

# DISABILITY LAW

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## TABLE OF CONTENTS

INTRODUCTION.....	699
I. SDMNY .....	701
II. THE POLICY BEHIND ARTICLE 82 .....	701
III. MAJOR ELEMENTS OF ARTICLE 82 .....	705
A. <i>Capacity</i> .....	705
B. <i>Participants’ Roles in Supported Decision-making</i> <i>Agreements</i> .....	707
C. <i>Elements of an Agreement</i> .....	708
D. <i>Third-Party Acceptance</i> .....	709
E. <i>Third-Party Immunity</i> .....	709
IV. IMPLEMENTATION .....	710
A. <i>Regulation</i> .....	710
B. <i>Facilitation</i> .....	711
C. <i>Education</i> .....	711
D. <i>Amendments to New York’s Guardianship Statute for</i> <i>People with Developmental Disabilities, Article 17A</i> ....	712
E. <i>Evaluation</i> .....	714
1. <i>Evaluation of Supported Decision-Making</i> .....	714
A. <i>Pell Evaluation</i> .....	714
B. <i>Stout Risius Ross Study</i> .....	715
C. <i>Burton Blatt Study</i> .....	715
CONCLUSION.....	716

## INTRODUCTION

Perhaps the most significant development in disability law during the period of 2021-2022 was the enactment of Article 82 of the Mental Hygiene Law, added to New York’s laws in 2022 by Chapter 481. The law recognizes supported decision-making agreements by individuals with intellectual, developmental, cognitive, and psychosocial

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disabilities, and encourages their enforcement by creating immunity for those who accept decisions made pursuant to agreements as specifically provided for in the legislation.<sup>1</sup>

The law defines “supported decision-making” 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, including, but not limited to, decisions related to where and with whom the decision-maker wants to live; decisions about finances; the services, supports and health care the decision-maker wants to receive; and where the decision-maker wants to work.<sup>2</sup>

A supported decision-making agreement is “an agreement a decision-maker enters into with one or more supporters . . . that describes how the decision-maker uses supported decision-making to make their own decisions”.<sup>3</sup>

While seeking support from friends and relatives to help with decisions is not a concept unique to individuals with developmental disabilities,<sup>4</sup> individuals with such a diagnosis are usually perceived as being unable to make their own decisions and requiring a guardian to make decisions for them.<sup>5</sup> Supported decision-making describes a way individuals with disabilities can live their lives without the specter or burden of losing their autonomy through guardianship or other forms of surrogate decision-making. In fact, Article 82 acknowledges that the use of supported decision-making “can be a less restrictive alternative to guardianship.”<sup>6</sup>

This article focuses on supported decision-making agreements under Article 82, and the statute’s relationship to New York’s developmental-disabilities guardianship statute—Article 17A of the Surrogate’s Court Procedure Act.

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1. S.B. 7107-B, 244th Leg. (N.Y. 2022); N.Y. MENTAL HYG. LAW § 82.01(a) (McKinney 2022)).

2. MENTAL HYG. § 82.02(i).

3. MENTAL HYG. § 82.02(j).

4. *See* MENTAL HYG. § 82.01(a).

5. New York has a guardianship law enacted in 1989 which specifically addressed individuals with a diagnosis of intellectual or developmental disability. *See* N.Y. SURR. CT. PROC. ACT LAW § 1750 (McKinney 2022). *See also* discussion *infra* Section IV(D).

6. N.Y. MENTAL HYG. LAW § 82.01(b) (McKinney 2022).

## I. SDMNY

In 2016, Supported Decision-Making New York (SDMNY)<sup>7</sup> was formed to explore the use of supported decision-making agreements in New York “to divert persons with developmental disabilities (DD) from guardianship, and to restore rights to those already subject to guardianship.”<sup>8</sup> SDMNY undertook a five-year pilot project on supported decision-making funded by a \$1.5 million grant from the New York State Developmental Disabilities Planning Council (DDPC).<sup>9</sup>

Under the SDMNY process:

[A] trained [volunteer] facilitator, supervised by an experienced mentor, works with the Decision-Maker and their chosen Supporters to negotiate and formalize an agreement, the Supported Decision-Making Agreement (SDMA), that sets out the responsibilities and obligations of the parties. Facilitation meetings are generally an hour long and can take place monthly or more frequently, as the parties agree. On average, the facilitation process requires between 9 and 12 meetings.<sup>10</sup>

SDMNY has operated in five locations: New York City, Westchester County, Rochester/Western New York, the Capitol region, and Long Island.<sup>11</sup>

## II. THE POLICY BEHIND ARTICLE 82

New York State’s stated policy toward individuals diagnosed with developmental disabilities is to “develop a comprehensive, integrated system of services which has as its primary purposes *the promotion and attainment of independence, inclusion, individuality* and productivity for persons with developmental disabilities.”<sup>12</sup>

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7. SDMNY is a “consortium of Hunter College/CUNY; The New York Alliance for Inclusion and Innovation (formerly NYSACRA), a statewide association of provider agencies; and Arc Westchester, a large provider organization.” *SDMNY History and Approach*, SDMNY, <https://sdmny.org/the-sdmny-project/history-and-goals/>, (last visited Jan 21, 2023).

