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2023 Disability Law Series: Civil Rights and Individuals with Developmental Disabilities

Consent in Health Care Decisions

February 9, 2023

80 NEW SCOTLAND AVENUE
ALBANY, NEW YORK 12208-3494
TEL: 518-472-5888 FAX: 518-445-2303
WWW.ALBANYLAW.EDU/CLE

2023 Disability Law Series:
Civil Rights and Individuals with Developmental Disabilities
Presented by the Government Law Center at Albany Law School

Consent in Health Care Decisions
February 9, 2023, 1:00 pm – 3:00 pm

1:00 p.m. **Introductions**

Hon. Leslie E. Stein ’81 (ret.), Director, Government Law Center
Alicia Ouellette ’94, President and Dean, Albany Law School (moderator)

1:10 p.m. **Overview of New York health care decision-making statutes: Family Health Care Decisions Act, PHL Art. 29CC, Health Care Decisions Act, SCPA 1750-B; Health Care Proxies, PHL Art. 29C**

Robert N. Swidler, Esq., Vice-President, St. Peter’s Health Partners

1:30 p.m. **Informed Consent for Medical Treatment**

Megan Applewhite, MD, MA, FACS, Director, Alden March Bioethics Institute at Albany Medical College Albany Medical Center

1:50 p.m. **Role of Supported Decision-making in Health Care Settings**

Sheila Shea, Esq. ’86, Mental Hygiene Legal Service
Haldan Blecher, Esq., Office of People with Developmental Disabilities

2:30 p.m. **Q&A**

2:50 p.m. **Closing Remarks**

The Government Law Center at Albany Law School Presents
The 2023 Disability Law Series: Civil Rights and Individuals with Developmental Disabilities

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Speaker Biographies

MEGAN APPLEWHITE is an Associate Professor in the Department of Surgery and Center for Ethics Education and Research at Albany Medical College. Dr. Applewhite is the Director of the Alden March Bioethics Institute at Albany Medical College and holds the John A. Balint, M.D., Chair of Medical Ethics in the College. She is also a Consultant Bioethicist for the Department of Defense Medical Ethics Center (DMEC). Dr. Applewhite is a board-certified General Surgeon and is fellowship trained in Endocrine Surgery. Her research interests include surgical ethics education, health care of the incarcerated patient population, utilization of limited resources, and quality of life after thyroid and parathyroid surgery.

HALDAN BLECHER is a Senior Attorney at the New York State Office for People with Developmental Disabilities (OPWDD) in the Bureau of Service Compliance and Fair Hearings. His work is primarily focused on the individual rights of people with developmental disabilities, including developing regulations, guidance, and policy in the areas of decision-making, consent, guardianship, community placement procedures, behavioral interventions, religious liberties, medical orders for life sustaining treatment, and privacy. He is a graduate of The City College of New York and City University of New York School of Law, and began his career in public service as a New York State Excelsior Service Fellow. Mr. Blecher was the principal author of New York's Supported Decision-Making Act, which will become Article 82 of the Mental Hygiene Law upon adoption of associated OPWDD regulations. Mr. Blecher obtained his J.D. at the City University of New York School of Law.

ALICIA OUELLETTE is President and Dean of Albany Law School. Prior to her appointment as President and Dean, she served as Associate Dean for Academic Affairs and Intellectual Life and a Professor of Law. Before joining the law school in 2001, Dean Ouellette was an Assistant Solicitor General in the New York State Attorney General's Office and a law clerk to the Honorable Howard A. Levine at the New York Court of Appeals. As a scholar, Dean Ouellette focuses on health law, disability rights, family law, children's rights, and human reproduction. Her book, *Bioethics and Disability: Toward a Disability Conscious Bioethics*, was published in

2011 by Cambridge University Press. She has authored numerous articles published in academic journals such as the *American Journal of Law and Medicine*, *American Journal of Bioethics*, *Nevada Law Journal*, *Hastings Law Journal*, *Indiana Law Journal*, and *Oregon Law Review*. Dean Ouellette obtained her J.D. at Albany Law School.

SHEILA E. SHEA '86 is Director of the Third Judicial Department of the Mental Hygiene Legal Service, where she provides legal services to individuals with mental health and developmental disabilities. She also serves as chair of the New York State Bar Association Task Force on Mental Health and Trauma Impacted Representation. Ms. Shea obtained her J.D. at Albany Law School.

