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

New York Task Force on Life and the Law
Special Advisory Committee
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I. Introduction

The Task Force on Life and the Law (the Task Force) was established by Executive Order in 1985 to undertake studies of issues arising at the interface of law, medicine, and ethics. In April 1992, the Task Force issued a report examining the ethical issues that arise when making decisions for individuals who lost the capacity to consent to medical treatment, but did not previously appoint a health care agent. The report, When Others Must Choose: Deciding For Patients Without Capacity,[1] set forth a proposal for legislation authorizing family members or close friends to decide about treatment for all incapacitated patients who have not signed a health care proxy or left specific oral or written treatment instructions.

The Family Health Care Decisions Act (FHCDA) was enacted in 2010 and included many of the recommendations made by the Task Force.[2] The FHCDA was designed to provide a way for surrogate decision-makers to honor the wishes of patients when those patients could not speak for themselves, or to act in the best interests of those patients when their wishes were unknown.

The FHCDA was influenced by and is similar in key respects to other New York surrogate decision-making laws that had been enacted earlier. The FHCDA's key influences were New York's Do Not Resuscitate (DNR) Law,[3] which authorized surrogate decision-making for resuscitation decisions, and the Health Care Decisions Act for Mentally Retarded Persons (HCDA),[4] which authorized surrogate end-of-life decision-making for incapacitated patients with developmental disabilities.

Prior to the passage of the FHCDA, family members and close friends of patients who were not covered by other limited surrogate decision-making laws did not have clear authority to consent to routine or major medical health care decisions on a patient's behalf. Family and friends also lacked any authority to make decisions other than DNR regarding the withdrawal or withholding of life-sustaining treatment.[5] As a result, family and friends faced barriers in making health care decisions based on their loved one's reasonably known wishes or best interests.

The FHCDA allows an incapacitated patient's family member or close friend to be designated by law as a surrogate for making health care decisions for an incapacitated patient who did not already make health care decisions or appoint a health care agent. In

[1] *Available at*: http://annals.org/article.aspx?articleid=706311.
[2] Chapter 8 of the Laws of 2010, codified principally in NY PHL Article 29-CC.
[3] NY PHL Article 29-B (1987).
[4] L. 2002, ch. 500, codified principally in NY SCPA § 1750-b.
[5] See Robert N. Swidler, *New York's Family Health Care Decisions Act: The Legal and Political Background, Key Provisions and Emerging Issues*, NYSBA Journal 17, at 18 (2010).

addition to making routine health care decisions, the surrogate is authorized by the FHCDA to direct the withdrawal or withholding of life-sustaining treatment from the incapacitated patient in specified clinical circumstances, based on the patient's wishes or, if wishes are not reasonably known, best interests.[6] The FHCDA only applies to decisions relating to treatment in hospitals, which means general hospitals,[7] nursing homes, or hospices.[8,9] For individuals outside of these health care settings, the Task Force, in a 2013 report, proposed extending the FHCDA to residential settings.[10] This proposal would allow surrogates to make life-sustaining treatment decisions on behalf of incapacitated individuals (including those with mental illness) in residential settings under a similar framework to that already required in medical facilities.

When the FHCDA was enacted, certain populations were excluded from the law because they were covered under existing laws like the Health Care Decisions Act for Mentally Retarded Persons (HCDA). Lawmakers wanted to study whether the FHCDA could appropriately be extended to meet their needs and circumstances. In the FHCDA the legislature explicitly assigned to the Task Force the project of considering 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 illness or mental retardation or developmental disabilities, and from patients residing in mental health facilities."[11]

In performing this task, the FHCDA required the Task Force to form a Special Advisory Committee (SAC) with six Task Force members, three members selected by the commissioner of the Office of Mental Health, and three members selected by the commissioner of the Office of Mental Retardation and Developmental Disabilities (now the Office for People With Developmental Disabilities). The Task Force formed this committee, which then sought comments from interested persons in the mental health and developmental disability communities including providers, patients, and advocates. The committee carefully considered all input and used its expertise to create recommendations for amendments. These recommendations were vetted by several rounds of discussion and debate, and the SAC tested the practical implications of their recommendations for patients in several plausible scenarios through a series of "table-top" exercises. SAC members

[6] *See* NY PHL § 2994-d(5).
[7] Hospitals under the FHCDA refers specifically to general hospitals governed under NY PHL Article 28, excluding a ward, wing, unit or other part of a general hospital operated for the purpose of providing services for persons with mental illness pursuant to an operating certificate issued by the Commissioner of Mental Health.
[8] Hospices under the FHCDA refers specifically to those governed under NY PHL Article 40
[9] The Task Force has recommended extending the FHCDA to agencies, programs, and health care settings that are Medicare and/or Medicaid-certified and State-licensed.
[10] *See Recommendations for Extending the Family Health Care Decisions Act to Medicare and/or Medicaid-Certified and State-Licensed Agencies, Programs, and Settings*, NY State Task Force on Life and the Law, June 3, 2013.
[11] Chapter 8 of the Laws of 2010 § 28.

designed situations involving hypothetical patients who differed according to several factors: location, health condition, mental condition, surrogate, and surrogate's disposition toward the patient. With the assistance of an experienced clinician, the SAC determined how the recommendations would apply to health care decisions for these hypothetical patients. These exercises helped the SAC refine the language of their recommendations.

After reviewing the SAC committee's reasoning and recommended amendments, the Task Force accepted and approved the report and the recommendations to amend the FHCDA and HCDA to clarify and streamline the relevant decision-making processes while preserving certain protections in existing law specific to each population.

II. Current Decision-Making Standards

Decision-making for adults without capacity is governed by a complex collection of New York laws and regulations. As the chart below shows, the rules vary for different types of patients, different settings, and different types of decisions.

Current Law for Patients Who Lack Medical Decision Making Capacity			
Law or Regulation	**Patients**	**Settings**	**Decisions**
Health Care Proxy Law PHL Art. 29-C	Adult patients without capacity who previously, when competent, appointed a health care agent	All settings	All health care decisions
Family Health Care Decisions Act PHL Art. 29-CC	Adult patients without capacity who are not covered by any other of law or regulations in the first column	General hospitals (excluding psychiatric units licensed by OMH), nursing homes and hospices.	All health care decisions
Non-Hospital Orders Not to Resuscitate PHL Art. 29-CCC	Adult patients without capacity, and specifically when receiving care from EMS, home care services agency, hospice or hospital emergency service personnel	Outside of a general hospital, nursing home, hospice, psychiatric hospital or unit.	DNR and DNI decisions
Surrogate Decision-making Committees MHL Art. 80 (See also SCPA § 1750-b)	Adult or minor patients without capacity, who do not have an available and willing surrogate to make major medical treatment decisions on their behalf and who are receiving, or have received, residential or other services from a program operated, licensed or funded by the Office for People With Developmental Disabilities (OPWDD), the Office of Mental Health (OMH), or Office of Alcoholism and Substance Abuse Services (OASAS)	All settings	• Major medical treatment decisions • Also, for people with developmental disabilities, decisions to withdraw or withhold life-sustaining treatment where no guardian has been appointed and there is no qualified family member to make such decision
Health Care Decisions Act for Mentally Retarded Persons	Adult or minor patients without capacity with developmental disabilities	All settings	For guardians appointed pursuant to SCPA Article 17-A, all health care

Current Law for Patients Who Lack Medical Decision Making Capacity			
Law or Regulation	**Patients**	**Settings**	**Decisions**
SCPA § 1750-b			decisions. For qualified family members as defined in 14 NYCRR § 633.10(a)(7)(iv), only decisions to withdraw or withhold life-sustaining treatment
Office for People With Developmental Disabilities surrogate medical treatment decision-making regulations 14 NYCRR § 633.11	Adult or minor patients without capacity with developmental disabilities	Residents of OPWDD operated or licensed facilities	Major medical treatment decisions
Office of Mental Health surrogate decision-making regulations 14 NYCRR §§ 27.9, 527.8	Adult patients without capacity	OMH operated or licensed facilities	Routine and major medical treatment decisions
Orders Not to Resuscitate for Mental Hygiene Residents PHL Art. 29-B	All patients	Psychiatric hospitals and units	Only DNR decisions

The Health Care Proxy Law offers adults with capacity—including many persons with mild developmental disabilities or with mental illness—the ability to designate a health care agent. For those who do so and later lose capacity, their health care decisions are governed by the health care proxy law and there is no need to rely upon a surrogate decision-making law.

The FHCDA provides a framework for surrogate decision-making for many patients who lack capacity and who do not have a health care agent. However, as noted previously, the FHCDA does not apply to persons with developmental disabilities, or persons in psychiatric hospitals or units, to the extent decisions for those persons are governed by other surrogate decision-making laws and regulations.[12] Moreover, the FHCDA only applies to decisions relating to treatment in general hospitals (excluding psychiatric units), nursing homes and hospices.[13]

[12] *See* NY PHL § 2994-b(3)(c).
[13] *See* NY PHL § 2994-b(1). The Task Force has recommended extending the FHCDA to other DOH or CMS licensed settings and services. *See Recommendations for Extending the Family Health care Decisions Act to Medicare and/or Medicaid-Certified and State-Licensed Agencies, Programs, and Settings*, NY State Task Force on Life and the Law, June 3, 2013.

The Non-Hospital Orders Not to Resuscitate Law governs DNR orders for persons in the community, directing home care services agency, hospice, emergency medical services and emergency room personnel to honor DNR orders. It refers to and relies upon other surrogate decision-making laws such as the FHCDA and HCDA for the authority of surrogate consent to a nonhospital DNR Order. Increasingly in New York, such nonhospital DNR orders are documented on the Medical Orders for Life-Sustaining Treatment (MOLST) physician order form, which also may be used to issue a non-hospital Do Not Intubate (DNI) order.[14]

The Surrogate Decision-Making Committee Program, administered by the Justice Center for the Protection of People with Special Needs, authorizes panels of volunteers to make major medical treatment decisions for patients without capacity who have received mental health or developmental disability services, and who do not have a guardian or an actively involved family member to act as a surrogate.[15] Surrogate Decision-Making Committees can authorize major medical treatment, and can also authorize the withholding or withdrawal of life-sustaining treatment for those receiving developmental disability services pursuant to the HCDA. SDMC's authority to hear cases regarding the withdrawal or withholding of life-sustaining treatment does not extend to those receiving mental health services.

