The Family Health Care Decisions Act Should Apply to End-of-Life Decisions for Persons Who Are Intellectually Disabled

By Robert N. Swidler

The following scenario is sad, but quite familiar to experienced doctors and nurses in hospitals, nursing homes and hospice: A patient is dying, and a decision must be made about whether to enter a DNR (do-not-resuscitate) order or to make some other life-sustaining treatment decision. The dying patient lacks capacity and did not leave instructions or appoint a health care agent. As a result, the attending physician follows the rules of the Family Health Care Decisions Act (FHCDA).[1] Those rules cover:

(i) a bedside process to determine patient incapacity;[2]

(ii) a priority list to identify a surrogate decision-maker;[3]

(iii) the clinical criteria needed to support a life-sustaining treatment decision;[4]

(iv) the ethical decision-making standard that a surrogate should follow;[5] and

(v) documentation and other administrative requirements.[6]

The FHCDA rules are clear, familiar and practical for staff to follow in most cases. And invariably, the rules are embodied in standard, frequently used facility forms. End-of-life decisions are never easy, but typically experienced staff understand the FHCDA process and requirements.[7]

But if the dying patient is intellectually disabled, this is not the case. The FHCDA does not apply.[8] Rather, such decisions are governed by the Health Care Decisions Act for Persons With Intellectual Disabilities, codified as Surrogate Court Procedure Act 1750-b.[9] (hereinafter "Section 1750-b"). Section 1750-b is similar to the FHCDA—indeed it preceded and influenced the FHCDA.[10] But Section 1750-b has *slightly different rules in every category listed above*, and additional requirements seen as needed to protect the intellectually disabled population. In practice, this can lead to confusion, disruption, delay, liability concerns, calls to hospital counsel and worst, disparate treatment. Section 1750-b's differences and additional requirements demand that hospital staff treat incapable patients with intellectual disabilities differently at the end of life from all other patients—and different is not necessarily better.

"Section 1750-b has slightly different rules in every category listed above, . . . *In practice, this can lead to confusion, disruption, delay, liability concerns, calls to hospital counsel and worse, disparate treatment."*

There is a compelling need to reconcile the FHCDA and Section 1750-b; to identify and examine in detail all of the specific disparities between the statutes; to consider in each instance whether there is an important rationale for a separate end of life care rule for persons with intellectual disabilities; and where there is no such rationale to establish a common rule.

Fortunately, the difficult groundwork has already been accomplished. Pursuant to a legislative mandate,[11] the New York State Task Force on Life and the Law formed a Special Advisory Committee (SAC) to consider whether to extend the FHCDA to persons with intellectual disabilities.[12] The SAC conducted an intensive review of the two laws, including their history, purpose, language and practical application; it heard testimony from numerous interested parties and organizations. It concluded that "for most disparities between the laws that are not necessary to serve differences between populations, the FHCDA will serve all patients without medical decision-making capacity in all settings equally well, with only a few minor modifications."[13]

The Task Force's report includes a table that is especially valuable: it is a catalog of the differences among the FHCDA, Section 1750-b, and pertinent OPWDD regulations.[14] Each row includes the SAC's recommendation for a common rule or adaptation. For example, the table notes these slight differences in the priority lists for the identification of a surrogate, and proposes a reconciliation.[15] (This table can be found at the end of the article.)

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In this manner, the SAC painstakingly charted a course to amend the FHCDA, a course that would iron out differences, supplying the preferred standard in each case, and thereby enable the FHCDA to apply to this population.

In many instances the SAC recommended retaining a Section 1750-b safeguard for intellectually disabled persons. As one notable example, the SAC called for preserving an important role for Mental Hygiene Legal Services (MHLS) in such cases. Indeed, in one respect it called for enhancing MHLS' role by encouraging providers to bring MHLS into the decision-making process earlier, as opposed to providing a later notification.[16] However, the SAC also recommended requiring MHLS to provide support before it could block a DNR order, "recognizing the primary authority of the surrogate, in consultation with the attending physician, to make decisions based on the patient's wishes and interests." [17]

Extending the FHCDA to cover persons with intellectual disabilities, with some special protections adapted from Section 1750-b, would accomplish three broad public policy objectives.

