DISABILITY LAW:

THE WILL & PREFERENCES OF AN INDIVIDUAL WITH PROFOUND COGNITIVE DISABILITIES IN END-OF-LIFE SUPPORTED DECISION-MAKING

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INTRODUCTION[1]

Supported decision-making has been hailed as a paradigm shift in the doctrine of legal capacity.[2] In 2006, the United Nations ("UN") Convention on the Rights of Persons with Disabilities ("CRPD") recognized that persons with cognitive disabilities have the right to enjoy "legal capacity" as a human right "on an equal basis with others in all aspects of life."[3] 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"[4] so that they can make decisions. 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,"[5] in other words, for health care treatment, providing informed consent regarding treatment.

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."[6] Comment No. 1 urged an

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[1] The Author acknowledges that the terms "intellectual disability" or "developmental disability" have replaced the term "mental retardation" and its derivatives in the federal government and most states, including New York with its renamed Office for People with Developmental Disabilities ("OPWDD"). However, the cases that preceded the enactment of this change use the old term. Where this Article relies on those cases, that older outdated term may be used.

[2] *See, e.g.*, Peter Blanck, *Supported Decision-Making: Emerging Paradigm in Research, Law and Policy*, 34 J. DISABILITY POL'Y STUDS. 3, 3 (2023); Joanne Watson, Hille Voss & Melissa J. Bloomer, *Placing the Preferences of People with Profound Intellectual and Multiple Disabilities At the Center of End-of-Life Decision Making Through Storytelling*, 44 RSCH. & PRAC. FOR PERS. WITH SEVERE DISABILITIES 267, 269 (2019); Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 COLUM. HUM. RTS. L. REV. 93, 98 (2012).

[3] Convention on the Rights of Persons with Disabilities, *adopted*, Dec. 13, 2006, 2515 U.N.T.S. 3, 78 (entered into force May 3, 2008); *id.* at 72 ("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.").

[4] Convention on the Rights of Persons with Disabilities, *supra* note 3, at 78.

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

[6] Comm. on the Rights of Persons with Disabilities on Its Eleventh Session, U.N. Doc. CRPD/C/GC/1 at 1 (May 19, 2014) [hereinafter General Comment No. 1].

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"[7] 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."[8] This call for the abolition of guardianship has been met with criticism and concern; in fact, at least one scholar has suggested that such "an absolute prohibition . . . is, at least at present, not credible."[9] Nevertheless, supported decision-making for individuals with developmental disabilities has found favor across the globe,[10] including in the United States.[11] Article 82 of the Mental Hygiene Law, Supported Decision-Making, was enacted in New York in 2022.[12] However, New York has not repealed its guardianship statutes—Article 81 of the Mental Hygiene Law and Article 17-a of the Surrogate's Court Procedure Act ("SCPA Art. 17-a").[13] SCPA Art. 17-a is most relevant to this discussion as it provides for the appointment of a guardian for individuals with intellectual and developmental

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[7] General Comment No. 1, *supra* note 6, at 2; *see* discussion *infra* at notes 119-141 about New York courts declining to accord equal protection to individuals with cognitive disabilities in New York.

[8] General Comment No. 1, *supra* note 6, at 2 (emphasis added).

[9] George Szmulker, *"Capacity", "Best Interests", "Will and Preferences" and the UN Convention on the Rights of Persons with Disabilities*, 18 WORLD PSYCHIATRY 34, 40 (2019); *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); 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, 230 (2018); Paul Appelbaum, *Protecting the Rights of Persons with Disabilities: An International Convention and Its Problems*, 67 PSYCHIATR. SERVS. 366, 368 (2016).

[10] *See Supported Decision-Making Agreement Laws Around the World*, SDMNY, 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/ (on file with Syracuse Law Review) (last visited Feb. 21, 2026); *Beyond Guardianship: Towards Alternatives that Promote Greater Self-Determination*, NAT'L COUNCIL ON DISABILITY (Mar. 22, 2018), https://www.ncd.gov/assets/uploads/docs/ncd-guardianship-report-accessible.pdf (on file with Syracuse Law Review).

[11] *See* SDMNY, *supra* note 10.

[12] *See* Act of July 26, 2022, 2022 McKinney's Sess. Laws of N.Y., ch. 481 (2025) (codified as amended at N.Y. MENTAL HYG. LAW §§ 82.01–82.15 (McKinney 2025)).

[13] *See* MENTAL HYG. §§ 81.01–81.44; N.Y. SURR. CT. PROC. ACT §§ 1750–1761 (McKinney 2024).

disabilities.[14] It also contains the provision applicable to end-of-life decisions by guardians and family members of an individual with a diagnosis of an intellectual or developmental disability.[15]

Advocates argue that the will and preferences of the individual should be at the center of all supported decision-making;[16] where a supporter has not been able to elicit a person's will and preferences, a decision should be based on their *best interpretation* of what the person's will and preferences would be.[17] According to the UN Committee, even this type of "support in the exercise of legal capacity . . . should never amount to substitute decision-making."[18]

The following story is offered as an illustration of supported decision-making that purports to use the will and preferences[19] of an individual with profound intellectual disabilities. It was originally published in a study intended to shed light on the "complex role of communication partners" in the supported decision-making process.[20] The authors of the study noted that:

> The starting point is not test of capacity, but the presumption that every human being is communicating all the time and that this communication will include preferences. Preferences can be built up into expressions of choice and these into formal decisions. From this perspective, where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices.[21]

A. Neil

> Because of aspiration pneumonia, Neil and his circle of support were faced with a range of decisions, including whether he should have potentially lifesaving medical treatment (i.e., a permanent tracheostomy) to

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[14] An Article 81 guardianship appointment is available to individuals with such diagnoses, but Article 17-a is the more popular choice. *See* Rose Mary Bailly, *Supported Decision-Making—Its Success Demands Guardianship Reform*, 75 SYRACUSE L. REV. 363, 382 (2025).

[15] *See* N.Y. S.C.P.A. § 1750-b.

[16] *See* CHRISTINE BIGBY ET AL., LA TROBE UNIV., DIVERSITY, DIGNITY, EQUITY AND BEST PRACTICE: A FRAMEWORK FOR SUPPORTED DECISION-MAKING 2 (2023); Blanck, *supra* note 2, at 4.

[17] *See* Scholten & Gather, *supra* note 9, at 228.

[18] General Comment No. 1, *supra* note 6.

[19] *See* Szmulker, *supra* note 9, at 38 ("Normally, [the meaning of] 'will' and 'preferences', by and large, run together."). This Article adopts that approach.

[20] Watson, Voss & Bloomer, *supra* note 2, at 274.

[21] *Id.* at 271.