Health Care Decisions Act for Mentally Retarded Persons (HCDA) applies to persons with developmental disabilities. It expressly authorizes guardians appointed pursuant to Surrogate's Court Procedure Act (SCPA) Article 17-A to make all health care decisions for the individual covered by the guardianship, including decisions to withhold or withdraw life sustaining treatment, if certain medical criteria are met. It was subsequently expanded to allow life sustaining treatment decisions to be made by non-guardian, "qualified" family members.[16] The HCDA was enacted in 2002 largely in response to a court case in which the family of a woman, Sheila Pouliot, with life-long developmental disabilities, sought to withdraw medical treatment from her when it was determined her condition was terminal.[17] In the case, Pouliot's treatment was continued, against the family's wishes, because the Attorney General's office intervened claiming the family did not have authority to direct the withdrawal of treatment from Pouliot. The court determined that "in the absence of specific legislation, and where there is no evidence of personal intent, a third party has no recognized right to decide that a patient's quality of life has declined to a point where treatment should be withheld and the patient allowed to die."[18]

[14] *See* NY PHL § 2994-dd(6); 10 NYCRR § 400.21; https://www.health.ny.gov/professionals/patients/patient_rights/molst/.
[15] 14 NYCRR 633.11(a)(1)(iii)(a) and (b).
[16] *See* NY SCPA § 1750-b(1)(a) and (b); 14 NYCRR § 633.10(a)(7)(iv).
[17] Blouin v. Spitzer, 213 F. Supp. 2d 184 (N.D.N.Y 2002); *aff'd by* Blouin v Spitzer, 356 F.3d 348 (2nd Cir. 2004).
[18] *Id.* at 192.

The HCDA allows an involved family member, identified from a priority list, to make life-sustaining treatment decisions on behalf of a person with a developmental disability if the patient is found to lack capacity, and meets strict clinical criteria.[19] The surrogate's decision must be based on the patient's best interests and, to the extent known, the patient's wishes. The HCDA applies in all treatment settings.[20]

OPWDD Surrogate Medical Treatment Decision-Making Regulations apply to persons residing in facilities licensed or operated by the Office for People With Developmental Disabilities (OPWDD). It sets forth criteria by which major medical treatment decisions can be made by surrogates for this population. These criteria include standards for obtaining informed consent by surrogate decision-makers that must be chosen from a surrogate hierarchy list.[21]

Office of Mental Health Surrogate Decision-Making Regulations apply to persons residing in facilities licensed or operated by the Office of Mental Health. 14 NYCRR § 27.9 lays out the standards for determining whether a patient in this population is capable of providing informed consent to major medical treatment, and if the patient does not have such capacity, it requires consent from certain family members or a court.[22] Decision-making priority among categories of surrogates is not specified. While these regulations govern major medical treatment decisions for OMH facility residents, decisions to withdraw or withhold life-sustaining treatment are not explicitly included under "major medical treatment." 14 NYCRR § 527.8 requires that any proposed treatment be explained to the patient residing in such a facility and also provides a framework for patients to object to such treatment.[23]

Orders Not to Resuscitate for Residents of Mental Hygiene Facilities, established under the FHCDA, supersedes New York's former DNR Law in most settings. But because the Legislature was reluctant to apply the FHCDA in mental hygiene facilities pending this study by the Task Force, it left the existing DNR law applicable in psychiatric hospitals and units (the HCDA applies in all settings).

Each of these laws or regulations arose from a set of historical circumstances, and was crafted to meet an identified need. But the proliferation of complex and inconsistent rules imposes a heavy burden on patients, families, caregivers, and oversight agencies.[24]

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[19] NY SCPA § 1750-b.
[20] *Id*.
[21] *See* 14 NYCRR § 633.11.
[22] *See* 14 NYCRR § 27.9 (2015).
[23] *See* 14 NYCRR § 527.8 (2015).
[24] *See* Robert N. Swidler, *Surrogate Decision-making for Incapable Adult Patients with Mental Disabilities: A Chart of Applicable Laws and Regulations*, NYSBA Health Law Journal 93-98 (Spring 2011): "[I]t is difficult to examine these charts without recognizing a need for reform. Indeed, the very fact that there is a need for complex charts like

III. Objectives

A robust surrogate decision-making law should have certain features to be effective and ethical. It should:

1) Provide a process for determinations of incapacity;
2) Enumerate an ordered list of potential surrogates (surrogate hierarchy);
3) Provide a process for identifying a surrogate;
4) Provide a standard by which surrogates may make decisions;
5) Provide a mechanism for resolving disputes among surrogates, between surrogates and physicians, or between physicians;
6) Provide a process for end-of-life decision-making for unbefriended patients, that is, for individuals without a family member or close friend who can act as their surrogate; and
7) Apply to a broad range of patients, settings, and treatments to reduce complexity and foster consistency.

These features consider the balance between empowering surrogates to make decisions for incapacitated patients and safeguarding the patient's integrity, best interests, and wishes.

The FHCDA contains a number of protections to ensure that: individuals with capacity retain their right to control their own health care decisions; the person with the closest relation to the patient who is available will be appointed as the surrogate decision-maker; and the surrogate will base treatment decisions on the patient's wishes, or on the patient's best interests if wishes are not known. It also contains provisions that allow a court, or under specific circumstances two physicians, to make decisions to withdraw or withhold life-sustaining treatment for patients without friends or family members who can act as surrogates.

The next sections will examine in more detail how these features of the FHCDA compare with the provisions in the HCDA and other laws governing decisions for persons with developmental disabilities and in mental health facilities.

these to navigate among multiple laws and regulations reveals a pressing need for simplification, such as through the consolidation, elimination, or reconciliation of some of these laws and regulations.

IV. The FHCDA and the HCDA Compared

As described earlier, the FHCDA currently provides a decision-making framework for those in general hospitals, nursing homes and hospice settings. The HCDA authorizes guardians appointed pursuant to SCPA Article 17-A to make all health care decisions for individuals, no matter what setting the individual is in when a health care decision needs to be made. It also authorizes certain surrogates to make life-sustaining treatment decisions for patients with developmental disabilities who do not have a guardian appointed pursuant to SCPA Article 17-A, regardless of setting. Moreover, for people with developmental disabilities who reside in OPWDD operated or licensed facilities, other health care decisions may be made by surrogates as authorized by 14 NYCRR § 633.11.

Determination of Incapacity

One of the most important steps in appointing a surrogate is determining if a patient is incapacitated with regard to making medical decisions on his or her own behalf. Capacity determinations are necessary to ensure that patients are given appropriate control over their own health care decisions when they are capable of exercising such choice.

Under the FHCDA, every adult patient without a court appointed guardian is presumed to have capacity until a determination is made otherwise.[25] Under the HCDA, no such explicit legal presumption exists. However, that difference has little practical impact, since both laws require a determination of incapacity before a surrogate is empowered to make decisions for a patient.

Moreover, the procedures in the two laws for determining incapacity are substantially similar, though not identical. Both laws require that the attending physician make a determination of incapacity to a reasonable degree of medical certainty, and that the determination set forth the cause and nature or extent of the incapacity.[26] Both laws require, in connection with decisions to forgo life-sustaining treatment, a concurring (second) determination of incapacity by another practitioner.[27]

When the determination relates to a mental illness or developmental disability, both laws require that either the attending physician or a concurring physician must possess special qualifications relating to that condition.[28] Under the FHCDA, for patients with an initial determination of incapacity due to mental illness, a concurring opinion must be sought from a licensed New York physician who is certified by, or eligible for certification by, at

[25] *See* NY PHL § 2994-c(1).
[26] *See* NY PHL § 2994-c(2); SCPA § 1750-b(4)(a).
[27] *See* NY PHL § 2994-c(3); SCPA § 1750-b(4)(a).
[28] *See* NY PHL § 2994-c(i)-(ii); SCPA § 1750-b(4)(a).

least one of two American boards of psychiatry.[29] For patients with an initial determination of incapacity due to developmental disability, the attending physician or a concurring physician or clinical psychologist must either: (a) be employed by a developmental disabilities services office named in Mental Hygiene Law § 13.17; or (b) have been employed for a minimum of two years to render care and service in a facility operated or licensed by the Office for People With Developmental Disabilities; or (c) have been approved by the commissioner of developmental disabilities in accordance with regulations promulgated by such commissioner. Such regulations shall require that a physician or clinical psychologist possess specialized training or three years' experience in treating developmental disabilities.[30] The HCDA qualifications in SCPA § 1750-b(4)(a) are similar, but not identical.

Regardless of an incapacity determination made in accordance with this section, the FHCDA grants priority to patients if they object to capacity determinations, to the choice of a surrogate, or to the health care decision made by a surrogate.[31] The patient's decision prevails unless a proper court determines the patient lacks decision-making capacity, or if the patient has been adjudged incompetent for all purposes.[32] The HCDA does not explicitly grant patients under its purview the same override power. However, an objection by specified parties, including the patient, suspends a surrogate's withholding or withdrawal decision under the HCDA. The objection can then be resolved by either dispute mediation or a court proceeding. [33]

[29] *See* NY PHL § 2994-c(3)(c)(i).
[30] *See* NY PHL § 2994-c(3)(c)(ii).
[31] *See* NY PHL § 2994-c(6).
[32] *See id.*
[33] *See* NY SCPA § 1750-b(5)(d).

