted SDMA statutes with no empirical, “on the ground” evidence, New York’s prescient decision to first thoroughly explore how SDM actually works for people with intellectual and developmental disability (I/DD) positions it as a leader in fostering the rights of people with intellectual, cognitive and psychosocial disabilities through an authentic practice of SDM.

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<sup>7</sup> 18 CUNY L. Rev. 287 (2015); also available at <https://www.nycbar.org/member-and-career-services/committees/reports-listing/reports/detail/revisiting-scpa-17-a-guardianship-for-people-with-intellectual-and-developmental-disabilities-cuny-law-review-vol-182>.

<sup>8</sup> Kristin Booth Glen, *Piloting Personhood: Reflections from the First Year of a Supported Decision-Making Project*, 39 Cardozo L. Rev. 495, 501 (2017).

<sup>9</sup> Kristin Booth Glen, *Supported Decision-Making From Theory to Practice: Further Reflections on an Intentional Pilot Project*, 13 Alb. Gov’t L. Rev. 94, 101 n.36 (2019-2020).

<sup>10</sup> SDMNY is a consortium of Hunter/CUNY, the NY Alliance for Inclusion and Innovation, a statewide association of provider agencies (formerly NYSACRA), and the Arc of Westchester, a large, parent-led provider agency, with New York’s federally funded Protection & Advocacy Agency, Disability Rights New York (DRNY), as its legal partner.

<sup>11</sup> The SDMNY model—including the 3-phase facilitation process, facilitator training, and oversight by trained mentors, and the U.S. and the international pilots from which it was derived—is described in detail in Glen, *supra* n. 9, and on the SDMNY website, [www.sdmny.org](http://www.sdmny.org).

## **II. BY RECOGNIZING SDM AS AN ALTERNATIVE TO GUARDIANSHIP, THE BILL WILL CLARIFY EXISTING LAW AND PROVIDE GUIDANCE TO COURTS, LITIGANTS AND COUNSEL**

Although New York has recognized the constitutional imperative of “least restrictive alternative” in case law,<sup>12</sup> and provided that other decisional supports must be considered before guardianship is imposed pursuant to Article 81 of the Mental Health Law (MHL),<sup>13</sup> SDM is nowhere specifically named.<sup>14</sup> Article 17-A of the Surrogate’s Court Procedure Act (SCPA) lacks any reference to consideration of alternatives whatsoever. By naming the process of SDM as “a way by which a decision-maker utilizes support from trusted persons in their life, in order to make their own decisions about their life,”<sup>15</sup> stating explicitly that SDM can be “a less restrictive alternative to guardianship,”<sup>16</sup> and recognizing that SDM may take a variety of forms,<sup>17</sup> including informal arrangements, all of which may be considered by courts as “less restrictive alternatives,”<sup>18</sup> the bill fills the existing lacuna, providing clear guidance to courts and litigants.

## **III. BY RECOGNIZING SDM, AND PRESCRIBING A MORE FORMALIZED PROCESS FOR MAKING SDMAS, THE BILL WILL PROVIDE FAMILIES AN ALTERNATIVE TO GUARDIANSHIP WHILE LEAVING EXISTING GUARDIANSHIP STATUTES IN PLACE AND AVAILABLE WHEN APPROPRIATE**

The bill does nothing to change existing guardianship law which has, in any event, proven relatively impervious to alteration.<sup>19</sup> No one is, or can be, required to use SDM or enter into an SDMA.<sup>20</sup> Nor does the use of SDM or the existence of an SDMA necessarily result in denial of a proposed guardianship, or termination of an existing guardianship; a factual inquiry into the need for the guardianship, and whether SDM or the SDMA actually constitutes a less restrictive alternative, is always required. SDM or an SDMA does not preclude parents or other potential petitioners from seeking—and obtaining—guardianship if the process is not effectively meeting the needs that guardianship is statutorily prescribed to fill. Studies consistently demonstrate that many parents who want to continue promoting the autonomy and self-determination of their adult

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<sup>12</sup> *Supra*. n.1.