First and foremost, it would serve the interests of persons with intellectual disabilities. They and their families are the ones who suffer from the confusion, delay and uncertainty that results when hospital staff must obtain and carry out an end of life decision based on unfamiliar procedures. To be sure, many families of intellectually disabled persons and residential providers will be familiar with Section 1750-b and comfortable with its requirements. But in most instances end of life decision will be implemented in hospitals and nursing homes. When the emergency room, ICU or cancer unit staff are faced with a nonstandard, unfamiliar process for an infrequently seen patient subpopulation, quality end of life decision-making can be compromised.

Second, extending the FHCDA to this population helps and respects health care professionals. They should not have to learn and apply a separate set of complex legal procedures for a subset of patients—except in those limited instances where there is a compelling rationale for the difference. And the law must strike a better balance, one that protects persons with intellectually disabilities without assuming that health care professionals will violate their oaths by devaluing and discriminating against them.

Third, extending the FHCDA to this population is consistent with the broader principle of seeking more equal treatment under the law for persons with intellectual disabilities. This same principle drives the broader debate regarding SCPA Article 17-A guardianship procedures. Advocates are asking whether SCPA 17-A should be (or constitutionally must be) amended to resemble more closely the MHL Article 81 guardianship procedures that apply to everyone else who needs a personal or property guardian due to incapacity. They should also call for a process for end of life decisions for persons with intellectual disabilities that resembles more closely the FHCDA procedures that apply to every other person who needs end of life decision making.

The principal objections to extending the FHCDA to decision for persons with intellectual disabilities appear to be:

- **Family/advocate satisfaction with SCPA 1750-b**. Reportedly, families of and advocates for persons with intellectual disabilities have been satisfied with that law, are familiar with it, and are rightfully proud of the advocacy efforts that achieved it. They see no reason to "fix it" when it is not broken, and no reason to learn new slightly different rules. But that view understates the real problems, confusion and delays that occur when decisions have to be made at the end of life in hospital settings for persons with intellectual disabilities. Conversely, the view overstates the difficulty of learning the FHCDA requirements, which are on the whole simpler than the 1750-b requirements. For example, if the proposed change is made, OPWDD's complex MOLST Checklist for persons with intellectual disabilities can either be eliminated or trimmed considerably.
- **Loss of safeguards**. Family and advocates may fear that extending the FHCDA to decisions for persons with intellectual disabilities will mean the loss of special safeguards for that population. But as explained in this article, the Task Force proposal would incorporate key safeguards from SCPA 1750-b.
- **Loss of SCPA 1750-b's application in all settings**. Currently, SCPA 1750 does not specify any limitations on where it applies, while the FHCDA applies only to patients in hospital, nursing homes and hospice. It is rare for life-sustaining treatment decisions to be carried out in non-FHCDA settings. But in any event, the Task Force proposal addresses this by applying FHCDA principles to decisions for persons with intellectual disabilities in settings outside of hospitals, nursing homes and hospice.

The FHCDA should apply to end of life decisions for persons with intellectual disabilities, with key safeguards adapted from Section 1750-b. Doing so will improve care for these persons at the time end of life decisions are made and implemented.

Endnotes

1. NY Public Health Law (PHL) Article 29-CC. *See generally*, Robert. N. Swidler, *New York's Family Health Care Decisions Act: The Legal and Political Background, Key Provisions and Emerging Issues*, N.Y. St. B.J. (June 2010).
2. PHL § 2994-c.
3. PHL § 2994-d.1.
4. PHL § 2994-d.4-5.
5. PHL § 2994-c.4-5.
6. PHL § 2994, passim.
7. Admittedly, this is the impression of this author, and not based on a survey or other data. But it is based on my experience as in-house counsel for a system with five hospitals, seven nursing homes and hospice, and hundreds of discussions with clinicians, administrators and lawyers who work in health care facilities over the eight years since the FHCDA was enacted.
8. PHL § 2994-b.3(b).
9. Chapter 500, L. 2002. *See generally,* Christie A. Coe, *Beyond Being Mortal: Developmentally Disabled and End of Life Treatment*, N.Y. St. B.J. (Oct. 2016). Section 1750-b was enacted in response to a 2001 case in Syracuse in which the family of a dying patient with a severe life-long intellectual disability was not allowed to authorize the withdrawal of medically provided nutrition and hydration and antibiotics. Advocates for the bill emphasized that a surrogate decision-making law was needed for adults who lack capacity due to lifelong intellectual disabilities because, unlike other adults, they have no opportunity to leave advance directives or other evidence of their wishes. Initially called the "Health Care Decisions Act for Mentally Retarded Persons," the term "mentally retarded" was changed to "intellectually disabled" throughout the section in 2016. Chapter 198, L. 2016.
10. *See* NYS Task Force on Life and the Law, Special Advisory Committee, 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 June 21, 2016 ("TF/SAC Recommendations"), available at https://www.health.ny.gov/regulations/task_force/reports_publications/.
11. Chapter 8 of the Laws of 2010 § 28. This is an uncodified section of the chapter law that enacted the FHCDA.
12. TF/SAC Recommendations, p.54.
13. *Id*., p.36.
14. *Id*., pp. 38-51. Appended to this article.
15. *Id*., p.41.
16. *Id*., p. 31.
17. *Id*. p.32