Surrogate Hierarchy

Both the FHCDA and HCDA have hierarchies to determine who can act as a surrogate for decisions to withdraw or withhold life-sustaining treatment. The chart below enumerates the surrogate hierarchy for the groups.

Surrogate List in Order of Priority	
FHCDA[34]	**HCDA as codified in SCPA § 1750-b (as implemented by 14 NYCRR § 633.10(a)(7)(iv)(c)) for incapacitated individuals with developmental disabilities**
MHL Art. 81 court-appointed guardian[35]	17-A guardian[36]
Spouse or domestic partner	Actively involved[37] spouse
Adult child	Actively involved parent
Parent	Actively involved adult child
Brother/Sister	Actively involved brother/sister
Close friend	Actively involved adult family member
	Consumer Advisory Board (CAB) for the Willowbrook Class
	MHL Art. 80 SDMC for withhold/withdraw decisions[38]

As shown above, there are a few distinctions between the HCDA and the FHCDA surrogate lists. The FHCDA gives higher surrogacy priority to an adult child of the

[34] Restrictions on who may be a surrogate: An operator, administrator, or employee of a hospital or a mental hygiene facility from which the patient was transferred, or a physician who has privileges at the hospital or a health care provider under contract with the hospital may not serve as the surrogate for any adult who is a patient of such hospital, unless such individual is related to the patient by blood, marriage, domestic partnership, or adoption, or is a close friend of the patient whose friendship with the patient preceded the patient's admission to the facility. If a physician serves as surrogate, the physician shall not act as the patient's attending physician after his or her authority as surrogate begins. NY PHL § 2994-d(2).

[35] Appointed by the New York Supreme Court (court of general jurisdiction).

[36] Appointed by the New York Surrogate's Court.

[37] "Actively involved" means the individual must have a significant and ongoing involvement in a person's life so as to have sufficient knowledge of their needs and, when reasonably known or ascertainable, the person's wishes, including moral and religious beliefs. SCPA § 1750-b(1)(a).

[38] Section 80.05 of the Mental Hygiene Law authorizes SMDCs to make major treatment medical decisions, and § 80.03 of the Mental Hygiene Law provides that the term major medical treatment does not include "the withdrawal or discontinuance of medical treatment which is sustaining life functions..." The authority to make withhold/withdraw decisions derives from NY SCPA § 1750-b(1)(a).

patient,[39] whereas the HCDA gives higher priority to a parent of the patient.[40] The HCDA requires that the individual chosen must be "actively involved" in the individual's life,[41] whereas the FHCDA makes no such explicit requirement. A person is actively involved if they have a "significant and ongoing involvement in a person's life so as to have sufficient knowledge of the person's needs."[42] While the FHCDA gives a domestic partner of the incapacitated individual the same decision-making status as a spouse,[43] the HCDA explicitly recognizes only a spouse as a surrogate decision-maker.[44]

Decisions to Withhold or Withdraw Life Sustaining Treatment for Unbefriended Patients[45] Under the FHCDA, if the individual is unbefriended (does not have someone who is reasonably available, willing and competent to serve as a surrogate), then a court of competent jurisdiction is allowed to make a decision to withdraw or withhold life-sustaining treatment according to the FHCDA decision-making standards.[46] If the attending physician and a concurring physician determine that life-sustaining 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, then the treatment can be withheld or withdrawn without judicial approval.[47] Under the HCDA, if the individual is unbefriended, then a surrogate decision-making committee (SDMC) may decide.[48] The SDMC is a panel of people with health care, advocacy, and legal experience to make investigation-based decisions about the patient's life-sustaining treatment.[49]

[39] *See* NY PHL § 2994-d(1)(c)-(d).
[40] *See* 14 NYCRR § 633.10(a)(7)(iv)(c)(2)-(3).
[41] *See* 14 NYCRR § 633.10(a)(7)(iv)(c).
[42] *See* 14 NYCRR § 633.99 (bh).
[43] *See* NY PHL § 2994-d(1)(b).
[44] *See* 14 NYCRR § 633.10(a)(7)(iv)(c)(1).
[45] Unbefriended patients are sometimes also referred to as "isolated patients." This Report uses the term "unbefriended" to refer to a patient who does not have a family member or friend willing and capable of acting as a surrogate on his or her behalf.
[46] *See* NY PHL § 2994-g(5)(a).
[47] *See* NY PHL § 2994-g(5)(b).
[48] *See* NY SCPA § 1750-b(1)(a).
[49] The SDMC is established under NY MHL, Article 80. The SDMC offers an alternative to the court system for obtaining informed consent regarding non-emergency major medical treatment on behalf of certain individuals who do not have capacity to make their own decisions and who do not have a legally authorized surrogate available and willing to make the decision on their behalf. The SDMC is available for individuals who are, or have received, residential or other services from a program operated, licensed or funded by the Office for People With Developmental Disabilities, the Office of Mental Health, or Office of Alcoholism and Substance Abuse Services. In 2009, NY SCPA § 1750-b was amended to include SDMC in the list of authorized surrogates for decisions to withdraw or withhold life sustaining treatment for individuals with developmental disabilities. SDMC's authority in such cases is limited to individuals who do not have an SCPA Article 17-A guardian, a qualified family member or Willowbrook CAB available to make such decisions.

Decision-Making Standards

Under the FHCDA, a surrogate gains the authority to make decisions regarding withholding or withdrawing life-sustaining treatment once the patient is determined to lack capacity, an appropriate surrogate is identified from the hierarchy,[50] required clinical determinations (described in the chart below) are made by the attending physician,[51] and there is an independent concurrence by another physician.[52] Under the HCDA, it is a surrogate's decision to withdraw or withhold life-sustaining treatment that triggers the requirement that two physicians or the attending physician and a licensed psychologist confirm the patient's incapacity. Prior to implementing a surrogate's decision to withdraw or withhold life-sustaining treatment, the attending physician and a concurring physician must verify that the patient's condition meets strict clinical criteria (as described below).[53]

Prior to withdrawing or withholding life-sustaining treatment under the FHCDA or the HCDA, the patient's condition must meet the following criteria:

<table>
<tr><th colspan="4">FHCDA Patient-Condition Criteria</th><th colspan="3">HCDA Patient-Condition Criteria</th></tr>
<tr><td></td><td colspan="3">Either</td><td colspan="3"></td></tr>
<tr><td>ROW ONE</td><td colspan="2">Treatment would be an extraordinary burden to the patient.</td><td>The treatment would involve such pain, suffering or other burden that it would be inhumane or an extraordinary burden to the patient.</td><td colspan="3">Life-sustaining treatment would impose an extraordinary burden, in light of
1) The person's medical condition, other than a developmental disability; and
2) The expected outcome of the life-sustaining treatment.</td></tr>
<tr><td></td><td colspan="2">-and either-</td><td>-and-</td><td colspan="3">- and one of the following-</td></tr>
<tr><td>ROW TWO</td><td>The patient has an illness or injury which can be expected to cause death within six months.</td><td>The patient is permanently unconscious.</td><td>The patient has an irreversible or incurable condition.</td><td>The patient has a terminal condition expected to cause death in less than one year.</td><td>The patient is permanently unconscious.</td><td>The patient has a condition, other than a developmental disability, that 1) requires life-sustaining treatment, 2) is irreversible, and 3) will continue indefinitely.</td></tr>
</table>

[50] *See* NY PHL § 2994-d(3)(b).
[51] *See* NY PHL § 2994-d(5)(a).
[52] *Id.*
[53] *See* NY SCPA § 1750-b(4).

Before a surrogate can make a decision regarding withholding or withdrawing life-sustaining treatment, both the FHCDA and the HCDA require a determination that *life-sustaining treatment would be an extraordinary burden to the patient* (see Row One in the chart above).[54] Both laws have an additional requirement, which can be met in several ways (see Row Two in the chart above). The additional requirement options in each law run parallel to each other with one prominent exception: the option based on the amount of time the patient is expected to live. Under the FHCDA the patient's condition must be expected to cause death within 6 months,[55] and under the HCDA the patient's condition must be expected to cause death within one year.[56]

Additionally, the HCDA places an affirmative obligation on surrogates to "advocate for the full and efficacious provision of health care, including life-sustaining treatment."[57] The HCDA also prohibits a patient's developmental disability from being considered a factor in deciding whether treatment would be a burden, and whether the patient has an irreversible condition.[58] Furthermore, the HCDA sets explicit standards for withholding artificial nutrition and hydration. To do so, the attending and concurring physicians must determine that either there is no reasonable hope of maintaining life, or that the artificial nutrition and hydration poses an extraordinary burden to the patient.[59] The FHCDA does not set parallel requirements for withholding artificial nutrition and hydration.