<sup>13</sup> MHL Sec. 81.01; *see, e.g. In re Isadora R.*, 5 A.D.3d 494 (2d Dept. 2004); *In re Janczak*, 167 Misc. 2d 766 (S. Ct. Ontario Co. 1995).

<sup>14</sup> This is not deliberate; the concept of SDM did not yet exist when Article 81 was enacted.

<sup>15</sup> The bill states “decision-maker” is defined as “an adult who has executed or seeks to execute a supported decision-making agreement.” Sec. 82.02(i).

<sup>16</sup> *Id.*

<sup>17</sup> Sec. 82.01(b).

<sup>18</sup> Sec.82.04(f).

<sup>19</sup> This is particularly true of SCPA Article 17-A, which was recognized as needing significant reform as early as 1990, as reflected in the Mental Health Law and Disability Law Committees’ earlier Report, *supra* n. 7. Despite a federal civil rights lawsuit challenging the law and numerous other calls for change, the guardianship law remains unchanged to this day. *See Disability Rights N.Y. v. New York*, 916 F.3d 129, 133–37 (2d Cir. 2019); *see also* Glen, *supra* n. 9 at 100-101.

<sup>20</sup> A specific provision of the bill prohibits conditioning of services on the execution of an SDMA, Sec. 82.04(g).

children with I/DD believe they have no alternative other than to seek guardianship and are unaware of existing alternatives.<sup>21</sup> The bill provides an alternative that families are free to try and which may prove a beneficial and less restrictive alternative, preserving the civil and legal rights of persons with I/DD.

At the same time, the bill will incentivize the use of SDM by families seeking to promote self-determination of their adult children with I/DD. One outcome from the DDPC-supported pilot project is particularly salient. Many parents and their adult children with I/DD are anxious to try SDM, but fear that, in the absence of legal recognition, they will inevitably find themselves in a situation where a third party (generally perceived to be a health-care provider) refuses to provide services to the Decision-Maker because of her/his perceived lack of capacity, insisting instead on a guardianship order. Many other families face pressure—whether intentional or through the well-intentioned recommendations of professionals—to seek guardianship.<sup>22</sup>

Those parents, facing what they understand to be the likely “inevitability” of guardianship, may say that the time and work that goes into creating an SDMA is simply not worth it—unless and until there is legal recognition of decisions made pursuant to the SDMA. Parents who have been surveyed are virtually unanimous in supporting legislation that “solves” this problem by providing for legislative recognition, and report that it would positively impact their decision to try SDM.<sup>23</sup> That is precisely what the bill will provide.

#### **IV. THE BILL WILL PREVENT DISCRIMINATION AGAINST PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL, COGNITIVE AND PSYCHOSOCIAL DISABILITIES BASED ON STIGMA, PREJUDICE OR FEAR OF LIABILITY**

For many reasons, third parties, both private and public, question the ability of persons with disabilities to make decisions and often refuse to accept their decisions.<sup>24</sup> In practice, this means individuals with disabilities are frequently deprived of the right to legal capacity.<sup>25</sup>

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<sup>21</sup> See, e.g., NATIONAL COUNCIL ON DISABILITY, BEYOND GUARDIANSHIP: TOWARD ALTERNATIVES THAT PROMOTE GREATER SELF-DETERMINATION, at 92 (2018).

<sup>22</sup> Carrie E. Rood et al., *Presumption of Incompetence: The Systematic Assignment of Guardianship Within the Transition Process*, 39 RES. & PRAC. FOR PERSONS WITH SEVERE DISABILITIES 319 (2015).

<sup>23</sup> See, e.g., ELIZABETH PELL, SUPPORTED DECISION-MAKING NEW YORK: EVALUATION REPORT OF AN INTENTIONAL PILOT (Aug. 2019), <https://sdmny.hunter.cuny.edu/wp-content/uploads/2019/12/Pell-SDMNY-Report-2019.pdf>; Report of Parent-to-Parent Convened Focus Groups on SDMA Legislation (May, 2021) (on file with Committee).