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Appendix A - Surrogate Decision-Making Laws in New York

	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
Who does it cover?	THE FHCDA covers incapable patients in general hospitals, nursing homes, and hospice2. PHL § 2994-b This includes patients with Mental Illness located in the above settings. It does not include: (1) patients with a health care agent (§ 2994-b(2)); (2) patients with a court-appointed guardian under SCPA Article 17-A; (3) patients for whom decisions about life-sustaining treatment may be made under SCPA § 1750-b; (4) patients for whom treatment decisions may be made pursuant to OMH or OPWDD surrogate decision-making regulations. PHL § 2994-b	HCDA covers: (1) persons with mental retardation or DD who have a guardian appointed under SCPA § 1750 or § 1750-a; (2) persons with mental retardation or DD without a guardian appointed pursuant to SCPA Article 17-A who have a qualified family member (SCPA § 1750-b(1)(a) and (b)); (3) members of the Willowbrook class, without a guardian appointed pursuant to SCPA Article 17-A or qualified family member, who are represented by the Willowbrook Consumer Advisory Board (SCPA § 1750-b(1)(a)); (4) persons with mental retardation or DD, without a surrogate in categories 1-3 above, whose decisions are made by a surrogate decision making committee (SCPA § 1750-b(1)(a)).	14 NYCRR § 633.10(a)(7)(iv) contains the list of qualified family members to implement the provision of SCPA § 1750-b(1)(a) related to persons with mental retardation or developmental disabilities without a guardian appointed pursuant to SCPA Article 17-A.	• Amend FHCDA to cover persons now covered by HCDA and OPWDD and OMH regulations (continue current exception for psychiatric treatment decisions for persons in psych hospitals/units and in facilities licensed or operated by OMH and behavioral intervention decisions for people in facilities or programs licensed, operated or funded by OPWDD). • Repeal existing HCDA (1750-b) language and replace it with language that would continue to cover persons with DD in FHCDA covered and non-FHCDA covered settings. • Amend HCDA to continue to cover persons in non-FHCDA settings, but incorporate FHCDA standards and procedures.
Is there a presumption that the patient has capacity?	Yes. (Unless there is a guardian pursuant to Art. 81) PHL § 2994-c	No	No	• Amend FHCDA to provide that an adult with a SCPA 17-A guardian is not presumed to have capacity,

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	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
				but FHCDA procedures to determine incapacity are still required before a surrogate decision to withdraw or withhold life-sustaining treatment. • Apply amended FHCDA provision to all.
Who makes capacity determinations?	Attending physician. Such determination shall include an assessment of the cause and extent of the patient's incapacity and the likelihood that the patient will regain decision-making capacity. PHL § 2994-c(2) Before executing withholding/ withdrawing treatment decision, a concurring determination from a health or social service practitioner is required. PHL § 2994-c(3)(b) For patients who lack capacity as a result of mental illness or developmental disability (DD), either the attending physician must have special credentials in mental illness or DD, or another physician with such credentials, must concur in the determination. PHL § 2994-	Attending physician must confirm to a reasonable degree of medical certainty that the person with DD lacks capacity to make health care decisions. Such determination shall contain the attending's opinion regarding the cause and nature of the person's incapacity as well as its extent and probable duration. SCPA § 1750-b(4)(a) Before executing withholding/ withdrawing treatment, the attending must consult with another physician or licensed psychologist to further confirm the person's lack of capacity. The attending or concurring physician or licensed psychologist must (i) be employed by a developmental disabilities services office named in MHL § 13.17 or	The OPWDD regulation in 14 NYCRR § 633.10(a)(7)(i)(a) and (b) contains the requirements for physicians and licensed psychologists to seek approval of the commissioner to serve as the concurring physician or licensed psychologist regarding capacity determinations under the HCDA.	• Amend FHCDA to expand qualifications of persons who can determine incapacity based on DD. • Apply amended FHCDA provision to all.