8. *Id.*

9. *Id.*

10. *How We Do It*, SDMNY, <https://sdmny.org/the-sdmny-project/how-we-do-it/>, (last visited Jan. 21, 2023).

11. ELIZABETH PELL, SUPPORTED DECISION-MAKING NEW YORK: EVALUATION REPORT OF AN INTENTIONAL PILOT iii (2019), <https://sdmny.org/wp-content/uploads/2019/12/Pell-SDMNY-Report-2019.pdf> [hereinafter PELL EVALUATION].

12. N.Y. MENTAL HYG. LAW § 13.01 (McKinney 2022) (emphasis added).

To that end, the Office for People with Developmental Disabilities (OPWDD)<sup>13</sup> focuses on helping individuals advocate for themselves<sup>14</sup> through programs that emphasize “person-centered planning,”<sup>15</sup> and a “Person First Transformation,” all of which are designed to improve opportunities for individuals with developmental disabilities in the areas of employment, integrated living, and self-direction of services.<sup>16</sup> The recent creation of the Chief Disability Officer<sup>17</sup> in the Executive Branch, and the 2022 package of legislation signed by Governor Hochul in addition to Article 82 of the Mental Hygiene Law<sup>18</sup> are consistent with that policy. In the Governor’s own words, these recent laws:

[Honor the Americans with Disabilities Act’s] legacy by expanding the rights of people with disabilities and combatting stigma so that people with disabilities can live rich and full lives. To make the New York dream a reality, we will continue to make New York inclusive, integrated and accessible for all.<sup>19</sup>

13. *About Us*, OFF. FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, <https://opwdd.ny.gov/about-us>, (last visited Jan. 21, 2023).

14. *Advocacy*, OFF. FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, <https://opwdd.ny.gov/types-services/advocacy>, (last visited Jan. 21, 2023).

15. *Person-Centered Planning*, OFF. FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, <https://opwdd.ny.gov/providers/person-centered-planning>, (last visited Jan. 21, 2023). Person-Centered Planning seeks to “listen, discover and understand . . . [the] individual. It is a process directed by the person to help providers learn how they want to live, and describes what supports are needed to help him or her move toward a life they consider meaningful and productive.” *Id.*

16. *See Self-Direction*, OFF. FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, <https://opwdd.ny.gov/types-services/self-direction>, (last visited Jan. 21, 2023).

17. Governor’s Press Off., *Governor Hochul Establishes Office of the Chief Disability Officer*, GOVERNOR KATHY HOCHUL (Feb. 14, 2022), <https://www.governor.ny.gov/news/governor-hochul-establishes-office-chief-disability-officer#:~:text=Governor%20Kathy%20Hochul%20today%20announced,State’s%20first%20Chief%20Disability%20Officer>.

18. Governor’s Press Off., *On 32nd Anniversary of the Americans with Disabilities Act, Governor Hochul Signs Legislative Package to Uphold and Strengthen Rights of People with Disabilities*, GOVERNOR KATHY HOCHUL (July 26, 2022), <https://www.governor.ny.gov/news/32nd-anniversary-americans-disabilities-act-governor-hochul-signs-legislative-package-uphold> (Varying legislation establishes a public awareness campaign to combat the stigma and stereotyping of individuals with developmental disabilities; replaces certain instances of term “mentally retarded” or variations of such term with term “developmentally disabled” or variations of such term; replaces certain references to “mentally retarded” or “mentally ill” persons with term “individuals with a developmental disability”; eliminates state residency requirement for designated beneficiaries in the New York ABLE program).

19. *Id.*

The seeds of Article 82’s concept of Supported Decision Making can be found in earlier developments: the process of Patient-Centered Care “in which an individual plans for her future by identifying goals and needed supports to reach those goals with the assistance of others”<sup>20</sup> and 1990s advocacy in Canada of a “system of support that would assist persons with disabilities in making decisions even if the person would have been considered to lack sufficient cognitive ability to make such a decision under traditional doctrines of informed consent and capacity to contract.”<sup>21</sup>

Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), adopted in 2006, reinforced the idea of enhancing a person’s ability to decide for themselves.<sup>22</sup> It provides that persons with disabilities have the right to enjoy “legal capacity” as a human right “on an equal basis with others in all aspects of life.”<sup>23</sup> Facilitating the exercise of that right may require support.<sup>24</sup> Depending on the decision-maker’s needs,<sup>25</sup> it may involve “gathering relevant information, explaining that information in simplified language, weighing the pros and cons of a decision, considering the consequences of making—or not making—a particular decision, communicating the decision to third parties, and assisting the person with a disability to implement the decision.”<sup>26</sup> Much has been written about the significance of Article 12,<sup>27</sup> and recognition of supported decision-

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20. Rebekah Diller, *Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision-Making*, 43 FORDHAM URB. L. J. 495, 527 (2016).

21. *Id.* at 511–12.

22. See G.A. Res. 61/160, art. 12 ¶¶ 1–3 (Dec. 13, 2006), (available at [https://treaties.un.org/doc/source/docs/A\\_RES\\_61\\_106-E.pdf](https://treaties.un.org/doc/source/docs/A_RES_61_106-E.pdf)).