<sup>24</sup> These reasons include stigma and prejudice against people with intellectual, developmental, cognitive and psychosocial disabilities, but also fear of liability if a transaction to which a person with such disability was a party is ultimately voided for “lack of capacity.” As to the latter, the bill and other SDMA statutes avoid the problem by conferring immunity for the acceptance of a decision made pursuant to an authorized SDMA “in good faith.” Sec. 82.12(b).

<sup>25</sup> The “right of legal capacity” is derived from the UN Convention on the Rights of Persons with Disabilities which requires recognition of the right to make one’s own decisions, and to have those decisions legally recognized, without regard to disability. Committee on the Rights of Persons with Disabilities, General Comment No. 1, Article 12: Equal Recognition Before the Law, ¶ 12, *U.N. Doc. CRPD/C/GC/1* (May 19, 2014).

Although existing law presumes that all adults have legal capacity,<sup>26</sup> a diagnosis of intellectual, developmental, cognitive, or psychosocial disability, or belief that a person has such disability, often results in discriminatory treatment, including refusal to recognize their decisions.<sup>27</sup> The bill, similar to existing SDMA legislation in other jurisdictions, avoids such discrimination by removing the ability of third parties to make their own “determinations” of a person’s legal capacity based on their disability. Instead, the bill provides that a decision made pursuant to a recognized SDMA is presumptively made with legal capacity.<sup>28</sup> In this respect, the bill reflects the principles and requirements of the Americans with Disabilities Act by recognizing SDM, through a prescribed process reflected in an SDMA, as an accommodation that enables people with disabilities equal access to contractual relationships.<sup>29</sup>

## V. THE BILL PROVIDES PROTECTION AGAINST POSSIBLE ABUSE OR EXPLOITATION OF DECISION-MAKERS

Families often are concerned about possible exploitation of their vulnerable adult children with I/DD and seek guardianship as “protection,” relying on supposed court oversight. In fact, Article 17-A of the SCPA has no provision for reporting once a guardian has been appointed, or for any periodic review.<sup>30</sup> In contrast, the bill provides significant protection by essentially creating “on-the-spot,” “point-of-transaction” monitoring, by permitting a third party to refuse to accept a decision if there is substantial cause to believe it is the product of abuse, coercion, undue influence or financial exploitation by a supporter,<sup>31</sup> and to report the alleged abuse, coercion, undue

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<sup>26</sup> Robert 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*,” Human Rights Brief 19, no. 2 (2012): 9.

<sup>27</sup> See, e.g., Crane, *supra* n. 6, noting that “individuals and businesses [may be] unwilling to enter into major contracts—such as lease agreements or automobile loans—with individuals with disabilities who do not have guardians, as a court may at some later point determine that the individual lacked capacity to enter into such contracts and therefore declare them invalid. Similarly, health care providers may be unwilling to provide treatment requested by a disabled individual, for fear that a court will later determine that the individual lacked capacity to consent to treatment.”

<sup>28</sup> See, e.g., Rachel Mattingly Phillips, *Note: Model Language for Supported Decision-Making Statutes*, 98 Wash. U. L. Rev. 615, 637 (2020) (proposing that a “statute should make it clear that any decision made or action taken by the principal with the aid of a supporter is legally valid and binding (absent the sort of extenuating circumstances that could void any decision). To this end, the statute should acknowledge that an individual using a supporter is considered to be competent to the same degree as if they had the same capability acting alone.”).

<sup>29</sup> Considering the ADA, one commentator has noted that “[t]he statute itself specifies that entering into contracts is a strategy that can be used to ensure the full participation and inclusion of those with disabilities. The ADA provides that the refusal of covered entities, including a broad swath of private actors, to enter into contracts with the disabled is an act of discrimination.” Sean M. Scott, *Contractual Incapacity and the Americans with Disabilities Act*, 124 Dick. L. Rev. 253, 288 (2020). The National Guardianship Summit, a convocation of experts and stakeholders, convened approximately every decade, makes influential recommendations in the field. The Fourth National Guardianship Summit, which met from May 12-16, 2021, just adopted a resolution calling on the Department of Justice to explicitly recognize SDM as an accommodation under the ADA. Fourth National Guardianship Summit, Recommendation VII (on file with Committee).

