NEW YORK STATE BAR ASSOCIATION

Report and Recommendation of the New York State Bar Association **Health Law Section and Committee on Disability Rights**

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Report and Recommendations of the New York State Bar Association Health Law Section and the New York State Bar Association Disabilities Rights Committee on Amending the Family Health Care Decisions Act to Cover Decisions for People with Intellectual or Developmental Disabilities

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I. INTRODUCTION

Currently, there are two principal laws that govern health care decisions for patients who lack capacity and who did not make an advance decision or appoint a health care agent: (1) The Family Health Care Decisions Act (FHCDA), which governs health care decisions for most such patients, and (2) the Health Care Decisions Act for People with Intellectual Disabilities (HCDA), which governs end-of-life decisions for people with intellectual or developmental disabilities.

These two statutes resemble each other but have numerous differences, most small, some large. Physicians, nurses and staff in hospitals, nursing homes and hospices have to follow the FHCDA routinely and are familiar with its requirements, forms, and processes. In contrast, they apply the HCDA infrequently and are less familiar with its requirements, forms and processes. As a result, end-of-life decisions for patients with intellectual or developmental disabilities are often hampered by confusion about the requirements, disruptions, delay or noncompliance.

At the direction of the Legislature, a Special Advisory Committee of the New York State Task Force on Life and the Law studied the differences in these statutes. It issued a report in 2016 (the "SAC/TF Report") recommending that the FHCDA should be amended to apply to decisions for people with intellectual or developmental disabilities, with certain safeguards adapted from the HCDA. However, to date no legislative bill has been introduced to accomplish that.

The NYSBA Health Law Section Executive Committee and the NYSBA Disabilities Rights Committee studied this issue and reviewed a draft legislative proposal. They concluded that amending the Family Health Care Decisions Act to apply to patients with intellectual or developmental disabilities would promote the interests of those patients and their families while also reducing confusion and disruption.

II. EXECUTIVE SUMMARY

The FHCDA and the HCDA

- Currently, there are two principal laws that govern health care decisions for patients who lack capacity and who did not make an advance decision or appoint a health care agent:
  - The Family Health Care Decisions Act (FHCDA), which governs health care decisions for most such patients, and
  - the Health Care Decisions Act for People with Intellectual Disabilities (HCDA), which governs end-of-life decisions for people with intellectual or developmental disabilities.

Differences and the Impact of Inconsistency

- There are numerous differences between the FHCDA and the HCDA, most small but some large. For example:
  - In cases where life-sustaining treatment is proposed to be withheld or withdrawn, the HCDA requires prior notice to three potential oversight agencies/entities, depending upon where the patient resides: Mental Hygiene Legal Service (MHLS), the mental hygiene facility director, and the OPWDD Commissioner.
  - The FHCDA applies only in hospitals, nursing homes and hospice whereas the HCDA is not limited to specific settings.
  - The FHCDA governs consent to treatment as well as decisions to forgo life-sustaining treatment, while the HCDA applies only to life-sustaining treatment decisions.
- The presence of two inconsistent decision-making laws has real-life clinical consequences.
- The Task Force on Life and the Law concluded that end-of-life decisions for patients with intellectual or developmental disabilities are often hampered by confusion about the requirements, disruptions, delay and/or noncompliance.
- Moreover, two inconsistent decision-making laws results in disparate treatment of patients with intellectual or developmental disabilities.

The NYS Task Force Recommendations

- The Legislature, in enacting the FHCDA in 2010, directed the New York State Task Force on Life and the Law to form a Special Advisory Committee (SAC) to recommend whether the FHCDA should be extended to include such decisions.
- In 2016 the SAC recommended extending the FHCDA to govern such decisions, with some safeguards borrowed from the HCDA. The Task Force unanimously approved that recommendation.
- Notably, the SAC/TF Report created a comprehensive chart of all the differences between the FHCDA and the HCDA and made recommendations as to each specific item. In most cases, it recommended achieving consistency by applying the FHCDA provision to people with intellectual or developmental disabilities.
- The SAC/TF Report recommended preserving the requirement of notice to MHLS, the facility director and OPWDD and the ability of oversight agencies to object in such cases. But it

called for some adjustments in the relationship of health care professionals, surrogates, and the oversight agencies, including MHLS.

The Draft Bill

- Two individuals with expertise on this issue, a member of the Health Law Section and a physician, prepared a draft bill and presented it to the Executive Committee of the Health Law Section and the Executive Committee of the Disability Rights Committee.