23. *Id.* at art. 12 ¶ 2. “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” *Id.* at art. 1.

24. *Id.* at art. 12 ¶ 3.

25. Kristin Booth Glen, *What Judges Need to Know About Supported Decision-Making, And Why*, 58 JUDGES’ J. 26, 27 (2019) [hereinafter *What Judges Need to Know*] (footnote omitted).

26. *Id.*

27. See, e.g., Sean Burke, *Person-Centered Guardianship: How the Rise of Supported Decision-Making and Person-Centered Services Can Help Olmstead’s Promise Get Here Faster*, 42 MITCHELL HAMLINE L. REV. 873 (2016); Kristin Booth Glen, *Supported Decision-Making and the Human Right of Legal Capacity*, 3 INCLUSION 2, 13 (2015); Nina A. Kohn, *Legislating Supported Decision-Making*, 58 HARV. J. LEGIS. 314 (2021); Emily A. Largent & Andrew Peterson, *Supported*

making in the lives of individuals with developmental disabilities has been growing around the world.<sup>28</sup> In the United States, the American Association on Intellectual and Developmental Disabilities (AAIDD) and The Arc issued a joint policy statement in 2016 endorsing supported decision-making,<sup>29</sup> and, to date, at least fifteen states and the District of Columbia have enacted legislation formally recognizing supported decision-making.<sup>30</sup>

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*Decision-Making in the United States and Abroad*, 23 J. HEALTH CARE L. & POL'Y 271 (2021); Andrew Peterson et al., *Supported Decision Making with People at the Margins of Autonomy*, 21 AM. J. BIOETHICS 4, 7–8 (2020); Rachel Mattingly Phillips, *Model Language for Supported Decision-Making Statutes*, 98 WASH. U. L. REV. 615 (2020); Matthé Scholten & Jakov Gather, *Adverse Consequences of Article 12 of the UN Convention on the Rights of Persons with Disabilities for Persons with Mental Disabilities and an Alternative Way Forward*, 44 J. MED. ETHICS 226 (2018); Eliana J. Theodorou, Note, *Supported Decision-Making in the Lone-Star State*, 93 N.Y.U. L. REV. 974 (2018); Alexandra Wallin, *Living in the Gray: Why Today's Supported Decision-Making-Type Models Eliminate Binary Solutions to Court-Ordered Guardianships*, 57 SAN DIEGO L. REV. 433 (2020). See also NAT'L COUNCIL ON DISABILITIES, BEYOND GUARDIANSHIP: TOWARD ALTERNATIVES THAT PROMOTE GREATER SELF-DETERMINATION FOR PEOPLE WITH DISABILITIES 44 (2018), (available at <https://ncd.gov/sites/default/files/Beyond%20Guardianship%20Literature%20Review.docx> [hereinafter NAT'L COUNCIL ON DISABILITIES, BEYOND GUARDIANSHIP]); Cathy E. Costanzo et al., *Supported Decision-Making: Lessons from Pilot Projects*, 72 SYRACUSE L. REV. 100 (2022).

28. See *Supported Decision-Making Agreement Laws Around the World*, SDMY, <https://sdmny.org/supported-decision-making-legislation/supported-decision-making-agreement-legislation-in-the-u-s-and-elsewhere/supported-decision-making-agreement-laws-around-the-world/> (last visited Jan. 21, 2023); NAT'L COUNCIL ON DISABILITIES, BEYOND GUARDIANSHIP, *supra* note 27, at 39.

29. *Autonomy, Decision-Making Supports, and Guardianship*, AM. ASS'N ON INTELL. & DEVELOPMENTAL DISABILITIES, <https://www.aaidd.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship> (last visited Jan. 21, 2023) (“Legally, each individual adult or emancipated minor is presumed competent to make decisions for himself or herself, and each individual with [intellectual and developmental disabilities] should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime.”).

30. Alaska, Delaware, Illinois, Indiana, Louisiana, Nevada, New Hampshire, New York, North Dakota, Oregon, Rhode Island, Texas, Washington, Wisconsin and the District of Columbia. *SDMA Legislation in the U.S. and Elsewhere*, SDMY, <https://sdmny.org/supported-decision-making-legislation/supported-decision-making-agreement-legislation-in-the-u-s-and-elsewhere/> (last visited Jan. 21, 2023).

## III. MAJOR ELEMENTS OF ARTICLE 82

The major elements of the statute are a) the treatment of capacity; b) the role of various participants in a supported decision-making agreement; c) the components of an enforceable agreement; d) the acceptance of supported decisions by third parties; and e) the immunity afforded third parties.