> extend his life. Neil's circle of support worked collaboratively to consider his options. Those in the circle of support drew upon what they knew about his past experience of a tracheostomy 3 years earlier.
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> "I remember, you do too [looking at Neil's mother], he hated it. It was horrible. He was so distressed he seemed so scared."
>
> Neil's past distress was evidenced not only through his supporters' memories, but also through documentation tools such as a video taken by his mother, and the service provider's house diary at the time of Neil's past tracheostomy. Referring to that documentation Neil's mother said,
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> "Don't you worry love, I remember. I videoed him on my phone, it was such a Godsend when they got rid of it. If they hadn't Neil would have pulled it out himself, don't you worry about that."
>
> Support worker: "Have you still got that video? I'd like to see it. I didn't know Neil back then."
>
> Support worker: "Yes, I've seen it—hard to watch. It might be good for us all to see it. Hey, what about the old diary, see what we wrote at that time? I'll dig it up when I get back to the house."
>
> This evidence was collated and shared with his circle of support who used it to support Neil in his decision making.
>
> Neil previously found the tracheotomy as an alternative method of breathing extremely distressing and is likely to find it distressing again.
>
> Guided by the preferences Neil had communicated to them through documentation (video and the house diary) of his previous experience, the group collectively made the difficult decision that a tracheostomy would not be carried out. Neil died a number of days later with his mother and father and house supervisor from his residential service by his side.[22]

Viewing Neil as *a decision-maker* in this story seemingly contradicts the general understanding of New York law on informed consent, which involves a voluntary decision made by a competent patient based on their understanding of information they receive from a

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[22] *Id.* at 274.

medical practitioner.[23] In light of this description of informed consent, using supported decision-making that involves the best interpretation of a person's will and preference under New York's law governing decisions about end-of-life care will be a challenging undertaking. This Article reviews that law and the treatment of the will and preferences of individuals with profound disabilities in end-of-life decisions under that law and raises some preliminary questions about their use as a result of New York's recognition of supported decision-making.

I. NEW YORK LAW

A. Informed Consent

It is well established in New York that "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body . . . ."[24] New York's Public Health Law presumes that every adult has capacity to make those health care decisions unless determined otherwise by a physician, pursuant to court order, or the appointment of a health care agent or guardian authorized to decide about health care for the adult.[25] While a physician might believe a certain treatment is desirable or necessary, the law, as originally articulated in the 1914 decision *Schloendorff v. Society of New York Hospital*, has been understood to prohibit the physician from overriding the patient's wishes.[26] An informed consent to medical treatment has three components: information, a competent patient, and a voluntary decision.[27] The physician has a duty not only to defer to the patient's choice, but to facilitate the proposed choice by informing the patient of "reasonably foreseeable risks and benefits involved,"[28] and plausible alternatives to, a proposed treatment.[29] Before the physician can proceed, the competent patient must voluntarily agree to a course of treatment based on a knowledgeable evaluation of the alternatives to

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[23] *See* Scholten & Gather, *supra* note 9, at 227. *See* also discussion *infra* at notes 24-32.

[24] Schloendorff v. Soc'y of N.Y. Hosp., 105 N.E. 92, 93 (N.Y. 1914).

[25] *See* N.Y. PUB. HEALTH LAW § 2994-c (McKinney 2024).

[26] *See* Robert N. Swidler, *New York's Family Heath Care Decisions Act: The Legal and Political Background, Key Provisions and Emerging Issues*, 82 N.Y. STATE BAR ASS'N J. 18, 18 (2010).

[27] *See* PUB. HEALTH § 2805-d; Paul Appelbaum & Manuel Trachsel, *The Doctrine of Informed Consent Doesn't Need Modification for Supported Decision-Making*, 21 AM. J. BIOETH. 27, 27 (2021) (the element of voluntariness is critical).

[28] PUB. HEALTH § 2805-d.

[29] *See id.*

the treatment disclosed by the health care professional.[30] Voluntariness "requires that the decision maker be free from coercive influences that determine the person's choice."[31] This articulation of informed consent has been described as "the competence model."[32]

B. Will & Preference of an Incompetent Patient Under New York's Common Law

If the person is incompetent—unable to provide informed consent—a third party, a surrogate, may in certain circumstances provide the necessary consent.[33] Adopting a common law approach, New York initially strictly limited the authority of a third party to consent to medical care on behalf of an incompetent patient, including the withholding or withdrawing of end-of-life health care.[34] Two decisions by the Court of Appeals, New York's highest court, illustrate the outcome for such individuals under the common law. In each of these cases the patient's ability or inability to express their will and preferences regarding treatment played a role in the Court's decision.

In *Eichner v. Dillon*, Brother Fox, a member of a Roman Catholic religious order, suffered cardiac arrest during hernia surgery and was placed on a respirator.[35] He was being maintained by artificial means in a permanent vegetative state and his physicians advised his colleagues that there was no hope that he would recover.[36] The director of the order requested the hospital remove the respirator, but the hospital refused.[37] The director then sought his appointment as the patient's Committee of the Person and Property with authority to remove the patient from the "extraordinary life support systems."[38] Prior to

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[30] *See id.*

[31] Appelbaum & Trachsel, *supra* note 27, at 28.

[32] Scholten & Gather, *supra* note 9, at 227.

[33] *See id.*

[34] *See* discussion *infra* at notes 35-78.

[35] *See* Eichner v. Dillon, 420 N.E.2d 64, 65 (N.Y. 1981).

[36] *See id.*

[37] *See id.*

[38] *Id.* at 65–66. The committee statute, Article 78 of the Mental Hygiene Law, was subsequently repealed in 1992 and replaced with the guardianship statute, Article 81 of the Mental Hygiene Law. Act of July 31, 1992, 1992 McKinney's Sess. Law News, ch. 698 (codified at N.Y. MENTAL HYG. LAW §§ 81.01–81.44 (McKinney 2026)). Neither the committee statute, nor the guardianship statute until 2010, authorized the appointment to include authority to withhold or withdraw life sustaining treatment, unless the committee or guardian could rely on "prior competent wishes and past values and preferences of the incapacitated person." *Law Revision Commission Comments*, *in* MCKINNEY'S CONSOLIDATED LAWS OF N.Y., BOOK 27, § 81.22.

becoming incompetent during the surgery, the patient had consistently expressed his desire not to have his life prolonged by medical means if there were no hope of recovery.[39] The trial court noted that Brother Fox's religious community discussed the religious teachings of the Church and the nationally publicized end-of-life case of Karen Ann Quinlan.[40] In *In re Quinlan*, New Jersey's highest court authorized the father of the young woman, who had become incapacitated and was languishing in a persistent vegetative state, to remove her respirator based on her constitutionally protected privacy interest, which was "broad enough to encompass a patient's decision to decline medical treatment under certain circumstances."[41] The trial court found that "Brother Fox not only repeatedly expressed agreement with the church's teaching on the subject of the withdrawal of extraordinary life support systems but also stated that he personally would not want any of this 'extraordinary business' done for him under [circumstances similar to Karen Ann Quinlan's situation]."[42] Similar to Karen Ann Quinlan, Brother Fox was "medically and legally alive, but in a persistent vegetative state."[43] The court declined to adopt the constitutional right to privacy argument successfully advanced in the Karen Ann Quinlan case and in *Superintendent of Belchertown State School v. Saikewicz*, where the Massachusetts Supreme Judicial Court had refused to order chemotherapy for Joseph Saikewicz, a sixty-seven-year-old profoundly mentally disabled man with a blood cancer.[44] Instead, the trial court held that the Committee could terminate life support for Brother Fox based on the common law right of an individual to determine their medical treatment.[45] The decision was voluntary and according to the trial court, "no fiction is created nor is the judgment of Father Eichner substituted for that of Brother Fox."[46]

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[39] *See In re* Eichner, 423 N.Y.S.2d 580, 589 (Sup. Ct. Nassau Cty. 1979), *modified and aff'd sub nom.*, Eichner v. Dillon, 426 N.Y.S.2d 517 (App. Div. 2d Dep't 1980), *aff'd*, 420 N.E.2d 64 (N.Y. 1981).