The Recommendation

- The Health Law Section and the Disability Rights Committee firmly support amending the FHCDA to cover decisions for people with intellectual or developmental disabilities, with the addition to the FHCDA of certain safeguards extracted or adapted from the HCDA.
- The current situation, where one surrogate decision-making law governs decisions for most patients, and another inconsistent law governs decisions for a small subpopulation of patients, is confusing and disruptive to patients, families and health care providers. Moreover, this patchwork of laws is also confusing to the bar and complicates efforts to advise clients. Finally, it is contrary to the principle of affording people with intellectual or developmental disabilities the same treatment as others, to the extent feasible.
- As the SAC/TF found, in most respects the FHCDA offers appropriate rules for health care decisions for people with intellectual or developmental disabilities.

III. BACKGROUND

The FHCDA and the HCDA

Currently, there are two principal laws that govern health care decisions for patients who lack capacity and who did not make an advance decision or appoint a health care agent:

The Family Health Care Decisions Act. The Family Health Care Decisions Act (FHCDA)[1] governs health care decisions for most patients who lack capacity and who did not decide in advance or appoint a health care agent. Enacted in 2010,[2] the FHCDA applies in hospitals, nursing homes and hospices, and provides a means to obtain both consent to treatment and a decision to withdraw or withhold life-sustaining treatment.[3] More specifically, the FHCDA includes a bedside process to determine incapacity, a priority list for the identification of a surrogate decision-maker, decision-making standards for the surrogate to follow, clinical criteria that must be met before the surrogate can authorize the withdrawal or withholding of life-sustaining treatments, and a process and standards for decisions for socially-isolated patients.[4] It also requires each hospital, nursing home and hospice program to either form or participate in an ethics review committee to assist in the resolution of disputes and perform certain decision-making functions.[5]

The Health Care Decisions Act for People with Intellectual Disabilities. Another statute, the Health Care Decisions Act for People with Intellectual Disabilities (HCDA),[6] governs end-of-life decisions for people with intellectual or developmental disabilities. It was enacted in 2002[7] in response to a legal case in which a family had no ability to decline aggressive end-of-life treatment for their dying daughter.[8] The HCDA both influenced and resembles the later FHCDA. Like the FHCDA, it addresses the determination of incapacity, identification of the surrogate, decision-making standards, and clinical prerequisites.[9]

Differences

There are numerous differences between the FHCDA and the HCDA, most small but some large.[10] For example, the FHCDA surrogate priority list places a patient's adult child as a higher priority than a patient's parent, while the HCDA places a parent higher than adult child.[11] More

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[1] New York Public Health Law (PHL) Article 29-CC.

[2] 2010 N.Y. Laws, ch. 8.

[3] NY PHL §§ 2994-a(12), 2994-a(14), 2994-a(18), 2994-b(1).

[4] NY PHL §§ 2994-c, 2994-d, 2994-g.

[5] NY PHL § 2994-m.

[6] NY Surrogate's Court Procedure Act (SCPA) § 1750-b.

[7] 2002 N.Y. Laws, ch. 500

[8] *Blouin v. Spitzer*, 213 F. Supp. 2d 184 (N.D.N.Y. 2002); *aff'd by Blouin v. Spitzer*, 356 F.3d 348 (2d Cir. 2004).

[9] NY SCPA § 1750-b(1)–(4).

[10] See New York Task Force on Life and the Law Special Advisory Committee, *Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities* June 21, 2016 ("SAC/TF Report"), at 9–18. The report is available online at https://www.empirestatebioethics.org/task-force-on-life-and-law.

[11] Compare NY PHL § 2994-d(1) with SCPA § 1750-b(1)(a), which refers to 14 N.Y.C.R.R. § 633.10(a)(7)(iv)(c)).

significantly, in cases where life sustaining treatment is proposed to be withheld or withdrawn, the HCDA requires prior notice to three potential oversight agencies/entities, depending upon where the patient resides. Oversight is provided by the Mental Hygiene Legal Service (MHLS), the mental hygiene facility director (for patients living in residences licensed or operated by OPWDD), and the OPWDD Commissioner (for patients living at home).[12] The FHCDA has no similar requirement for the general patient population. Another key difference is that the FHCDA applies only in hospitals, nursing homes and hospice whereas the HCDA is not limited to specific settings.[13] The FHCDA also governs consent to treatment as well as decisions to forgo life-sustaining treatment, while the HCDA applies only to life-sustaining treatment decisions.

[12] NY SCPA § 1750-b(4)(e)(ii).

[13] NY PHL §§ 2994-a(12), 2994-a(14), 2994-a(18), 2994-b(1).