However, under the FHCDA, in a general hospital, if the attending physician objects to a surrogate's decision to withhold artificial nutrition or hydration because the physician does not believe that the treatment would cause such *pain, suffering or other burden as to be an extraordinary burden or deemed inhumane* or the physician does not believe *the patient has an incurable or irreversible condition* (see chart above), then an ethics review committee or court must review the surrogate's decision.[60]

Under both the FHCDA and the HCDA, standards that surrogates must consider when deciding whether to withdraw or withhold life-sustaining treatment include: 1) the patient's

[54] *See* NY PHL § 2994-d(5); NY SCPA § 1750-b(4)(b). The FHCDA allows an alternative to extraordinary burden: that treatment would be "inhumane." *See* NY PHL § 2994-d(5)(a)(ii). Under the HCDA, "extraordinary burden" is further qualified as a) in light of the patient's medical condition other than his or her mental retardation, and b) in light of the expected outcome of the treatment notwithstanding his or her mental retardation. *See* NY SCPA § 1750-b (4)(b)(ii).
[55] *See* NY PHL § 2994-d(5)(a)(i).
[56] NY SCPA uses the term "terminal" which is defined as "illness from which there is no recovery, and can be expected to cause death within one year." *See* NY PHL § 2961(27).
[57] *See* NY SCPA § 1750-b(4).
[58] *See* NY SCPA § 1750-b(4)(b)(i)(C) and (ii)(A) and (B).
[59] *See* NY SCPA § 1750-b(4)(b)(iii).
[60] *See* NY PHL § 2994-d(5)(c).

best interests,[61] and 2) the patient's wishes to the extent known.[62] However, the FHCDA places greater emphasis on making the decision in accordance with the patient's wishes, whereas the HCDA places greater emphasis on making the decision in accordance with the patient's best interests. The FHCDA only permits consideration of best interests when the patient's wishes, including moral and religious beliefs, are not known.[63] In contrast, the HCDA requires that the surrogate should base the decision "solely and exclusively" on the best interests of the patient and on the patient's wishes, including moral and religious beliefs, if known or ascertainable.[64]

Expression of Decisions

While both laws require that the surrogate make a decision to withdraw or withhold life-sustaining treatment from the incapacitated patient either orally or in writing, the standards for doing so are stricter under the HCDA. The FHCDA only requires the surrogate to express the decision "either orally to an attending physician or in writing."[65] Under the HCDA, the guardian may choose to write the decision, but this must be signed and dated in the presence of an adult witness who must also sign it.[66] This writing must then be presented to the attending physician.[67] If the surrogate chooses to express the decision to withdraw or withhold life-sustaining treatment orally, this must be done to two adult persons, at least one of whom is the patient's attending physician.[68]

Notification of Decisions

After a physician has determined that a patient is incapacitated, the FHCDA requires that notice must be given to: the patient (if there is any indication of the patient's ability to comprehend the information); 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.[69]

For an individual with a developmental disability the HCDA requires notice only after the surrogate expresses to the attending physician a decision to withdraw or withhold life-sustaining treatment. The physician must provide notification 48 hours prior to implementing a surrogate decision to *withdraw* life-sustaining treatment, or at the earliest possible time prior to the implementation of a decision to withhold life-sustaining

[61] *See* NY PHL § 2994-d(4)(a)(ii); NY SCPA § 1750-b(2)(a) and (b).
[62] *See* PHL § 2994-d(4)(a)(i); NY SCPA § 1750-b(2)(a).
[63] *See* NY PHL § 2994-d(4)(a)(ii).
[64] *See* NY SCPA § 1750-b(2)(a).
[65] *See* NY PHL § 2994-d(5)(e).
[66] *See* NY SCPA § 1750-b(4)(c)(i).
[67] *See* NY SCPA § 1750-b(4)(c)(i).
[68] *See* NY SCPA § 1750-b(4)(c)(ii).
[69] *See* NY PHL § 2994-c(4).

treatment,[70] to the following individuals: 1) the patient, unless doing so would cause her immediate and severe injury; and 2) the CEO of the residential facility licensed or operated by OPWDD from which the patient was transferred and MHLS, or 3) the Commissioner of OPWDD if the patient was not transferred from such a facility.[71]

Significantly, the "earliest possible time" requirement applies to a common decision to withhold life-sustaining treatment – a DNR order, which is an order to withhold cardiopulmonary resuscitation in the event of cardiac or respiratory arrest. Once the notice is provided, the order can be entered and would be honored unless and until one of the notified parties objects.[72]

Review of Decisions

There are certain circumstances under the FHCDA where a surrogate's decision to withdraw or withhold life-sustaining treatment, prior to implementation, must be reviewed by more parties than just the attending physician. For incapacitated patients in a residential health care facility who have an irreversible or incurable condition and for whom treatment would be an extraordinary burden, the FHCDA requires that the facility's ethics review committee or a court review the surrogate's decision to withdraw or withhold life-sustaining treatment for compliance with FHCDA standards.[73] This review is *not* required for patients in a residential health care facility when the withdrawal of treatment is expected to cause death within 6 months, or the patient is permanently unconscious. The same holds true for certain decisions to withdraw or withhold artificial nutrition and hydration, in the hospital setting: the decision must be reviewed by the hospital ethics review committee (ERC), or a court of competent jurisdiction.[74] Under the HCDA, there are no parallel circumstances requiring automatic review of the surrogate's decision beyond the attending physician unless an objection is made to the decision.

However, substantial notifications are required under the HCDA when a withholding or withdrawing treatment decision is made, as described in the previous section. Additionally, under 14 NYCRR § 633.10, if the patient is in or transferred from a residential facility licensed or operated by OPWDD, then the CEO of the organization operating the facility must review the withholding or withdrawing decision to confirm the patient's condition meets all of the criteria under the HCDA.[75] If the patient is *not* in, and was not transferred

[70] *See* NY SCPA § 1750-b(4)(e).
[71] *See* NY SCPA § 1750-b(4)(e)(i)-(iii).
[72] See NY SCPA § 1750-b(5).
[73] *See* NY PHL § 2994-d(5)(b). But this review is not required for withholding CPR.
[74] *See* NY PHL § 2994-d(5)(c). The ethics review committee must contain at least one physician who is not directly responsible for the patient's care.
[75] *See* 14 NYCRR § 633.10(a)(7)(ii).

from, such a facility, then the director of a Developmental Disabilities Services Office must review the decision to confirm the patient's condition meets the specified criteria.[76]

Objections to Decisions

When a physician or surrogate objects to a decision about whether or not to withdraw or withhold life-sustaining treatment, the FHCDA requires the referral of the matter to an Ethics Review Committee (ERC) whereas the HCDA permits either referral to the dispute mediation system created under the DNR Law,[77] or the commencement of a court proceeding.

More specifically, under the FHCDA, if the attending physician objects to the surrogate's decision to withdraw or withhold life-sustaining care, the physician must first make the surrogate aware of the objection and then either: transfer the case to another doctor; or refer the matter to the ethics review committee.[78] 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 ethics review committee.[79] For patients without a surrogate, if the physician makes a decision regarding withholding or withdrawing life-sustaining treatment that does not receive concurrence from a consulted physician, then the matter must be referred to the ERC.[80] However, these ERC decisions are advisory and nonbinding.[81] The law provides no further guidance if the non-binding ERC decision does not resolve the dispute.

Under the HCDA, if one of the authorized parties objects to a decision to withdraw or withhold life-sustaining treatment, the implementation of the decision is suspended.[82] In addition, the objecting party is required to promptly notify the guardian and other authorized objecting parties of the objection. While the decision is suspended, the parties

[76] *See* 14 NYCRR § 633.10(a)(7)(iii).

[77] The reference under NY SCPA § 1750-b(5)(d) to a dispute mediation system established pursuant to NY PHL § 2972 is an outdated cross reference. A bill introduced in both the NYS Senate and Assembly in 2014 would have, among other things, updated this reference to the FHCDA Ethics Review Committees. S. 7157 (Hannon) /A.9549 (Gunther).

[78] *See* NY PHL § 2994-f(1). If a physician objects to a surrogate's decision to withhold or withdraw artificial nutrition or hydration, an ERC or competent court must review the decision. *See* NY PHL § 2994-d(5)(c).

[79] *See* NY PHL § 2994-f(2).

[80] *See* NY PHL § 2994-g(6).

[81] *See* NY PHL § 2994-m(2)(c). There are two cases when decisions made by the ethics review committee are binding. The first is for review of a surrogate's decision to refuse life-sustaining treatment at a residential health care facility. Whenever a surrogate makes such a decision in a residential health care facility, the ethics review committee must verify that it complies with surrogate decision-making standards. NY PHL § 2994-d(5)(b). The second concerns when an emancipated minor has decision-making capacity and makes a life-sustaining treatment decision for herself. In this latter case, the ethics review committee decides whether the minor's decision complies with standards for surrogate decision-making for adults. NY PHL § 2994-e(3).

[82] *See* NY SCPA § 1750-b(5)(a),(c). The suspension will not be allowed if it is likely to result in the death of the patient.

may try to resolve the issue by nonbinding dispute mediation.[83] If there is no resolution within 72 hours, then the issue can go before a court of competent jurisdiction for decision.[84] However, if the objecting physician, guardian, facility CEO, MHLS or Commissioner of OPWDD chooses, he/she can bypass dispute mediation and initiate the court proceeding first.[85]

Finally, there is a potentially significant difference in these laws with respect to judicial review. Both laws encourage that certain disputes be resolved by non-judicial resolution mechanisms, and neither law precludes an objecting party from commencing a judicial proceeding at any time. The two main differences are (1) the FHCDA does not explicitly preserve the right to commence a judicial proceeding as an alternative to ERC resolution. Instead, the right to do so is not precluded; and (2) the FHCDA does not specify the next step if ethics review fails to resolve the dispute.[86] In contrast, the HCDA provides that if dispute mediation fails, "the objection shall proceed to judicial review...."[87] Any one of the involved parties listed in SCPA § 1750-b(6) may commence a special proceeding to resolve a dispute.

[83] *See* NY SCPA § 1750-b(5)(d), referring to NY PHL § 2972.
[84] *See* NY SCPA § 1750-b(5)(d).
[85] *See* NY SCPA § 1750-b(6).
[86] *See* NY PHL § 2994-r.
[87] NY SCPA § 1750-b(5)(d).

V. Individuals with Mental Illness

The FHCDA provides that it does not apply to persons who were transferred from a facility operated or licensed by the state Office of Mental Health, if consent for the decision may be provided pursuant to the mental hygiene law or OMH regulations.[88] The FHCDA sought to defer to existing surrogate decision-making laws and regulations for transferred mental health facility patients, and to address only the gaps – pending the Task Force study of the issue.

This principle resolves some applicability questions clearly, but leaves others unresolved. First, it is quite clear that individuals with mental illness who are in a general hospital, nursing home, or hospice but who were *not* transferred from a facility licensed by OMH are covered by the FHCDA. They are treated under the FHCDA like any other patient with the same rules regarding, for example, determination of incapacity, identification of a surrogate, and end of life decisions.