*A. Capacity*

Several provisions of Article 82 are devoted to recognition of capacity, the central element of supported decision-making. The statute provides that, for its purposes, every adult is presumed “to have the capacity to enter into a supported decision-making agreement,” unless they have a legal guardian.<sup>31</sup> The presumption is similar to the presumption to execute a health care proxy<sup>32</sup> or an “Act Now” health care proxy.<sup>33</sup> Notwithstanding this presumption, the statute provides a definition of capacity for purposes of Article 82 when it describes a “decision-maker” as an adult who “understands that they are making and executing an agreement with their chosen supporters and that they are doing so voluntarily.”<sup>34</sup> In this regard it differs from the law governing health care proxies which permits a decisionmaker to create or revoke health care proxies and override a health care agent’s decision without regard to the decisionmaker’s capacity.<sup>35</sup>

Including a different definition of capacity may undercut the presumption of capacity.<sup>36</sup> The new definition suggests a form of capacity other than contractual capacity is required to enter into an agreement; however, an “agreement” is a form of contract. The new definition

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31. N.Y. MENTAL HYG. LAW § 82.03(a) (McKinney 2022).

32. See N.Y. PUB. HEALTH LAW § 2981(1)(b) (McKinney 2022).

33. See N.Y. MENTAL HYG. LAW § 33.03(e) (McKinney 2022).

34. MENTAL HYG. § 82.03(f) (capacity can be achieved with the use of supports).

35. See N.Y. PUB. HEALTH LAW § 2985(1) (McKinney 2022) (principal’s presumed capacity to revoke a health care proxy in the absence of a judicial determination of incapacity); PUB. HEALTH § 2983(5) (priority of a principal’s decision over that of the agent’s decision under a health care proxy).

36. Compare N.Y. MENTAL HYG. LAW § 82.03(f) (McKinney 2022) (“A decision-maker may make and execute a supported decision-making agreement, *if the decision-maker understands that they are making and executing an agreement with their chosen supporters and that they are doing so voluntarily.*”) (emphasis added), with MENTAL HYG. § 82.07(a) (“The decision-maker may revoke all or part of a supported decision-making agreement by notifying the supporters orally or in writing, or by any other act evincing a specific intent to revoke the agreement.”).

also appears to conflict with an existing state regulation governing when a patient receiving services in a facility, including “a resident in a school” can execute legal instrument.<sup>37</sup> To the extent that a supported decision-making agreement is considered a contract/legal instrument, it would fall within the coverage of the regulation which imposes a medical capacity evaluation and requests a physician to determine if the person understands the transaction and the nature and consequences of executing the instrument.<sup>38</sup>

The statutory presumption of capacity to enter an agreement can be overcome by “clear and convincing evidence.”<sup>39</sup> However, the presence of a diagnosis of a developmental disability cannot be used to demonstrate incapacity,<sup>40</sup> nor can the way an individual communicates.<sup>41</sup> Likewise, the fact that an individual has either entered or not entered into a supported decision-making agreement (SDM), or expressed or not expressed interest in doing so cannot be used as evidence of their incapacity.<sup>42</sup> This last provision, similar to the law governing health care proxies,<sup>43</sup> is intended to deflect the concern that a supported decision-making agreement will be treated as a mandatory alternative to guardianship.<sup>44</sup> The need for clear and convincing evidence to rebut the presumption of capacity conflicts with New York’s developmental disabilities guardianship statute which does not require clear and convincing evidence of incapacity for the appointment of a

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37. See 14 N.Y.C.R.R. §§ 22.3(a), 22.1(c) (2022).

38. 14 N.Y.C.R.R. § 22.3(a) (2022); see also 14 N.Y.C.R.R. § 633.99(p) (2022).

39. N.Y. MENTAL HYG. LAW § 82.03(a) (McKinney 2022).

40. MENTAL HYG. § 82.03(c).

41. MENTAL HYG. § 82.03(d).

42. MENTAL HYG. § 82.03(e).

43. See N.Y. PUB. HEALTH LAW § 2989 (McKinney 2022).

44. See, e.g., *in re Robert C. B.*, 125 N.Y.S.3d 253 (Sur. Ct. Dutchess Cnty. 2020), *rev’d*, *Robert C. B. v. Callahan*, 170 N.Y.S.3d 619 (App. Div. 2d Dep’t 2022). The trial court declined to remove guardian of the property because of the young man’s purchase of overvalued used car so that he could get to and from work without being dependent on others for rides, notwithstanding the fact that he sought legal advice to undo the transaction and “demonstrated that he no longer needs a guardian of his person, and that it would be in his best interest to restore his right to manage his personal affairs without the oversight or control of a guardian of the person.” *In re Robert C. B.*, 125 N.Y.S.3d 253, 269–70, 272 ((Sur. Ct. Dutchess Cnty. 2020). The decision was reversed on appeal. *Robert C. B. v. Callahan*, 170 N.Y.S.3d 619, 620 (App. Div. 2d Dep’t 2022).

guardian.<sup>45</sup> It is not clear how to interpret this dichotomy given that use of a supported decision-making agreement cannot be executed by a person for whom a guardian has been appointed.

*B. Participants' Roles in Supported Decision-making Agreements*

Participants in a supported decision-making agreement play one of three roles: decision-maker, supporter, or facilitator.