IV. ANALYSIS AND PRESENTATION OF RECOMMENDATIONS

The Impact on Patients of Two Inconsistent Laws

The presence of two inconsistent decision-making laws has real-life clinical consequences. Physicians, nurses and staff in hospitals, nursing homes and hospice apply the FHCDA routinely, and are familiar with its requirements, forms, and process. In contrast, they apply the HCDA infrequently and are less familiar with its requirements, forms and process. The Task Force on Life and the Law concluded that end-of-life decisions for patients with intellectual or developmental disabilities are often hampered by confusion about the requirements, disruptions, delay and/or noncompliance.[14] Moreover, two inconsistent decision-making laws result in disparate treatment of patients with intellectual or developmental disabilities.[15]

The NYS Task Force Recommendations

The NYS Task Force on Life and the Law Special Advisory Committee Report. The Legislature, in enacting the FHCDA, was aware that the HCDA already governed end-of-life decisions for people with intellectual or developmental disabilities. Rather than work on reconciling the laws from the start, it "carved out" of the FHCDA decisions governed by the HCDA.[16] But it directed the New York State Task Force on Life and the Law to form a Special Advisory Committee (SAC) to recommend whether the FHCDA should be extended to include such decisions.[17] The SAC was formed, studied the issue, and in 2016 recommended extending the FHCDA to govern such decisions, with some safeguards borrowed from the HCDA.[18] The Task Force unanimously approved that recommendation. Notably, the SAC/TF Report created a comprehensive chart of all the differences between the FHCDA and the HCDA, and made recommendations as to each specific item.[19] In most cases, it recommended applying the FHCDA provision to people with intellectual or developmental disabilities, achieving consistency. In a few instances, it proposed amending the FHCDA to adopt or adapt HCDA safeguards with respect to decisions for people with intellectual or developmental disabilities.

Mental Hygiene Legal Service. The SAC/TF Report recognized that MHLS as well as mental hygiene facility directors and OPWDD provide essential advocacy services for people with intellectual or developmental disabilities.[20] It recommended preserving the requirement of notice to MHLS, the facility director and OPWDD and the ability of oversight agencies to object in such cases. But it called for some adjustments in the relationship of health care professionals,

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[14] SAC/TF Report at 23.

[15] To be sure, in important respects this disparate treatment can be said to further the objectives of the statute to ensure that people with developmental disabilities receive efficacious treatment where possible and dignity at the end-of-life when treatment options have been exhausted. See Christy Coe, *Beyond* Being Mortal*: Safeguarding the Rights of People with Developmental Disabilities to Efficacious Treatment and Dignity at the End of Life*, 88 N.Y. St. Bar J. 9 (2016), available at https://nycourts.gov/ad3/mhls/articles/document2016-10-24-171316.pdf.

[16] NY PHL § 2994-b(3).

[17] 2010 N.Y. Laws, ch.8, § 28.1.

[18] SAC/TF Report at 36–37.

[19] *Id.*at 38–51.

[20] *Id.* at 28.

surrogates, and the oversight agencies, including MHLS.[21]

Specifically, it proposed that health care providers should be encouraged to involve MHLS and the other oversight agencies, as applicable, earlier in the decision making process, and that participation would take the place of formal notice to oversight agencies of a decision. It also recommended that, for MHLS and the other oversight agencies to object to a DNR decision, it must provide a basis in the statute for its objection.

The Draft Bill

After the SAC/TF Report was issued, the Task Force staff prepared a draft bill that was never introduced. Recently, two individuals with expertise on this issue, a member of the Health Law Section[22] and a physician,[23] prepared an updated version of the bill, with footnote explanations of each section, and presented it to the Executive Committee of the Health Law Section and to the Disability Rights Committee. (Attachment 1).

The Section and the Committee reviewed the draft bill and concluded that it will accomplish the objective: extending the FHCDA to cover decisions by people with intellectual and developmental disabilities, while preserving adequate safeguards for that population.

[21] *Id.* at 29–30.

[22] Robert N. Swidler is a longstanding member and former President of the Health Law Section. He was also a member of the NYS Task Force on Life and the Special Advisory Committee that developed the report on this topic.

[23] Patricia Bomba, MD, MACP, FRCP is a nationally and internationally recognized palliative care/end of life expert, especially known in New York State for developing Medical Orders for Life-Sustaining Treatment (MOLST).

V. CONCLUSION

The Health Law Section and the Disability Rights Committee firmly support amending the FHCDA to cover decisions for people with intellectual or developmental disabilities, with the addition to the FHCDA of certain safeguards extracted or adapted from the HCDA.

The current situation, where one surrogate decision-making law governs decisions for most patients, and another inconsistent law governs decisions for a small subpopulation of patients, is confusing and disruptive to patients, families and health care providers. Moreover, this patchwork of laws is also confusing to the bar and complicates efforts to advise clients. Finally, it is contrary to the principle of treating people with intellectual or developmental disabilities equally with other people, to the extent feasible. As the SAC/TF found, in most respects the FHCDA offers appropriate rules for health care decisions for people with intellectual or developmental disabilities.

