

Beyond *Being Mortal*:

Safeguarding the Rights of People with Developmental Disabilities to Efficacious Treatment and Dignity at the End of Life

By Christy A. Coe

Introduction

In his *New York Times* bestselling book *Being Mortal: Medicine and What Matters in the End*,¹ Atul Gawande, M.D., explains that at the end of life, medicine often fails the people it is supposed to help. He laments that the “waning days of our lives are given over to treatments that addle our brains and sap our bodies for a sliver’s chance of benefit.”² Commentators observed that *Being*

Mortal demonstrates the harm we do as a society by turning aging and death into a medical problem rather than a human one.³ The author himself states that his book is “[a]bout the struggle to cope with the constraints of our biology, with the limits set by genes and cells and flesh and bones.”⁴

The complexity of the issues surrounding death and dying as artfully captured by Dr. Gawande in his book

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were presaged in New York State by the case of Sheila Pouliot, a person with a profound intellectual disability who never had the ability to make her own health care decisions. She could never consider the questions Dr. Gawande suggests are essential when a person is confronted with a life-threatening illness or terminal process: "What is your understanding of the situation and its potential outcomes? What are your fears and what are your hopes? What are the tradeoffs you are willing to make and not willing to make? And what is the course of action that best serves this understanding?"⁵ In Sheila Pouliot's case, substituted decisions by involved family members who recognized the limits of medicine to reverse the course of an incurable disease process could not be implemented because of the constraints of the New

closes with a discussion of legal and ethical principles demonstrating that HCDA has promoted fairness, justice and dignity for people with developmental disabilities.

Thoughtful Vision and Revision¹¹

Upon the HCDA's March 13, 2003 effective date, and for the first time in New York, a court-appointed guardian for a person with mental retardation¹² was expressly authorized to make all health care decisions for her ward even absent a prior competent choice, including decisions to withhold and withdraw life-sustaining treatment. Subsequent chapter amendments broadened the meaning of the term "guardian" to permit surrogates to make end-of-life elections on behalf of people with developmental disabilities. Legally authorized surrogates

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York common law. At that time, the law did not permit a third party to decide that a patient's quality of life had declined to a point where treatment could be withheld absent a prior competent choice.⁶

Seemingly little known among the legal and medical professions, and largely as a result of the courageous legacy of Sheila Pouliot, is that since 2003, there has been a law in place to address decisions regarding end-of-life care for people with developmental disabilities who never had the capacity to make known their wishes and preferences. The Health Care Decisions Act for Persons with Mental Retardation (HCDA)⁷ is codified at Surrogate's Court Procedure Act (SCPA) 1750-b and applies to the approximately 180,000 people in New York State with developmental disabilities. The statute protects the right of people with developmental disabilities to receive efficacious treatment when medically indicated while promoting dignity at the end of life by permitting excessively burdensome treatments to be withheld or withdrawn upon the consent of legally authorized surrogates and pursuant to statutory standards.

Codified seven years before the 2010 Family Health Care Decisions Act (FHCDA),⁸ SCPA 1750-b remains a discrete health care decision-making statute for people with developmental disabilities.⁹ By design, the FHCDA yields to preexisting surrogate decision-making statutes and regulations that apply to people with developmental disabilities and mental illness.¹⁰ Thus, an understanding of SCPA 1750-b by lawyers and clinicians remains a timely and compelling exercise in New York State. This article provides historical context for the enactment of the HCDA and explains its essential provisions using two case studies to illustrate application of the law. The article

now include actively involved family members, such as a spouse, parent, adult child or adult sibling.¹³ The Consumer Advisory Board (CAB) is a legally authorized surrogate for developmentally disabled people who are members of the Willowbrook Class.¹⁴ In addition, SCPA 1750-b protects an especially vulnerable class of people with developmental disabilities, those without guardians or interested family members, by recognizing Surrogate Decision-Making Committees which operate pursuant to Article 80 of the Mental Hygiene Law as "guardians" within the meaning of the act.¹⁵ Thus, any narrative about § 1750-b assumes that a "guardian" is a person or entity with standing to consent or refuse life-sustaining treatment on behalf of a developmentally disabled person, with or without a court appointment.