<sup>30</sup> See Mental Health Law Committee’s prior Report, *supra* n. 7 at 313-31. One court has required periodic reporting and review as constitutionally compelled. *In re Mark C. H.*, 28 Misc. 3d 765 (Surr. Ct. N.Y. Co. 2010).

<sup>31</sup> Sec. 82.11 (d).

influence or exploitation to the appropriate protective agency, in real time, without fear of any penalty.<sup>32</sup>

In addition, existing SDMA statutes have been subject to criticism that, by creating a “legal status” for supporters unrelated to any court proceeding or oversight, people with disabilities entering into SDMAs easily could be exploited through a kind of “guardianship on the cheap.” If a supporter had the right to “communicate” and/or enforce (or “implement”) the alleged decision of a person with a disability, they would essentially have all the powers of a guardian, but with none of the protections of court-imposed guardianship.<sup>33</sup> The bill protects against this in several ways. First, it explicitly states that a supporter may not make decisions for the Decision-Maker,<sup>34</sup> be considered a substitute decision-maker, or legally bind the Decision-Maker to any legal agreement.<sup>35</sup> Second, where other SDMA laws have accorded legislative recognition to decisions made pursuant to SDMAs that are simply signed forms, with no requirement of any education or facilitation process to ensure that both the Decision-Maker and supporters understand and have committed to a process of trust and respectful support, the Bill draws on the experience of the DDPC-funded project and requires completion of a meaningful facilitation process for Decision-Makers and their supporters for SDMAs in order to require recognition.<sup>36</sup> Finally, as noted below, the bill also draws on empirical evidence—and the lack thereof—to initially limit recognition to SDMAs made by people with I/DD for whom there is consensus on what constitutes appropriate decision-making support.

## **VI. THE BILL ENCOURAGES SDM AND THE USE OF SDMAS FOR EVERYONE WHILE INITIALLY LIMITING LEGISLATIVE RECOGNITION TO PEOPLE WITH I/DD FOR WHOM EFFECTIVE AND APPROPRIATE SUPPORTS HAVE BEEN EMPIRICALLY DEMONSTRATED**

The bill provides that an SDMA can be made by any adult, thus “normalizing”<sup>37</sup> the process, and recognizing that, in making decisions, “everyone uses supports, as do people with disabilities, who may just need more or different kinds of supports.”<sup>38</sup> How an SDMA is made, what it may and may not contain, and provisions ensuring that the making of an SDMA can neither

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<sup>32</sup> Sec. 82.14 (a).

<sup>33</sup> Nina A. Kohn, *Legislating Supported Decision-Making*, \_\_ Harvard J. of Legislation \_\_ (forthcoming 2021). An earlier article by Professor Kohn and others cautioned against embracing SDM and SDMAs in the absence of empirical evidence. Nina A. Kohn et al, *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 Penn St. L. Rev. 1111 (2013). In response, New York’s commitment to developing an adequate evidentiary base is reflected throughout the pending bill.

<sup>34</sup> Sec. 82.05 (b)(1).

<sup>35</sup> Sec. 82.05 (d).

<sup>36</sup> Sec. 82.09. Family members surveyed in focus groups about SDMA legislation believe this to be an important protection against others “taking advantage of” their adult children with I/DD. See Parent-to-Parent Report, supra at n. 23. Commentators have called for a training or education requirement. See, e.g., Megan S. Wright, *Dementia, Autonomy and Supported Healthcare Decisionmaking*, 79 Md. L. Rev. 257, 289 (2020).

<sup>37</sup> WOLF P. WOLFENBERGER ET AL., *THE PRINCIPLE OF NORMALIZATION IN HUMAN SERVICES* (1972).