For patients transferred from OMH facilities to a general hospital, nursing home, or hospice setting, the FHCDA refers first to the Mental Hygiene Law (MHL) for principles governing surrogate treatment decisions, if they exist and remain applicable.[89]

OMH regulations do prescribe surrogate decision-making rules for consent to various types of treatment.[90] So those regulations, not the FHCDA, would appear to apply to the transferred patient. Moreover, Public Health Law (PHL) Article 29-B covers orders not to resuscitate for patients in OMH facilities, including general hospital psychiatric units.[91] But there appear to be no MHL regulations specifically governing decisions to withdraw or withhold life-sustaining treatment other than DNR decisions for patients in OMH facilities. Accordingly, it appears that the FHCDA applies to end of life decisions, other than DNR, for patients transferred from OMH facilities to general hospitals, nursing homes, and hospices. But as is apparent, the analysis to reach that conclusion is complex.

There also is uncertainty about the definition of "transferred" regarding patients who relocate from an OMH facility to a general hospital. If the patient is officially discharged from the former, then OMH would seem to have relinquished its regulatory oversight of the patient, making the patient subject to the FHCDA.[92] Because of this and the lack of guidance in the OMH regulations, the FHCDA might provide the only relevant surrogate

[88] *See* NY PHL § 2994-b(3).
[89] *See* NY PHL § 2994-b(3)(c).
[90] *See* 14 NYCRR §§ 27.9; 527.8.
[91] *See* NY PHL §§ 2960-2979.
[92] Swidler, *supra* note 24, at 98 nn. 27-28 (noting that "[i]f the patient was discharged from the OMH-regulated facility or unit, then OMH regulations become inapplicable.").

decision-maker hierarchy for patients with mental illness, regardless of whether the patient was transferred from an OMH facility.

Further confusion may arise when a patient is transferred from a psychiatric unit of a general hospital to a medical unit of the general hospital. The psychiatric unit of a general hospital is considered a mental hygiene facility, and not part of a "hospital" within the meaning of the FHCDA. As a result, a patient in the psychiatric unit, or temporarily moved from psychiatric unit to the medical unit, is subject to MHL and OMH regulations, not the FHCDA.

In instances where the FHCDA is applicable to the patient transferred from a mental hygiene facility, certain special rules apply. First, the FHCDA contains explicit provisions for the determination of incapacity due to mental illness.[93] Additionally, notification of determination of incapacity must be sent to the director of the mental hygiene facility from which he was transferred and to MHLS.[94] MHLS has the right to "initiate and take any legal action deemed necessary to safeguard the right of any patient or resident to protection from abuse or mistreatment."[95] Thus MHLS has the ability to object to a determination of incapacity and can delay the appointment of a surrogate to make decisions regarding withdrawing treatment until they have had time to review the case.

For individuals with mental illness outside of hospitals, the Task Force, in a 2013 report, proposed extending the FHCDA to home care and community-based settings.[96] This proposal would allow surrogates to make life-sustaining treatment decisions on behalf of incapacitated individuals (including those with mental illness) in the community setting under a similar framework to that already required in more institutional settings. However, the proposal would mirror the more stringent requirements of the FHCDA by requiring an Ethics Review Committee to approve all surrogate withdrawal and withholding decisions. Furthermore, the Task Force recommended the initial application of the proposal only

[93] In a general hospital, determinations of incapacity for individuals with mental illness require review by a properly licensed health care practitioner. Proper licensure requires that a physician is "licensed to practice medicine in New York State, is a diplomate or eligible to be certified by the American Board of Psychiatry and Neurology or who is certified by the American Osteopathic Board of Neurology and Psychiatry or is eligible to be certified by that board." *See* NY PHL § 2994-c(3)(c)(i). Either an attending physician or an independently concurring physician must have these qualifications in order to make an initial determination that a patient lacks decision-making capacity due to mental illness.
[94] NY PHL § 2994-c(4)(c).
[95] NY MHL § 47.03(e).
[96] *See Recommendations for Extending the Family Health care Decisions Act to Medicare and/or Medicaid-Certified and State-Licensed Agencies, Programs, and Settings*, NY State Task Force on Life and the Law, June 3, 2013.

extend to those institutions that "opt-in."[97] This would allow institutions beyond hospital settings adequate time to adapt their procedures to the framework.[98]

[97] *See id.* at 11.
[98] *See id.*

VI. Analysis

The Special Advisory Committee (SAC) heard from a number of advocates, patients, and providers from communities representing individuals with mental illness and individuals with developmental disabilities. Advocates representing those with mental illness, including representatives from the Mental Health Empowerment Project, explained that many within their community do not want to be treated differently from the general population. Advocates representing those with developmental disabilities, including representatives from NYSARC, explained that there are times when members of their community, who cannot advocate for themselves, need special safeguards and thus require being treated differently. All advocates expressed a desire for adequate patient protections during end of life decisions, to ensure that withdrawing and withholding treatment choices are made according to the patient's wishes and best interests. Speakers also provided insight into the nature of treatment and care in both community and hospital settings, describing the structure of care teams and shared decision-making between providers and patients. In light of these facts, many patient advocates and providers acknowledge the value of existing protections, but believe that amendments could facilitate care that better aligns with patients' wishes and interests.

The SAC examined whether historical and present biases against, and vulnerabilities of, those with developmental disabilities and mental illness justify requiring additional legal checks (beyond those for people who are incapacitated for other reasons) to ensure their lives are not undervalued for end-of-life decisions. Some advocates have expressed opposition to special decision-making rules on the basis of mental health or developmental disability status, whereas other advocates argue in favor of special treatment for the reasons discussed above. The SAC accepts the general principle that end of life treatment decisions should be uniformly protective for all incapacitated populations, regardless of the nature or cause of each individual's incapacity.

The SAC also holds the position that uniformly protective decisions should not imply that choosing to provide life-sustaining treatment is always a superior option to withholding or withdrawing such treatment. The ethos of Western medicine has evolved in recent decades toward accepting that death is not the worst possible outcome of care. Rather, pain and suffering for no medical benefit is the outcome to be avoided. Commonly held moral assumptions of medicine reject the provision of care that increases pain and prolongs the dying process for many, including for patients with intellectual or developmental disabilities.

Determining the optimal balance of clarity, uniformity, and comprehensiveness of protection guided the SAC's decision whether to eliminate or modify the HCDA. Many people who spoke with the Advisory Committee expressed that the HCDA has served a

vital function in the State. Its provisions were crafted with careful attention to the vulnerability of individuals with developmental disabilities at the end of their lives. However, the SAC recognizes that greater legal clarity and efficiency might be achieved by unifying the HCDA and the FHCDA. Confusion that results from the current set of divergent standards likely prevents health care practitioners from facilitating timely decisions. The lack of clarity might also be responsible for incorrect administration of surrogate decisions. Health care providers indicated that, at times, legal complexity and certain aspects of mandatory procedure delay the administration of necessary life-sustaining treatment decisions.

Furthermore, disparate laws create concern about equal treatment. Even if the frameworks are followed correctly, similarly situated incapacitated patients might be subject to different surrogate life-sustaining treatment decisions for no reason beyond differences in governing laws that have no rationale. Such disparate treatment could lead to disparate outcomes that are not predicated on the unique needs of each patient.

For the foregoing reasons, the Special Advisory Committee recommends that the FHCDA and the HCDA should be consolidated and streamlined in order to: make the decision process more intelligible as well as efficient for health care providers and surrogates; protect the rights of all patients to have decisions made according to their wishes and in their best interests; and ensure equal protections for different populations. Specifically, the current surrogate decision-making laws and regulations for patients with developmental disabilities and patients in mental health facilities should be merged into the FHCDA for treatment decisions made in facilities covered by the FHCDA, while preserving those principles and safeguards that have proven necessary for these populations.

Finally, SCPA § 1750-b should be adapted to authorize surrogate decisions in settings not covered by the FHCDA (including decisions in residential settings licensed or operated by OPWDD). It should do this by referring to the standards and procedures in the FHCDA, with some adjustments.

The following summarizes the primary issues considered by the SAC with regard to reconciling the FHCDA and the HCDA, and provides rationale for the SAC's recommendations.[99]

Decision-making standards: Members and advocates voiced concern over how to ensure that surrogate decisions accurately reflect the patient's wishes if known, and the patient's best interests. Some advocates and SAC members were concerned that doctors or

[99] Some members discussed how educational opportunities, including CME or CLE courses for physicians, family members, and attorneys on the topic of withdrawal and withholding treatment decisions for the incapacitated could be helpful. However, creating these opportunities was determined to be beyond the scope of the present assignment.

surrogates might undervalue the quality of life of patients with mental illness or developmental disabilities and might opt for withdrawal or withholding treatment too quickly. On the other hand, the SAC also voiced concern that doctors or surrogates might opt to continue life-sustaining treatment out of personal interests or legal fears. The SAC recommends mechanisms to prevent surrogates from substituting their own judgment in making withholding and withdrawal decisions, and ensure that these decisions for all patients reflect the patient's wishes if known and if not known, the patient's best interests.

The FHCDA prioritizes the patient's wishes over best interests, and includes consideration of the patient's religious and moral beliefs under the category of wishes. Under the FHCDA, if the patient's wishes are not known, then the surrogate should base the decision on the patient's best interests. In contrast, the HCDA requires that the surrogate's decision be based on the patient's best interests and then on the patient's wishes, if known. Many SAC members agree that patient's wishes, when known, should be prioritized over best interests for all surrogate decisions regarding withdrawing or withholding treatment. This prioritization is designed to respect the patient's autonomy. Under this standard, if a patient's wishes are not known or cannot be ascertained, then their best interests should form the basis of the surrogate decision.