The HCDA may seem imposing at first, particularly to health care professionals who must navigate its essential provisions. Over time, however, the statute has demonstrated fulfillment of its thoughtful vision to end disparities in the law that permitted individuals who possessed decision-making capacity to confront the inescapable realities of aging and death by forgoing treatments that only prolonged suffering while denying such compassionate choices to individuals with lifelong intellectual disabilities.¹⁶ As stated by the Court of Appeals in *In re M.B.*,¹⁷ in the wake of its prior precedent in *In re Storar*:¹⁸

[A] distinction arose between the common-law rights of competent adults, who could make their wishes concerning end-of-life care known to family and friends, and mentally retarded persons who had never been competent to make their own health care decisions and for whom life-sustaining treatment could not be refused. When these mentally retarded indi-

viduals 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.

As a consequence of this disparity, family members, caregivers and advocacy groups for the mentally retarded sought relief from the Legislature. They shared the stories of mentally retarded patients forced to suffer painful, intrusive life-sustaining medical treatments after it was clear that they would never regain any quality of life because the requests of their guardians (usually parents or siblings) to end life-sustaining measures could not be honored. This was the situation the Legislature sought to remedy when it enacted the Health Care Decisions Act for Persons with Mental Retardation.¹⁹

In perspective, the act was intended to prevent care from being forced upon a person, causing suffering. However, there was also a countervailing consideration that treatment might be arbitrarily withheld from a person with developmental disabilities due to their perceived diminished quality of life.²⁰ The HCDA attempts to balance these competing interests and is a reflection of legislative intent that life should be maintained in all but those situations where treatment would be an extraordinary burden on the person, in the life that they have, and in the case of artificial nutrition and hydration, that there is no reasonable hope of maintaining life.

The HCDA

Prior to the enactment of the HCDA, an SCPA article 17-A guardian was understood to exercise some degree of medical decision-making authority.²¹ However, the scope of this power was unclear, particularly in the aftermath of *Storar*. Because article 17-A is a diagnosis-driven statute, a jurisdictional prerequisite exists requiring petitioners to file certificates from two physicians or a physician and a psychologist²² that the subject of the proceeding is "incapable to manage him or herself and/or his or her affairs by reason of mental retardation and that such condition is permanent in nature or likely to continue indefinitely."²³ The 2003 chapter amendments to the SCPA imposed an additional certification requirement applicable to all future guardianship proceedings requiring the supporting certificates obtained from physicians or psychologists to address whether the subject possesses the capacity to make health care decisions.²⁴

In the event the individual has the ability to make health care decisions, a guardian can still be appointed to make other types of decisions.²⁵ If the subject of the proceeding is found to lack capacity, the guardian is granted full medical decision-making authority.²⁶ In the latter event, the HCDA removed any uncertainty concerning the scope of that authority, clarifying that health care decisions include "any decision to consent or refuse to consent to health care,"²⁷ including decisions to with-

hold or withdraw life-sustaining medical treatment for a person who never had capacity to make such a decision.²⁸

A substantive health care decision-making standard also emerged with the 2003 chapter amendments. Guardians must base all health care decisions "solely and exclusively 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."²⁹ The statutory factors that must be considered in determining the person's best interests include the dignity and uniqueness of the individual; the preservation, improvement or restoration of the person's health; the relief of the person's suffering by means of palliative care and pain management; the effect of treatment, including artificial nutrition and hydration, on the person; and the patient's overall medical condition.³⁰ A medical decision cannot be based on financial considerations or a failure to afford the mentally retarded individual the respect that would be afforded any other person in the same circumstances.³¹

Quite significantly, the HCDA places an *affirmative* obligation on the part of the guardian "to advocate for the full and efficacious provision of health care, including life-sustaining treatment."³² Life-sustaining treatment is defined as "medical treatment, including cardiopulmonary resuscitation and nutrition and hydration provided by means of medical treatment, which is sustaining life functions and without which, according to reasonable medical judgment, the patient will die within a relatively short time period."³³ In the event a guardian contemplates the withdrawal or withholding of life-sustaining treatment, SCPA 1750-b imposes a decision-making procedure that must be followed before the decision can be implemented.