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	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
	c(3)(c).The professional who determines incapacity based on a DD must be a physician or clinical psychologist who either is employed by a development disabilities services office (DDSO) named in section 13.17 of the mental hygiene law, or who has been employed for a minimum of two years to render care and service in a facility operated or licensed by OPWDD, or has been approved per OPWDD regulations, which must require that a physician or clinical psychologist possess specialized training or three years' experience in treating DD. An attending physician must confirm the adult patient's continued lack of decision-making capacity before complying with health care decisions made pursuant to the FHCDA, other than those decisions made at or about the time of the initial determination. A concurring determination of the patient's continued lack of decision-making capacity shall be	employed by OPWDD to provide treatment and care to people with DD, or (ii) have been employed for a minimum of 2 years to render care and service in a facility or program operated, licensed or authorized by OPWDD, or (iii) have been approved by the commissioner of OPWDD in accordance with regulations promulgated by such commissioner. Such regulations shall require that a physician or licensed psychologist possess specialized training or 3 years experience in treating individuals with DD. SCPA § 1750-b(4)(a)		

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	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
	required if the subsequent health care decision concerns the withholding or withdrawal of life-sustaining treatment. PHL § 2994-c(7)			
Notifications of capacity determinations?	Notice of a determination that a surrogate will make health care because the patient lacks decision-making capacity must be given to: (1) to the patient, where there is any indication of the patient's ability to comprehend the information; (2) to at least one person on the surrogate list highest in order of priority, pursuant to § 2994-d(1); (3) if the patient was transferred from a mental hygiene facility, to the director of the mental hygiene facility and to the Mental Hygiene Legal Service. PHL § 2994-c(4)	N/A	N/A	• Apply FHCDA provision to all.
Objections to capacity determinations?	If an attending physician has determined that the patient lacks decision-making capacity and if the health or social services practitioner consulted for a concurring determination disagrees with the attending physician's determination, the	N/A	N/A	• Apply FHCDA provision to all.

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	matter shall be referred to the ethics review committee if it cannot otherwise be resolved. PHL § 2994-c(3)(d) If the patient objects to the determination of incapacity, the patient's objection or decision shall prevail unless: (1) a court of competent jurisdiction has determined that the patient lacks decision-making capacity or the patient is or has been adjudged incompetent for all purposes and, in the case of a patient's objection to treatment, makes any other finding required by law to authorize the treatment, or (2) another legal basis exists for overriding the patient's decision. PHL § 2994-c(6)			
Who makes withhold/ withdraw decisions?	• An MHL Article 81 court-appointed guardian (if there is one); • The spouse or domestic partner (as defined in the FHCDA); • An adult child; • A parent; • A brother or sister; or • A close friend.	• A guardian appointed pursuant SCPA Article 17-A; • A qualified family member pursuant to OPWDD regulations; • The Consumer Advisory Board for the Willowbrook Class (only for class	List of qualified family members is contained in OPWDD regulation 14 NYCRR § 633.10(a)(7)(iv) • An actively involved spouse; • An actively involved parent; • An actively involved adult child;	• Amend FHCDA to add to the end of the priority list the Willowbrook Consumer Advisory Board, and the SDMC "in cases where such article is applicable". • Apply amended FHCDA decision to all.

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	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
		members it fully represents); or • A surrogate decision-making committee (SDMC).	• An actively involved adult sibling; • An actively involved adult family member.	
Standard by which decisions should be made?	(1) "in accordance with the patient's wishes," or (2) "if the patient's wishes are not reasonably known and cannot with reasonable diligence be ascertained," in the best interests of the person. PHL § 2994-d(4)(a)(ii)	The best interests of the person and, when reasonably known or ascertainable with reasonable diligence, on the person's wishes, including moral and religious beliefs. SCPA § 1750-b(2)(a)	N/A	• Amend FHCDA to clarify that the "wishes standard" refers to the patient's wishes "held when the patient had capacity." • Prohibit certain presumptions about patients with development disability or mental illness, and certain financial considerations.
What constitutes "best interest?"	An assessment of the patient's best interests shall include: • consideration of the dignity and uniqueness of every person; • the possibility and extent of preserving the patient's life; • the preservation, improvement or restoration of the patient's health or functioning; • the relief of the patient's suffering; and any medical condition and such other concerns and values as a reasonable person in the patient's circumstances would wish to consider.	An assessment of the person's best interests shall include consideration of: • the dignity and uniqueness of every person; • the preservation, improvement or restoration of the mentally retarded person's health; • the relief of the mentally retarded person's suffering by means of palliative care and pain management; • the unique nature of artificially provided nutrition or hydration, and the effect it may have on the mentally retarded person; and	N/A	• Apply FHCDA provision to all.