<sup>38</sup> Sec. 82.01(a); see also Committee on the Rights of Persons with Disabilities, General Comment No. 1, Article 12: Equal Recognition Before the Law, ¶ 12, *U.N. Doc. CRPD/C/GC/1* (May 19, 2014) [hereinafter CRPD Committee].



be used against the person, nor required of them,<sup>39</sup> apply to everyone. To confer legislative recognition, however, there should be some significant level of confidence that the person who has executed the SDMA has appropriate and adequate supports to make decisions. To date, virtually all of the pilot projects and evaluations around the world have involved people with I/DD and have resulted in a general consensus on the use of a process of facilitation for Decision-Makers and their supporters;<sup>40</sup> the DDPC-funded pilot in New York has confirmed that facilitated SDM provides the necessary and appropriate support for legislative recognition of decisions made by persons with I/DD pursuant to an SDMA. There is no corresponding evidentiary base, or the existence of any pilot projects for persons with other disabilities, and no clear understanding of what kinds of support would be necessary for them to achieve or be afforded legal capacity.<sup>41</sup> The bill acknowledges this gap while calling on government and civil society “to develop appropriate and effective means of support for older persons with cognitive decline, persons with traumatic brain injury, and persons with psychosocial disabilities, so that full legislative recognition can also be accorded to the decisions made with supported decision-making agreements by persons with such conditions.”<sup>42</sup>

## **VII. THE BILL SHOULD INCLUDE A REQUIREMENT THAT RELEVANT STATE ENTITIES PROVIDE ACCESSIBLE INFORMATION ON SDM AND SDMAS AS AN ALTERNATIVE TO GUARDIANSHIP**

Few, if any, of the many benefits of this bill will actually occur unless stakeholders know about SDM and SDMAS. Research consistently shows that parents of transition-age adults with I/DD are routinely and repeatedly informed about, and encouraged to pursue, guardianship when

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<sup>39</sup> Under the bill, making an SDMA is not evidence of lack of capacity, nor can it be used to deprive a person of benefits to which they are otherwise entitled. Sec. 82.03(e). Conversely, making an SDMA “may not be a condition of participation in any activity, service or program.” Sec.82.04(g).

<sup>40</sup> See, e.g., Bigby et. al, *Delivering decision making support to people with cognitive disability — What has been learned from pilot programs in Australia from 2010 to 2015*, 52:3 AUST J SOC ISSUES 222, 244 (Sept. 27, 2017), <https://doi.org/10.1002/ajs4.19> (Australia); BULGARIAN CTR. FOR NOT-FOR-PROFIT LAW, SUFFICIENCY OF LAW, DEFICIENCY OF RIGHTS 28 (2015) (Bulgaria); QUIP, *Black and White*, <https://perma.cc/S6TH-9Q7N> (Czech Republic); *Decision-Making Service for Persons with Disabilities, Service Model* (on file with Committee) (Israel); ZELDA, *Handbook: First Steps in Implementation of Supported Decision Making in Latvia* (Apr. 26, 2016), <https://perma.cc/428C-EZB8> (Latvia).

Significantly, the only jurisdiction that, to date, has enacted an SDMA statute based on a pilot project, Israel, specifically requires a significant amount of training for supporters—though not for Decision-Makers—for the legislative recognition of decisions made pursuant to SDMAS. Glen, *supra* n. 9. For examples in the U.S., see ELIZABETH PELL & VIRGINIA MULKERN, THE HUMAN SERVICES RESEARCH INSTITUTE, SUPPORTED DECISION MAKING PILOT: A COLLABORATIVE APPROACH, PILOT EVALUATION YEAR 1 (Nov. 30, 2015) [HTTPS://SUPPORTEDDECISIONS.ORG/WP-CONTENT/UPLOADS/2019/05/CPR-SDM-HSRI-EVALUATION-YEAR-1-REPORT-2015.PDF](https://supporteddecisions.org/wp-content/uploads/2019/05/CPR-SDM-HSRI-EVALUATION-YEAR-1-REPORT-2015.PDF); ELIZABETH PELL & VIRGINIA MULKERN, THE HUMAN SERVICES RESEARCH INSTITUTE, SUPPORTED DECISION MAKING PILOT: PILOT PROGRAM EVALUATION YEAR 2 REPORT, <https://supporteddecisions.org/wp-content/uploads/2019/05/CPR-SDM-HSRI-Evaluation-Year-2-Report-2016.pdf>.

