SUPPORTED DECISION-MAKING—ITS SUCCESS DEMANDS GUARDIANSHIP REFORM

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INTRODUCTION

People generally take for granted that they have capacity to make decisions about their lives; in fact, "[a]ll adult persons are presumed

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to possess legal capacity unless and until a guardian is appointed for them."[1] Individuals with developmental disabilities are unlikely to enjoy that presumption.[2] By the time they reach eighteen years of age, their families are being pressured by schools, physicians, service providers, and other parents to "get guardianship" for them.[3] Families are likely to succumb to this pressure because they want to protect their children and ensure the child being accepted to participate in appropriate programs offered or supported by the Office of People With Developmental Disabilities notwithstanding a desire to support their child's development as an adult and their treatment as an adult.[4]

The decision to become their child's guardian is not surprising because New York's process for obtaining a guardian for a person with developmental disability, at least under one of New York's

1. Kristin Booth Glen, *Not Just Guardianship: Uncovering the Invisible Taxonomy of Laws, Regulations and Decisions that Limit or Deny the Right of Legal Capacity for Persons with Intellectual and Developmental Disabilities*, 13 ALB. GOV'T L. REV. 25, 25 n.2 (2020) (quoting Richard C. Boldt, *The "Voluntary" Inpatient Treatment of Adults Under Guardianship*, 60 VILL. L. REV. 1, 18 (2015)).

2. *See, e.g.*, N.Y. REAL PROP. LAW § 11 (McKinney 2024) ("A person other than a minor, *person with a developmental disability*, or person of unsound mind, seized of or entitled to an estate or interest in real property, may transfer such estate or interest.") (emphasis added); *see also* Matter of Robert C. B., 125 N.Y.S.3d 253, 272 (Surr. Ct. Duchess Cty. 2020), *rev'd*, 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." *Id.*

3. ELIZABETH PELL, SUPPORTED DECISION-MAKING NEW YORK: EVALUATION REPORT OF AN INTENTIONAL PILOT 80 (2019), https://sdmny.hunter.cuny.edu/wp-content/uploads/2019/12/Pell-SDMNY-Report-2019.pdf (referring to the school to guardianship pipeline) [hereinafter PELL EVALUATION]; LOOKING BACK, LOOKING FORWARD: AN EVALUATION OF THE SUPPORTED DECISION-MAKING NEW YORK PROJECT WITH RECOMMENDATIONS TO INCREASE KNOWLEDGE, USE AND ACCEPTANCE OF SUPPORTED DECISION-MAKING IN NEW YORK, THE BURTON BLATT INST. AT SYRACUSE UNIV. 126 (2022) (on file with the author) [hereinafter LOOKING FORWARD] (a summary of LOOKING FORWARD is available at https://cdd.ny.gov/system/files/documents/2023/09/looking-back-looking-forward-eval-exec.-summary_2.pdf.); *see also* Sheida K. Raley et al., *Age of Majority and Alternatives to Guardianship: A Necessary Amendment to the Individuals with Disabilities Education Improvement Act of 2004*, 34 J. DISABILITY POL'Y STUD. 17, 18 (2023).

4. *See* PELL EVALUATION, supra note 3, at 80 (noting that "guardians and potential guardians want their family members with [intellectual and developmental disabilities] to gain independent living skills and live meaningful lives connected to their communities.").

guardianship statutes for adults, Surrogate's Court Procedure Act, Article 17A – Guardianship for people with Developmental Disabilities, is simple:[5] the application is available online[6] and no hearing is required if the applicants are parents.[7] The parents' decision may ignore or discount alternatives to guardianship, such as powers of attorney and health care proxies, alternatives which have been available for many years.[8]

Supported decision-making is a recent addition to the list of guardianship alternatives.[9] Anyone who has ever sought advice from a friend before choosing a new car, which neighborhood to live in, what restaurant has the best sushi, or even what pasta sauce to buy, is familiar with the concept of supported decision-making. Gathering information and advice is a common, informal part of everyday life.[10] Ultimately the person making the choice may follow the advice of their friend or go their own way but the support of family and friends can be helpful. It is one thing to be familiar with supported decision-making as something one does casually among friends; however, individuals and their families may be skittish about, or even unaware, that supported decision-making can operate as an alternative to guardianship.

In 2022, New York turned casual informal supported decision-making into a formal arrangement for individuals with developmental disabilities through the enactment of Article 82 of the Mental Hygiene Law, entitled Supported Decision-Making. Article 82 acknowledges that the use of supported decision-making "can be a less restrictive alternative to guardianship."[11]

Article 82 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

5. *See* N.Y SURR. CT. PROC. ACT LAW § 1750-A (McKinney 2016)

6. *See id.*

7. *See* N.Y. SURR. CT. PROC. ACT LAW § 1754 (McKinney 2016).

8. *See* notes 70–74 *infra* and accompanying text.

9. *See, e.g.*, PELL EVALUATION, *supra* note 3, at 80; LOOKING FORWARD, *supra* note 3, at 119–20.

10. Andrew Peterson, Jason Karlawish & Emily Largent, *Supported Decision Making with People at the Margins of Autonomy*, 11 AM. J. BIOETHICS 4, 10 (2021) ("In practice, even people with unimpaired decision making capacity seldom deliberate and reach decisions wholly independently. Rather, they engage with family and friends or consult with experts. Arguably, such engagement enhances rather than diminishes rational decision making, as trusting in and consulting with others can improve deliberative processes.").

11. N.Y. MENTAL HYG. LAW § 82.01(b) (McKinney 2024).

> 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.[12]

Using this definition, the statute recognizes both informal and formal supported decision-making and authorizes the creation of formal supported decision-making agreements.[13] The formality is demonstrated by the written agreement between the decision-maker and their supporter or supporters describing the use of supported decision-making and the review of the agreement by a facilitator, an individual or organization authorized by the Office of People with Developmental Disabilities (OPWDD) to work with the decision-maker and their supporters.[14] Decisions made in pursuant to a formal agreement created under the auspices of OPWDD[15] between a decision-maker and third parties which accept such decisions are protected by a liability shield.[16]

Proponents of supported decision-making often advocate for the abolition of guardianship, decrying it as "civil death."[17] When other alternatives to guardianship, such as durable powers of attorney, health care proxies, and living wills, were established, guardianship was not damned with such rhetoric, perhaps because they, like

12. N.Y. MENTAL HYG. LAW § 82.02(i) (McKinney 2024).

13. *See id.* § 82.02(j).

14. *See* N.Y. MENTAL HYG. LAW §§ 82.02(j), (m); 82.09 (McKinney 2024).

15. *See* N.Y. MENTAL HYG. LAW § 82.11 (McKinney 2024).