ROBERT N. SWIDLER is Vice President of Legal Services for St. Peter's Health Partners. Previously, Mr. Swidler was Counsel to the Northeast Health (1998–2011), Counsel to the New York State Office of Mental Health (1992–95), Assistant Counsel to Governor Mario Cuomo (1990–92), and Staff Counsel to the New York State Task Force on Life and the Law (1985–90). He is on the adjunct faculty of both the Alden March Bioethics Center at Albany Medical College and the Union Graduate College/Mt. Sinai Bioethics Program. Mr. Swidler obtained his J.D. at Columbia Law School.

Fact Pattern No. 1
"George"

George is a 28-year-old man with Autism Spectrum Condition (ASD/ASC), mild to moderate intellectual disability, and impaired communication ability. He communicates verbally, but generally only with those he knows and trusts. With others, he is hesitant to vocalize, but may use other modes of communication, such as conventional gesturing or individualized signaling ("stimming") like finger snapping, hand-flapping, or averting his gaze.

George lived with his mother and attended school until age-21, at which point he moved to an OPWDD-certified Individualized Residential Alternative (IRA), where he currently resides with three other individuals with developmental disabilities.

George's mother occasionally visits the IRA, and calls regularly, but does not wish to be involved in medical or behavioral decision-making for George or attend program planning meetings with George and his Care Manager. George has no legal guardian or other known family members; however, he has a close friend, (Edward) with whom he attended school and continues to play games and chat over the internet. He also has positive relationships with a number of the staff at his IRA and a former teacher, who occasionally visits George. A now-retired staff member also now attends George's planning meetings as his advocate.

George has no major health concerns, but struggles to maintain his oral hygiene, smokes cigarettes and is significantly overweight. Over the past year, he has expressed to staff that he experiences consistent pain in two of his back molars. He also has noticeable gum recession, and occasionally complains of shortness of breath. George's treatment team has scheduled appointments at a local dentist for regular cleanings and evaluation of the tooth pain, but the dental provider requires that all patients complete and execute a broad consent form prior to an initial evaluation or treatment.

The dentist refuses to provide care unless and until this consent form is signed, but has not indicated that she would allow for George to sign the form himself.

Questions

1) Who is authorized to provide consent for routine or major medical treatment under this fact pattern?
2) If George is unable to provide consent for treatment, when does the authority of the legally authorized surrogate begin?
3) If George had a supported decision-making agreement (SDMA) how could the SDMA alter decision-making under this fact pattern, if at all?

Now consider this variation on George's case.

Emily is a 95 year old woman who had been a lawyer for many years. Now as a result of Alzheimer's Disease she has dementia and impaired communication ability. She lives in a nursing home.

She has no involved relatives, but she has a close friend who is another nursing home resident. And she is close to some nursing home staff members who have long cared for her.

Emily has the same dental issues as George and the same dentist who is imposing the same requirement regarding consent.

Consider George's questions 1 -3 above, as applied to Emily.

Is George's case handled differently than Emily's, and it there a policy/ethical rationale for that disparate treatment?

Fact Pattern No. 2
Lisa

Lisa is a 65 year old woman born with Down syndrome. She resides in an Individualized Residential Alternative (IRA) a 4-bed congregate care setting operated by a voluntary agency that has an operating certificate issued by the Office for People With Developmental Disabilities (OPWDD). Lisa was generally in good health and enjoyed an active life. She was expressive and had an extreme fondness for her younger sister (Joann) who visited often and advocated for Lisa whenever necessary so that Lisa would receive all services she was entitled to and medical care in the community.

As Lisa neared the age of 60, her health declined. She began to experience seizure activity and her cognitive abilities diminished. It appeared to staff and medical professionals that Lisa could be experiencing the onset of dementia. By the age of 65, Lisa was withdrawn from her typical activities and physically frail. She did not speak and could no longer ambulate. She was closely followed by her primary care physician and a neurologist who concurred that Lisa met diagnostic criteria for end-stage Alzheimer's Disease.

Lisa's physical decline was marked by congestive heart failure, osteoporosis, the continuing seizure activity and frequent aspiration. Routine blood tests ordered by the physician revealed elevated white blood cell counts and high creatine levels. It became very difficult to feed Lisa. She required total assistance and seemed to have lost all interest in eating. Decisions need to be made about Lisa's course of treatment - specifically would treatment be more aggressive or palliative in nature.