The threshold requirement of the process is that the attending physician confirm to a reasonable degree of medical certainty, after consultation with another physician or a licensed psychologist, that the person currently lacks the capacity to make health care decisions.³⁴ Additionally, the attending physician and a concurring physician must attest that the person has a terminal condition, or is permanently unconsciousness or has "a medical condition other than such person's mental retardation which requires life-sustaining treatment, is irreversible and which will continue indefinitely," and must further certify that the life-sustaining treatment imposes or would impose an extraordinary burden on the person in light of the person's medical condition and the expected outcome of the life-sustaining treatment.³⁵ Before artificially provided nutrition or hydration may be withheld or withdrawn, two physicians must also confirm that "there is no reasonable hope of maintaining life" or that the artificial nutrition or hydration itself "poses an extraordinary burden" on the patient.³⁶ These conclusions by medical professionals are a condition precedent to any decision to

end life-sustaining treatment – without them, life-sustaining treatment must be afforded to the person.³⁷

If the requisite medical determinations are made, the next step is for the guardian to express a decision to end life-sustaining treatment either in writing, signed by a witness, or orally in the presence of the attending physician and another witness, and the decision must be included in the person's medical record. The physician can then issue the appropriate medical orders or object to the guardian's decision but, in either case, the decision to end life-sustaining treatment cannot be implemented immediately.³⁸ The act grants a number of persons and organizations automatic standing to lodge an objection to a guardian's decision upon receiving notice from the attending physician – the mentally retarded person;³⁹ a parent or adult sibling; the attending physician; any other health care practitioner providing services to the patient; the director of a mental hygiene facility and the Mental Hygiene Legal Service, where the patient resides or resided in a mental hygiene facility;⁴⁰ and the commissioner of the Office of People with Developmental Disabilities (OPWDD), where the developmentally disabled person does not reside in a facility.⁴¹ The statute provides that notice be provided to parties with standing by the attending physician at least 48 hours prior to the implementation of a decision to withdraw life-sustaining treatment, or at the earliest possible time prior to the implementation of a decision to withhold life-sustaining treatment.⁴²

If there is no objection, the guardian's decision to withdraw or withhold life-sustaining treatment is put into effect, without judicial involvement. An objection, however, will suspend implementation of the guardian's decision (unless the suspension would itself result in the death of the patient) until the dispute is resolved through a dispute mediation where available, such as through a hospital ethics committee,⁴³ or by a court of competent jurisdiction.⁴⁴ Thus, the HCDA clarifies that guardians can make health care decisions for people with developmental disabilities who themselves were never competent to make those decisions, including elections to forgo life-sustaining treatment. But it imposes a series of procedural requirements – intended to safeguard the interests of the patient and prevent an improvident decision by the guardian – that must be satisfied prior to the implementation of such a decision.⁴⁵

Medical Orders for Life Sustaining Treatment

New York State is one of the many states that subscribes to the use of Medical Orders for Life-Sustaining Treatment (MOLST). The MOLST is intended for patients who want to make end-of-life treatment decisions, who reside in long-term care facilities or require long-term care services and/or may die within a year.⁴⁶ Completion of the MOLST begins with a conversation between the patient, the patient's health care agent or surrogate, and a qualified, trained health care professional that defines

the patient's goals for care, reviews possible treatment options, and ensures shared, informed medical decision-making.⁴⁷ The MOLST is an optional form, and only one of many to document a patient's treatment preferences concerning end-of-life care. However, the MOLST is the only authorized form in New York State for documenting both non-hospital DNR and DNI⁴⁸ orders. Additionally, the MOLST has proven beneficial to patients and providers as it provides specific medical orders and is recognized and used in a variety of health care settings, not just hospitals.⁴⁹

Effective January 21, 2011, OPWDD approved the use of the MOLST for individuals with developmental disabilities. For people with developmental disabilities who never had capacity to make a decisions, the MOLST must be accompanied by the Legal Requirements Checklist for Individuals with Developmental Disabilities.⁵⁰ The required checklist mirrors the requirements of the HCDA, ensuring that SCPA 1750-b standards have been met prior to implementation of a decision to withhold or withdraw life-sustaining treatment for an individual with developmental disabilities.⁵¹

SCPA 1750-b as Applied

Decisions regarding end-of-life care for another are fraught with emotion and uncertainty for guardians, families, providers and advocates. Increased moral distress occurs when providers and medical systems are unfamiliar with the legal processes and are unable to effectively guide guardians. In addition, the procedural protections imposed by the law are seen by some as obstructions to providing quality care. There is no simple resolution to factual disputes, but experience tells us that familiarity with the mandated processes can ease this distress and ensure that appropriate treatment is rendered. While each case will turn on the person and his or her medical condition, the following examples demonstrate how the standards codified at SCPA 1750-b have been applied.