The Section and the Committee also support incorporating some key safeguards from the HCDA into the FHCDA to better protect people with intellectual or developmental disabilities. That includes modifying the role of MHLS to align more closely with clinical operations and promote greater collaboration with healthcare providers. It also includes preserving the important role currently assigned to the Consumer Advisory Board for the Willowbrook class, and to Surrogate Decision Making Committees established by Mental Hygiene Law Article 80.

The draft bill that the Section and Committee reviewed will accomplish these objectives, and the Section and Committee recommend that the House of Delegates support it.

ATTACHMENT 1

Proposed act to extend the Family Health Care Decisions Act to apply to health care decisions for patients with intellectual or developmental disabilities[24]

§ 1. Subdivision 3 of Section 2994-b of the public health law is amended as follows:

3. Prior to seeking or relying upon a health care decision by a surrogate for a patient under this article, if ~~**the attending practitioner has reason to believe that the patient has a history of receiving services for an intellectual or developmental disability; it reasonably appears to the attending practitioner that the patient has an intellectual or developmental disability; or**~~ the practitioner in a general hospital has reason to believe that the patient has been temporarily transferred from a mental hygiene facility operated or licensed by the office of mental health ~~**or the office for people with developmental disabilities, then such physician, nurse practitioner or physician assistant shall make reasonable efforts to determine whether paragraph (a), (b) or (c) of this subdivision is applicable:**~~

~~**(a) If the patient has a guardian appointed by a court pursuant to article seventeen-A of the surrogate's court procedure act, health care decisions for the patient shall be governed by section seventeen hundred fifty-b of the surrogate's court procedure act and not by this article.**~~

~~**(b) If a patient does not have a guardian appointed by a court pursuant to article seventeen-A of the surrogate's court procedure act but falls within the class of persons described in paragraph (a) of subdivision one of section seventeen hundred fifty-b of such act, decisions to withdraw or withhold life-sustaining treatment for the patient shall be governed by section seventeen hundred fifty-b of the surrogate's court procedure act and not by this article.**~~

~~**(c) If a health care decision for a patient cannot be made under paragraphs (a) or (b) of this subdivision, but**~~ **and that** consent for the decision may be provided pursuant to the mental hygiene law or regulations of the office of mental health ~~**or the office for people with developmental disabilities**~~, then the decision shall be governed by such statute or regulations and not by this article.[25]

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[24] This draft bill is based on recommendations of a Special Advisory Committee of the Task Force in its 2016 report, *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*, which was approved by the full Task Force (Hereinafter, "SAC/TF Report"). In its report, the SAC and Task Force recommended extending the FHCDA to govern life-sustaining treatment decisions for persons with intellectual or developmental disabilities who lack capacity, thus superseding the Health Care Decisions Act for People with Intellectual Disabilities (SCPA § 1750-b) ("the HCDA").

This bill includes language developed by the Task Force staff in 2015 but with changes made mostly to limit the bill's scope to people with intellectual or developmental disabilities (not people in psychiatric hospitals or units), and to update and simplify some provisions. Also, it applies to all health care decisions for people with intellectual or developmental disabilities who are in hospitals, nursing homes and hospice (Section 1); and to life-sustaining treatment decisions in other settings (Section 8). The changes were drafted by Robert N. Swidler, J.D., a member of both the Task Force on Life and the Law and the Special Advisory Committee that developed the 2015 recommendations. Send comments and corrections to rswidler@outlook.com.

[25] This is the key provision of this bill that makes the FHCDA applicable to health care decisions for people with intellectual or developmental disabilities in hospitals, nursing homes and hospice. The current PHL § 2994-b(3) "carves out" persons with intellectual or developmental disabilities and persons temporarily transferred from psychiatric hospitals and units from the FHCDA. That is, the subsection makes the FHCDA inapplicable to health care decisions for such persons. This bill would delete the language that "carves out" decisions for people with intellectual or developmental disabilities and thereby make the FHCDA applicable. See SAC/TF Report at 23. (A separate bill would make the FHCDA applicable to people in or from psychiatric hospitals and units. See S.7507-A (2024) (Senator

§ 2. Subsection 1 and paragraph (a) of Subsection 4 of Section 2994-c of the public health law is amended as follows:

1. Presumption of capacity. For purposes of this article, every adult shall be presumed to have decision-making capacity unless

(a) determined otherwise pursuant to this section or pursuant to court order, or

(b) ~~**unless**~~ a guardian is authorized to decide about health care for the adult pursuant to article eighty-one of the mental hygiene law**, or**

(c) a guardian has been appointed for the adult pursuant to Article 17-A of the surrogate's court procedure act.[26]

4. Informing the patient and surrogate. Notice of a determination that a surrogate will make health care decisions because the adult patient has been determined to lack decision-making capacity shall promptly be given:

(a) to the patient where there is any indication of the patient's ability to comprehend the information**, provided that such notice to a patient with an intellectual or developmental disability is governed by subsection 1 of section twenty-nine-ninety-four-h of this article**;[27]

§ 3. Subsections 1 and 5 of Section 2994-d of the public health law are amended as follows:

§ 2994-d. Health care decisions for adult patients by surrogates.