<u>Questions</u>

1) Who is authorized to provide consent for major medical or life sustaining treatment under this fact pattern?
2) If Lisa is unable to provide consent for treatment elections, when does the authority of the legally authorized surrogate begin?
3) Does it matter whether Lisa lives in an IRA or do life sustaining treatment elections, if made, require that she be a hospital patient?
4) Before Lisa experienced her cognitive decline, could she have appointed a health care agent under article 29-C of the Public Health Law?
5) If Lisa had a supported decision-making agreement (SDMA) how could the SDMA alter decision-making under this fact pattern, if at all?
6) What external agency, if any, would receive notice of a decision to withhold or withdraw life sustaining treatment?
7) What if LM did not have a family member; who could decide?

Now consider this variation on the Lisa's case.

Edith is a 95 year old woman who had been a lawyer for many years. Now as a result of Alzheimer's Disease she has dementia and lives in a nursing home.

Edith has the same family/friend situation as Lisa and the same diminished cognitive ability as Lisa, and the same medical condition (apart from Down Syndrome) as Lisa. The same decisions need to be made as with Lisa.

Consider questions 1-7 above, as applied to Edith.

Is Lisa's handled differently than Edith's, and it there a policy/ethical rationale for that disparate treatment?

Fact Pattern No. 3
James

James is a 55 year old man with profound intellectual disabilities. He is non-verbal and can express joy or pain through his expressions and some manual signs. He has cerebral palsy with spastic quadriplegia, and curvature of the spine.

James resided in an OPWDD state operated IRA when he became ill and was admitted to the hospital where he was diagnosed with aspiration pneumonia. While in the hospital, James could no longer tolerate oral feedings. A swallowing study revealed dysphagia. His ability to swallow would not improve according to the medical professionals attending to him in the hospital. An IV and NG tube were placed to support fluids and medication administration in the short-term.

A decision needed to be made about whether or not to consent to the insertion of a PEG tube to maintain nutritional status. The insertion of a PEG tube would require surgery. James' parents are his SCPA art 17-a guardians, appointed over 35 years ago, when James was 20 years old.

Questions

1) Who is authorized to provide consent for major medical treatment under this fact pattern?
2) If James is unable to provide consent for treatment elections, when does the authority of the legally authorized surrogate begin?
3) If James' legally authorized surrogate declined to provide consent for a PEG tube what would happen?
4) Would any external agency be required to receive notice of a decision to afford major medical treatment or decline life sustaining treatment?
5) If James had a supported decision-making agreement (SDMA) how could the SDMA alter decision-making under this fact pattern, if at all?

Now consider this variation on James' case.

Eleanor is a 95 year old woman who had been a lawyer for many years. Now as a result of Alzheimer's Disease she has dementia and lives in a nursing home.

Eleanor has the same family/friend situation as James, the same diminished cognitive ability as James, and the same medical condition (apart from the developmental disability) as James. The same decisions need to be made as with James.

Consider questions 1-5 above, as applied to Eleanor.

Is James' case handled differently than Eleanor, and it there a policy/ethical rationale for that disparate treatment?

Surrogate Decision Making for Incapable Adult Patients with Mental Disabilities: A Chart of Applicable Laws and Regulations[1]

By Robert N. Swidler

Introduction

The Family Health Care Decisions Act governs health care decisions for patients in hospitals or nursing homes who lack capacity and who did not previously appoint a health care agent. However, a section in the FHCDA identifies circumstances where decisions for adult patients with mental disabilities are governed by laws or regulations other than the FHCDA, specifically NY Surrogate Court Procedure Act Article 17-A (the Health Care Decisions Act for People with Developmental Disabilities), MHL Article 80 (Surrogate Decision Making Committees), or OPWDD or OMH surrogate decision-making regulations.[2]

The following two charts are intended to help hospitals and nursing homes identify the applicable decision-maker, and the applicable law or regulation, for consent to treatment, or to withdraw or withhold life-sustaining treatment, for adult hospital and nursing home patients with mental disabilities in different circumstances. There is a chart for patients with developmental disabilities, and a chart for patients with mental illness.