A decision-maker is “an adult who has executed, or seeks to execute, a supported decision-making agreement.”<sup>46</sup>

One or more supporters may be chosen by the decision-maker to assist them in decision-making.<sup>47</sup> If a supporter is an employee of an organization which provides services to the decision-maker, the supporter must adhere to regulations governing their employer in order to avoid conflicts or potential conflicts of interest, and otherwise comply with labor laws.<sup>48</sup> The supporters must respect the decision-maker's right to make a decision, even if they disagree with the decision and act honestly and diligently, in good faith, and within the scope of the executed supported decision-making agreement.<sup>49</sup> The role of supporter is not defined as that of a fiduciary although it is described as “one of trust and confidence,”<sup>50</sup> and the supporter's obligations of care, loyalty and confidentiality are similar to those of a fiduciary.<sup>51</sup> Supporters are prohibited from making decisions for the decision-

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45. A guardian for the individual may be appointed under New York's developmental disabilities guardianship statute based on the best interests of the individual. N.Y. SURR. CT. PROC. ACT LAW §§ 1750, 1750-a(1).

46. N.Y. MENTAL HYG. LAW § 82.02(d) (McKinney 2022).

47. MENTAL HYG. § 82.10(c)(1).

48. MENTAL HYG. § 82.08(a) (recognizing the potential for a conflict of interest in a service provider employee serving as a guardian).

49. MENTAL HYG. § 82.05(a)(1)–(3).

50. MENTAL HYG. § 82.05(c).

51. *See, e.g.*, N.Y. EST. POWERS & TRUSTS LAW § 13-A-4.1(a)(1)–(3). *See also* Meinhard v. Salmon, 164 N.E. 545, 551 (N.Y. 1928) (Andrews, J., dissenting); Mantella v. Mantella, 701 N.Y.S.2d 715, 716 (App. Div. 3d Dep't 2000); Moglia v. Moglia, 533 N.Y.S.2d 959, 960 (App. Div. 3d Dep't 1988).

maker,<sup>52</sup> exerting undue influence over them, coercing them,<sup>53</sup> or acting without the decision-maker's consent.<sup>54</sup> The goal is to limit the ability of a supporter to become a *de facto* guardian, a possibility that is recognized in the literature.<sup>55</sup>

Facilitators educate and work with decisionmakers and their supporters on supported decision-making and the creation of agreements authorized by Article 82.<sup>56</sup> Their role is significant because only agreements signed by a facilitator<sup>57</sup> and produced by a facilitation or educational process authorized by OPWDD are entitled to provide immunity to third parties accepting decisions of a decision-maker.<sup>58</sup> The facilitation or educational process is not defined by statute; rather, it is to be promulgated in OPWDD regulations.<sup>59</sup> The statute does not provide specifically for an ongoing role for facilitation after the agreement is signed. However, the statute provides that a decision enforceable under Article 82 “*shall be signed by a facilitator*,”<sup>60</sup> suggesting that a facilitator will be involved in a very immediate and regular way.

### C. Elements of an Agreement

A supported decision-making agreement enforceable under Article 82 must be in writing, dated, signed by the decision-maker,<sup>61</sup> all their supporters, and the facilitator.<sup>62</sup> The signed agreement must be

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52. N.Y. MENTAL HYG. LAW § 82.05(b)(1)–(3). The statute does provide that a supporter who is named as a surrogate in an advance directive may act pursuant to that directive. *Id.* § 82.05(b)(1). The Family Health Care Decisions Act also provides for surrogate health care decisions when the patient lacks capacity. A surrogate recognized under the Family Health Care Decision Act may also be a supporter under Article 82. That possibility is not addressed in Article 82; it may be clarified in regulation or otherwise.

53. MENTAL HYG. § 82.05(b)(1)–(3).

54. MENTAL HYG. § 82.05(b)(4)–(5).

55. See Malcolm Parker, *Getting the Balance Right: Conceptual Considerations Concerning Legal Capacity and Supported Decision-Making*, 13 BIOETHICAL INQUIRY 381, 387 (2016); see also Eilionóir Flynn & Anna Arstein-Kerslake, *The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?*, 32 BERKELEY J. INT’L L. 134, 134–35 (2014).

56. N.Y. MENTAL HYG. LAW § 82.02(m) (McKinney 2022).

57. MENTAL HYG. LAW § 82.10(d)(1).

58. MENTAL HYG. LAW § 82.09; MENTAL HYG. § 82.10(d).

59. MENTAL HYG. § 82.09.

60. MENTAL HYG. LAW § 82.11(a) (emphasis added).

61. N.Y. MENTAL HYG. LAW § 82.06(b) (McKinney 2022). The signature may be in any form, including an electronic signature.

62. MENTAL HYG. § 82.10(d)(1).

notarized or witnessed by two adults who are not supporters,<sup>63</sup> list the categories of decisions for which a supporter is providing assistance and the kinds of support that each supporter may give,<sup>64</sup> contain an attestation that the supporters agree to honor the rights of the decision-maker,<sup>65</sup> and include a statement that the agreement was made in accordance with the requirements of OPWDD.<sup>66</sup> For a particular decision to be recognized, it apparently must be accompanied by the above described agreement, an attestation by the decision-maker that the decision was made in accordance with the provisions of the agreement,<sup>67</sup> and the signature of the facilitator.<sup>68</sup> The statute does not provide a form for the agreement.<sup>69</sup> Perhaps, OPWDD regulations will do so.