[40] *See id.* at 590.

[41] *In re* Quinlan, 355 A.2d 647, 663–64 (N.J. 1976), *cert. denied sub nom.*, Garger v. New Jersey, 429 U.S. 922 (1976).

[42] *In re Eichner*, 423 N.Y.S.2d at 586.

[43] *Id.* at 587 (citing *In re* Quinlan, 348 A.2d 801, 810 (N.J. Super. Ct. Ch. Div. 1975)).

[44] *See id.* at 595–96; *see also* Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 419 (Mass. 1977).

[45] *See In re Eichner*, 423 N.Y.S.2d at 594.

[46] *Id.* at 597.

The appellate division affirmed,[47] as did the Court of Appeals.[48] Brother Fox died shortly after the appeal was heard in the Second Department.[49] The Court of Appeals held in *Eichner v. Dillon* that under the common law,[50] the patient's Committee could properly discontinue Brother Fox's treatment when he was being maintained in a permanent vegetative state with no reasonable chance of recovering because the decision was based on clear and convincing evidence of his prior competent wishes that he would not want to be maintained on life support in those circumstances.[51] According to the Court, "[w]hat occurred to him was identical to what happened in the Karen Ann Quinlan case, which had originally prompted his decision. In sum, the evidence clearly and convincingly shows that Brother Fox did not want to be maintained in a vegetative coma by use of a respirator."[52] Brother Fox's prior expression of his will and preferences, while competent, governed the decision of his legally appointed Committee and its approval by the Court.

In *Soper v. Storar*,[53] a companion Court of Appeals case to *Eichner v. Dillon*, the mother, who was the appointed Committee of her fifty-two-year-old son with profound mental disabilities, sought to terminate blood transfusions administered to her son to replenish the blood loss caused by terminal bladder cancer which had spread throughout his body.[54] His prognosis was a "very limited life span"[55]—his condition was terminal and incurable.[56] His physicians had ordered blood transfusions because Mr. Storar was losing massive quantities of blood.[57] "At the time of the hearing the transfusions were being administered on the average of once every eight days."[58] He had to be physically restrained during administration of the painful

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[47] *See* Eichner v. Dillon, 426 N.Y.S.2d 517 (App. Div. 2d Dep't 1980).

[48] *See* Eichner v. Dillon, 420 N.E.2d 64, 72 (N.Y. 1981).

[49] *See Eichner*, 426 N.Y.S.2d at 523.

[50] Although the appellate division held that a constitutional right to privacy also supported the decision to withdraw life-sustaining treatment, the Court of Appeals declined to reach that issue. *See Eichner*, 420 N.E.2d at 70.

[51] *See id.* at 72.

[52] *Id.*

[53] *See In re* Storar, 433 N.Y.S.2d 388 (Sup. Ct. Monroe Cty. 1980), *aff'd*, 434 N.Y.S.2d 46 (App. Div. 4th Dep't 1980), *rev'd sub nom.*, Soper v. Storar, 420 N.E.2d 64 (N.Y. 1981).

[54] *See id.* at 391.

[55] *Storar*, 420 N.E.2d at 69.

[56] *See In re Storar*, 433 N.Y.S.2d at 393.

[57] *See id.* at 391.

[58] *Id.*

transfusions.[59] The trial court described him as physically weakened by his illness and the transfusions, and in a great deal of pain because of "frequent clotting in Storar's urine which makes urination quite painful."[60] "There is no question but that Storar's illness causes him intense pain and discomfort," the physicians agreeing at the hearing "that cancer of the bladder is extremely painful."[61]

The trial court observed that Mr. Storar's mother understood her son's preferences regarding treatment:

> Mrs. Storar, over her son's lifetime, has come to understand his wants and needs and is acutely sensitive to his best interests. She has provided much love, personal care and affection for John, more so than any other person or institution. She has been very protective of him and consistently refers to him as her "child". The best interests of John are of crucial importance to Mrs. Storar. She is closer to feeling what John is feeling than anyone else. In her judgment Storar does not want the transfusions continued. They are painful, they make him uncomfortable and he seems to dread them. She believes that to prolong Storar's life does nothing but prolong his pain. She wants his suffering to stop and believes that he would want this also.[62]

The trial court in *In re Storar* concurred with Mrs. Storar that "Storar's best interests will be served by terminating the transfusions and that this would be, in fact, Storar's preference were he able to make a decision and to articulate it."[63] Relying on the lower court's decision in *In re Eichner*, the trial court ordered the transfusions to be discontinued.[64] The court also approvingly cited *Superintendent of Belchertown State School v. Saikewicz*.[65] In declining to order chemotherapy for an older profoundly mentally disabled man with a blood cancer,[66] the court in *Saikewicz* "was very concerned with [his] subjective desires in coming to a substitute judgment of his

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[59] *See id.*

[60] *Id.* at 392.

[61] *In re Storar*, 433 N.Y.S.2d at 392.

[62] *Id.* at 393.

[63] *Id.* at 394.

[64] *See id.* at 393–94.

[65] *See id.* (citing Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417 (Mass. 1977)).

[66] *See Saikewicz*, 370 N.E.2d at 422.

preferences."[67] Although it did not consider Mr. Saikewicz's physical resistance to the treatment,[68] the Supreme Judicial Court of Massachusetts concluded that "Saikewicz was unable to cooperate with the treatment due to his profound retardation and so that even if the 'competent Saikewicz' preferred treatment, he would still resist it."[69] The Court opined that:

> Individual choice is determined not by the vote of the majority but by the complexities of the singular situation viewed from the unique perspective of the person called on to make the decision. To presume that the incompetent person must always be subjected to what many rational and intelligent persons may decline is to downgrade the status of the incompetent person by placing a lesser value on his intrinsic human worth and vitality.[70]

The Fourth Department affirmed in a memorandum decision, citing the decisions in *Saikewicz*, *In re Quinlan*, and the Second Department's decision in *Eichner*.[71]

Notwithstanding the discomfort Mr. Storar manifested and his mother's interpretation of his preferences, the Court of Appeals reversed the decision, relying on "different principles"—the rules governing the right of a parent to make decisions for a child.[72] According to the Court of Appeals, "it [was] unrealistic to attempt to determine whether [Mr. Storar] would want to continue potentially life prolonging treatment if he were competent."[73] The Court of Appeals' view of the evidence also differed substantially from that of the trial court. It relied on testimony indicating that the transfusions gave the fifty-two-year-old "more energy."[74] "He was able to resume most of his usual activities—feeding himself, showering, taking walks and running—including some mischievous ones, such as stealing cigarette butts and

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[67] Eric C. Miller, Note, *Listening to the Disabled: End-Of-Life Medical Decision Making and the Never Competent*, 74 FORDHAM L. REV. 2889, 2903 (2006) (citing *Saikewicz*, 370 N.E.2d at 430–32).

[68] *See id.*

[69] *Id.* (quoting *Saikewicz*, 370 N.E.2d at 421).

[70] *Saikewicz*, 370 N.E.2d at 428.