Loretta's Story

Loretta was 65 years old when this author met her. She had been born with Down syndrome and lived most of her life in facilities licensed or operated by OPWDD. While she lacked the capacity to make her own health care decisions, she was fortunate to have her sister as her advocate. By the time Loretta was 65 years old, she was burdened with many of the age-related health problems most of us will experience. She was also having seizure activity of unknown etiology and had been diagnosed with dementia. Loretta had become increasingly withdrawn from her usual activities and she found any deviation from her routine disruptive. She was physically frail, no longer ambulated, and spent her days dozing while in bed or a Geri-Chair. Devoted staff in her residential setting were sensitive to her needs.

Loretta was closely followed by her primary care physician and a neurologist. She continued to decline and was diagnosed with end-stage Alzheimer's disease, hypertensive heart disease, congestive heart failure, osteoporosis, recurrent pneumonia, seizure disorder, and aspiration. Her sister, confronted with Loretta's deteriorating condition, contacted the primary care physician, who agreed it was appropriate to limit aggressive treatment. The physician determined Loretta lacked capacity to make health care decisions and obtained a concurring opinion as to her capacity. The attending physician and a concurring doctor determined that Loretta had several irreversible medical conditions meeting the standards set forth in SCPA 1750-b.

Joseph's parents were his legally authorized surrogates and refused to consent to the insertion of a feeding tube. The attending physician and the chief medical officer of the hospital supported the parents' decision based upon their determination that providing such treatment would impose an extraordinary burden on Joseph. Upon receiving notice of the decision to withhold life sustaining treatment from Joseph, OPWDD objected. A proceeding was commenced pursuant to SCPA 1750-b seeking, among other things, an order authorizing surgical insertion of a feeding tube to deliver nutrition and hydration to Joseph.

Following a hearing, the Supreme Court denied OPWDD's petition, concluding that the guardians,

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Among the elections made for Loretta, her sister consented to a do-not-resuscitate order, a do-not-intubate order, no artificial nutrition or hydration and limited medical interventions. A MOLST form, with completed checklist, implementing the treatment elections was completed. The physician provided notice of the elections to the facility director and to my office, the Mental Hygiene Legal Service (MHLS). The medical literature, the opinions of the attending physicians and familiarity with the progression of end-stage Alzheimer's disease, in particular, led the MHLS and the facility to agree that the plan of care developed for Loretta would provide her with comfort and support at the end of her life, while sparing her the bodily insults that can come with intrusive interventions that are not curative and prolong suffering. In Loretta's case, the SCPA 1750-b standards were met and no objection was lodged to her surrogate's end-of-life decisions by either the facility director or MHLS. The doctor's orders were implemented and thus began a plan of compassionate care for Loretta.

Joseph's Story

The case of *In re Joseph P.* is not personal to this author, but is one of the few reported decisions applying the HCDA.⁵² Joseph was a 55-year-old man who had profound intellectual disabilities, cerebral palsy with spastic quadriplegia, and curvature of the spine. He resided in an OPWDD group home when he became ill and was admitted to a hospital where he was diagnosed with aspiration pneumonia. An evaluation revealed that he suffered from dysphagia. It was determined that Joseph could no longer tolerate food or liquid orally and that, unless he received nutrition and hydration through a feeding tube, he would die within a short period of time.

through the respondent hospital, met their burden of establishing that insertion of a feeding tube would impose an extraordinary burden on Joseph in light of his medical condition other than mental retardation and the expected outcome of the life-sustaining treatment. Pursuant to SCPA 1750-b(5)(a), the decision to withhold artificially provided nutrition and hydration was suspended pending the completion of judicial review, including the determination of an appeal.