#### *D. Third-Party Acceptance*

A third party must accept a decision made in accordance with the provisions of a supported decision-making agreement created under OPWDD's auspices.<sup>70</sup> The statute does provide a safe harbor for third parties, however. The third party can refuse to act on a decision if the third party has substantial cause to believe the underlying agreement has been revoked, the decision-maker is being abused, coerced or exploited, or the decision "will cause the decision-maker substantial and imminent physical or financial harm."<sup>71</sup> The ability to decline to accept the decision based on an evaluation of the consequences puts the third party at an advantage over that of a supporter who must respect the decision even if they "believe[] that it is not in the decision-maker's best interests."<sup>72</sup>

#### *E. Third-Party Immunity*

In addition to providing the third party with some flexibility to accept a decision, Article 82 provides the third party with immunity for accepting a decision so long as the third party has acted "in good faith and in reliance on a decision made by a decision-maker" pursuant

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63. MENTAL HYG. § 82.10(b)(9).

64. MENTAL HYG. § 82.10(b)(4)–(5).

65. MENTAL HYG. § 82.10(b)(6).

66. MENTAL HYG. § 82.10(b)(7).

67. N.Y. MENTAL HYG. LAW § 82.10(d)(3) (McKinney 2022).

68. MENTAL HYG. § 82.11(a).

69. MENTAL HYG. § 82.10(a).

70. MENTAL HYG. § 82.11(b).

71. MENTAL HYG. § 82.11(d).

72. N.Y. MENTAL HYG. LAW § 82.05(a)(1) (McKinney 2022).

to an enforceable agreement.<sup>73</sup> Immunity of the supporters and facilitators is not explicitly addressed in the statute. The statute specifically protects health care providers who accept consent of a decision-maker based on an enforceable agreement unless the provider had “actual knowledge or notice that the decision-maker had revoked the supported decision-making agreement,” or had been abused or coerced into consenting by a supporter.<sup>74</sup> An organization which provides the decision-maker’s personal information to a supporter authorized to receive it is protected unless they “had actual knowledge that decision-maker had revoked such authorization.”<sup>75</sup>

The existence of an enforceable agreement does not relieve a third party from “any legal obligation to provide services to individuals with disabilities,” nor for causing personal injury as a result of a negligent, reckless, or intentional act; acting inconsistently with the expressed wishes of a decision-maker; failing to provide information to either decision-maker or their supporter that would be necessary for informed consent; or acting inconsistently with applicable law.<sup>76</sup>

The creation of immunity for third parties raises the possibility that third parties may require agreements before engaging in transactions with an individual they perceive to have a developmental disability diagnosis. It also has been criticized as “creat[ing] new rights for third parties” and absolving them from acts in violation of pre-existing duties.<sup>77</sup>

#### IV. IMPLEMENTATION

Effective implementation of the statute will require detailed regulations, and trained facilitators; education about the availability of supported decision-making agreements and other alternatives to guardianship; amendments to the guardianship statute for people with developmental disabilities; and evaluation of the use of supported decision-making.

##### *A. Regulation*

Article 82 does not become effective until OPWDD has issued regulations implementing the statute.<sup>78</sup> These regulations form the

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73. MENTAL HYG. § 82.12(b).

74. MENTAL HYG. § 82.12(c).

75. MENTAL HYG. § 82.12(d).

76. MENTAL HYG. § 82.12(e)–(f).

77. Kohn, *supra* note 27, at 332.

78. N.Y. MENTAL HYG. LAW § 82.12(a) (McKinney 2022).

heart of the legislation because agreements will not be enforceable unless they are the product of training programs authorized by OPWDD and signed by OPWDD trained facilitators.<sup>79</sup>

### *B. Facilitation*

The lack of post-agreement facilitation and/or monitoring creates the potential for extra-judicial informal guardianship and puts the individual in jeopardy. “[I]t is left to individuals—the principal, supporter, or third parties—to identify possible abuses or violations and report them, with no consequences outlined in the SDM statutes themselves. With no real safeguards in place, [supported decision-making] may put the principal at significant risk.”<sup>80</sup>

OPWDD has already announced that it intends to develop on a “new model” with the aim of defining the “scope of supported decision-making facilitation services.”<sup>81</sup>

### *C. Education*

Educating the public about supported decision-making agreements is crucial to their successful implementation. A study of preliminary work done by SDMNY showed that families with members who have developmental disabilities need information in order to make informed decisions about the choices for decision-making.<sup>82</sup>

Family members, both guardians and potential guardians, are typically advised that guardianship is necessary, most persuasively from other parents with children with disabilities, from schools, and from health care providers.<sup>83</sup> Guardianship is not well understood. Most guardians and potential guardians reported awareness, but not a clear understanding, of the specific loss of rights that accompanies guardianship in New York.<sup>84</sup> The court websites do not provide sufficient information about alternative forms of decision-making. In the absence of information about SDM, as well as powers of attorney, health care proxies, Act-Now health care proxies, ABLE accounts, joint bank

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79. *Id.*

80. Mattingly Phillips, *supra* note 27, at 636 (2020); *see also* Kohn, *supra* note 27, at 335.

81. Kerri E. Neifeld, *Supported Decision Making Pilot Program*, OFF. FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES (Dec. 15, 2021), <https://opwdd.ny.gov/news/supported-decision-making-pilot-program>.