16. *See* MENTAL HYG. LAW § 82.02(i).

17. *See* Sydney J. Sell, *A Potential Civil Death: Guardianship of Persons with Disabilities in Utah*, 2019 UTAH L. REV. 215, 215 n.3 (citing Michael L. Perlin, *"Striking for the Guardians and Protectors of the Mind": The Convention on the Rights of Persons with Mental Disabilities and the Future of Guardianship Law*, 117 PA. ST. L. REV. 1159, 1159 (2013) (stating that entry of guardianship orders in much of the world is a kind of "civil death")); s*ee generally* Nat'l Council on Disability, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination* (Mar. 22, 2018), https://www.ncd.gov/report/beyond-guardianship-toward-alternatives-that-promote-greater-self-determination-for-people-with-disabilities/ (In 1987, U.S. Representative Claude Pepper famously described guardianship as follows: "The typical [person subject to guardianship] has fewer rights than the typical convicted felon. . . .By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception, of course, of the death penalty.").

guardianship, involve surrogate decision making by an agent or proxy.[18] Nevertheless, guardianship has been described as what should be the last resort in seeking remedies for an individual with diminishing or diminished capacity.[19]

Abandoning guardianship, in particular Article 17A, in favor of the newest alternative—supported decision-making, seems shortsighted, and offers the same all-or-nothing approach as currently found in Article 17A. Rather than tossing out or ignoring the statute, policy makers should view the emerging acceptance of supported decision-making as an opportunity to transform Article 17A. This transformation would convert the statute from a one-size fits all straitjacket for an individual with a diagnosis of a developmental disability into a statute that acknowledges and addresses their complex and diverse needs. By offering a variety of remedies and tools, including supported decision-making, the statute can give individuals and their families more flexibility. Recently, Supported Decision-Making New York (SDMNY),[20] a major advocate for supported decision-making and a backer of Article 82, has acknowledged that

> while [supported decision-making] works for the vast majority of people with I/DD, there are still those, with severe impairments, for whom we have not yet devised effective supports. Until that happens, there will still be a need, though greatly reduced, for guardianship . . . While we look forward to a time when guardianship is no longer necessary for anyone, a major, rights-based reform of 17-A is long overdue.[21]

18. *See* NAT'L COUNCIL ON DISABILITY, BEYOND GUARDIANSHIP: TOWARDS ALTERNATIVES THAT PROMOTE GREATER SELF-DETERMINATION OF PEOPLE WITH DISABILITIES 119–38 (2018), https://ncd.gov/publications/2018/beyond-guardianship-toward-alternatives (detailing alternatives to guardianship recognized in the United States in Chapter 8) [hereinafter BEYOND GUARDIANSHIP].

19. *See Guardianship: Less Restrictive Options*, U.S. DEP'T OF JUST., https://www.justice.gov/elderjustice/guardianship-less-restrictive-options (last visited Jan. 8, 2025).

20. 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*, SUPPORTED DECISION-MAKING N.Y., https://sdmny.org/the-sdmny-project/history-and-goals/ (last visited Jan 7, 2025).

21. *A New Resource for Reforming Guardianship Law for People With I/DD*, SUPPORTED DECISION-MAKING N.Y. (Dec. 13, 2024), https://myemail.constantcontact.com/Good-News-from-SDMNY.html?soid=1140185827857&aid=DSct6BvhYfs.

This article examines the possibilities of such reform and transformation.

I. FORMAL SUPPORTED DECISION-MAKING'S EMERGENCE

In 2006, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) recognized 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."[22] Article 12 of the CRPD also recognized that persons with disabilities should be provided with "the support they may require in exercising their legal capacity."[23] Supports will be unique to each individual and may involve a variety of activities, including "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."[24]

In May 2014, the UN Committee on the Rights of Persons with Disabilities issued General Comment No. 1 on Article 12, the purpose of which was to "explore the general obligations deriving from the various components of article 12."[25] Comment No. 1 urged an examination of "all areas of law to ensure that the right of persons with disabilities to legal capacity is not restricted on an unequal basis with others" and recommended that "substitute decision-making regimes such as guardianship, conservatorship . . . *be abolished* in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others."[26] This call for the abolition of guardianship has been met with criticism and concern;[27] nevertheless,

22. Convention on the Rights of Persons with Disabilities, art. 12, *adopted* Dec. 13, 2006, *entered into force* May 3, 2008, 2515 U.N.T.S. 3. "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." Convention on the Rights of Persons with Disabilities, art. 1.

23. Convention on the Rights of Persons with Disabilities, art. 12.

24. Kristin Booth Glen, *What Judges Need to Know About Supported Decision-Making, and Why*, 58 JUDGES' J. 26, 27 (2019).

25. Comm. on the Rts. of Prs. with Disabilities of Its Eleventh Session, Gen. Comment No. 1, art. 12: Equal Recognition Before the Law, U.N. Doc. CRPD/C/GC/1 (2014).

26. *Id.* (emphasis added).

27. *See, e.g.*, Julia Duffy, *What if Britney Spears Lived in Australia? Disrupting the Binary Framing of Guardianship Versus Supported Decision-Making*, 33 TRANSNAT'L L. & CONTEMP. PROBS. 40, 48–49 (2024); Paul Appelbaum, *Protecting*

supported decision-making for individuals with developmental disabilities has found favor across the globe,[28] including in the United States. In 2016, the American Association on Intellectual and Developmental Disabilities (AAIDD) and the Arc issued a joint policy statement in support of SDM, noting that "[l]egally, 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."[29] In at least fifteen states and the District of Columbia, legislation has been enacted that formally recognizes supported decision-making as a way to enhance a person's legal capacity,[30] and adopts supported decision-making as an alternative to guardianship.[31]

New York's recognition of supported decision-making to enhance the exercise of legal capacity is significant because by doing so it acknowledges the ability of individuals with developmental disabilities to live independent lives; underscores New York's public policy that promotes "independence, inclusion, individuality and productivity for persons with developmental disabilities"[32] particularly through programs and service offered or supported by OPWDD;[33] and helps

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the Rights of Persons with Disabilities: An International Convention and Its Problems, 67 PSYCH. SERV. 366, 366–68 (2016).

28. *See Supported Decision-Making Agreement Laws in the US*, SUPPORTED DECISION-MAKING N.Y., https://sdmny.org/supported-decision-making-legislation/supported-decision-making-agreement-legislation-in-the-u-s-and-elsewhere/supported-decision-making-agreement-laws-in-the-u-s/ ((last visited Feb. 2, 2025); BEYOND GUARDIANSHIP, *supra* note 18, at 51.