However, if the patient did not, or cannot, provide an explanation of his or her wishes that are explicitly tied to withdrawal or withholding life-sustaining treatment, it is important to consider which, if any, of the patient's wishes are sufficient to serve as the decision basis. A patient might have sufficient capacity to express a wish to remove life-sustaining apparatus because it is causing the patient discomfort or fear, while at the same time he or she is unable to comprehend that the result of removal will be the termination of his or her own life. The SAC spoke with patient advocates and self-advocates from the disability rights community who strongly recommended that individual patients have control over their own end-of-life decisions to the greatest extent possible. Health care providers and caretakers who have a history of attending to the patient should be involved in identifying the patients' wishes and best interests. 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. [100] To respect dignity and personhood, advocates believe that patients with any degree of communication ability should be given the opportunity to provide input regarding the decision, supported by those who know them best, and this input should be taken seriously by decision makers.

[100] Close individuals were not necessarily those that would have decision making authority under either the FHCDA or HCDA, but rather anyone that interacts with the person on a regular basis such as health aides, friends, and others they may regularly encounter.

The SAC believes that a patient's wishes should be given precedence if the patient expressed relevant wishes at a time when he or she had capacity. Members recommend using the FHCDA standard with minor clarification to ensure that wishes are drawn from a time when the patient had decision-making capacity. The SAC also recommends that individuals close to the patient assist the surrogate decision maker in considering the patient's past and present wishes.

The SAC recognizes the possibility that some physicians and surrogates might discount the quality or value of a patient's life on the basis of that patient's mental illness or developmental disability. Disability Rights Professor William Peace explains that "people with significant disabilities are at risk of having presumptions about the quality of their lives influence the way medical providers, including physicians, respond to them."[101] In a moving example, Professor Peace, who has been paralyzed since he was eighteen, discussed his own hospital experience in 2010 for a serious open wound. During this event, a physician indicated to Professor Peace that receiving comfort care with the expectation of death might be preferable to treatment that could leave him permanently bedridden and financially disadvantaged.[102] Professor Peace had the autonomy to navigate his physician's bias framing of treatment options that implied Professor Peace's condition was too great a burden. Unfortunately, the populations that are the subject of this Report may not have such autonomy.

Accordingly, the SAC recommends that language be added to the FHCDA which explicitly prohibits the presumption that people with mental illness or developmental disabilities are entitled to less care, dignity or respect as patients without such conditions. This language is similar to language which currently exists in the HCDA. The SAC also recommends that surrogates should not base their decisions on financial considerations, except as the patient would have wished them to be considered.

Settings of Care: The HCDA currently covers patients in all medical settings, including care at home. However, the FHCDA only covers decisions in general hospitals (excluding a ward, wing, unit or other part of a general hospital operated for the purpose of providing services for persons with mental illness pursuant to an operating certificate issued by the Commissioner of Mental Health), nursing homes, and hospices. Representatives of OPWDD and NYSARC raised the concern that integrating the HCDA into the FHCDA could undermine valuable rights and protections for patients treated in community settings. They opposed the integration of the HCDA into the FHCDA unless the proposed amendments to the FHCDA would preserve decision-making in home and community

[101] William J. Peace, "Comfort Care as Denial of Personhood," *Hastings Center Report* 42, no. 4 (2012): 14-17, at 15.
[102] *See id.*

based care. That concern includes the need to preserve the current ability of a surrogate and a physician in the community to complete a Medical Orders for Life-Sustaining Treatment (MOLST) form pursuant to the HCDA. To meet these concerns, the SAC recommends amending the HCDA so that people with developmental disabilities are covered by FHCDA standards in all settings, including those not otherwise covered by the FHCDA, like community settings.

In addition, it has become apparent that there is no need for a separate law for DNR orders in psychiatric hospitals and units, and its existence is a source of complexity and confusion. Bills to repeal this vestige of the original DNR law and apply the FHCDA to DNR orders in those settings have been introduced in the state Legislature.[103]

Advocating for Treatment: The HCDA places an affirmative obligation on surrogates to "advocate for the full and efficacious provision of health care, including life-sustaining treatment," whereas the FHCDA does not. The SAC considered whether this provision helps prevent surrogate decisions from being made without adequate consideration of the patient's wishes and best interests, or helps prevent patient's mental illness or developmental disability from being used as a justification for withholding or withdrawing treatment. The SAC does not recommend incorporating the advocacy provision of the HCDA into the FHCDA. The protocol in the FHCDA, with SAC recommended amendments, is designed to ensure that decisions regarding life-sustaining treatment are tailored to the needs of specific patients, which reflects advocacy for the reasonably known wishes, or else best interests of the patient. In some situations, an obligation to advocate for the "full and efficacious treatment" may be contrary to a patient's wishes or even best interests. Including the provision would also violate the general principle of a single standard for all patients. However, the SAC does recommend preserving a provision, adapted from the HCDA that prohibits surrogates or providers from presuming that a person with a developmental disability is not entitled to the full and equal rights, equal protection, respect, medical care, and dignity afforded to persons without a developmental disability. The SAC believes this provision should be extended to prohibit similar presumptions about persons with mental illness.

Expression of a Decision to Withdraw or Withhold Life-Sustaining Treatment: The FHCDA only requires the surrogate to express a decision to withdraw or withhold life-sustaining treatment "either orally to an attending physician or in writing,"[104] whereas the HCDA requires a written decision to be signed, dated, and witnessed, then presented to the attending physician.[105] Under the HCDA, if the surrogate chooses to express the decision to

[103] S.7152(Hannon)(2014)/A.9548 (Gunther)(2014); A.1023 (Gunther)(2015).
[104] *See* NY PHL § 2994-d(5)(e).
[105] *See* NY SCPA § 1750-b(4)(c)(i).

withdraw or withhold life-sustaining treatment orally, this must be done to two adult persons, at least one of whom is the patient's attending physician.[106] The SAC believes that the less rigorous standard employed by the FHCDA – the surrogate communicating the decision directly to the attending physician – is sufficient for ensuring both efficiency and protection against misunderstanding or miscommunication. The physician will confirm that the surrogate understands the implications of the decision, and will apply his or her own professional expertise to verify that the decision complies with the requirements set forth by the FHCDA.

Capacity Determinations: The FHCDA and the HCDA maintain slightly different technical requirements for determination of incapacity for purposes of a decision to withdraw or withhold life-sustaining treatment. The SAC reviewed these standards in the FHCDA and the HCDA to ensure determinations of incapacity that are both accurate and practical, and to ensure those with capacity retain control over their own end-of-life treatment decisions. The FHCDA contains a presumption of capacity for patients, which the SAC recommends preserving except for persons with guardians appointed pursuant to Mental Hygiene Law Article 81 or Surrogate's Court Procedure Act Article 17-A. Regardless of this presumption, for end-of-life decisions, the FHCDA requires the attending physician to determine incapacity to a reasonable degree of medical certainty, and to assess the cause and extent of incapacity, and the likelihood that the patient will regain decision-making capacity. In the opinion of the SAC, the FHCDA standards are sufficient for determinations of incapacity for these populations. For a decision to withdraw or withhold life-sustaining treatment, however, the SAC recommends using the HCDA standard of capacity determination.

Credential Requirements for Concurring Health Care Professionals: In connection with decisions to forgo life-sustaining treatment, both laws require a concurring (second) determination of incapacity by another practitioner.[107] When the determination relates to a mental illness or developmental disability, both laws require that either the attending physician or a concurring physician possess special qualifications relating to that condition.[108] The requirements for a physician to concur with an incapacity determination due to developmental disability are more rigorous than for concurrence with a determination due to mental illness. Members of the SAC as well as several practitioners that spoke with the SAC report that general hospitals and residential care facilities, especially in rural areas, have had difficulty finding practitioners that meet the qualifications for concurring with an initial determination of incapacity due to developmental disability, which unnecessarily delays the treatment decision process. To

[106] *See* NY SCPA § 1750-b(4)(c)(ii).
[107] *See* NY PHL § 2994-c(3); NY SCPA § 1750-b(4)(a).
[108] *See* NY PHL § 2994-c(i)-(ii); NY SCPA § 1750-b(4)(a).

address this, the SAC recommends adding another option by which a physician concurring on an incapacity determination due to developmental disability can meet the necessary requirements in a way that mirrors the requirements for an incapacity determination due to mental illness. This option would allow a physician to concur on an incapacity determination due to developmental disability if the physician is certified by a board of psychiatry or is eligible for certification by such a board.

Clinical Determinations: The FHCDA and the HCDA both require that clinical determinations must be made before a surrogate may authorize the withdrawal or withholding of life-sustaining treatment. As a safeguard, both laws require that the determinations must be made by an attending physician, and then confirmed by another physician. The SAC noted that, given the risk of persons with developmental disabilities being devalued, concerns arise when the concurring physician is subject to hierarchical pressures from the attending physician. Notably the FHCDA requires an "independent concurrence by another physician." The SAC encourages hospitals to take steps to ensure that the concurrence is in fact truly independent.

Patients in or Transferred from OMH Facilities: When the FHCDA was being drafted, OMH asked to exclude from FHCDA coverage individuals in or transferred from its facilities. This request was made in order to have additional time to consider whether FHCDA coverage would best protect OMH facility residents. Without FHCDA coverage, there are no rules governing decision to withdraw or withhold life-sustaining treatment for this population. When patients are transferred to general hospitals from OMH facilities, many providers are uncertain as to the proper legal authority guiding decision to withdraw or withhold life-sustaining treatment; others simply assume the FHCDA applies to such patients as it does to all other patients. The SAC recommends extending the FHCDA to patients in or transferred from OMH facilities.