[71] *See In re Storar*, 434 N.Y.S.2d at 46–47 (App. Div. 4th Dep't 1980) (citing *Saikewicz*, 370 N.E.2d 417; *In re* Quinlan, 355 A.2d 647 (N.J. 1976); Eichner v. Dillon, 426 N.Y.S.2d 517 (App. Div. 2d Dep't 1980)).

[72] Soper v. Storar, 420 N.E.2d 64, 73 (N.Y. 1981).

[73] *Id.* at 72.

[74] *Id.* at 69.

attempting to eat them."[75] The Court acknowledged the evidence that the patient did not like the transfusions, but dismissed that as a reaction to be expected from "one with an infant's mentality"[76] and focused on the fact that he was sedated prior to the transfusions and "received regular doses of narcotics to alleviate the pain associated with the disease."[77] According to the Court of Appeals:

> Mentally John Storar was an infant and that is the only realistic way to assess his rights [as a fifty-two-year-old man] in this litigation. . . .
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> A parent or guardian has a right to consent to medical treatment on behalf of an infant . . . [but] may not deprive a child of lifesaving treatment . . . . [T]he State's interests, as *parens patriae*, in protecting the health and welfare of the child [override a parent's decision, notwithstanding the best intentions of the parent.][78]

In reaching its decision regarding John Storar, the Court never mentioned the holding in *Saikewicz*.

Subsequent to the decision in *Storar*, when such "individuals became irreversibly, terminally ill they were, in effect, ineligible for hospice or other palliative care because their guardians were unable to refuse more intrusive, acute medical treatments aimed at extending life for as long as possible."[79] Cases were recorded where life-sustaining treatment was continued in patients with profound cognitive disabilities notwithstanding the adverse effects of the treatment on the patient.[80]

C. New York's Statutory Treatment of Will & Preferences Regarding Treatment

Over the course of the past twenty years or so, New York's approach to decision-making on behalf of incompetent patients has

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[75] *Id.*

[76] *Id.* at 73.

[77] *Storar*, 420 N.E.2d at 69.

[78] *Id.* at 73 (first citing Robert M. Byrn, *Compulsory Lifesaving Treatment for the Competent Adult*, 44 FORDHAM L. REV. 1, 24 n.107 (1975); then citing N.Y. PUB. HEALTH LAW § 2504(2) (1972); and then citing Sampson v. Taylor, 278 N.E.2d 918 (1972)).

[79] *In re* M.B., 846 N.E.2d 794, 796 (N.Y. 2006).

[80] *See, e.g.*, Legislative Memoranda, *reprinted in* N.Y. Bill Jacket, 2002 S.B. 4622, ch. 500 (2002), https://digitalcollections.archives.nysed.gov/index.php/Detail/objects/30692 (on file with Syracuse Law Review) (discussing cases including Blouin *ex rel.* Estate of Pouliot v. Spitzer, 213 F. Supp. 2d 184 (N.D.N.Y 2002), *aff'd*, 356 F.3d 348 (2d Cir. 2004)).

evolved. It adopted two statutory regimes that recognize guardians can be authorized to make health care decisions, including end-of-life care for an incompetent patient based on their best interest, or where known or ascertainable, their prior wishes.[81] In 2002, the Legislature addressed the authority of a guardian of an individual diagnosed with "mental retardation" to make health care decisions, including end-of-life decisions, based on the *best interest* of the individual by amending SCPA Art. 17-a.[82] The statute, section 1750-b of the Surrogate's Court Procedure Act ("SCPA 1750-b"), requires that the court appointing a guardian for an individual with a mental disability first determine whether the respondent has the ability to make health care decisions.[83] If the individual has that ability, a guardian can still be appointed to make other types of decisions.[84] If the individual is determined not to have that ability, the guardian is granted authority over health care decisions, including those involving end-of-life care.[85] The burden of proof of clear and convincing evidence of prior competent wishes articulated in *Eichner* was replaced with the best interest standard.[86] The 2002 amendment marked a major shift in the law, overruling the decision in *Storar* and the view that an adult with a cognitive disability should be treated as if they were a child, and providing certainty for guardians and medical personnel regarding the authority of a guardian regarding all types of health care. The authority of a guardian of a person with a mental retardation regarding health care decisions had been an area of ambiguity, as appointments under the earlier version of the statute did not specify this authority.[87] The statute also included procedural protections to ensure that treatment would not be "arbitrarily

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[81] *See* discussion *infra* notes 82-92; 114-118. New York also adopted legislation governing health care proxies, N.Y. PUB. HEALTH LAW §§ 2980–2994 (McKinney 2026), and it is possible that an individual with a diagnosis of a mental disability may appoint an agent for health care decisions. *See, e.g.*, *In re* United Health Servs. Hosps., Inc., 2021 N.Y. Slip Op. 50612(U), at 3 (Sup. Ct. Broome Cty. June 30, 2021); *see also* N.Y. MENTAL HYG. LAW § 33.03(e)(1) (McKinney 2025) (a simplified advance health care directives for individuals receiving services from OPWDD was enacted in 2008 but has yet to take effect). A discussion of health care proxies, and livings wills, which New York courts have recognized, is beyond the scope of the discussion of the portion of the Article.

[82] *See* Health Care Decisions Act for Persons with Mental Retardation, 2002 McKinney's Sess. Laws of N.Y., ch. 500 (codified as amended at N.Y. SURR. CT. PROC. ACT §§ 1750, 1750-b (McKinney 2026)).

[83] *See* N.Y. S.C.P.A. § 1750-b(1).

[84] *See id.* § 1750-b(1)(c).

[85] *See id.* § 1750-b(2)(a)(iii).

[86] *See* Ben Golden, *New Law Gives Guardians Authority to End Futile Treatment For Adults With Retardation*, 75 N.Y. STATE BAR ASS'N J. 16, 16 (2003).

[87] *See In re M.B.*, 846 N.E.2d at 795.

withheld from a person with developmental disabilities due to their perceived diminished quality of life."[88] A series of additional amendments to SCPA 1750-b elaborating on end-of-life decision-making followed. In 2003, it was amended to allow corporate guardians to make end-of-life health care decisions for individuals with "mental retardation."[89] In 2005, the provisions regarding health care decisions, including end-of-life decisions, were expanded to include individuals with developmental disabilities.[90] In 2007, the statute was again amended to authorize end-of-life decision-making by family members for a person who has been diagnosed as having mental retardation or a developmental disability but has no guardian.[91] In 2008, the statute was further amended to allow a surrogate decision-making panel under Article 80 of the Mental Hygiene Law to make end-of-life decisions for an individual who met the criteria of SCPA Art.17-a.[92]

Despite these numerous amendments, the standard for end-of-life decision-making in SCPA 1750-b remained the same. The guardian must affirmatively advocate for the individual,[93] and "base all advocacy and health care decision-making solely and exclusively on the best interests of the person who is intellectually disabled and, when reasonably known or ascertainable with reasonable diligence, on the person who is intellectually disabled's wishes, including moral and religious beliefs."[94]

A challenge was raised to the retroactive application of the 2002 legislation in *In re M.B.*, questioning whether guardians appointed prior to the amended law should be required to seek a judicial finding as to the individual's capacity to make end-of-life and other health care decisions.[95] M.B. was a forty-two-year-old man with Down's Syndrome; his brother was appointed his SCPA Art. 17-a guardian.[96]

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[88] Christy A. Coe, *Beyond Being Mortal: Safeguarding the Rights of People with Developmental Disabilities to Efficacious Treatment and Dignity at the End of Life*, 88 N.Y. STATE BAR ASS'N J. 9, 11 (2016).