29. *Autonomy, Decision-Making Supports, and Guardianship*, AAIDD https://www.aaidd.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship (last visited Feb. 2, 2025).

30. *See Supported Decision-Making Agreement Laws in the US*, SUPPORTED DECISION-MAKING N.Y., https://sdmny.org/supported-decision-making-legislation/supported-decision-making-agreement-legislation-in-the-u-s-and-elsewhere/supported-decision-making-agreement-laws-in-the-u-s/ (last visited Feb. 2, 2025) (including Alaska, Delaware, Indiana, Louisiana, Nevada, North Dakota, Rhode Island, Texas, Washington, Wisconsin and the District of Columbia).

31. *See, e.g.*, UNIF. GUARDIANSHIP, CONSERVATORSHIP, & OTHER PROTECTIVE ARRANGEMENTS ACT § 301 (UNIF. L. COMM'N 2017) (a guardian should not be appointed unless there is a finding by clear and convincing evidence that an individual "is unable to receive or evaluate information or make or communicate decisions, even with appropriate supportive services, technological assistance, or supported decision making.").

32. N.Y. MENTAL HYG. LAW § 13.01 (McKinney 2024).

33. *See Self Advocacy*, OFF. FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, https://opwdd.ny.gov/types-services/self-advocacy (last visited Apr. 15, 2025);

avoid the imposition of guardianship under New York law. Although New York supports the idea of independence and self-determination of individuals with developmental disabilities,[34] Article 17A, New York's developmental-disabilities guardianship statute, is inconsistent with New York's vision for those individuals—a vestige of an earlier time when individuals with developmental disabilities were considered children for life.

II. ARTICLE 17A—NEW YORK'S DEVELOPMENTAL-DISABILITIES GUARDIANSHIP STATUTE

New York has two guardianship statutes for adults: Article 81 of the Mental Hygiene Law, a general statute applicable to any individual found by clear and convincing evidence to be incapacitated to make some or all decisions for themselves, and Article 17A of the Surrogate's Court Procedure Act, a statute reserved almost exclusively for individuals with developmental disabilities.[35] "Article 81 applies to all persons with functional limitations that allegedly impair their capacity to make decisions," without distinguishing between individuals with mental illness, intellectual disabilities, developmental disabilities, or any other disability.[36] "Article 81 requires a court to assess the individual's 'functional limitations which impair the person's ability to provide for personal needs or property management' regardless of the origin of the functional limitation."[37] The court is required to tailor the guardian's authority to the "functional limitations of the person rather than based on an individual's diagnosed disability . . . [and] to impose the least restrictive form of intervention, when taking into account the

Person-Centered Planning, OFF. FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, https://opwdd.ny.gov/providers/person-centered-planning (last visited Apr. 15, 2025) ("Providers use a person-centered planning approach to listen, discover and understand each person as an 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 them move toward a life they consider meaningful and productive."); Kerry A. Delaney, *People First Care Coordination*, OFF. FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, https://www.health.ny.gov/health_care/medicaid/program/medicaid_health_homes/idd/webinars/docs/2017/hhidd_stakeholder_08_07_2017.pdf (last visited Apr. 15, 2025).

34. *See supra* notes 20–22 and accompanying text.

35. *See* N.Y. MENTAL HYG. LAW § 81.02 (McKinney 2024); N.Y. SURROGATE CT. PROC. ACT LAW § 1750-A (McKinney 2016). Article 17A of the Surrogate's Court Procedure Act is also available to individuals with traumatic brain injury suffered at any age, SURROGATE CT. PROC. ACT § 1750-A(1)(d), but the emphasis is on developmental disabilities and similar diagnoses.

36. Jennifer J. Monthie, *The Myth of Liberty and Justice for All: Guardianship in New York State*, 80 ALB. L. REV. 947, 948 (2016–17).

37. *Id.*

community supports, resources and existing advance directives that render a guardianship unnecessary."[38] Article 17A has none of those features.

Notwithstanding Article 81's more nuanced approach to the appointment of a guardian, more often than not families seeking guardianship for an individual with a developmental disability view Article 17A as their "lifeline into the legal system."[39] The basic concepts behind Article 17A, enacted more than fifty years ago,[40] are that appointing a guardian for an individual with a developmental disability is in their best interest, and that the individual's guardian acts "in loco parentis"—in other words, as a parent to the adult with developmental disabilities.[41] The guardian is given complete authority over the person's life for an indeterminate period of time because of the person's developmental disability.[42] The statute's emphasis on the parents' continued role during the individual's adulthood is evident from its placement in New York's Consolidated Laws immediately following Article 17 of the Surrogate's Court Procedure Act, the statute governing the appointment of guardians for minors in the Surrogate's Court.[43] To emphasize this relationship, Article 17A provides that the

> provisions of [Article 17—the statute for infants] shall apply to all proceedings under [Article 17A] with the same force and effect as if an "infant" . . . were "a person who is intellectually disabled" or . . . "developmentally disabled" . . . and a "guardian" [of an infant] were a "guardian of the person who is intellectually disabled" or a "guardian of a person who is developmentally disabled" . . . .[44]

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38. *Id.* at 948–49.

39. *In re* Robert C. B., 125 N.Y.S.3d 253, 258 (Surr. Ct. Dutchess Cty. 2020).

40. *See* SURR. CT. PROC. ACT LAW § 1750-A (McKinney 2016).

41. *In re* Cruz, No. 500001/01, 2001 N.Y. Misc LEXIS 546, at *4 (Sup. Ct. N.Y. Cty. July 16, 2001).

42. *See* N.Y. SURROGATE CT. PROC. ACT LAW § 1759(1) (McKinney 2016) (stating that "[s]uch guardianship shall not terminate at the age of majority or marriage of such person who is intellectually disabled or person who is developmentally disabled but shall continue during the life of such person, or until terminated by the court.").

43. *See generally* N.Y. SURROGATE CT. PROC. ACT LAW § 1701–1761 (McKinney 2012) (organizing the Surrogate's Procedure Act such that Article 17-A follows Article 17).