1. Identifying the surrogate. One person from the following list from the class highest in priority when persons in prior classes are not reasonably available, willing, and competent to act, shall be the surrogate for an adult patient who lacks decision-making capacity. However, such person may designate any other person on the list to be surrogate, provided no one in a class higher in priority than the person designated objects:

(a) A guardian authorized to decide about health care pursuant to article eighty-one of the mental hygiene law **or article 17-A of the surrogate's court procedure act;**[28]

(b) The spouse, if not legally separated from the patient, or the domestic partner;

(c) A son or daughter eighteen years of age or older;

(d) A parent;

(e) A brother or sister eighteen years of age or older;

(f) A close friend;

(g) the Willowbrook Consumer Advisory Board for members of the Willowbrook class who are fully represented by the consumer advisory board, as provided in section 2994-h of this Act.

(h) A surrogate decision-making committee under article 80 of the Mental Hygiene Law, for persons eligible for such decision-making, provided that as an alternative such decision may also be made pursuant to section 2994-g(5) of this

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Brouk).

[26] This section amends the list of exceptions to the presumption of capacity. It adds to that list cases where the patient has an SCPA article 17-A guardian. However, it clarifies that the procedures for a determination of incapacity must still be followed before a withdrawal or withholding of treatment decision can be made. See SAC/TF Report at 27, 38.

[27] This is intended to conform the language here to language in proposed PHL § 2994-h relating to notification to a person with an intellectual or developmental disability of an end-of-life decision. The language guards against an assumption that a person with an intellectual or developmental disability cannot comprehend the information.

[28] This paragraph amends the FHCDA surrogate priority list to add SCPA article 17-A guardians to the highest priority category. In other words, if a person has an SCPA 17-A guardian, that guardian will have the authority of a surrogate under the FHCDA. This becomes necessary if the FHCDA applies to people with intellectual or developmental disabilities.

article.[29]

5. Decisions to withhold or withdraw life-sustaining treatment. In addition to the standards set forth in subdivision four of this section, decisions by surrogates to withhold or withdraw life-sustaining treatment (including decisions to accept a hospice plan of care that provides for the withdrawal or withholding of life-sustaining treatment) shall be authorized only if the following conditions are satisfied, as applicable:

(a)(i) Treatment would be an extraordinary burden to the patient and an attending practitioner determines, with the independent concurrence of another physician, nurse practitioner or physician assistant, that, to a reasonable degree of medical certainty and in accord with accepted medical standards, (A) the patient has an illness or injury which can be expected to cause death within ~~six months~~**one year**[30], whether or not treatment is provided; or (B) the patient is permanently unconscious; or

(ii) The provision of treatment would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances and the patient has an irreversible or incurable condition, **other than mental illness or intellectual or developmental disability,**[31] as determined by an attending practitioner with the independent concurrence of another physician, nurse practitioner or physician assistant to a reasonable degree of medical certainty and in accord with accepted medical standards.

(b) In a residential health care facility, a surrogate shall have the authority to refuse life-sustaining treatment under subparagraph (ii) of paragraph (a) of this subdivision only if the ethics review committee, including at least one physician, nurse practitioner or physician assistant who is not directly responsible for the patient's care, or a court of competent jurisdiction, reviews the decision and determines that it meets the standards set forth in this article. This requirement shall not apply to a decision to withhold cardiopulmonary resuscitation.

(c) In a general hospital, if the attending practitioner objects to a surrogate's decision, under subparagraph (ii) of paragraph (a) of this subdivision, to withdraw or withhold nutrition and hydration provided by means of medical treatment, the decision shall not be implemented until the ethics review committee, including at least one physician, nurse practitioner or physician assistant who is not directly responsible for the patient's care, or a court of competent jurisdiction, reviews the decision and determines that it meets the standards set forth in this subdivision and subdivision four of this section.

(d) Providing nutrition and hydration orally, without reliance on medical treatment, is not health care under this article and is not subject to this article.

(e) Expression of decisions. The surrogate shall express a decision to withdraw or withhold life-sustaining treatment either orally to an attending practitioner or in writing.