[89] Act of July 29, 2003, 2003 McKinney's Sess. Law News, ch. 232 (codified as amended at N.Y. S.C.P.A. § 1750-b).

[90] *See* Act of Oct. 18, 2005, 2005 N.Y. McKinney's Sess. Law News, ch. 744 (codified as amended at N.Y. S.C.P.A. § 1750-a).

[91] *See* Act of July 3, 2007, 2007 N.Y. McKinney's Sess. Law News, ch. 105 (codified as amended at N.Y. S.C.P.A. § 1750-b).

[92] *See* Act of July 8, 2008, 2008 N.Y. McKinney's Sess. Law News, ch. 262 (codified as amended at N.Y. S.C.P.A. § 1750-b).

[93] *See* Coe, *supra* note 88.

[94] N.Y. S.C.P.A. § 1750-b(2)(a).

[95] *See In re* M.B., 846 N.E.2d 794, 800 (N.Y. 2006).

[96] *See id.* at 798.

The appointment order did not describe the guardian's authority to make health care decisions for M.B., and no judicial determination had been made as to whether M.B. could make health care decisions because the appointment had occurred before the 2002 legislation became effective.[97] When M.B. later became seriously ill, his physicians concluded that his illness was terminal and irreversible, and that the life-sustaining treatment currently being provided imposed a substantial burden on him.[98] The guardian sought to terminate life-sustaining treatment.[99] Following the procedure in the new legislation, notwithstanding it was not yet effective, the hospital notified various parties of the decision, including Mental Hygiene Legal Service ("MHLS").[100] MHLS filed an objection on the grounds that the appointment made prior to the statute's effective date did not include any authority to make medical decisions.[101] The decision to discontinue life-sustaining treatment was suspended so the court could conduct a hearing on the matter.[102] MHLS argued that the guardian should be required to seek to expand his authority under SCPA 1750-b.[103] The trial court rejected MHLS's view that the new statute did not apply retroactively, concluding that the newly added provisions regarding health care decisions apply to all guardians.[104] The appellate court reversed,[105] acknowledging that, "[l]ike all individuals, mentally-retarded persons are not all the same. . . . Mentally-retarded persons can be competent to make their own medical decisions and can be capable of pursuing their legal rights without the aid of a guardian."[106] The court concluded that the statute's application was not retroactive and "persons with guardians appointed prior to the effective date of the new legislation lacked an opportunity to have their capacity to make

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[97] *See id.*

[98] *See id.*

[99] *See id.* at 799.

[100] *See In re M.B.*, 846 N.E.2d at 799. MHLS is "a New York State agency responsible for representing, advocating and litigating on behalf of individuals receiving services for a mental disability." *Mission Statement*, MENTAL HYGIENE LEGAL SERV., https://www.nycourts.gov/courts/ad2/pdf/mhlsart10/mhls_Mission-Statement.pdf (on file with Syracuse Law Review) (last visited Feb. 25, 2026).

[101] *See In re M.B.*, 846 N.E.2d at 799.

[102] *See id.* at 798.

[103] *See In re* M.B., 773 N.Y.S.2d 206, 206 (Surr. Ct. Richmond Cty. 2003), *rev'd*, 797 N.Y.S.2d 510 (App. Div. 2d Dep't 2005), *rev'd*, 846 N.E.2d 794, 800 (N.Y. 2006).

[104] *See id.* at 208.

[105] *See In re M.B.*, 797 N.Y.S.2d at 515.

[106] *Id.* at 512–13 (citing *In re* Baby Boy W., 773 N.Y.S.2d 255, 262–63 (Surr. Ct. Broome Cty. 2004)).

health care decisions specifically considered . . . [and thus] would not be adequately protected."[107]

The Court of Appeals reversed, holding that the legislation was intended to clarify the health care decision-making authority of all guardians; previously appointed guardians were not required to obtain expanded authorization for health care decisions because the procedural protections in the decision-making process protected all individuals under guardianship.[108] The Court further observed that an individual is protected by the statutorily required capacity assessment when any decision to end life-sustaining treatment is implemented.[109] The Court dismissed MHLS's argument that such an assessment during a medical crisis is not the same because it "fails to adequately account for the possibility that the patient might once have had the capacity to make health care decisions."[110] According to the Court, that concern is addressed by the fact that at the time of the decision, the guardian must take into account any wishes reasonably known or ascertainable.[111] In conclusion, the Court emphasized that:

> [I]n circumstances where the mentally retarded person formerly had some capacity to make medical decisions, the guardian is nonetheless required to base medical decision-making "on the best interests of the mentally retarded person and, when reasonably known or ascertainable with reasonable diligence, on the mentally retarded person's wishes, including moral and religious beliefs." Thus, the wishes of a mentally retarded individual who once had capacity to make health care decisions are not disregarded under the new statutory scheme.[112]

It should be noted, however, that a hearing for previously appointed guardians on the issue of expanding their authority to include health care decision-making might also have provided an opportunity for the guardian to learn or ascertain what the individual's wishes might be—something unlikely to occur in a medical emergency when the individual may be unresponsive.[113]

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[107] *In re M.B.*, 846 N.E.2d at 800.

[108] *See id.* at 803.

[109] *See id.*

[110] *Id.* at 805.

[111] *See id.*

[112] *In re M.B.*, 846 N.E.2d at 805 (quoting N.Y. SURR. CT. PROC. ACT § 1750-b(2)(a) (McKinney 2003)).

[113] *See, e.g.*, Sloane v. M.G., 84 N.Y.S.3d 12, 28 (App. Div. 1st Dep't 2018).

It was not until 2010 that New York enacted legislation—the Family Health Care Decisions Act—Public Health Law, Art. 29-CC ("PHL Art. 29-CC"), which authorized end-of-life decisions for individuals not covered by SCPA 1750-b.[114] Individuals who have a guardian appointed under SCPA Art. 17-a, or are covered by that statute as it relates to end-of-life decisions,[115] are excluded from coverage under PHL Art. 29-CC.[116] This statute flips the order of what the guardian must consider in making their decision: end-of-life treatment decisions must be made "in accordance with the patient's wishes, including the patient's religious and moral beliefs;"[117] only if the patient's wishes are not reasonably known and cannot with reasonable diligence be ascertained, must the guardian's decisions regarding health care for the incapacitated person be in accordance with the patient's best interests.[118]

Several equal protection challenges have been raised about the treatment of the will and preferences of individuals with mental disabilities in light of the dual framework of SCPA 1750-b and PHL Art. 29-CC: one set of end-of-life treatment rules including the role of the individual's will and preferences regarding end-of-life treatment for individuals with a diagnosis of an intellectual or development disability, and another for individuals without such a diagnosis.[119]

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[114] *See* Family Health Care Decisions Act, 2010 McKinney's Sess. Law News, ch. 8 (codified as amended at N.Y. PUB. HEALTH LAW §§ 2994-a to 2994-u (McKinney 2026)).