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	FHCDA – PHL Article 29-CC	**HCDA – SCPA § 1750-b**	**OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)**	**TASK FORCE PROPOSAL**
	PHL § 2994-d(4)(a)(ii)	• the entire medical condition of the person. SCPA § 1750-b(2)		
What standards must be met for a guardian/surrogate to make a decision to withhold/ withdraw LST?	If the treatment would be an extraordinary burden to the patient; and attending and concurring physician determine with reasonable certainty: (1) the treatment would be an extraordinary burden to the patient and (a) the patient's illness or injury will cause death within 6 months; *or* (b) the patient is permanently unconscious**,** *or* (2) the provision of treatment would involve such pain or suffering that it would be reasonably deemed inhumane or extraordinarily burdensome AND the patient has an irreversible or incurable condition. PHL § 2994-d(5)	If the attending with the concurrence of another physician determines to a reasonable degree of medical certainty that: (i) the person with DD has a medical condition as follows: A. a terminal condition expected to cause death within one year defined by PHL § 2961; *or* B. permanent unconsciousness; *or* C. a medical condition other than such person's DD which requires life-sustaining treatment, is irreversible and which will continue indefinitely; and (ii) the life sustaining treatment would impose an extraordinary burden on such person, in light of: A. such person's medical condition, other than the person's DD; and B. the expected outcome of the life sustaining treatment, notwithstanding the person's DD.	N/A	• Amend FHCDA to replace the six month definition for terminal illness with the HCDA's one year definition. • Apply the amended FHCDA standard to all.

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	FHCDA – PHL Article 29-CC	**HCDA – SCPA § 1750-b**	**OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)**	**TASK FORCE PROPOSAL**
		SCPA § 1750-b(4)(b)(i)-(iii)		
Does LST include artificial nutrition and hydration?	Yes. Standards for this are the same as for all withholding and withdrawing decisions. Where a physician objects to a withhold/withdraw decision for artificial nutrition/hydration based on "inhumane" criteria, requires ethics review committee (ERC) review. PHL § 2994-d(5)(c) [Note: providing nutrition and hydration orally, without reliance on medical treatment, is not "health care" under this law.]	Yes. However, in the case of a decision to withdraw or withhold artificially provided nutrition or hydration there is an additional requirement that: (1) there is no reasonable hope of maintaining life; or (2) the artificially provided nutrition or hydration must pose an extraordinary burden. SCPA § 1750-b(4)(b)(iii)	N/A	• Apply FHCDA provision to all.
Is CPR a LST ?	Yes. PHL § 2994-a(19). A surrogate decision to consent to a DNR order must be based on the FHCDA's clinical criteria.	Yes. SCPA § 1750-b(1) Cardiopulmonary resuscitation is presumed to be life-sustaining treatment without the necessity of a medical judgment by an attending physician. FHCDA made SCPA § 1750-b applicable to DNR orders for persons with developmental disabilities.	N/A	• Apply FHCDA provision to all.
Grounds for DNR	*Same as for all withhold/withdraw decisions under FHCDA* No standard specifically relating to the medically futility	Same as for other decisions regarding withholding or withdrawing of life sustaining treatment under the HCDA.	The FHCDA amended SCPA § 1750-b to include CPR within the definition of life sustaining treatment. As a result, a DNR order is issued in compliance with the HCDA process, and	• Apply FHCDA provision to all.