82. PELL EVALUATION, *supra* note 11, at vi, 17.

83. *See id.* at 5.

84. *Id.* at 52–53.

accounts, they are unable to make informed decisions about guardianship or alternatives.<sup>85</sup>

*D. Amendments to New York's Guardianship Statute for People with Developmental Disabilities, Article 17A*

A goal articulated by Article 82 is to affirm supported decision-making as a viable alternative to guardianship.<sup>86</sup> New York already recognizes many decision-making options which may eliminate the need for guardianship, including power of attorney,<sup>87</sup> health care proxy,<sup>88</sup> joint bank accounts,<sup>89</sup> Able Accounts,<sup>90</sup> supplemental needs trusts,<sup>91</sup> as well as recognition of the role of family members in facilities operated and/or certified by OPWDD.<sup>92</sup> In order to achieve the goal of diversion, individuals, family members, service providers, health care professionals and others who counsel families should be educated about their options. Although this education can be achieved in a variety of ways, the most important way of educating families is by amending Surrogate's Court Procedure Act (SCPA), Article 17A, to require consideration of SDM, as well as decision-making alternatives to guardianship.<sup>93</sup>

No decision-making options are currently mentioned in SCPA Article 17A. The guardianship statute was enacted in 1969 when individuals with developmental disabilities were considered "children forever," and well before many decision-making alternatives were recognized in the law.<sup>94</sup> Later amendments to the SCPA Article 17A ignored

85. See *supra* notes 86–90.

86. N.Y. MENTAL HYG. LAW § 82.02(b) (McKinney 2022); see also PELL, *supra* note 11, at 81.

87. N.Y. GEN. OBLIG. LAW § 5-1504–5-1504(b) (McKinney 2022).

88. N.Y. PUB. HEALTH LAW § 2983 (McKinney 2022).

89. N.Y. BANKING LAW § 675 (McKinney 2022).

90. N.Y. MENTAL HYG. LAW § 84.01–.11 (McKinney 2022) (establishing an Able Account will likely require the assistance of the court).

91. N.Y. EST. POWERS & TRUSTS LAW § 7-1.12 (McKinney 2022) (establishing a supplemental needs trust will likely require the assistance of the court).

92. 14 N.Y.C.R.R. § 633.11(a)(1)(iii) (2021).

93. See Theodorou, *supra* note 27, at 1011 ("To further reduce guardianship appointments and promote the autonomy of people with disabilities, states should also consider adopting laws similar to the Texas Judicial Council Guardianship Reform Bill, which requires that judges find by clear and convincing evidence that alternatives to guardianship and available supports and services cannot be used to avoid the need for guardianship.").

94. See Sheila E. Shea & Carol Pressman, *Guardianship: A Civil Rights Perspective*, 90 N.Y. STATE BAR ASS'N J. 19, 21 (2018).

those developments. The statutory silence is exacerbated by the fact that families can seek an SCPA Article 17A guardian by filling out forms on the website of the Office of Court Administration (OCA) which is also silent about alternatives to guardianship. This self-help accessibility further isolates families from information about their options. The fact that some surrogate courts have engaged with families about alternatives to guardianship is not a satisfactory solution in the face of current statutory silence. The courts doing so are exercising their discretion and the exercise of that discretion is not uniformly employed across the state.<sup>95</sup> Nor is it a satisfactory solution that Article 81 of the Mental Hygiene Law, New York’s general guardianship statute, identifies such alternatives for respondents.<sup>96</sup> Although Article 81 applies to individuals diagnosed with developmental disabilities,<sup>97</sup> more often than not families view “Article 17-A guardianship [as] a lifeline into the legal system.”<sup>98</sup> Given the pressure on families to resort to guardianship, their lack of awareness of decision-making alternatives, and Article 82’s goal of guardianship diversion, a failure to amend SCPA Article 17A will undermine the supported decision-making legislation.<sup>99</sup>

The statute should also be amended to allow the appointment of a special guardian, and to allow approval or ratification transactions without appointing a guardian.<sup>100</sup> This appointment of a special guardian would allow the family to have authority to advocate on behalf of their loved one while they consider SDMAs, the development of which may take up to eighteen months, and alternative decision-making tools. An approval or ratification would also provide for any court

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95. *See in re Robert C. B.*, 125 N.Y.S.3d 253, 259 (Sur. Ct. Dutchess Cnty. 2020) (citing cases reflecting the differing views of the court’s power) *rev’d*, *Robert C. B. v. Callahan*, 170 N.Y.S.3d 61 (App. Div. 2d Dep’t 2022).

96. *See* N.Y. MENTAL HYG. LAW § 81.03(e) (McKinney 2022); MENTAL HYG. § 81.08(a)(14).

97. *See* MENTAL HYG. § 81.02.

98. *In re Robert C. B.*, 125 N.Y.S.3d at 258 (quoting Margaret Valentine Turano, *Practice Commentaries*, in MCKINNEY’S CONSOLIDATED LAWS OF N.Y., Book 59A, § 1750 (2011)).