<sup>41</sup> For discussion of why there has been so little attention to older persons, and how SDM could be important to that population, see Rebekah Diller, *Legal Capacity for All: Including Older Persons in the Shift from Guardianship to Supported Decision-Making*, 43 FORDHAM URB. L. J. 495, 498 (2016). For discussion of legal capacity and persons with psychosocial disabilities, see generally PIERS GOODING, A NEW ERA FOR MENTAL HEALTH LAW AND POLICY: SUPPORTED DECISION-MAKING AND THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (2017).

<sup>42</sup> Sec. 82.01(d).



their children turn 18.<sup>43</sup> This leads to what the National Council on Disability calls the “school to guardianship pipeline.”<sup>44</sup> Similarly, many parents report that they had no idea of available alternatives, and had never heard of SDM.<sup>45</sup> Parents and self-advocates believe that information about SDM should be more readily available, and national organizations have likewise called for information on SDM to be made available in the educational and court systems<sup>46</sup> as well as for professionals and others.<sup>47</sup> This is also a “learning” and recommendation of the DDPC-funded project.<sup>48</sup>

To ensure that persons with developmental, intellectual, cognitive and psychosocial disabilities, those who might seek guardianship, and current guardians have access to information about SDM, potentially preventing unnecessary guardianships and protecting the civil and legal rights of persons with disabilities, the bill should include a provision directing the Department of Education to require that schools provide information on SDM and SDMA as an alternative to guardianship to students and parents during transition planning.<sup>49</sup> Additionally, the bill should require the Office of Court Administration to provide similar information in the appropriate clerks’ offices in Surrogates Courts and Supreme Court, Civil Term, and that all such information should be made available in accessible form.

Mental Health Law Committee  
Karen Simmons, Chair

Disability Law Committee  
Katherine R. Carroll, Chair

July 2021

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<sup>43</sup> See, e.g., Rood, *supra* note 23; Crane, *supra* n. 6 at 193, 203.

<sup>44</sup> National Council on Disabilities Report, *supra* n. 21.

<sup>45</sup> See, e.g., Parent-to-Parent Report, *supra* n. 23, Pell, *supra* n. 23; Cathy Constanzo et al, *Supported Decision-Making: Lessons from Pilot Projects*, Syracuse L. Rev. (forthcoming)

<sup>46</sup> Some New York Surrogates Courts are already including information in their clerks’ offices, and the Office of Court Administration website has a video on alternatives that mentions SDM. See, e.g., *Guardianship Information Session 17A Alternatives to Guardianship*, <https://www.youtube.com/watch?v=O6Fe1w-LQo>.

<sup>47</sup> See, e.g., NCD Report, *supra* n. 23 at 18-19, Fourth National Guardianship Summit, *supra* n. 30, Recommendations.

<sup>48</sup> Constanzo et al., *supra* n. 45. See also SDMNY, *Principles for Supported Decision-Making Legislation*, Principle IX, <https://sdmny.org/supported-decision-making-legislation/principles-for-supported-decision-making-agreements-in-new-york/principles-for-a-supported-decision-making-agreement-sdma-law-long/>.

<sup>49</sup> A similar provision can be found in the Wisconsin SDMA Statute, *supra* n. 4 at Sec. 115.807 and the bill currently pending in Massachusetts, S. 124 Section 4, available at <https://legiscan.com/MA/bill/S124/2021> (requiring the Massachusetts Department of Education to provide information on SDM to parents and students in the transition planning process).