[115] *See* N.Y. S.C.P.A. § 1750-b(1)(a) ("[I]n the case of a person for whom no guardian has been appointed pursuant to section seventeen hundred fifty or seventeen hundred fifty-a of this article, a 'guardian' shall also mean a family member of a person who (i) has intellectual disability, or (ii) has a developmental disability, as defined in section 1.03 of the mental hygiene law, which (A) includes intellectual disability, or (B) results in a similar impairment of general intellectual functioning or adaptive behavior so that such person is incapable of managing himself or herself, and/or his or her affairs by reason of such developmental disability.").

[116] *See* Family Health Care Decisions Act, sec. 2, § 2994-b(3)(b) (codified as amended at PUB. HEALTH § 2994-b).

[117] PUB. HEALTH § 2994-d(4)(a)(i).

[118] *See id.* at § 2994–d(4)(a)(ii).

[119] *See, e.g.*, *In re* M.B., 773 N.Y.S.2d 206, 206–07 (Surr. Ct. Richmond Cty. 2003); *In re* Chantel Nicole R., 821 N.Y.S.2d 194, 195 (App. Div. 1st Dep't 2006); Sloane v. M.G., 84 N.Y.S.3d 12, 22 (App. Div. 1st Dep't 2018); *see also* Margie Hodges Shaw, Timothy E. Quill & Bernard L. Sussman, *The Legacy of* Cruzan*: Balancing the Moral Agency of Surrogates and the State*, 73 SMU L. REV. 179, 182 (2020) ("This distinction reveals discriminatory beliefs about the never capacitated patient and results in disparate treatment, disrespect for the moral authority of the family, and misdirected state involvement.").

In *In re Chantel Nicole R.*, respondent argued that "equal protection '[was] violated by [requiring an evaluation of] the validity of a mentally retarded person's expressions of a desire to be kept alive when at common law the expressed wishes to live of all others would be taken at face value.'"[120] The respondent's mother sought a SCPA Art. 17-a guardian for her twenty-six-year-old daughter, "who had an IQ of 52 and was functionally independent in the area of self-care, but was found to be incapable of considering end-of-life questions, even in the abstract."[121] The trial court held that the daughter's objection to having her mother granted authority with respect to end-of-life care "failed to reflect a true appreciation of the consequences of such decisions or even an awareness of the context in which such a determination might be required, concluding that respondent's utterances should not be accorded legal effect."[122] MHLS argued that mentally retarded persons were denied equal protection when they were deprived of the common law right to personal autonomy accorded adults who had expressed wishes about life-ending treatment while competent.[123] The trial court dismissed this argument and appointed the mother as guardian with authority to make end-of-life decisions.[124] At the time of the guardian's appointment, the daughter was in good health and was not facing an end-of-life care decision.[125]

The result was affirmed by the First Department[126]:

> The Surrogate properly concluded that a mentally retarded person's expression of a desire to continue life-sustaining measures is categorically distinguishable from the same desire expressed by a mentally competent individual because only the latter has the capacity to appreciate the consequences of the decision and thus the ability to make the choice to pursue an uninformed or irrational alternative. . . . The Equal Protection Clause only prohibits the government from treating persons differently from others who are similarly

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[120] *In re Chantel*, 821 N.Y.S.2d at 198. *In re Chantel*'s comparison between SCPA 1750-b and the common law of *Eichner* is explained by the fact that PHL Art. 29-CC was not yet the law.

[121] *Sloane*, 84 N.Y.S.3d at 24.

[122] *In re Chantel*, 821 N.Y.S.2d at 197.

[123] *See id.* at 198.

[124] *See id.* at 198, 200.

[125] *See id.* at 200.

[126] *See id.*

> situated, and mentally retarded persons are not similarly situated to those who were once competent.[127]

The appellate court's decision relied heavily on the sharp distinction between individuals with and without a diagnosis of a developmental disability drawn by the Court of Appeals in *Storar*.[128]

Sloane v. M.G. involved an equal protection challenge based on the failure of the hospital to consider prior competent wishes of the respondent.[129] It was likewise rejected on the grounds that "intellectually and developmentally disabled persons are not similarly situated to once competent persons and that the disparate treatment of the SCPA 1750–b was rationally related to a 'legitimate [government] interest in advancing the right of [intellectually and developmentally disabled] persons to be free from prolonged suffering.'"[130]

On December 2, 2016, M.G. was examined by NYU's Emergency Department because of shortness of breath, and then kept overnight.[131] Three days after his discharge with a diagnosis of "Chronic Obstructive Pulmonary Disease, Exacerbation," he suffered cardiac arrest and was admitted to the hospital.[132] He was in a permanent vegetative state, dependent on a ventilator, and had "no meaningful hope of recovery."[133] MHLS challenged the guardian's decision to remove his ventilator on the grounds that "a meaningful inquiry into M.G.'s end-of-life wishes should have been conducted because M.G. had some prior capacity to make health care decisions."[134]

The hospital staff had not asked M.G. his "preference with regard to life-sustaining treatment"[135] nor was the guardian able to identify his wishes.[136] However, M.G.'s medical records contained a "Full Code" order regarding cardiac care which, according to the testimony, "presumed that the patient was competent to make the decision."[137] MHS argued that M.G.'s equal protection rights were violated because there was "no meaningful inquiry into his preferences and wishes as

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[127] *In re Chantel*, 821 N.Y.S.2d at 198.

[128] *See id.* at 198–99 (citing Soper v. Storar, 420 N.E.2d 64, 72–73 (N.Y. 1981)).

[129] *See* Sloane v. M.G., 84 N.Y.S.3d 12, 15–16 (App. Div. 1st Dep't 2018).

[130] *Id.* (quoting *In re Chantel*, 821 N.Y.S.2d at 198).

[131] *See id.* at 16.

[132] *Id.*

[133] *Id.*

[134] *Sloane*, 84 N.Y.S.3d at 16.

[135] *Id.* at 18.

[136] *See id.* at 17.

[137] *Id.* at 18.

'a person who once had the capacity to make health care decisions'" that a "similarly situated nondisabled person would have received pursuant to article 29–CC of the Public Health Law."[138] The court concluded that "any perceived disparity in the treatment of an intellectually or developmentally disabled person who formerly had some capacity to make health care decisions and the treatment of nondisabled persons is rational."[139]

> The legislature has made the policy decision that while some intellectually and developmentally disabled persons may be higher-functioning than others, only mentally competent, nondisabled individuals have the full capacity to appreciate the consequences of the decision to end their life and, thus, that intellectually and developmentally disabled persons are not similarly situated to those who were once competent and may be treated differently with respect to an end-of-life decision. Such disparate treatment furthers a legitimate state interest.[140]

Some twenty-three years after the enactment of SCPA 1750-b, and fifteen years after the enactment of PHL Art. 29-CC, a proposal to consolidate the two statutes has been made public.[141] The proposal essentially repeals SCPA 1750-b, adopting for all individuals the standard for health care decisions by third parties provided in PHL Art. 29-CC. An accompanying report recommends consolidation of the statutes to, among other reasons, address the fact that "disparate laws create concern about equal treatment. Even if the [current] 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."[142] The result would

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[138] *Id.* at 23–24.

[139] *Sloane*, 84 N.Y.S.3d at 24.