44. SURROGATE CT. PROC. ACT § 1761. The Governor's suggestion that the statute would be more appropriately included in the Mental Hygiene Law was unavailing. VETO MEMORANDUM NO. 199, S. B. 1345-A, 191st Reg. Sess. (N.Y. 1968) (quoting the Governor's Veto Memorandum of an earlier version of the statute in

Indeed, comments on an earlier version of the law noted that the statute was intended as an extension of the parent's authority past the age of majority.[45] In enacting Article 17A the Legislature acknowledged the desire of parents to "provide for [a] lifetime guardianship" because in 1969 "[the law did] not take into account the unique status of a retardate in that the fact and degree of retardation and the need for guidance and assistance are determinable at a very early age and remain so for life."[46]

In addition to basing the appointment on a diagnosis of a developmental disability**,** Article 17A lacks any provision for evaluating the continued need for a guardian on a regular basis. An adult under an Article 17A guardianship seeking to restore their autonomy has the burden of establishing that a continued guardianship is not in their best interest.[47] Requiring the adult to justify the termination of the guardianship contradicts the common understanding of the state's exercise of its *parens patriae* power to protect its vulnerable citizens. The state, or in this case, the guardian, should be required to justify the continued exercise of the *parens patriae* power.[48] The lack of a regular evaluation of the continued need for the guardianship and requiring the individual under guardianship to bear the burden of showing guardianship is no longer needed essentially ensures a lifelong appointment. This fundamental element of Article 17A—providing lifelong appointments over adults with developmental disabilities—has remained unchanged over the years.[49]

1968 which stated, "that the problem addressed by this bill [the extension of the parent's authority passed the age of majority] may well be better treated as a part of that revision [of the mental hygiene law] rather than a piecemeal amendment at this time.").

45. VETO MEMORANDUM NO. 199, *supra* note 44.

46. 1969 N.Y. LEGIS. ANN. 24–25, 326.

47. *See In re* Guardianship of Capurso, 98 N.Y.S.3d 381, 382 (Surr. Ct. Westchester Cty. 2019); *see also In re* Robert C. B., 125 N.Y.S.3d 253, 263 (Surr. Ct. Dutchess Cty. 2020).

48. *See* Rivers v. Katz, 495 N.E.2d 337, 343–44 (N.Y. 1986); *see also* Monthie, *supra* note 36, at 953; *see also* N.Y. MENTAL HYG. LAW § 81.36(d) (McKinney 2024) ("To the extent that relief sought under this section would terminate the guardianship or restore certain powers to the incapacitated person, the burden of proof shall be on the person objecting to such relief. To the extent that relief sought under this section would further limit the powers of the incapacitated person, the burden shall be on the person seeking such relief.").

49. *See* N.Y. SURROGATE CT. PROC. ACT LAW § 1750-A (McKinney 2016). The statute has been amended over the years to include individuals with traumatic brain injury and various developmental disabilities, clarify the guardian's authority to make health care decisions, and update its terminology. *Id.*

The long-held presumption that individuals with developmental disabilities should be subjected to lifelong plenary guardianship[50] came under scrutiny as early as the 1960s,[51] even as Article 17A was enacted. By the 1990s, policy experts were recommending reform of guardianship laws across the country.[52] In 1992, at the recommendation of the New York State Law Revision Commission, the New York Legislature adopted Article 81 incorporating the provisions described earlier.[53] The statute requires that guardianship be established by clear and convincing evidence of potential harm caused by a person's lack of appreciation of their functional impairments, that due process apply in guardianship proceedings, and the need for continuing the guardianship be periodically reviewed. Policy makers were aware at that time that Article 17A lacked similar requirements[54] yet no change to that statute occurred then or at any subsequent time. Notwithstanding calls for reform, ultimately nothing has changed.[55] In 1990, while policy makers were considering the guardianship reforms that led to the enactment of Article 81, the Legislature called on the Office of Mental Retardation and Developmental Disabilities, now OPWDD, to re-evaluate Article 17A in light of the fact that society's recognition of the "right and capacity of persons with mental retardation and

50. *See* Sheila E. Shea & Carol Pressman, *Guardianship: A Civil Rights Perspective*, 90 N.Y. STATE BAR ASS'N J. 19, 22 (2018). "'Plenary guardianship' involves the [individual's] entire set of decision-making rights . . . [and] the greatest deprivation of autonomy . . . ." JOHN PARRY & ERIC Y. DROGIN, MENTAL DISABILITY LAW, EVIDENCE AND TESTIMONY: A COMPREHENSIVE REFERENCE MANUAL FOR LAWYERS, JUDGES AND MENTAL DISABILITY PROFESSIONALS 118 (2007)

51. *See* JOHN PARRY, CIVIL MENTAL DISABILITY LAW, EVIDENCE AND TESTIMONY 3 (2010); *see also* DAVID L. BAZELON & ELIZABETH M. BOGGS, THE PRESIDENT'S PANEL ON MENTAL RETARDATION, FOREWORD TO REPORT OF THE TASK FORCE ON LAW (1963); Developmental Disabled Assistance and Bill of Rights Act of 1975, Pub. L. No. 94-103, 89 Stat. 486 (1975) (codified as amended in scattered sections of 42 U.S.C.). The Developmental Disabilities Assistance and Bill of Rights Act was originally enacted as Pub. L. No. 88-164, 77 Stat. 282 in 1963; over the years the Act has been reorganized and amended extensively. *See History of the DD Act*, ADMIN. FOR COMMUNITY LIVING, https://acl.gov/about-acl/history-dd-act#:~:text=In%201975%20the%20Developmentally%20Disabled,age%2018%2C%20are%20expected%20to (last visited Apr. 10, 2025).

52. *See* Monthie, *supra* note 36, at 953.

53. *See id.*

54. Historical and Statutory Notes, McKinney's Consolidated Laws of New York, Book 58A, Surrogate Court's Procedure Act Law § 1750, L. 1990, c. 516 (ordering the Commissioner of the Office of Mental Retardation and Developmental Disabilities to undertake a study of Article 17A in light of the changes in guardianship laws).

55. *See, e.g.*, Shea & Pressman, *supra* note 50, at 23.

developmental disabilities to function independently and make many of their own decisions."[56] That Legislature observed that "[w]hile guardians appointed pursuant to [Article 17A] must have the authority to make decisions to ensure the ward's best interest, *such decision-making authority by the guardian should not infringe on the right of the ward to make decisions when he or she is capable*."[57] The legislation required OPWDD to issue a report to the Legislature by December 1, 1991. The agency subsequently formed a committee that spent four years examining the trends in guardianship reform across the country and drafting various reform proposals for the statute.[58] Finally, in 1995, it prepared a draft final report: "*Guardianship: A Tool for Independent Living, A Method for Providing Services*," recognizing the legal weaknesses of Article 17A and recommending changes.[59] The report was never delivered to the Legislature, however, and has languished without action ever since.[60]

Eighteen years later, in 2013, when New York's Olmstead Cabinet was convened by then Governor Andrew M. Cuomo to consider New York's treatment of individuals with disabilities, the Olmstead Cabinet identified Article 17A as needing reform.[61] It recommended that the statute be amended with respect to appointment procedures, hearings, functional capacity of the individual and "consideration of choice and preference in decision making."[62] Its proposal that Article 17A be modernized "*to mirror the more recent Article 81*"[63] in light of the Olmstead mandate likewise has languished without action.