On appeal, the Appellate Division, Fourth Department reversed the decision of the trial court.⁵³ In the court's view, the factors advanced by respondent, i.e., the difficulty Joseph would encounter when he was moved to a new facility; the need for restraints to prevent him from removing the feeding tube; the continuing risks of aspiration; and the potential complications arising from the feeding tube did not support finding that the treatment would impose an extraordinary burden on Joseph. The court relied on the testimony of the witnesses from the agency, the nurse and physician who cared for Joseph at his residential placement, and found that Joseph was "alert, responsive, seemingly pain free and the burdens of prolonged life are not so great as to outweigh any pleasure, emotional enjoyment or other satisfaction that [he] may yet be able to derive from life."⁵⁴

Legal/Ethical Considerations

As the cases of Loretta and Joseph illustrate, when making a best interest determination for a person with developmental disabilities, there are many objective factors a surrogate must consider, such as the patient's ability to function, the degree of pain the person may be experiencing either with or without treatment, the person's overall condition and chance for recovery, as well as the risks,

side effects and benefits of proposed treatment. Even where objective criteria may be identified and applied, ambiguities inevitably consume surrogates, physicians and advocates when considering whether life-sustaining treatment would impose an “extraordinary burden” on another person.

The concept of “extraordinary burden” is not explicitly defined in the law or medicine. One court commented that extraordinary burden on the patient “could, in terms of the nature of the burden, reasonably mean an

The HCDA is crafted to mitigate the potential that negative perceptions about the quality of life led by people with developmental disabilities will intrude into surrogate decision-making. Primarily, surrogates must advocate for the full and efficacious provision of health care, including life-sustaining treatment.⁵⁹ Nonetheless, people with developmental disabilities are increasingly vulnerable and confront many health care inequalities.⁶⁰ Many depend upon governmental assistance which limits their access to medical providers and choice of care.

The law requires the physician to opine if the provision of a medical treatment would pose an extraordinary burden on the patient.

extraordinary physical, psychological, emotional or even economic burden.”⁵⁵ While the HCDA defined parameters for when a treatment burden should be deemed “extraordinary” – consideration of the patient’s medical condition and the expected outcome of the treatment – other factors no doubt weigh on physicians and surrogates. For instance, rendition of life-sustaining treatment might cause a person to be tethered to a respirator for the balance of her life in a skilled nursing home far from the people who supported her throughout her life. Such an outcome might be intolerable to some, but may not be intolerable to someone who has lived her life in residential settings.⁵⁶

Additionally, the law requires the physician to opine if the provision of a medical treatment would pose an extraordinary burden on the patient. Some physicians complain that this is a judgment for surrogates, not physicians, to render. The doctor often has to assess the burdens on her patient at the bedside with little knowledge of the quality of life her patient enjoys. Medical records for people with developmental disabilities often describe the patient as “unfortunate” before all else, revealing a negative impression or bias toward the patient’s circumstances that may intrude into the assessment of treatment benefit and burdens. Thus, conceivably, individuals who are not dying become the subject of DNR orders precisely because they are disabled.

Placing reliance on actively involved family surrogates to make elections for people with developmental disabilities who lack capacity is a thoughtful revision of the statutory framework. No doubt, however, the bond to an ever present caretaker can be stronger than attachments to family members in certain cases. Regrettably, still near are the days when doctors told parents of a child born with developmental disabilities to “send him away and put him out of your mind.”⁵⁷ Those who care for people with developmental disabilities may have quite a different perspective on whether certain treatments would pose an extraordinary burden.⁵⁸

Issues relating to health care access, coupled with competing legal precepts, compound the difficulty in evenly applying a uniform system of end-of-life care for people with developmental disabilities.

Conclusion

Pursuant to the FHCDA, the Task Force on Life and the Law⁶¹ is studying whether the FHCDA should be amended to incorporate procedures, standards and practices for decisions about the withdrawal or withholding of life-sustaining treatment from patients with mental disabilities, including those with developmental disabilities.⁶² The outcome of the study and potential legislative action are unknown, but experience demonstrates that SCPA 1750-b continues to fulfill its laudable goals.

A simple yet enduring observation was made by Dr. Gawande in *Being Mortal*, when he said “as a person’s end draws near, there comes a moment when responsibility shifts to someone else to decide what to do.”⁶³ When others must choose, SCPA 1750-b has promoted fairness, justice and dignity during life and as it comes to an end.⁶⁴ ■