An OMH rule at 14 NYCRR § 27.9 governs major medical treatment decisions for OMH facility residents, but withdrawal and withholding life-sustaining treatment decisions are not explicitly included under "major medical treatment." Under 14 NYCRR § 27.9, if a patient in an OMH facility does not have the capacity to consent to major medical treatment, consent must be obtained from a spouse, parent, adult child, or a court. Decision-making priority among categories of surrogates is not specified. The SAC recommends applying the FHCDA surrogate hierarchy in these situations.

Mental Hygiene Legal Service Notification: MHLS provides essential advocacy services for people with mental illness and developmental disabilities across New York State. Currently under the FHCDA, MHLS must be notified if a patient transferred from any mental hygiene facility, including those licensed or operated by OMH or OPWDD, is determined incapacitated for purposes of decision to withdraw or withhold life-sustaining

treatment. The FHCDA does not require that MHLS be notified for the decision itself. The HCDA does require that notice be given to MHLS prior to implementing the decision. These notification requirements were created to provide vulnerable populations with legal advocacy to ensure that end-of-life treatment decisions are motivated strictly by the patient's wishes and best interests.

Presentations to the SAC by MHLS representatives from the Appellate Division, Third Department confirmed the agency's capacity to provide a critical service during decisions about whether or not to withdraw or withhold life-sustaining treatment for patients incapacitated due to mental illness or developmental disability. Many health care providers who spoke to the SAC described positive collaborative experiences with specific MHLS departments including the third. It was explained that some facilities without general counsel often rely directly on MHLS for legal support during end-of-life decision-making.

Some health care practitioners described experiences in which MHLS routinely objected (formally or informally) to decisions to withdraw or withhold life-sustaining treatment on the basis of having inadequate information about the patient's condition. MHLS's review to ensure these decisions were patient-protective caused delays, which in some cases increased the suffering of patients for whom withdrawal or withholding of life-sustaining treatment was medically indicated.[109]

The SAC recommends a policy that would preserve MHLS's ability to act as an effective patient advocate while recognizing the primary authority of the surrogate, in consultation with the attending physician, to make decisions based on the patient's wishes and interests.

First, this would encourage the clinical team to include MHLS in the clinical team's end-of-life decision process before the surrogate's decision is officially made. The team meeting would include the attending physician, the surrogate, a representative from MHLS, and other care providers deemed essential by the physician and could take place in person or by phone. By being present for this meeting, MHLS would receive comprehensive information about the patient's status and could thus advocate effectively on the patient's behalf.[110] Accordingly, MHLS's participation at this meeting would serve as official notice to MHLS of the decision as required by the FHCDA, eliminating the need for any redundant paper notification. If MHLS is unable to participate in this meeting, the clinical team would be required provide notice of its decision to withdraw or withhold treatment to MHLS at least 48 hours prior to implementing the decision. MHLS would also be required

[109] Descriptions of experiences with different MHLS offices revealed that the offices do not operate with equal degrees of efficiency and timeliness. Providers who worked with the MHLS in the 3rd Department described positive experiences, while those who worked with MHLS in other departments shared less positive experiences.
[110] According to some practitioners, certain MHLS departments are already involved in this fashion.

to provide practitioners with a practical means to notify them at any time, so decisions are not delayed because they need to be made outside of regular business hours.

MHLS may still object to the decision regardless of whether they participated in the clinical meeting. For decisions to withdraw, such objection by MHLS would continue to cause an automatic stay on the withdrawal, preserving the status quo, as it does under the HCDA. But DNR orders are different: if MHLS's objection to a DNR results in an automatic stay, it would not preserve the status quo – in the event of cardiac arrest, this would cause the patient to be subject to an aggressive treatment that the surrogate maintains is contrary to the patient's wishes. There is a need to balance respect for a surrogate's role as the patient's principal spokesperson with the need for MHLS to protect against an unwarranted DNR. Accordingly, the SAC recommends that in the case of an objection by MHLS to a DNR order, in order for the objection to stay the decision, MHLS must provide specific reasons indicating why the surrogate's decision is not supportable under the FHCDA. If these reasons are medical, they must be substantiated by a physician, physician's assistant, or a nurse practitioner. This would prevent delay of time-sensitive treatment decisions that are necessary to honor a patient's wishes or interests and relieve suffering, while allowing MHLS to intervene when it has a legal basis to do so.

These recommendations would afford MHLS the opportunity to be fully integrated in the decision process by ensuring it receives complete and timely information, and allowing it to ask questions of those most intimately involved in the patient's care.

DNR Orders and Intubation: Tracheal intubation often is a critical component of cardiopulmonary resuscitation. For this reason, the SAC's recommendations for requiring specific reasons for an objection to an order not to resuscitate (DNR) in a hospital would also apply to intubation procedures critical to cardiopulmonary resuscitation.

However, it is important to note that a patient's or surrogate's consent to a DNR order does not imply an order not to intubate for conditions unrelated to cardiac arrest. There are situations in which a patient might want life-saving measures such as intubation in the event of respiratory distress, but does not want life-saving measures in the event of cardiac arrest. Accordingly, a surrogate's consent to a DNR order in a hospital typically carries with it a decision not to intubate *for purposes of cardiopulmonary resuscitation*, but may still allow pre-arrest intubation.

Measures to improve ventilation and cardiac function in the absence of a cardiac or pulmonary arrest are explicitly excluded from the FHCDA definition of cardiopulmonary

resuscitation.[111] The law does not clarify the relationship between DNR orders and intubation. An amendment to this effect is beyond the scope of the SAC and Task Force's assignment at this time.

Life Expectancy and Other Patient-Condition Requirements: Under both the FHCDA and the HCDA, there are different clinical criteria, outlined on page 13, which must be satisfied before a decision to withdraw or withhold life-sustaining treatment can be implemented. Both laws require that life-sustaining treatment would be an extraordinary burden to the patient. Then, both laws have additional requirements that can be met by choosing from among several options. One option under each law is based on the amount of time the patient is expected to live. Under the FHCDA time option, the patient's condition must be expected to cause death within 6 months, and under the HCDA time option, the patient's condition must be expected to cause death within one year.

The SAC does not believe that maintaining disparate time-frame standards is justified, and recommends only using the one-year expectation. The SAC learned that medical staff members are often reluctant to offer a narrow-window prognosis regarding a patient's time remaining before death largely because this is difficult to predict with accuracy. Evidence suggests that physicians' predictions that a patient will die within a year are more accurate than predictions regarding the number of weeks or months a patient has left to live.[112] The SAC believes that physicians can determine with reasonable accuracy that a patient will die within a year, and using this time frame as one of the options for patient-condition requirements will allow physicians to focus their analysis on whether life-sustaining treatment would provide medical benefit and/or relieve suffering. The time frame requirement does not justify a withholding or withdrawing decision by itself. It must always be accompanied by a determination that treatment would be an extraordinary burden. In conjunction with this latter "quality of life" determination, the SAC believes that a within-one-year "quantity of life" determination creates an ethical basis for a withholding or withdrawing decision.

The SAC also recommends adopting language from the HCDA to prevent consideration of the patient's developmental disability or mental illness from being used to satisfy the "incurable" or "irreversible" condition requirement. Under the HCDA, a decision to withdraw or withhold life-sustaining treatment may also be considered if life-sustaining treatment would pose an extraordinary burden and the patient has a condition *other than a*

[111] *See* NY PHL § 2994-a(3). When CPR is so defined, a non-hospital DNR order may not prevent emergency medical services personnel from intubating a patient whose heart was failing if the patient still has some pulse and breathing. A non-hospital DNI order may also need to be issued. *See* NY PHL §§ 2994-aa(4), 2994-dd(6).
[112] *See* Alvin Moss, et al., *Prognostic Significance of the "Surprise" Question in Cancer Patients,* 13 J PALLIATIVE CARE 837, 838-839 (2010) (explaining that physicians consistently overestimate when providing specific term survival prognoses for patients with cancer, and that their accuracy significantly improved when answering the question, "would you be surprised if this patient died in the next year?").

developmental disability that requires life-sustaining treatment, is irreversible, and will continue indefinitely. Because the patient's preceding mental status should never form the basis for a life-sustaining treatment decision, this language should be incorporated into the FHCDA to provide a requirement that the patient has an irreversible or incurable condition *other than mental illness or a developmental disability.*

The above two suggested amendments reconcile arbitrary disparities between the FHCDA and the HCDA, and apply a uniformly protective standard to all populations. The SAC believes that amending any other criteria that a patient's condition must meet prior to implementing a decision to withdraw or withhold life-sustaining treatment is beyond the scope of its assignment. It is possible that the evolution of palliative and hospice care since the passage of the FHCDA warrants a future re-examination of these criteria– such as defining "extraordinary burden" or "incurable" or "irreversible."

Preserving Psychiatric Treatment and Behavioral Intervention Provisions in NYCRR: Because of the unique nature of psychiatric treatment and behavioral interventions, the SAC recommends that the current exception under the FHCDA continue in facilities licensed or operated by the Office of Mental Health (OMH) and facilities or programs licensed, operated or funded by the Office for People With Developmental Disabilities. For patients without legal guardians in psychiatric units, there are regulations promulgated by the Office of Mental Health that govern determinations of capacity for medical decision-making, obtaining consent to treatment from the patient or a surrogate, and processes for objection to treatment.[113] For patients without legal guardians in OPWDD facilities or programs, there are regulations that govern the use of behavioral interventions, including the use of medication, and the process for obtaining consent to such interventions.[114]

These regulations take into consideration circumstances in which the administration of psychiatric treatment, including psychotropic medication, is necessary to reduce danger in emergencies, objections from any party, or lack of consent, notwithstanding.[115] While the FHCDA should be extended to apply to facilities licensed or operated by OMH for purposes of general medical treatment and decisions to withdraw or withhold life-sustaining treatment, detailed regulations promulgated by OMH and OPWDD regarding psychiatric treatment or the use of behavioral interventions should remain intact. To this end, the SAC recommends that the FHCDA's definition of "health care" be modified to exclude psychiatric treatment in a facility licensed or operated by OMH or the use of behavioral interventions in a facility or program licensed, operated or funded by OPWDD.