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56. Historical and Statutory Notes, McKinney's Consolidated Laws of New York, Book 58A, Surrogate Court's Procedure Act Law § 1750, L. 1990, c. 516.

57. *Id.* (emphasis added).

58. *See* GUARDIANSHIP: A TOOL FOR INDEPENDENT LIVING, A METHOD FOR PROVIDING SERVICES (Apr. 7, 1995). A copy of the draft report secured through a FOIL application of OPWDD, and made public in *DRNY v. New York*, disclosure pursuant to Rule 26 of the Federal Rules of Civil procedure. A copy of the report on file with the author.

59. *See id.*

60. *See id.*

61. *See generally*, ANDREW M. CUOMO, REPORT AND RECOMMENDATIONS OF THE OLMSTEAD CABINET: A COMPREHENSIVE PLAN FOR SERVING NEW YORKERS WITH DISABILITIES IN THE MOST INTEGRATED SETTING, OLMSTEAD CABINET (2013). The cabinet was charged with and charged with developing "a plan consistent with New York's obligations under the United States Supreme Court decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999) . . . that the state's services, programs, and activities for people with disabilities must be administered in the most integrated setting appropriate to a person's needs." *Id.* at 8.

62. *Id.* at 28.

63. *Id.* (emphasis added).

More recently, several bills with similar provisions and the similar goal of modernizing Article 17A with Article 81 as a guide have been put forward. They include S. 4983 (2015), A. 8171 (2017), a proposal by the Surrogate's Advisory Committee of the Office of Court Administration (OCA 30) (2019), and a bill recommended by the New York State Law Revision Commission (LRC) (2019).[64] The bills propose a variety of changes to the statute including requirements regarding consideration of alternatives to guardianship, pleadings describing the individual's functional abilities/limitations; appointment of guardian ad litem and appointment of counsel; the hearing and respondent's presence at it; appointment of limited purpose/scope/duration guardians; the guardian's decision-making standard; the duration of guardianship; modification/termination of guardianship; and guardian accountability.[65] None of these bills have been enacted. The reasons for such inertia are not necessarily clear, although the desire to protect vulnerable individuals with profound disabilities, and the modest cost of Article 17A guardianships do present challenges to reform.[66]

Nevertheless, advocates continue to pursue change. Disability Rights New York (DRNY), a Protection and Advocacy System and Client Assistance Program, has pursued reform of Article 17A through litigation. In 2016, DRNY commenced an action in federal court against New York State and the Office of Court Administration comparing Article 17A to Article 81 of the Mental Hygiene Law and alleged that Article 17A, lacking the standards and requirements of Article 81, was unconstitutional.[67] The district court dismissed the action on abstention grounds, and the dismissal was affirmed by the Second Circuit in August 2019.[68] Undaunted, DRNY filed a complaint in Albany County Supreme Court in early 2024, alleging that New York State and the Unified Court System of the State of New York are "subjecting New Yorkers to illegal and discriminatory guardianships under

64. *See* N.Y. Senate Bill No. 4983, 238th Sess. (2015); N.Y. Assembly Bill No. 8171, Reg. Sess. 240th Sess. (2017); SURROGATE'S CT. ADVISORY COMM., REPORT OF THE SURROGATE'S COURT ADVISORY COMMITTEE TO THE CHIEF ADMINISTRATIVE JUDGE OF THE COURTS OF THE STATE OF NEW YORK 87 (2019).

65. *See id.* (a comparison of the bills is on file with the author).

66. *See* Rose Mary Bailly & Charis B. Nick-Torok, *Should We Be Talking?—Beginning a Dialogue on Guardianship for the Developmentally Disabled in New York*, 75 ALB. L. REV. 807, 809–10 (2012).

67. *See* Disability Rights N.Y. v. State, No. 16 Civ. 7363, 2017 U.S. Dist. LEXIS 222629, at *3–*5 (S.D.N.Y. Aug. 16, 2017).

68. *See* Disability Rights N.Y. v. New York, 916 F.3d 129, 131 (2d Cir. 2019).

New York State Surrogate's Court Procedure Act Article 17-a."[69] DRNY's complaint against the Unified Court System was dismissed in December 2024 on the grounds that DRNY lacked standing to assert its claims and the individual plaintiffs' claims were barred by the statute of limitations.[70]

In late 2024, the New York State Bar Association's Disability Rights Committee submitted a document to the New York State Bar Association Reports Group urging statutory reform of Article 17A as a constitutional imperative.[71] The report identifies and explains fourteen principles, "which a guardianship statute for adults with intellectual and developmental disabilities should contain" and observes that Article 17-A "requires immediate reform by the Legislature because the statute violates procedural and substantive due process, the Americans with Disabilities Act, and other well-established principles addressing the rights of people with developmental disabilities and their need for empowerment, advocacy and quality decision-making."[72] Several recent court decisions[73] and scholarly articles[74] have similarly expressed concerns about the legal shortcomings of Article 17A.

Notwithstanding the intransigence facing the efforts to reform the statute, New York's policy toward the treatment of individuals with developmental disabilities in areas not involving guardianship has

69. Press Release, Disability Rts. N.Y., Illegal and Discriminatory Guardianships in New York State (Feb. 7, 2024), https://www.drny.org/page/news—press-3/news/illegal-and-discriminatory-guardianships-in-new-york-state-14.html; Complaint at 4, J.M. v. State, No. 901369-24 (Sup. Ct. Albany Cty. filed Feb. 6, 2024).

70. *See* J.M. v. New York, No. 901369-24, slip op. at 6 (Sup. Ct. Albany Cty. Jan. 9, 2025) (a copy of the decision is on file with the author).

71. *See* N.Y. STATE BAR ASS'N COMM. ON DISABILITY RTS., GUARDIANSHIP FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES: EXAMINATION AND REFORM OF SURROGATE'S COURT PROCEDURE ACT ARTICLE 17-A IS A CONSTITUTIONAL IMPERATIVE (2024).

72. *Id.* at 4, 6.

73. *See, e.g.*, *In re* Derek, 821 N.Y.S.2d 387, 389–90 (Surr. Ct. Broome Cty. 2006) (showing patient-physician privilege applicable to an SCPA Article 17-A proceeding); *In re* Mark C.H., 906 N.Y.S.2d 419, 422–23 (Surr. Ct. N.Y. Cty. 2010) (providing a guardian's reporting requirement under Article 81 read into the SCPA Article 17-A appointment).