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[29] This paragraph amends the FHCDA list to add the MHL Article 80 surrogate decision-making committee as surrogate, if there is no higher category available. See SAC/TF Report at 35, 42. See also bill section 9 below, which adds the Willowbrook Advisory Council to the surrogate list, but in an uncodified section (because it is temporary).

[30] This amendment reconciles the conflicting life-expectancy standards for terminal illness in the FHCDA (six months) and the HCDA (one year) by adopting the HCDA standard. See SAC/TF Report at 31, 44.

[31] This clarifies that an intellectual or developmental disability or mental illness is not an "irreversible or incurable condition" that can serve as a basis for a withdrawal or withholding of life-sustaining treatment decision. See SAC/TF Report at 31–32.

§ 4. The Public Health Law is amended by adding a new Section 2994-h, to read as follows:

§ 2994-h Health care decisions for intellectually or developmentally disabled persons.[32] With respect to an intellectually or developmentally disabled person:

1. Notice of a determination that a surrogate will make health care decisions because the patient has been determined to lack decision-making capacity shall promptly be given:

(a) to the patient unless, due to a medical condition other than an intellectual or developmental disability (such as unconsciousness) it is medically certain that the patient is unable to comprehend the information;[33] and

(b) as otherwise provided by paragraph (a) of subdivision 4 of section twenty-nine-ninety-four-c of this article.

2. No health care decision shall be influenced in any way by a presumption that people with an intellectual or developmental disability are not entitled to the full and equal rights, equal protection, respect, medical care and dignity afforded to people without an intellectual or developmental disability.[34]

3. For an intellectually or developmentally disabled person, at least forty-eight hours prior to the implementation of a decision to withdraw life-sustaining treatment, or at the earliest possible time prior to the implementation of a decision to withhold life-sustaining treatment, the attending practitioner shall notify:[35]

(a) the intellectually or developmentally disabled person unless, due to a medical condition other than intellectual or developmental disability (such as unconsciousness) it is medically certain that the patient is unable to comprehend the information;

(b) if the person is in or was transferred from a residential facility operated, licensed or authorized by the office for people with developmental disabilities, the chief executive officer of the agency or organization operating such facility and the mental hygiene legal services; and

(c) if the person is not in and was not transferred from such a facility or program, the commissioner of developmental disabilities, or his or her designee.

4. Agencies or organizations described above and mental hygiene legal service:

(a) must adopt and disclose upon request a practical means to be notified at any time by an attending practitioner.[36]

(b) may waive the right to notified at any time; and

(c) after notice of a proposed withdrawal of life sustaining treatment, should respond as soon as reasonably possible. If all notified parties respond that they

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[32] This new section adapts FHCDA end of life decisions for people with intellectual or developmental disabilities by including many of the safeguards and procedures of HCDA, with some modifications. See SAC/TF Report at 23 *et seq*.

[33] This language is intended to guard against an undue assumption that a person with an intellectual or developmental disability cannot comprehend the information.

[34] This amendment prohibits decisions from being based on discriminatory presumptions about persons with intellectual or developmental disabilities.

[35] The section largely copies the HCDA requirement that, with respect to a patient with an intellectual or developmental disability, prior to withdrawing or withholding life-sustaining treatment, the attending physician must notify certain persons. Those include (a) the patient; (b) if the patient was transferred from an OPWDD facility, the CEO of the facility and MHLS; and (c) if the person was not transferred from an OPWDD facility to the commissioner of intellectual or developmental disabilities. See SAC/TF Report at 47 Subsequent footnotes will highlight differences from the current HCDA requirements.

[36] This sentence requires the facility director and MHLS to adopt and disclose a practical means to be notified. See SAC/TF Report at 29–30.

do not object, the decision may be implemented without regard to the forty-eight hour notification period.[37]

5. An inability to notify an agency or organization or the mental hygiene legal service after a good faith attempt to do so, or the absence of a response from any such entity after notification, shall not require a delay in the issuance of an order not to resuscitate.[38]

6. (a) If an agency, organization or mental hygiene legal service participates in the treatment meeting at which a decision by a surrogate is made to withdraw or withhold life-sustaining treatment, such participation shall be considered notice to the participating party for purposes of paragraphs 3(b) and no further notice to such entity shall be necessary, but all rights to object are preserved.[39]

(b) For purposes of this paragraph, a "treatment meeting" is a meeting (in person, or by any other means allowing communication by all participants) to review treatment options with and obtain a decision by the surrogate pursuant to this article, and that includes the attending practitioner, the surrogate, at least one other health or social services practitioner involved in provision of care to the patient, and such other persons as the attending practitioner or surrogate might invite for this purpose. The treatment meeting shall be documented in the medical record.