99. Even after twenty years, researchers of the use of SDM in Canada “have found that there is still a need for education and greater awareness of SDM and how it can be used more effectively – i.e., just having an SDM regime in law is not enough.” NAT’L COUNCIL ON DISABILITY, BEYOND GUARDIANSHIP, *supra* note 27, at 43.

100. Such relief is already available under the general guardianship law. *See* N.Y. MENTAL HYG. LAW § 81.16 (McKinney 2022).

intervention needed for some substitute decision-making tools such as an Able Account and a Supplemental Needs Trust without the appointment of a guardian.

Other amendments to the guardianship law are necessary to bring the statute into compliance with constitutional requirements but they are beyond the scope of this article.<sup>101</sup>

### *E. Evaluation*

#### *1. Evaluation of Supported Decision-Making*

Three evaluations are already associated with the use of supported decision-making in New York: 2019 Pell Evaluation,<sup>102</sup> the Stout Risius Ross study,<sup>103</sup> and the Burton Blatt Institute of Syracuse University evaluation, which was slated for completion in December 2021 but has yet to be published.<sup>104</sup>

#### *A. Pell Evaluation*

The 2019 Pell Evaluation was intentionally limited in scope.<sup>105</sup> It examined “why parents petition for guardianship, what they know about guardianship, and how supported decision-making may alleviate their concerns and avoid guardianship.”<sup>106</sup> Its findings described positive impacts on potential decision-makers and their families, and facilitators participating in the program.<sup>107</sup>

The findings also identified several challenges, including recruitment of volunteer facilitators,<sup>108</sup> development of a “paid professional mentor pool” to assist and oversee the facilitators,<sup>109</sup> the unanticipated length of time (eighteen months) involved in facilitation,<sup>110</sup> the

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101. Sheila Shea, *Guardianship’s Article 17-A: Marooned in Time and In Need of Reform*, N.Y. STATE BAR ASS’N (Dec. 29, 2022), <https://nysba.org/guardianships-article-17-a-marooned-in-time-and-in-need-of-reform/>.

102. PELL EVALUATION, *supra* note 11.

103. *See* Memorandum in Support, S.B. S7107, 244th Sess. (N.Y. 2021).

104. *Independent Evaluations*, SDMNY, <https://sdmny.org/the-sdmny-project/independent-evaluations/> (last visited Jan. 21, 2023).

105. PELL EVALUATION, *supra* note 11, at iv.

106. *Independent Evaluations*, *supra* note 104.

107. PELL EVALUATION, *supra* note 11, at vi.

108. *Id.*

109. *Id.* at v.

110. *Id.* at iv (“Developing a Supported Decision-Making Agreement using the SDMNY facilitation process takes at least twice as long as originally planned. The

traditional path to guardianship offered by schools, health care providers, the courts, and other parents,<sup>111</sup> and development of safeguards against potential for abuse, neglect, and financial exploitation by the supporters.<sup>112</sup>

The evaluation did not examine the “facilitation process, the types of decisions made using SDMNY, satisfaction with decisions, or third-party acceptance of decisions.”<sup>113</sup>

### *B. Stout Risius Ross Study*

This study is described in the Memorandum in Support of the Article 82 legislation as “[a] comprehensive study on the potential for supported decision-making to provide long term fiscal savings in New York.”<sup>114</sup> Its findings about a law yet to become effective may be premature.<sup>115</sup>

### *C. Burton Blatt Study*

Completion of a final evaluation of SDMNY’s work under a contract with the Burton Blatt Institute at Syracuse University, scheduled for release in December 2021 has not yet been published.<sup>116</sup>

More will be known about the implementation of supported decision-making and supported decision-making agreements in the SDMNY pilot project when Burton Blatt publishes its completed study. Going forward it will be important for policy makers, courts, and families to learn about the usefulness of supported decision-making as a real alternative for persons with developmental disabilities, the acceptance of agreements by third parties, and the effect of the immunity offered third parties on their decisions.

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three-stage facilitation process was designed to occur over 6 to 9 months. Completed and signed agreements have taken a year to 18 months.”).

111. *See id.* at 44.

112. PELL EVALUATION, *supra* note 11, at v.

113. *Id.* at 7.

114. *See* Memorandum in Support, S.B. S7107, 244th Sess. (N.Y. 2021). *See* also Cost-Benefit Analysis for New York on Facilitated Supported Decision Making, STOUT, <https://www.stout.com/en/experience/cost-benefit-analysis-new-york-facilitated-supported-decision-making> (last visited Feb. 4, 2023).

115. PELL EVALUATION, *supra* note 11, at v.

116. *See Independent Evaluations*, *supra* note 102; PELL EVALUATION, *supra* note 11, at 81. A FOIL request has been made to the DDPC for information about the delay. *Id.*

CONCLUSION

Article 82's recognition of supported decision-making is a welcomed first step for the voices of individuals with developmental disabilities to be heard. The concept of supported decision-making is consistent with New York's policy toward the treatment of individuals with developmental disabilities which focuses on helping individuals advocate for themselves. The legislation raises some issues that should be clarified through regulation, evaluation, and amendments to New York's guardianship statute for individuals with developmental disabilities in order to further its goals.