74. *See, e.g.*, Rose Mary Bailly, *Disability Law*, 73 SYRACUSE L. REV. 699, 713 (2023); Shea & Pressman, *supra* note 50, at 22; Monthie, *supra* note 36, at 993; Karen Andreasian et al., *Revisiting S.C.P.A. 17-A: Guardianship for People with Intellectual and Developmental Disabilities*, 18 CUNY L. REV. 287, 289 (2015); Maria Campigotto & Brian E. Hilburn, *Petitioning for Protection: Without Repeal or Reform of Article 17A, Can Practitioners Maintain Ethical Guardianship Practices While Simultaneously Protecting the Rights of Persons with Intellectual Disabilities*, 43 FORDHAM URB. L.J. 869, 869–70 (2016); Bailly & Nick-Torok, *supra* note 66, at 812–27.

advanced from viewing them as "perpetual children" to helping individuals advocate for themselves, and to improving their opportunities in employment, integrated living, and self-direction. OPWDD pursues a "person centered planning" approach:

> Providers use a person-centered planning approach to listen, discover and understand each person as an 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 them move toward a life they consider meaningful and productive. *The planning process empowers the person by building on their specific abilities and skills, building a quality lifestyle that supports them to find ways to contribute to your community*.[75]

OPWDD's programs focus on a person-centered approach for people with developmental disabilities that prioritizes individual choices, needs, and desires in making decisions.[76] OPWDD's most recent effort in this regard is its support of supported decision-making. Regrettably, these perspectives toward the lives of individuals with developmental disabilities have never been made part of Article 17A.

III. SUPPORTED DECISION-MAKING AND GUARDIANSHIP REFORM

As noted earlier, when their child reaches the age of eighteen, family members are advised that guardianship is necessary, most persuasively from other parents with children with disabilities, from schools, and from health care providers. Also noted earlier, when individuals are faced with decisions, both consequential and mundane, they like to consider their options and seek guidance from family and friends. Thus, faced with the consequential decision of a guardianship appointment, individuals should be made aware of alternative options, such as formal supported decision-making. Armed with that information, they will be able to make informed decisions about how to

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75. *Person Centered Planning*, N.Y. STATE OFF. FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, https://opwdd.ny.gov/providers/person-centered-planning (last visited Mar. 18, 2025) (emphasis added).

76. *See Types of Services*, N.Y. STATE OFF. FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, https://opwdd.ny.gov/types-services (last visited Mar. 18, 2025); *see also ACCES-VR*, N.Y. STATE. EDUC. DEP'T https://www.acces.nysed.gov/vr (last visited Mar. 18, 2025) (explaining that Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCES-VR), a program within the New York Department of Education, assists "individuals with disabilities to achieve and maintain employment and to support independent living through training, education, rehabilitation, and career development.").

proceed. Guardianship should be properly regarded as a last resort.[77] And when the remedy of guardianship is appropriate, the procedure and appointment should protect the rights of the respondent. The following proposals would do just that.

A. Amend the Statute to Include Recognition of Formal Supported Decision-Making and Substitute Decision-Making Alternatives

A goal articulated by Article 82 is to affirm formal SDM as a viable alternative to guardianship.[78] Article 81 of the Mental Hygiene Law[79] and other New York statutes and regulations already recognize many decision-making options which may eliminate the need for guardianship, including power of attorney,[80] health care proxy,[81] joint bank account,[82] Able Accounts[83] and supplemental needs trusts,[84] as well as the role of family members in facilities operated and/or certified by OPWDD**.**[85] None of these alternatives are identified in Article 17A, however, as options for decision-making. As noted earlier, Article 17A was enacted in 1969 when individuals with developmental disabilities were considered "children forever," and well before many decision-making alternatives to guardianship were recognized in the law. Article 17A should be amended now to include them. In order to achieve the laudable goal of diversion from guardianship, individuals, family members, service providers, health care professionals and others who counsel families should be educated about these options.[86] Although this education can be achieved in a variety of ways, as the New York City Bar Association notes,[87] the most important way of educating families is by amending Article 17A to require that the petitioner (most likely parents) allege in their guardianship application

77. *See* N.Y. MENTAL HYG. LAW § 81.02 (McKinney 2024).

78. *See* PELL EVALUATION, *supra* note 3, at 81.

79. *See* N.Y. MENTAL HYG. LAW §§ 81.08(a)(14), 81.16(b) (McKinney 2024).

80. *See* N.Y. GEN. OBLIG. LAW § 5-1501A (McKinney 2024).

81. *See* N.Y. PUB. HEALTH LAW § 2982 (McKinney 2024).

82. *See* N.Y. BANKING LAW § 675 (McKinney 2024).

83. *See* N.Y MENTAL HYG. LAW § 84.07 (McKinney 2024) (establishing that an Able Account will likely require the assistance of the court).

84. *See* N.Y. EST. POWERS & TRUSTS LAW § 7-1.12 (McKinney 2024) (establishing that a Supplemental Needs Trust will likely require the assistance of the court).

85. *See* N.Y. COMP. CODES R. & REGS. tit. 14 § 633.11 (McKinney 2024).

86. *See* PELL EVALUATION, *supra* note 3, at 80–81; *see* LOOKING FORWARD, *supra* note 3, at 121.

87. *See Supported Decision Making*, N.Y.C. BAR (July 7, 2021), https://www.nycbar.org/member-and-career-services/committees/reports-listing/reports/detail/supported-decision-making.

that both supported decision-making and surrogate decision-making alternatives to guardianship have been considered and the petitioner has determined they are insufficient or unreliable.

The fact that the Office of Court Administration acknowledges the existence of alternatives to guardianship on its website[88] and that some surrogate courts have engaged with families about alternatives to guardianship does not excuse the current statutory silence. The courts doing so are exercising their discretion and the exercise of that discretion may not be uniformly employed across the state.[89] Given the pressure on families to resort to guardianship, their lack of awareness of decision-making alternatives, and the supported decision-making legislation's goal of guardianship diversion, a failure to amend SCPA Article 17A will undermine the supported decision-making legislation. Policy makers should consider the fact that even after 20 years, researchers of the use of supported decision-making 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."[90] New York can begin to address the issue by amending Article 17A.

B. Amend the Statute to Allow the Use of Supported Decision-Making by the Guardian

Article 82 currently provides that supported decision-making is not available when the "adult has a legal guardian . . . whose granted authority is in conflict with the proposed supported decision-making agreement."[91] Advocates for supported decision-making recognize, however, that there is "a significant way in which Supported Decision-Making can be useful to, and should be used by, guardians."[92] They

88. *See Guardianship of an Intellectually or Developmentally Disabled Adult*, N.Y. STATE UNIFIED CT. SYS. (Mar. 8, 2022), https://www.nycourts.gov/courthelp/guardianship/17A.shtml.