1. Atul Gawande, *Being Mortal: Medicine and What Matters In the End* (2014) (*Being Mortal*).
2. *Id.* at 9.
3. Marcia Angell, *A Better Way Out, Being Mortal: Medicine and What Matters in the End*, N.Y. Rev. of Books (Jan. 2015).
4. *Being Mortal* at 259.
5. *Id.*
6. See *Blouin v. Spitzer*, 213 F. Supp. 2d 184 (N.D.N.Y. 2002). Under the common law at that time, the refusal or termination of life-sustaining treatment was only permitted where there was “clear and convincing” evidence of the patient’s intentions (see *In re Storar*, 52 N.Y.2d 363 (1981)).
7. 2002 N.Y. Laws ch. 500.
8. 2010 N.Y. Laws ch. 8, § 1. The legislature amended the Public Health Law (PHL) to “establish a decision-making process . . . whereby a surrogate is selected and empowered to make health care decisions for patients who lack capacity to make their own health care decisions and otherwise have not appointed a [health care] agent.” See Robert Swidler, *New York’s Family Health Care Decisions Act: The Legal and Political Backgrounds, Key Provisions and Emerging Issues*, N.Y. St. B.J., June 2010, p. 18.

9. PHL § 2994(b)(3)(c).
10. FHCDA also only applies in general hospitals, nursing homes and hospice programs. See PHL § 2994-b(1).
11. Turano, Practice Commentaries (McKinney's Cons Laws of NY, Book 59-A, SCPA 1750-b, p. 451).
12. Article 17-A of the SCPA is titled "Guardians of Mentally Retarded and Developmentally Disabled Persons." The term "mental retardation" has been largely repealed and removed from New York State statutes in favor of the term "developmental disability" (see 2010 N.Y. Laws ch. 168; 2011 N.Y. Laws ch. 37). A bill is pending in the New York State Senate to substantially reform Article 17-A of the SCPA and will, if enacted, repeal the term "mental retardation" while otherwise substantially modernizing the statute S. 04983.
13. The legislature delegated to the commissioner of the then Office of Mental Retardation and Developmental Disabilities the responsibility to promulgate a surrogate list (2007 N.Y. Laws ch. 105). The surrogate list is found at 14 N.Y.C.R.R. § 633.10.
14. The *Willowbrook* litigation was a civil rights action concerning the care and treatment of children and adults with developmental disabilities residing at the former Willowbrook State Developmental Center on Staten Island (see generally *N.Y. State Ass'n for Retarded Children v. Carey*, 393 F. Supp. 715 (E.D.N.Y.1975)). Pursuant to the Willowbrook consent decree, the Consumer Advisory Board (CAB) was created to oversee the care and treatment of class members and advocate for their due process rights.
15. MHL §§ 80.01 *et seq.*
16. Turano, *supra* note 11, at p. 451.
17. 6 N.Y.3d 437 (2006).
18. 52 N.Y.2d 363 (1981).
19. 6 N.Y.3d at 440.
20. Leslie P. Francis, *Discrimination in Medical Practice: Justice and the Obligations of Health Care Providers to Disadvantaged Patients*, The Blackwell Guide to Medical Ethics, Eds. Rosamond Rhodes, Leslie Francis and Anita Silvers, Blackwell Publishing Ltd. 2007, 162-79.
21. See Rose Mary Bailly & Charis Nick-Torok, *Should We Be Talking? Beginning a Dialogue On Guardianship for the Developmentally Disabled in New York*, 75 Alb. L. Rev 807 (2012).
22. SCPA 1750(1).
23. *Id.*
24. SCPA 1750(2). Capacity to make health care decisions is defined at PHL § 2980(3) and means the ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and alternatives to any proposed health care and to reach and informed decision.
25. SCPA 1750(2).
26. *Id.*
27. See SCPA 1750-b(1), cross-referencing PHL § 2980(6).
28. In *In re MB, supra*, the Court of Appeals determined that guardians appointed before the effective date of the HCDA were empowered to make end-of-life treatment elections without the necessity of a judicial proceeding for an amended guardianship order that specifically authorized the guardian to make these elections.
29. SCPA 1750-b(2)(a).
30. SCPA 1750-b(2)(b)(i)-(v).
31. SCPA 1750-b(2)(c).
32. SCPA 1750-b(4).
33. SCPA 1750-b(1). Under the statute, cardiopulmonary resuscitation is presumed to be life-sustaining treatment without the necessity of a medical judgment by an attending physician (*id.*)
34. SCPA 1750-b(4)(a).
35. SCPA 1750-b(4)(b)(i)(ii).
36. SCPA 1750-b(4)(b)(iii).
37. *In re MB*, 6 N.Y.3d at 443.
38. SCPA 1750-b(4)(e).