[140] *Id.*

[141] *See* Health L. Section & Comm. on Disability Rts., N.Y. State Bar Ass'n, Report and Recommendations on Amending the Family Health Care Decisions Act to Cover Decisions for People with Intellectual or Developmental Disabilities (2025), https://nysba.org/wp-content/uploads/2025/04/2025-April-Report-and-Recommendations-of-HLS-and-Committee-on-Disability-Rights-HOD-Approved-1.pdf?srsltid=AfmBOopl94XjGTDgtEi2uWkS_YkLMXlmILAluSZA9RVOs9iMZrofdLLB (on file with Syracuse Law Review).

[142] 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) https://static1.squarespace.com/static/5fcc1e7bde434d6c8ff91b5e/t/66e18aa2545fd

include individuals with developmental disabilities under PHL Art. 29-CC and incorporate the SCPA 1750-b safeguards for people with developmental disabilities in PHL Art. 29-CC.[143] Concern over this consolidation focuses on the proposed elimination of the direction in SCPA 1750-b that guardians of individuals with developmental disabilities strongly advocate for their individual. The fear is that single, generalized standard would be less effective in protecting a particularly vulnerable population, leading to potentially divergent and unjust decisions compared to the current specialized system.[144]

Since the 1981 decision of the Court of Appeals declining to consider the will and preferences of John Storar at the end of his life as expressed by his mother, the debate over the treatment of the will and preferences of individuals who are profoundly mentally disabled has continued, and it has emerged again with the adoption of this consolidation proposal. Patient-advocates and self-advocates from the disability rights community who consulted about the changes shared valuable insight:

> [They] strongly recommended that individual patients have control over their own end-of-life decisions to the greatest extent possible. . . . They noted that some patients who are declared incapacitated for purposes of medical decision-making and who communicate nonverbally, with assistance from close individuals, might still be capable of communicating information relevant to determining their best interests.[145]

This view is also supported by the authors of Neil's story described earlier.[146]

With the enactment of Article 82 of the Mental Hygiene Law ("MHL Art. 82"), recognizing supported decision-making, the debate will continue.

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[143] *See* N.Y. STATE BAR ASS'N, *supra* note 141, at 10.

[144] *See* N.Y. STATE TASK FORCE ON LIFE & THE L., *supra* note 142 at 26.

[145] N.Y. STATE TASK FORCE ON LIFE & THE L., *supra* note 142 at 24.

[146] *See* Watson, Voss & Bloomer, *supra* note 2, at 274.

II. WILL & PREFERENCES FOR HEALTH CARE OF INDIVIDUALS WITH PROFOUND COGNITIVE DISABILITIES & SUPPORTED DECISION-MAKING IN NEW YORK

Although 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,"[147] as we have seen, the will and preferences of individuals with intellectual or developmental disabilities have been regularly treated in statute and case law differently from those of individuals without such a diagnosis.[148] Moreover, the issue of what treatment they should be accorded frequently occurs in the context of a judicial proceeding to approve a guardian's decision based on those wishes. Although supported decision-making is intended to "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,"[149] whether that perspective will change the treatment of will and preferences of individuals with profound cognitive disabilities with the implementation of MHL Art. 82 remains to be seen.

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[147] N.Y. MENTAL HYG. LAW § 13.01(McKinney 2026) (emphasis added). OPWDD focuses on helping individuals advocate for themselves through programs that emphasize "person-centered planning" and a "Person First Transformation," all of which are designed to improve opportunities for individuals with developmental disabilities. *See About Us*, OFF. FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, https://opwdd.ny.gov/about-us (on file with Syracuse Law Review) (last visited Feb. 25, 2026); *Advocacy*, OFF. FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, https://opwdd.ny.gov/types-services/advocacy (on file with Syracuse Law Review) (last visited Feb. 25, 2026); *Person-Centered Planning*, OFF. FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, https://opwdd.ny.gov/providers/person-centered-planning (on file with Syracuse Law Review) (last visited Feb. 25, 2026). 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." *Person-Centered Planning*, OFF. FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, https://opwdd.ny.gov/providers/person-centered-planning (on file with Syracuse Law Review) (last visited Feb. 25, 2026); *see also Self-Direction*, OFF. FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, https://opwdd.ny.gov/types-services/self-direction. (on file with Syracuse Law Review) (last visited Feb. 25, 2026).

[148] *See* discussion *supra* at notes 53–139.

[149] 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, 512 (2016).

New York has not repealed its guardianship statutes and provides that supported decision-making is not available for individuals who have guardians.[150] This treatment suggests that it has adopted a so called "binary approach" to supported decision-making, in which it is considered the polar opposite of substitute or surrogate decision-making.[151]

> The purpose of supported decision-making and the role of supporters are to extend the decision-making autonomy (and capacity) of a person to the maximum extent possible. When the person is perceived to lack sufficient decision-making capacity for a particular decision, even with access to support, then substitute decision-makers rather than supporters become necessary.[152]

The difficulty posed by the binary approach is that it "demands active participation by a person in decision-making and does not extend to the idea of supporters interpreting a person's will and preferences."[153] On the other hand, the UN Committee on the Rights of Persons with Disabilities has stated that "where it is not possible to determine a person's will and preference, a 'best interpretation' of their will and preference should be adopted."[154] This viewpoint differs from the binary approach by not drawing such "a sharp distinction between supported and substituted decision-making."[155] "This second perspective conceptualizes supported decision-making as *a principled approach* that applies to all people irrespective of whether a person actively participates in making a decision or it is made by a supporter based on interpretation of the person's will and preferences."[156] Advocates adopting this approach view the two types of decision making as being on a continuum with the most important element "the individual's stated or perceived will and preferences."[157]

Several concerns have been voiced about the use of this "principled approach" in practice. Interpreting the will and preferences of an individual with profound disabilities may be difficult even with the

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[150] *See* MENTAL HYG. LAW § 82.03(a).

[151] *See* BIGBY ET AL., *supra* note 16, at 25.

[152] *Id.* at 20.

[153] *Id.* at 21.

[154] *Id.*

[155] *Id.* at 23.

[156] BIGBY ET AL., *supra* note 16, at 25.

[157] *Id.*

supporters' best of intentions.[158] As noted in *Storar* and in the case of Neil reported above, the mother and the supporters, respectively, relied in large part on evidence of the individual's physical responses to the questioned care. Whether physical responses of incompetent patients as evidence of their will and preferences will be accepted by third parties is not clear.[159]

Supporters may be inclined to interpret the will and preferences of the individual as what serves the best interests of the supporters, rather than the individual, suggesting coercion, undue influence, and possible abuse, and thus diluting the voluntariness of the decision.[160] If the supporters resort to their understanding of the individual's will and preferences, either because of difficulty understanding the actual wishes or driven by coercion or undue influence, "the distinction between the interest of the patient and those of the support person becomes diffuse."[161] Challenges to the decision will become more difficult "because any treatment decision made will not count as the decision of the support person *on behalf* of the patient but as the decision *of the patient*."[162]

MHL Art. 82 is silent on the treatment of will and preferences. While the statute endorses both formal[163] and informal[164] supported decision-making agreements, its emphasis is on formal agreements: the role of various participants in such an agreement, third-party acceptance of supported decisions pursuant to such an agreement, and an individual's capacity to enter into a formal agreement,[165] suggesting an expectation that the individual's will and preferences will be known and understood.