89. *See In re* Robert C. B., 125 N.Y.S.3d 253, 263 (Surr. Ct. Dutchess Cty. 2020) (citing multiple cases reflecting the differing views of the court's power), *rev'd*, 170 N.Y.S.3d 619 (App. Div. 2d Dep't 2022).

90. NAT'L COUNCIL ON DISABILITY, BEYOND GUARDIANSHIP: TOWARDS ALTERNATIVES THAT PROMOTE GREATER SELF-DETERMINATION OF PEOPLE WITH DISABILITIES 263–64 (2018).

91. N.Y. MENTAL HYG. LAW § 82.03(a) (McKinney 2024).

92. Cathy E. Costanzo, Kristin Booth Glen, & Anna M. Krieger, *Supported Decision-Making: Lessons from Pilot Projects*, 72 SYRACUSE L. REV. 99, 112 (2022); *see also* Duffy, *supra* note 27, at 48–49; *see also Ethics Grand Rounds: Should 'Supported' Decision-Making Be Used in Research?*, NAT. INST. OF HEALTH VIDEO CASTING (Feb. 7, 2024, 12:00 PM), https://videocast.nih.gov/watch=54269 (stating that "[s]upported decision-making can improve surrogate decision making.").

observe that "[g]uardians are not appointed only to make decisions, in perpetuity, for their 'wards.' They are expected to maximize autonomy and, indeed, to do what is necessary and possible to restore the decision-making capacity of those over whom they have been given legal power . . . a seldom noted obligation . . . ."[93] Article 17A should be amended to require the guardian's responsibilities to include an obligation to "maximize the self-reliance and independence of the person,"[94] and allow the guardian to support decisions by, rather than dictate decisions for, the individual.

C. Amend the Statute to Allow the Appointment of a Transitional Guardian and to Allow Judicial Approval or Ratification Transactions Without Appointing a Guardian[95]

Individuals turning eighteen are "navigating the potentially perilous developmental years of growing out of childhood and into adulthood—a time of facing more adult-like challenges without having yet mastered the tools and cognitive maturity of adulthood."[96] The challenges of this period are no less true for individuals with developmental disabilities.[97] Notwithstanding the recognition of these challenges, the law establishes a bright line age of majority for many decisions, thus prompting parents to seek guardianship when their child with a developmental disability turns eighteen.

Article 17A should be amended to authorize the court to appoint a transition guardian while individuals and their families consider alternative decision-making options. This appointment would allow the family, where appropriate, to have authority to advocate on behalf of their loved one, enroll them in programs, and obtain services while the individual and their family consider options such as supported

93. Costanzo et al., *supra* note 92, at 112.

94. *Id.* at 110 (quoting NAT'L GUARDIANSHIP ASS'N, STANDARDS OF PRACTICE 9 (4th ed. 2013), https://www.guardianship.org/wp-content/uploads/2017/07/NGA-Standardswith-Summit-Revisions-2017.pdf.).

95. *See* N.Y. MENTAL HYG. LAW § 81.16(b) (McKinney 2024) (such relief is already available under the general guardianship statute); *see also supra* notes 56 – 57 and accompanying text.

96. Timothy E. Wilens & Jerrold F. Rosenbaum, *Transitional Aged Youth: A New Frontier in Child and Adolescent Psychiatry*, 9 J. AM. CHILD & ADOLESCENT PSYCH. 887, 887 (2013); *see also* Elizabeth S. Scott, *The Legal Construction of Adolescence*, 29 HOFSTRA L. REV. 547, 547 (2000); Arlene S. Kanter, *Guardianship for Young Adults with Disabilities as a Violation of the Purpose of the Individuals with Disabilities Education Improvement Act*, 8 J. INT'L AGING L. & POL'Y 1, 29–31 (2015).

97. *See* Kanter, *supra* note 96, at 30.

decision-making agreements, the development of which may take up to eighteen months,[98] as well appropriate substitute decision-making tools. The transition guardian could even be made available prior to the individual reaching age eighteen and, in any event, would end no later than when the individual reached age twenty-six, a transition age selected by the federal Affordable Care Act,[99] and section 413-b of New York's Family Court Act, which authorizes "child" support for certain individuals with a diagnosis of a developmental disability until they reach age twenty-six.[100]

At the end of the transition period, the guardian would report to the court on what alternatives are in place and if there is still a need for a guardian. If that were the case, the court would consider an application for a guardianship appointment. A 2024 decision in Surrogate's Court in Queens demonstrates the advantage of such a remedy.[101]

Using as a blueprint the dispositional alternatives provisions of Article 81 of the Mental Hygiene Law, which authorizes the guardianship court to create protective arrangements and approve single transactions,[102] the statute should also be amended to provide the

98. *See* PELL EVALUATION, *supra* note 3, at 80.

99. *See* Patient Protection and Affordable Care Act of 2010, Pub. L. No. 111-148, 124 Stat. 119, 132.

100. *See* N.Y. FAM. CT. ACT § 413-b(1) (McKinney 2024).

101. *See An Especially Exciting Restoration of Rights*, SUPPORTED DECISION-MAKING N.Y. (May 29, 2024), https://sdmny.org/an-especially-exciting-restoration-of-rights/.

102. *See* N.Y. MENTAL HYG. LAW § 81.16(b) (McKinney 2024) (providing: "If the person alleged to be incapacitated is found to be incapacitated, the court without appointing a guardian, may authorize, direct, or ratify any transaction or series of transactions necessary to achieve any security, service, or care arrangement meeting the foreseeable needs of the incapacitated person, or may authorize, direct, or ratify any contract, trust, or other transaction relating to the incapacitated person's property and financial affairs if the court determines that the transaction is necessary as a means of providing for personal needs and/or property management for the alleged incapacitated person. Before approving a protective arrangement or other transaction under this subdivision, the court shall consider the interests of dependents and creditors of the incapacitated person, and in view of the person's functional level, whether the person needs the continuing protection of a guardian. The court may appoint a special guardian to assist in the accomplishment of any protective arrangement or other transaction authorized under this subdivision. The special guardian shall have the authority conferred by the order of appointment, shall report to the court on all matters done pursuant to the order of appointment and shall serve until discharged by order of the court. The court may approve a reasonable compensation for the special guardian; however, if the court finds that the special guardian has failed to discharge his or her duties satisfactorily in any respect, the court may deny or reduce the amount of compensation or remove the special guardian.").

availability of court intervention for some substitute decision-making tools, such as an Able Account and a Supplemental Needs Trust, without the appointment of a guardian.[103]

D. Amend the Statute to Address Constitutional Shortcomings of Article 17A and Reflect New York's Current Policy Toward Treatment of Individuals with Developmental Disabilities