7. Objection to health care decision.[40]

(a) Suspension. A health care decision made pursuant to this article shall be suspended, pending judicial review or withdrawal of the objection, except if the suspension would in reasonable medical judgment be likely to result in the death of the intellectually or developmentally disabled person, in the event of an objection to that decision at any time by persons entitled to notification under subdivision 1 of this section.

(b) Form of objection. Such objection shall occur orally or in writing. Notwithstanding the foregoing, in cases where the attending practitioner has notified the agency or organization and the mental hygiene legal service of the entry of an order not to resuscitate pursuant to subdivision 1 of this section, and if such notice includes either the practitioner's statement of the diagnostic and prognostic basis for the medical determination in support of the order or an excerpt from the patient's medical record that is sufficient to support such determination, an order not to resuscitate shall not be stayed by an objection by such persons unless the objection is accompanied by

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[37] This sentence allows the party to be noticed the right to waive notice—so that, for example, if the facility director or MHLS have actual notice of a DNR order, they will not feel compelled to oppose the DNR order on the technical grounds that they were not given formal notice. See SAC/TF Report at 47.

[38] This sentence states that an inability to notify the facility director or MHLS shall not delay issuance of a DNR order. It recognizes that DNR decisions often must be made on an urgent basis, sometimes when the Director or MHLS is not reachable. It is also consistent with the principle that notification is not for the purpose of a securing the Director or MHLS's approval, it is to enable the Director or MHLS to object if they have a basis to do so. See SAC/TF Report at 29–30.

[39] This paragraph recognizes the common use of a facility-based treatment meeting for the purpose of making a decision to withdraw or withhold life sustaining treatment. As defined here, such meeting involves the surrogate, the attending practitioner and at least one other health or social service practitioner. The meeting would also permit and encourage the participation of MHLS. If MHLS attends, its attendance would be considered notice that a decision to withhold or withdraw care was made. This process would enable MHLS to be more involved in the care decision, so they could advocate for the patient if they feel that their view is not being fully considered. It would also provide them with more information on the case and provide a forum to ask clinical questions to the medical staff and treatment questions to the surrogate. And it would eliminate the need for a redundant formal notice of the decision to MHLS. However, if MHLS is unable to attend the meeting, the physician would be required to provide them with the required prior to withdrawing or withholding treatment. See SAC/TF Report at 29.

[40] This subsection adopts the HCDA provision regarding objections to a decision to withdraw or withholding life-sustaining treatment, with a significant modification noted in the next footnote.

(i) a written statement by the objecting party setting forth a basis for asserting that a standard in this article for entering such an order has not been met; and

(ii) if the basis relates to the failure to meet medical criteria in this article for the issuance of the order, the written statement must be based on information from or consultation with a physician, physician's assistant or nurse practitioner.[41]

8. For purposes of the surrogate priority list in section 2994-d of the public health law, the Willowbrook Consumer Advisory Board shall be the surrogate for any person who

(a) was a resident of the former Willowbrook state school on March seventeenth, nineteen hundred seventy-two and those individuals who were in community care status on that date and subsequently returned to Willowbrook or a related facility, who are fully represented by the consumer advisory board and who have no guardians appointed and

(b) persons in classes (a) – (f) of section 2994-d are not reasonably available, willing, and competent to act. However, with respect to a decision to withdraw or withhold life-sustaining treatment, as an alternative such decision may also be made pursuant to section 2994-g(5) of this article.[42]

§ 5. Section 2994-m of the public health law, is amended as by adding subsections 7 and 8 as follows:

7. A decision by a surrogate decision-making committee described in article 80 of the mental hygiene law for an intellectually or developmentally disabled person in any setting shall not be subject to review by an ethics review committee or other dispute resolution process described in this section.[43]

8. Special Proceeding. Nothing in this section shall preclude a person connected with the case from seeking judicial relief from a court of competent jurisdiction before, during or after ethics committee review.[44]

§ 6 Section 2994-t of the public health law, as added by chapter 8 of the laws of 2010, is amended as follows:

1. The commissioner, **in collaboration with the commissioner of the office of mental health and the commissioner of the office of people with developmental disabilities**, shall establish such regulations as may be necessary to implement this article.[45]This

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[41] As stated in the SAC/TF Report at 30:

> 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.

[42] This paragraph describes the class of patients for whom the Willowbrook Consumer Advisory Board will be surrogate, if there is no higher category available. See SAC/TF Report at 42.

[43] The state-sponsored SDMC is not subject to review by a hospital ethics review committee.

[44] This section confirms that parties have the right to seek judicial relief for decisions such as withdrawing and withholding life sustaining treatment. This is based on a similar provision found in the HCDA. See SAC/TF Report at 33.