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	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
	of resuscitation (although all or most such cases would meet the "inhumane or extraordinarily burdensome" standard).		the DNR regulation in 14 NYCRR § 633.18 is no longer applicable.	
Must anyone approve guardian/ surrogate's decision to withhold/ withdraw LST?	*In a residential healthcare facility*, the Ethics Review Committee or court of competent jurisdiction reviews and approves a surrogate's decision to *refuse* life sustaining treatment based on the "inhumane or extraordinarily burdensome" standard" (not required in the case of CPR). PHL § 2994-d(5)(b). For decisions in other locations, not unless an objection is made to the decision. PHL § 2994-f(1) and (2)	Although approval is not specifically required, certain parties must be provided notice of a decision to withhold or withdraw LST and can file objections. Specific requirements are included in notification section below.	N/A	• Apply FHCDA provision relevant to residential healthcare facilities. • Apply FHCDA provision for objection resolution with amendment for persons with developmental disability outside of institutional settings (see section below on Objections).
What is the proper method for the guardian/surrogate to express a withhold/ withdraw decision?	The surrogate shall express a decision to withdraw or withhold life-sustaining treatment either orally to an attending physician or in writing. PHL § 2994-d(5)(e)	The guardian shall express a decision to withdraw or withhold life-sustaining treatment either: (1) in writing, dated and signed in the presence of one witness eighteen years of age or older who shall sign the decision, and presented to the attending physician…; or (2) orally, to two persons eighteen years of age or older,	N/A	• Apply FHCDA provision to all.

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	FHCDA – PHL Article 29-CC	**HCDA – SCPA § 1750-b**	**OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)**	**TASK FORCE PROPOSAL**
		at least one of whom is the mentally retarded person's attending physician. SCPA § 1750-b(4)(c)(i-ii)		
Notification of decision to withhold/ withdraw life sustaining treatment (LST)?	No notification requirement for decision to withhold/withdraw LST. After a physician has determined that a patient is incapacitated, the FHCDA requires that notice must be given to: the patient; a person in the highest available category of the surrogate decision-making hierarchy; and to the Director of the Mental Hygiene facility and Mental Hygiene Legal Service (MHLS) if the person is transferred from a mental hygiene facility. PHL § 2994(c)(4)	At least 48 hours before the implementation of a decision to *withdraw* LST, or at the earliest possible time prior to the implementation of a decision to *withhold* LST, the attending physician shall notify: (1) the patient (unless the attending physician determines with confirmation that the individual would suffer immediate and severe injury from such notification); (2) if the person is in or was transferred from a residential facility operated, licensed, or authorized by OPWDD, the CEO of the agency or organization operating such facility and MHLS; (3) if the person is not in and was not transferred from such a facility or program, the Commissioner of OWPDD or his or her designee. SCPA § 1750-b(4)(e)(i)-(iii)	Upon receipt of notification the CEO of the agency shall confirm that the person's condition meets all of the criteria set forth in SCPA § 1750-b(4)(a) and (b). In the event that the CEO is not convinced that all of the necessary criteria are met, he or she may object to the decision and/or initiate a special proceeding to resolve such dispute in accordance with SCPA § 1750-b(5) and (6). 14 NYCRR § 633.10(a)(7)(ii) For purposes of communicating the notification required by § 1750-b(4)(e)(iii) the commissioner designates the directors of each of the DDSOs to receive such notification from an attending physician. In any such case, the DDSO director shall confirm that the person's condition meets all of the criteria set forth in SCPA § 1750-b(4)(a) and (b). In the event that the director is not	• Amend FHCDA to include, in the case of patient with developmental disabilities (DD), HCDA notifications to facility director and MHLS. • Include requirement that MHLS be available to receive notice at any time, and can waive its right to receive notice. • For patients with DD, amend FHCDA to establish that MHLS's attendance at a clinical team meeting with the physician, surrogate, and other relevant health care providers satisfies the notice requirement. • Apply amended FHCDA provision to all.