In order to make the relationship between Article 17A, supported decision-making, and other guardianship alternatives meaningful, the statute itself must meet constitutional requirements. Indeed, the Pell Evaluation of New York's supported decision-making pilot project recommended revisions to the statute that "reflects current standards of practice and human rights progress."[104] These recommended revisions are echoed in all the reform efforts that have gone before,[105] and already are included in Article 81 of the Mental Hygiene Law, which as noted earlier does apply to individuals alleged to have a developmental disability, although it is rarely used.[106]

Article 17A should be amended as follows:

1. In the absence of an individual's consent to the guardianship, the appointment should be based on clear and convincing evidence that the individual is likely to suffer harm because they are functionally unable to provide for personal needs and/or property management, and cannot adequately understand and appreciate the nature and consequences of such inability even with appropriate supportive services, technological assistance or supported decision making that allows them to exercise their legal capacity. Neither the alleged developmental disability nor the age of the individual alleged to have a developmental disability should be the sole basis for the appointment of a guardian.

2. The individual should be represented by counsel. Counsel should advocate for the respondent's expressed wishes, if known. If the respondent's wishes are not known and cannot be ascertained after investigation, counsel should safeguard the respondent's procedural rights throughout the proceeding toward achieving the least restrictive disposition consistent with the respondent's needs.

3. Any hearing should be held in the presence of the individual unless the individual is excused.

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103. *See* Andreasian et al., *supra* note 74, at 310.
104. PELL EVALUATION, *supra* note 3, at 80.
105. *See id.*
106. *See id.*

4. The court should make findings regarding 1) the extent of the functional level, including the functional limitations and the level of the impairment in the individual's intellectual functioning and/or adaptive behaviors; and the individual's lack of understanding and appreciation of the nature and consequences of their functional limitations and impairment in intellectual functioning and/or adaptive behaviors; 2) the sufficiency and reliability of available resources and alternatives to guardianship; 3) the necessity of the appointment of a guardian to prevent such harm; 4) the specific powers of the guardian which constitute the least restrictive form of intervention consistent with the court's findings.

5. In any application to terminate the guardianship**,** the burden of proof should be on the person objecting to discharge or seeking increased powers for the guardian.

6. The guardian should be authorized to exercise only the authority necessitated by the limitations of the person with a developmental disability, and, to the extent possible, use supported decision-making where appropriate. The guardian's obligation should include encouraging the person with a developmental disability to participate in decisions and to act on his or her own behalf, and to develop or regain, to the maximum extent possible, the capacity to meet his or her needs. A guardian should consider the expressed desires and personal values of the person with a developmental disability to the extent known when making decisions and should consult with the person with a developmental disability whenever meaningful communication is possible. If the person's wishes are unknown and remain unknown after reasonable efforts to discern them, the decision should be made on the basis of the best interests of the person with a developmental disability, as determined by the guardian. In determining the best interests of the person with a developmental disability, the guardian should weigh the reason for, and nature of, the proposed action, the benefit or necessity of the action, the possible risks and other consequences of the proposed action, and any available alternatives with their risks, consequences, and benefits. The guardian should take into account any other information, including the views of family and friends, that the guardian believes the person with a developmental disability would have considered if able to act for herself or himself.

7. The statute should provide for review at regular intervals to evaluate the continued need for guardianship or modifications to the appointment.

A periodic review is important because it comports with constitutional requirements of due process.[107] It also provides for assessing the needs of the individual under guardianship which may change over time, and it offers support to the guardian "in the undertaking of a daunting role."[108] As the court in *Mark C. H.,* noted "[t]he great weight of commentary supports the need for, and wisdom of, a reporting and review requirement for guardians of the person, as well as those of the property."[109]

CONCLUSION

Supported decision-making has been heralded as a "significant and growing alternative to guardianship."[110] Undoubtedly, it will benefit many, but its use is not a process that happens overnight.[111] In the meantime, Article 17A—the purported protection offered to individuals with developmental disabilities—languishes in the past. Policy makers have known of the reforms needed to Article 17A for a long time. They have developed person-focused policies for individuals receiving services through OPWDD and they have either proposed themselves, or been offered, recommendations for change to Article 17A. Perhaps most importantly, they have been made aware either through scholarly articles or through federal and state litigation, that Article 81 of the Mental Hygiene Law, New York's other guardianship law, already complies with constitutional requirements urged for Article 17A. One might be moved to ask whether there is any continued justification for having Article 17A, a separate statute which treats adult persons, and their due process rights, differently in guardianship proceedings based solely on a diagnosis of a developmental disability. The choice between the two statutes allows the petitioner to decide the rights of the respondent even before there is a determination of the need for a guardian. If policy makers are persuaded of the recommended reforms to Article 17A this article offers, might they also be persuaded that a single guardianship statute could better achieve the

107. *See In re* Mark C. H., 906 N.Y.S.2d 419, 425 (Surr. Ct. N.Y. Cnty. 2010).

108. *Id.* at 424 (quoting Sally Balch Hurme & Erica Wood, *Guardian Accountability Then and Now: Tracing Tenets for an Active Court Role*, 31 STETSON L. REV. 867, 872 (2002)).

109. *Id.* at 425.

110. David M. English, *Supported Decision-Making in the US: History and Legal Background*, SPECIAL NEEDS ALL. (Aug. 2022), https://www.specialneedsalliance.org/the-voice/supported-decision-making-in-the-us-history-and-legal-background/.

111. *See* PELL EVALUATION, *supra* note 3, at iv, 21.

changes proposed. A proposal has already been made public to combine the Health Care Decision Act, applicable only to individuals with developmental disabilities (section 1750-B of the Surrogate's Court Procedure Act) with the Family Health Care Decisions Act applicable to individuals other than those with developmental disabilities (Public Health Law, art. 29-CC), both of which address health care decision-making by individuals or their surrogates. The proposal recommends consolidation of the statutes in order to, among other reasons, address the fact that "disparate laws create concern about equal treatment. Even if the frameworks are followed correctly, similarly situated incapacitated patients might be subject to different . . . decisions for no reason beyond differences in governing laws that have no rationale."[112] Spurred by the supported decision-making legislation and the attention it brings to guardianship, policy makers should act now to reform New York's law on guardianship for individuals with developmental disabilities.

112. N.Y. STATE TASK FORCE ON LIFE & THE L., RECOMMENDATIONS FOR AMENDING THE FAMILY HEALTH CARE DECISIONS ACT TO INCLUDE HEALTH CARE DECISIONS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES AND PATIENTS IN OR TRANSFERRED FROM MENTAL HEALTH FACILITIES 23 (2016).