[45] This section requires the DOH Commissioner to collaborate with the OMH and OPWDD Commissioners regarding

§ 7. Subsection 26 of Section 2994-a of the public health law is amended as follows:

26. "Person connected with the case" means the patient, any person on the surrogate list, a parent or guardian of a minor patient, the hospital administrator, an attending physician, any other health or social services practitioner who is or has been directly involved in the patient's care, and any duly authorized state agency, including the facility director or regional director for a patient transferred from a mental hygiene facility ~~and~~, the facility director for a patient transferred from a correctional facility **and any person entitled to notice under section 2994-h of this article, relating to decisions to withdraw or withhold life sustaining treatment for intellectually or developmentally disabled persons.**[46]

§ 8 Subdivision 6 of **Section 2994-dd of the public health law is amended as follows:**

6. (a) The commissioner may authorize the use of one or more alternative forms for issuing a nonhospital order not to resuscitate (in place of the standard form prescribed by the commissioner under subdivision two of this section). Such alternative form or forms may also be used to issue a non-hospital do not intubate order.

(b) Any such alternative forms intended for use for persons with developmental disabilities or persons with mental illness who are incapable of making their own health care decisions or who have a guardian of the person appointed pursuant to article eighty-one of the mental hygiene law or article seventeen-A of the surrogate's court procedure act must also be approved by the commissioner of developmental disabilities or the commissioner of mental health, as appropriate.

(c) An alternative form under this subdivision shall otherwise conform with applicable federal and state law.

(d) A Medical Order for Life-Sustaining Treatment (MOLST) form in the version previously approved by the commissioners of health, mental health and developmental disabilities meets the requirements of this section, provided that the commissioner of health may authorize updated versions of the MOLST form as needed, subject to paragraph (b). The MOLST form and guidance and checklists for using the MOLST form for any patient in any setting shall be posted on the department's website

(e) This subdivision does not limit, restrict or impair the use of an alternative form for issuing an order not to resuscitate in a general hospital or residential health care facility under article twenty-eight of this chapter or a hospital under subdivision ten of section 1.03 of the mental hygiene law.

FHCDA regulations.

[46] This section amends the definition of "Person connected to the case," the term which is used to identify who can commence an ethics committee review of a case and who can bring a special proceeding in court. This amendment would add to the definition any person entitled to notice under a new PHL § 2994-h relating to decisions to withdraw or withhold life-sustaining treatment for a person with an intellectual or developmental disability. It would thereby enable the CEO of a residential facility, MHLS or OPWDD to commence such proceedings in cases where they are entitled to notice of such decision.

§ 9. Section 1750-b of the Surrogate's Court Procedure Act is amended to read as follows:

§ 1750-b. Life-sustaining treatment decisions for persons with intellectual or developmental disabilities.[47]

1. Decisions to withdraw or withhold life-sustaining treatment for persons who have been found, pursuant to the provisions of this article, to lack capacity to make health care decisions, or for persons for whom no guardian has been appointed pursuant to section seventeen hundred fifty or seventeen hundred fifty-a of this article, but who have an intellectual or developmental disability, as defined in section 1.03 of the mental hygiene law shall be governed by:

(a) Public Health Law Article 29-c (Health Care Agents and Proxies) if applicable; or else

(b) Public Health Law Article 29-ccc with respect to nonhospital orders not to resuscitate if applicable; or else

(c) Public Health Law Article 29-cc article, for all other health care decisions, without regard to where the decision is made or where the care is provided.

2. With respect to decisions made pursuant to section 1 above outside of a hospital or hospice as those terms are defined in section 2994-a(i) of the public health law:

(a) "Attending practitioner" shall mean a practitioner who has primary responsibility for the treatment and care of the patient. Where more than one practitioner shares such responsibility, or where a practitioner is acting on the attending practitioner's behalf, any such practitioner may act as an attending practitioner pursuant to this article; and

(b) the commissioner of developmental disabilities may promulgate regulations setting forth a process for the resolution of disputes, provided that in a residential facility licensed or operated by the Office for People With Developmental Disabilities such process shall include review by a committee similar to the ethics review committee, but with composition and procedures promulgated by the Commissioner.

Section 10. This act shall take effect on the ninetieth day after it shall become a law.

[47] Section 8 amends the HCDA (SCPA §1750-b) by deleting most of the existing language and replacing it with language that references the three successive statutes that will govern health care decisions for people with intellectual or developmental disabilities. The reason for preserving the HCDA at all is that the FHCDA only applies to hospitals, nursing homes, and hospices whereas HCDA applies to all settings, including those outside of hospitals. The amended HCDA would make the FHCDA apply to end-of-life decisions for people with intellectual or developmental disabilities without regard to the setting, but with some technical adjustments regarding the definition of attending physician and the ethics review committee. See SAC/TF Report at 25–26.