[113] *See* 14 NYCRR §§ 27.9, 527.8 (2015).
[114] *See* 14 NYCRR § 633.16 (2015).
[115] *See* 14 NYCRR §§ 527.8(c)(1), 633.16 (2015).

Ethics Review Committee and Special Proceedings: The HCDA explicitly grants surrogates, attending physicians, MHLS, mental hygiene facility CEOs, and OPWDD the right to take disputes (related to decisions to withdraw or withhold life sustaining treatment) to dispute mediation, or to bypass dispute mediation in favor of commencing a proceeding in a court of competent jurisdiction. Under the FHCDA, objections made by the attending physician, a health care professional called upon to concur with a capacity determination or a health care decision, a parent of a minor, or anyone on the surrogate list must be referred to an ethics review committee (ERC) for advisory nonbinding guidance. However, the FHCDA does not preclude persons connected with the case from seeking relief in courts of competent jurisdiction at any time.

Although both laws allow either alternative dispute resolution or resolution by a court of competent jurisdiction, the language of the FHCDA does not emphasize the latter option. The SAC discussed a range of experiences with ethics review committees providing guidance on end of life decision disputes. To ensure that objecting parties understand their rights for dispute resolution, the SAC recommends incorporating language into the FHCDA that explicitly grants parties the option of bringing their objections before a court of competent jurisdiction, in addition to the present language that requires referral to an ethics review committee for guidance.

The SAC discussed the need to preserve HCDA dispute resolution guidance for persons with developmental disabilities in all settings, including those beyond health care institutions and residential facilities. It is unclear which mechanism is best suited to resolve disputes over decisions to withdraw or withhold life-sustaining treatment for persons with developmental disabilities in settings like private homes. The nearest hospital ethics review committee might lack expertise in decision-making for those with developmental disabilities. Accordingly, the SAC recommends that the Commissioner of OPWDD have the authority to promulgate regulations for resolving such disputes, which could include convening a panel of individuals with appropriate expertise. In addition, the SAC recommends that a decision by a SDMC should not be subject to ERC review. The SAC also recommends a provision explaining that those involved in the dispute can always bring the case before a court of competent jurisdiction for judicial relief before, during, after, or instead of ethics committee review.

Surrogate Priority: The surrogate priority lists under the FHCDA and the HCDA do not run perfectly parallel. Under the HCDA, parents are given priority above adult children, whereas under the FHCDA, adult children are prioritized above parents. Members of the SAC agreed that if the patient has adult children, they should be given priority over the patient's parents regardless of the nature of the patient's incapacity. As such, the SAC recommends the use of the FHCDA hierarchy for all populations.

Active Involvement: The HCDA currently requires that a surrogate chosen for decision-making be "actively involved" in the patient's life, whereas the FHCDA makes no such requirement. To resolve this disparity, SAC members considered the following facts. One advocate explained that forty percent or fewer individuals with developmental disabilities in residential care have anyone actively involved enough in their lives who can be called upon to act as surrogate decision makers. It also was explained that individuals with mental illness tend to be even more estranged from family members than those with developmental disabilities. However, the experience of health care providers indicates that individuals who are not actively involved in the patient's life do not come forward to serve as surrogates. If someone on the surrogate list objects to the assignment of a different surrogate, the FHCDA requires the physician to refer the matter to an ethics review committee for resolution.[116]

After discussing the application of an "actively involved" standard for all surrogate decision makers, the SAC decided this requirement would unnecessarily hinder the surrogate appointment process. Advocates explained that those who are available to act as surrogates generally are "actively involved." Including this term in the law would create complications by introducing an ambiguous standard for involvement. It also was explained that health care providers who are concerned about a potential surrogate's lack of prior involvement do not require a legal standard in order to intervene appropriately.

However, one SAC member suggested that, in the case of a person with a developmental disability who is transferred from an OPWDD-licensed facility, the facility director can offer valuable guidance on which person within the priority class has been most actively involved or would serve as a better decision-maker. The SAC believes the attending physician should solicit this information before identifying the surrogate in life-sustaining treatment cases.

Unbefriended Patients and Surrogate Decision-Making Committees: Patients incapacitated due to mental illness or developmental disability who lack an authorized surrogate available and willing to make a decision are assigned different decision-makers under the FHCDA and the HCDA. The FHCDA allows a court of competent jurisdiction to make the decision to withdraw or withhold life-sustaining treatment if the patient is certified to lack capacity, and the patient's condition meets the necessary standards. The FHCDA also allows the attending physician and a concurring physician to make the decision if life-sustaining treatment will offer the patient no medical benefit and the patient will die imminently even if the treatment is provided, and the provision of such treatment would violate acceptable medical standards. The HCDA sends such life-sustaining treatment decisions to Surrogate Decision-Making Committees (SDMCs). The SAC acknowledges

[116] *See* NY PHL § 2994-f(2)(b).

that all unbefriended patients are particularly vulnerable to unethical or inappropriate surrogate decisions and deserve equally strong advocacy. The SAC examined whether courts and physicians (under FHCDA) or SDMCs (under the HCDA) provide strong enough representation for both or either population.

The SAC agreed that allowing the attending physician and a concurring physician to make decisions to withdraw or withhold life-sustaining treatment for unbefriended patients incapacitated due to mental illness based on the same "no medical benefit / will die imminently" standard that applies to other patients provides sufficient protections for this vulnerable population. Because these patients are unbefriended, their strongest personal connections are with their health care providers. These providers also have the keenest understanding of their patients' medical conditions. Before implementing a decisions to withdraw or withhold life-sustaining treatment, the attending physician and concurring provider are required to verify that the patient meets the condition requirements set forth by the FHCDA. The attending physician and concurring provider also must make the decision in accordance with the patient's wishes and best interests, as would any other surrogate. If one of these providers bases her decision on any other criteria, then the other will act as a safeguard and could initiate a dispute that will go to an ethics review committee or a court.

For unbefriended patients incapacitated due to developmental disability, it was discussed whether SDMCs convene quickly enough, have adequate decision-making expertise, and are comfortable issuing withholding decisions when necessary. Several SAC members reported positive professional experiences with SDMCs in these situations. The SAC discussed recommending that if a patient is transferred from a residential facility, the SDMC proceeding should include representation from that facility. Some members believed that a judicial process is too time consuming and abstracted from the patient's personal situation to ensure decisions that adequately reflect the patient's wishes and best interests. Accordingly, the SAC recommends incorporating SDMCs into the FHCDA hierarchy list so that they will continue to serve their decision-making function for unbefriended patients incapacitated due to developmental disability.

The SAC also considered a recommendation to extend SDMC decision-making to unbefriended patients with mental illness. However, the SAC decided that requiring SDMCs to serve as surrogate decision-makers for unbefriended individuals with mental illness was beyond the scope of its task. The Justice Center for the Protection of People with Special Needs oversees the operation of SDMCs and as such understands the extent of SDMC resources and capacity, whereas the SAC does not. The SAC recommends that the Justice Center examine whether this role extension would be advisable.

VII. Conclusion

For years, medicine and the law have poorly served patients without capacity, especially those with mental illness and developmental disabilities, in the end-of-life treatment context. Thorough legal guidance developed in recent years represents a historic shift toward protecting both the wishes and interests of incapable patient populations in their most dire moments. With meticulous effort, discrete groups of policy makers designed the existing laws and regulations discussed in this report that govern end-of-life treatment decisions for patients without medical decision-making capacity and with no legal guardian. The nuanced language of each was crafted to ensure processes that would lead to decisions that most closely align with each patient's wishes and interests. Multiple frameworks for patients who are incapacitated for different reasons and located in different settings came into existence because concerned groups acted on behalf of specific populations.

Now that the FHCDA and HCDA have co-existed for a few years, some facts have led to administrative complication. Patients travel between settings and do not always fit neatly into one framework; the laws have minor arbitrary differences that are difficult to remember; and certain requirement details cause delays during time-sensitive decisions without adding measurable protection. These circumstances have led to sub-optimal treatment for the intended patients.

For almost two years, the SAC of the Task Force on Life and the Law has worked to develop recommendations that alleviate these concerns while preserving the components of the FHCDA and the HCDA that are tailored to the unique needs of specific populations. To shape its recommendations, the SAC studied and debated the fine details of each law, and heard from experts and advocates about the laws in practice. The SAC 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. The SAC's recommendations also balance each setting's available resources and practitioner expertise with maintaining standards for arriving at the best decision for each patient. Of equal importance to the SAC was honoring the specific intentions of the crafters of the HCDA. Accordingly, the new recommendations preserve elements of the latter that were hard-fought and won to rectify years of discrimination against people with developmental disabilities.

The SAC's greatest challenge, and hopefully accomplishment, was consolidating the primary substance of these two laws into one while maintaining the crucial tailored differences. Reducing the quantity and complexity of the laws to which practitioners must

refer will streamline end-of-life treatment decisions. The recommendations should clarify what process applies in each setting and for each patient. Processes for determining capacity, determining the appropriate surrogate, and guiding, reviewing, and objecting to end-of-life treatment decisions remain entirely focused on enacting each patient's wishes and protecting each patient's interests. It is the SAC's hope that this clarity for providers and respect for vulnerable patients represents the next phase of moral progress in healthcare guidance, building on the essential work of the FHCDA and the HCDA.

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,

	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.

	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)		

	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.

	FHCDA – PHL Article 29-CC	**HCDA – SCPA § 1750-b**	**OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)**	**TASK FORCE PROPOSAL**
	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.

	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.

	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.

	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.

	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.

	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.

	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.

	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.

	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.

	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.

Appendix B - Members of the FHCDA Special Advisory Committee

<table>
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Appendix B - Members of the Task Force on Life and the Law (as of June 1, 2015)

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