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	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
			convinced that all of the necessary criteria are met, he or she may object to the decision and/or initiate a special proceeding to resolve such dispute in accordance with SCPA § 1750-b(5) and (6). 14 NYCRR § 633.10 (a)(7)(iii)	
What if there is an objection to the Guardian/surrogate withhold/ withdraw decision?	If patient objects to a health care decision by a surrogate, the patient's objection shall prevail unless a court makes any finding required by law to authorize the treatment. PHL § 2994-c(6) If attending physician objects to the surrogate's decision to provide life-sustaining care, the physician must first make the surrogate aware of the objection and then either: transfer the case to another doctor; or make sure the matter is referred to the ethics review committee (ERC) or a court of competent jurisdiction. PHL § 2994-f(1) In a general hospital, if an attending physician objects to surrogate's decision to withdraw/withhold nutrition or	The decision to withhold or withdraw LST is suspended, pending judicial review, except if the suspension would in reasonable medical judgment be likely to result in the death of the person, in the event of an objection to such decision at any time by: (i) the person with developmental disabilities on whose behalf the decision was made; or (ii) a parent or adult sibling who either resides with or has maintained substantial and continuous contact with the person with developmental disabilities; or (iii) the attending physician; or (iv) any other health care practitioner providing services to the person with developmental disabilities, who is licensed pursuant to	N/A	• Amend FHCDA to impose stay of DNR order on objection by MHLS or Director only if their objection provides a basis for the objection, and if the basis is a medical objection, that it is written by a physician, physician's assistant, or nurse practitioner. • Apply FHCDA standard allowing for ERC resolution to all persons, except, for persons with developmental disabilities outside of institutional settings (i.e. private home), empower Commissioner of OPWDD to promulgate regulations to establish dispute resolution body. • Exempt decisions made by surrogate decision making committees (SDMC) from ERC review.

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

	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
	hydration, then the ERC or a court of competent jurisdiction must review the decision. PHL § 2994-d(5)(c) If any other party, including the surrogate or another on the surrogate hierarchy list, makes an objection to the decision and this objection is known to the physician, the physician must refer the matter to the ERC. PHL § 2994-f(2)	Education Law Article 131, 131-B, 132, 133, 136, 139, 141, 143, 144, 153, 154, 156, 159 or 164; or (v) the Chief Executive Officer; (vi) the Mental Hygiene Legal Service if the person is in or was transferred from a residential facility or program operated, approved or licensed by OPWDD (vii) the Commissioner of OPWDD, or the Commissioner's designee, if the person is not in and was not transferred from such a facility or program. SCPA § 1750-b(5)(a) While the decision is suspended, the parties may try to resolve the issue through nonbinding dispute mediation. SCPA § 1750-b(5)(d) However, only certain parties are authorized to initiate a special proceeding with respect to any dispute. They are the surrogate, the attending physician, the CEO of the OPWDD operated or certified residential agency, MHLS, and		• Amend FHCDA to explicitly allow all parties to bypass dispute resolution in favor of a court proceeding, or to initiate a court proceeding at any time during ethics committee review.

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	FHCDA – PHL Article 29-CC	**HCDA – SCPA § 1750-b**	**OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)**	**TASK FORCE PROPOSAL**
		the OPWDD commissioner or designee. SCPA § 1750-b(6)		
Are there special rules/procedures for the unbefriended patient (i.e., a patient without capacity and without a surrogate)?	Yes. A decision to withdraw or withhold life-sustaining treatment can be made either: (1) by a court, in accordance with the FHCDA surrogate decision-making standards, or (2) if the attending physician and a second physician determine that the treatment offers the patient no medical benefit because the patient will die imminently, even if the treatment is provided, and the provision of the treatment would violate accepted medical standards. PHL § 2994-g(5)	Yes. Under the HCDA, if the individual does not have someone who is available to serve as a surrogate, then a surrogate decision-making committee (SDMC) decides. SCPA § 1750-b (1)(a). The SDMC is a panel of people with health care, advocacy, and legal experience to make investigation-based decisions for the patient's life-sustaining treatment. MHL § 80.05(c).	See SCPA § 1750-b(1)(a) regarding the SDMC's authority.	• Preserve FHCDA standard and SDMC availability for relevant populations.
Are dispute resolution bodies' decisions binding?	Only binding for: (1) decisions made in nursing homes based on the inhumane and extraordinary burden standard (not applicable to DNR). PHL § 2994-(d)(5)(b) (2) artificial nutrition/hydration. Where a physician objects to a withhold/withdraw decision for artificial nutrition/hydration. PHL § 2994-m(2)(c) (referring to § 2994-d(5)) (3) For an emancipated minor who seeks to withdraw or	No. SCPA § 1750-b(5)(d)	N/A	• Apply FHCDA provision to all.

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

	FHCDA – PHL Article 29-CC	**HCDA – SCPA § 1750-b**	**OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)**	**TASK FORCE PROPOSAL**
	withhold LST and who the attending physician determines has decision-making capacity and is making a decision that accords with surrogate standards for adults PHL § 2994-m(2)(c) (referring to § 2994-e(3)(a))			
Is there a requirement for the provision of "Full and Efficacious Treatment?"	No.	Yes. SCPA § 1750-b(4)	N/A	• Apply FHCDA provision to all.