39. SCPA 1750-b(4)(e)(i). Notice to the patient can be dispensed with where it is determined within a reasonable degree of medical certainty that the person with would suffer immediate and severe harm from receiving notice.
40. A mental hygiene facility is a residential facility licensed or operated by the Office for People with Developmental Disabilities (OPWDD) and includes, a developmental center or school, a community residence and a family care home (MHL § 1.03(6); *In re Alexis H*, 174 A.D.2d 1030 (4th Dep't 1991)).
41. SCPA 1750-b(5); Presumably notice to the OPWDD Commissioner is designed to ensure oversight of the surrogate's decision in the absence of review by the Mental Hygiene Legal Service where the developmentally disabled person does not reside in a setting where the Service has jurisdiction.
42. SCPA 1750-b(4)(e).
43. SCPA 1750-b(5)(d). The statute provides that an objection shall be referred to a dispute mediation system, or similar entity for mediating disputes in a hospice. In the event that such dispute cannot be resolved within seventy-two hours or no such mediation entity exists or is reasonably available for mediation of a dispute, the objection shall proceed to judicial review pursuant to this subdivision.
44. SCPA 1750-b(6). Special proceeding authorized. The guardian, the attending physician, the chief executive officer, the MHLS (if the person is in or was transferred from residential facility or program operated, approved or licensed by the OPWDD) or the commissioner of OPWDD or his or her designee (if the person is not in and was not transferred from such a facility or program) may commence a special proceeding in a court of competent jurisdiction with respect to any dispute arising under this section.
45. *In re MB, supra* note 17 at 443-44.
46. Patricia Bomba, *Landmark Legislation in New York Affirms Benefits of a Two-Step Approach to Advance Care Planning Including MOLST: A Model of Shared Informed Medical Decision Making and Honoring Patient Preferences for Care at the End of Life*, 17 Widener Law Review 475 (2011).
47. See New York State Department of Health website, www.health.ny.gov/professionals/patients/patient_rights/molst.
48. "DNI" means do-not-intubate. A DNR order is distinct from a DNI order. A person whose respiratory status is failing may experience cardiac arrest, but not all patients do. It is important legally to separate "do-not-intubate" from "do-not-resuscitate" discussions. Katz, Paula. "Separating DNI from DNR Discussion," *Today's Hospitalist*, October 2014.
49. See New York State Department of Health Website, *supra* note 47.
50. *Id.*
51. See New York State Office for People with Developmental Disabilities website, www.opwdd.ny.gov/opwdd_resources/information_for_clinicians/MOLST.
52. *In re Joseph P*, 106 A.D.3d 1548 (4th Dep't 2013).
53. *Id.*
54. *Id.* at 1551, citing *In re DH*, 15 Misc. 3d 565 (Sup. Ct., Nassau Co. 2007).
55. *In re Leonard B.*, 164 Misc. 2d 518, 525 (Sup. Ct., Albany Co. 1995), modified on other grounds, *Finn v. Leonard C.*, 221 A.D.2d 896 (3d Dep't 1995).
56. Felicia Nimue Ackerman, *Patient and Family Decisions About Life-Extension and Death*, The Blackwell Guide to Medical Ethics, Eds. Rosamond Rhodes, Leslie P. Francis and Anita Silvers, Blackwell Publishing 2007, 52-68.
57. Lisa Reswick, *My Banished Brother*, New York Times, <http://well.blogs.nytimes.com/2016/04/01>.
58. Kathleen M. Fisher, Michael J. Green, Frederick K. Orkin & Vernon M. Chinchilli, *A Content Analysis from a US Statewide Survey of Memorable Health-care Decisions for Individuals with Intellectual Disability*, Journal of Intellectual and Developmental Disability 34(3), 258-65 (2009).
59. SCPA 1750-b(4).
60. Roland L. Ward, Amanda Nichols, Ruth Freedman, *Uncovering Health Care Inequalities Among Adults with Intellectual and Developmental Disabilities*, Health and Social Work 35:4, November 2010.
61. The Task Force on Life and the Law, established in 1985, consists of experts who advise on public policy and issues arising at the interface of medicine, law and ethics (www.health.ny.gov/regulations/task_force).
62. 2010 N.Y. Laws ch. 8, § 28.
63. *Being Mortal* at 252.
64. *Health Care Choices: Who Can Decide?*, OPWDD (February 2012) (April 5, 2015), www.opwdd.ny.gov/health-care-choices-brochure.