Agreements facilitated by OPWDD and executed in accordance with the statutory requirements and the decisions emanating from

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[158] *See, e.g.*, Wieneke Penning et al., *Meaningful Moments of Interaction with People with Profound Intellectual Disabilities: Reflections from Direct Support Staff*, 35 J. APPL. RES. INTELLECT. DISABIL. 1307, 1314 (2022).

[159] *See* Miller, *supra* note 67, at 2905–06 (citing *In re* O'Brien, 517 N.Y.S.2d 346, 348 (Sup. Ct. N.Y. Cty. 1986) ("Life and death are not to be determined by the interpretation of a passing gesture or expressions of annoyance and frustration.")).

[160] *See* Scholten & Gather, *supra* note 9, at 228.

[161] *Id.* at 229.

[162] *Id.*

[163] *See* N.Y. MENTAL HYG. § 82.06(b) (McKinney 2026).

[164] *See id.* at § 82.04(f) ("The availability of supported decision-making agreements is not intended to limit the informal use of supported decision-making, or to preclude judicial consideration of such informal arrangements as less restrictive alternatives to guardianship.").

[165] *See id.* at §§ 82.03, 82.05–82.07, 82.11.

them are given legal recognition.[166] The statute creates a presumption that the person has the capacity to enter into a supported decision-making agreement unless a guardian has been appointed for them[167] and defines that capacity.[168] For purposes of the statute, capacity is the individual's understanding that "they are making and executing an agreement with their chosen supporters and that they are doing so voluntarily."[169] The statutory presumption of capacity to enter an agreement can be overcome by "clear and convincing evidence,"[170] but neither a diagnosis of a developmental disability and nor the way an individual communicates can be used to demonstrate incapacity.[171] Moreover:

> An adult who has entered into a formal supported decision-making agreement is not required to separately demonstrate an understanding or appreciation of the nature and consequences of a decision made in accordance with such supported decision-making agreement in order to demonstrate their capacity to make such decision on their own behalf.[172]

The decisions made pursuant to the agreement created in accordance with statutory requirements[173] must be accepted by third parties.[174] The third party can refuse to act on a decision, however, if the third party has substantial cause to believe, the decision "will cause the decision-maker substantial and imminent physical or financial harm."[175] Health care providers who accept consent of a decision-maker based on an enforceable agreement have immunity from any action alleging that the decision-maker lacked capacity to provide informed consent. There are limits, however. The provider can decline to accept a decision if the provider has "actual knowledge or notice that the decision-maker" had been abused or coerced into consenting

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[166] *See id.* at § 82.11(d); 14 N.Y.C.R.R. §§ 634.1–634.99 (2026).

[167] The presumption is similar to the presumption to execute a health care proxy or an "Act Now" health care proxy. *See* N.Y. PUB. HEALTH LAW § 2981(2) (McKinney 2026).

[168] *See* N.Y. MENTAL HYG. § 82.03(a).

[169] *Id.* at § 82.03(f) (capacity can be achieved with the use of supports).

[170] *See id.* at § 82.03(a).

[171] *See id.* at § 82.03(c), (d).

[172] 14 N.Y.C.R.R. § 634.7(c) (2026).

[173] *See* N.Y. MENTAL HYG. § 82.11(b).

[174] *See id.*

[175] *Id.* at § 82.11(d).

by a supporter.[176] A court can also override the decision pursuant to a formal agreement, on notice to MHLS.[177]

Informal agreements are given less attention. The implementing regulations-provide that "[t]hird parties may, but are not required to, recognize decisions made in accordance with informal supported decision-making agreements and, if they do, are not entitled to the liability protections [accorded formal agreements.]"[178] The regulations further provide that in considering whether to accept a decision made pursuant to an informal agreement, due consideration be given to that agreement.[179]

Limited research is available on implementing "supported decision-making for people with severe cognitive impairments."[180] Since New York is at the beginning of this project, policy makers and lawyers interpreting this new law have much to learn. In the meantime, while free standing formal and informal agreements are the goal of MHL Art. 82, perhaps there is room to amend the statute to permit informal agreements even when the individual has a legal guardian. The amendment could allow for the adoption of the so-called *principled approach* which would acknowledge a supporter's best interpretation of the decision-maker's wishes.[181] Including the possibility of such an informal agreement in the context of guardianship should not be interpreted to mean *all* informal agreements must be treated thus. Informal agreements can and should also stand alone. "There is, however, a significant way in which Supported Decision-Making can be useful to, and should be used by, guardians."[182] Guardians are appointed not only to make decisions, sometimes in perpetuity, for the individuals under guardianship: "[t]hey are expected to maximize autonomy and, indeed, to do what is necessary and possible to restore

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[176] *Id.* at § 82.12(c).

[177] *See* 14 N.Y.C.R.R. § 634.7(e)(3) (2026).

[178] *Id.* at § 634.6(b); N.Y. MENTAL HYG. § 82.12(a).

[179] The regulations provide that in deciding to accept a health care decision made pursuant to an informal arrangement, "due consideration [be] paid to the supports and accommodations available under an informal supported decision-making agreement," but there is no requirement that the decision be accepted. 14 N.Y.C.R.R. § 633.11(a)(1)(iii)(*b*) (2026). Reference to due consideration of decisions made pursuant to informal agreements can be found throughout the regulations. *See e.g.*, 14 N.Y.C.R.R. §§ 633.13(a)(2)(i), 633.13(a)(3)(ii)(*a*), 633.13(b)(1), 633.16(g)(6)(ii)–(iii).

[180] BIGBY, ET AL., *supra* note 16, at 28.

[181] *See id.* at 25.

[182] Cathy E. Costanzo, Kristin Booth Glen & Anna M. Krieger, *Supported Decision-Making: Lessons from Pilot Projects*, 72 SYRACUSE L. REV. 99, 109 (2022).

the decision-making capacity of those over whom they have been given legal power[, a] seldom noted obligation."[183] The supporters could assist the individual where their choices are known and could interpret their decisions where appropriate and the decision-maker would be recognized as such for those decisions.[184] Embedding the possibility of an informal agreement within guardianship also provides a forum for asserting the protections recognized as appropriate for vulnerable individuals to ensure against abuse, coercion and disrespect.

CONCLUSION

New York is at the beginning of implementing supported decision-making with much to be learned. One constant, however, is advocates for persons with profound cognitive disabilities seeking to preserve the autonomy of individuals but also recognizing that the interests of vulnerable individuals should be protected. New York's treatment of the will and preferences of such individuals appears to lean toward protection, both in its interpretation of the common law and in its statutes. The idea of a principled approach to supported decision-making for individuals with profound disabilities may help achieve a better balance. As New York enters this new legal world, the treatment of the will and preferences of profoundly mentally disabled individuals should remain at the center of supported decision-making as well as at the center of policy and legislative decision-making so that the evolution in the treatment of individuals with developmental disabilities that New York has already embraced continues.

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[183] *Id.*

[184] A similar concept of decision-making is envisioned in New York's "Act Now" health care proxy legislation. *See* N.Y. MENTAL HYG. LAW § 33.03(e) (effective upon the approval of the form for the legal document); *see also* Scholten & Gather, *supra* note 9, at 228 (proposing a combined model: decision support and competence assessment).