During Nov. 2010 - Jan. 2011, Greater New York Hospital Association convened a group that reviewed and proposed corrections and improvements to an earlier version of these charts.[3] Eileen Zibell, Associate Attorney for OPWDD, John Tauriello, Counsel to OMH, and John Carroll, Deputy Counsel to OMH, also participated in that review, and suggested edits to the charts. This revised version is the product of that review.

A few caveats:

- These charts reflect only the views of the author.
- These charts do not reflect the official guidance of any state agency.
- Some of these issues are not clearly resolved, or are subject to conflicting interpretations.
- These charts point to the applicable laws and regulations and the decision maker, but do not summarize other requir-ments or conditions relating to such decisions.
- Ultimately, users must rely upon the language of the applicable laws and regulations, and any official guidance provided by the applicable agency. These charts are not a substitute for legal advice.

Even with those caveats, these charts should be useful. Please direct any corrections, suggestions to swidlerr@nehealth.com.

The Need for Reform

The charts describe what the law is, not what it should be. But it 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 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. The Legislature, when it enacted the FHCDA, anticipated this need and directed the NYS Task Force on Life and Law to form a special subcommittee to consider extending the FHCDA to cover life-sustaining decisions for persons with mental disabilities, thereby replacing at least some other laws and regulations. L.2010, ch.8, § 28.1.

But the charts also reveal other specific problems and anomalies that could be addressed more promptly, without waiting for or intruding upon the Task Force's assignment. In this author's view, the following steps would help reduce confusion, and improve decision making for persons with mental disabilities:

1. Amend SCPA §1750-b to confirm that a surrogate decision is not necessary if the developmentally disabled person made a prior oral or written decision, or appointed a health care agent, and had capacity at the time. (This would confirm Chart 1 boxes 1B and 2B).
2. Amend 14 NYCRR §633.10(a)(7)(iv)(c) to include domestic partner or close friend on OPWDD's surrogate priority list. (This would affect Chart 1 boxes 4B and 6B).

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3. Amend the FHCDA to make the MHL Art. 80 surrogate decision-making committee (SDMC) available as an optional alternative to securing a decision pursuant to the FHCDA, as opposed to the required decision-maker. (This would affect Chart 1 boxes 5A and 5B).

4. Amend SCPA §1750-b to allow a DNR order to be entered based on medical futility for a patient who does not have a family member or friend to act as surrogate, eliminating the need to SDMC approval of such cases. (This would affect Chart 1 box 5B).

5. Repeal PHL Article 28-B, the DNR Law for patients of mental hygiene facilities, because there is no need for the law. For patients in OPWDD facilities, DNR orders generally are issued pursuant to SCPA §1750-b, not PHL Art. 29-B. For patients in psychiatric hospitals and general hospital psychiatric units, DNR orders should be made subject to the FHCDA—a change that would eliminate the confusion and illogic of inconsistent DNR procedures within general hospitals that have psychiatric units. (This would confirm Chart 1 boxes 6B and 7B, and affect Chart 2 boxes 6B and 7B).

6. Amend SCPA §1750 to restore role of MHLS with respect to DNR orders to what it was under the former DNR Law: for patients who are in or transferred from a mental hygiene facility, notice of a DNR order went to the mental hygiene facility director, not to MHLS; and the order would be temporarily stayed if there was an objection by the facility director, not by MHLS. As an alternative, require notice of DNR orders to MHLS but provide that its objection will not cause a stay of the DNR order unless it sets forth a specific basis for asserting that the DNR order is improper. (This would affect the procedures within Chart 1 column B rows 3-7).

A final note: If the Legislature adopts amendments that impact these charts, revised charts will be placed on the NYSBA Family Health Care Decisions Act Information Center website, www.nysba.org/fhcda.

Surrogate Decision Making for Incapable Adult Patients with Developmental Disabilities:

A Chart of Applicable Laws and Regulations

	Follow the rules in the first row that applies:	Decisions in Hospitals and Nursing Homes	
		A **Consent to treatment**	**B** **Decision to withdraw or withhold life-sustaining treatment (including entering a DNR Order)**
1	**Patient, previously when capable, left prior written or oral directions**	Follow patient's prior oral or written directions[4]	Follow: (i) patient's prior written directions, or (ii) patient's prior oral directions if made during hospitalization before two witnesses[5]
2	**Patient, previously when capable, appointed health care agent***	Health care agent decides per PHL 29-C[6]	Health care agent decides per PHL 29-C[7]
3	**Patient has a court-appointed guardian per SCPA Art. 17-A***	Guardian decides per SCPA §1750-b[8]	Guardian decides per SCPA §1750-b[9]
4	**Patient resides in community (and not an OPWDD-licensed residence) and has involved family***	Surrogate decides per FHCDA[10]	Involved family member decides per SCPA §1750-b.[11] The prioritized list of qualified family member is set forth in 14 NYCRR §633.10(a)(7)(iv)(c). Note—A domestic partner or close friend would not qualify.[12]
5	**Patient resides in community (and not an OPWDD-licensed residence) but has no involved family***	Surrogate Decision Making Committee (SDMC) decides per MHL Art. 80[13]	SDMC decides per SCPA §1750-b[14]
6	**Patient resides in OPWDD-licensed or operated facility, is temporarily in a hospital or NH, and has involved family***	Involved family member decides per 14 NYCRR §633.11[15]	Involved family member decides per SCPA §1750-b. The prioritized list of qualified family member is set forth in 14 NYCRR §633.10(a)(7)(iv)(c).[16] Note—A domestic partner or close friend would not qualify.
7	**Patient resides in OPWDD-licensed or operated facility, is temporarily in the hospital or NH, but has no involved family***	SDMC decides per 14 NYCRR §633.11	SDMC decides per SCPA §1750-b.[17]

* Applies only if no row above it applies.

Surrogate Decision Making for Incapable Adult Patients with Mental Illness[18]

A Chart of Applicable Laws and Regulations[19]

	Follow the rules in the first row that applies:	**Decisions in Hospitals (excluding MH unit) and Nursing Homes**	
		A **Consent to Treatment**	**B** **Decision to withdraw or withhold life-sustaining treatment (including entering a DNR Order)**
1	**Patient, previously when capable, left prior written or oral directions**	Follow patient's prior oral or written directions	Follow: (i) patient's prior written directions, or (ii) patient's prior oral directions if made during hospitalization before two witnesses
2	**Patient, previously when capable, appointed health care agent***	Health care agent decides per PHL 29-C	Health care agent decides per PHL 29-C
3	**Patient has court-appointed guardian per MHL Art 81 with health care decision-making authority.***	Guardian with health care decision-making authority decides per the FHCDA[20]	Guardian with health care decision-making authority decides per the FHCDA[21]
4	**Patient resides in community (including an OMH-licensed residence) and has family or close friend***	Surrogate decides per FHCDA[22]	Surrogate decides per FHCDA[23]
5	**Patient resides in community (including and OMH-licensed residence) but has no family or close friend***	(i) Surrogate Decision Making Committee (SDMC) decides per MHL Art. 80 if the patient is eligible [24] (ii) Otherwise, attending physician decides per FHCDA[25]	Attending physician or court decides, per FHCDA[26]
6	**Patient brought to hospital or NH from OMH-licensed or operated psych hospital or unit. Patient has family or close friend.***	(i) If patient was discharged from the OMH-licensed or operated psych hospital or unit, then surrogate decides per FHCDA[27] (ii) If patient was not discharged, then spouse, parent or adult child decides per 14 NYCRR §27.9	(i) For DNR, surrogate decides per PHL Art 29-B (ii) For other decisions, surrogate decides per FHCDA[28]
7	**Patient brought to hospital or NH from OMH-licensed or operated psych hospital or unit. Patient has no family or close friend***	Decision by either (i) SDMC per MHL Art. 80 (ii) Court per §27.9[29]	(i) For DNR, attending phys'n decides per PHL Art. 29-B (ii) For other decisions, attending physician or court decides, per FHCDA[30]

*Applies only if no row above it applies

Endnotes

1. This document is the January 12, 2010 version of a document that appears on the NYS Bar Association Family Health Care Decisions Act Information Center, www.nysba.org/fhcda. It is reprinted here with the permission of the NYS Bar Association.

2. The relevant clauses of the FHCDA are PHL § 2994-b.3-4, which state:

> 3. Prior to seeking or relying upon a health care decision by a surrogate for a patient under this article, if the attending physician has reason to believe that the patient has a history of receiving services for mental retardation or a developmental disability; it reasonably appears to the attending physician that the patient has mental retardation or a developmental disability; or the attending physician has reason to believe that the patient has been transferred from a mental hygiene facility operated or licensed by the office of mental health, then such physician shall make reasonable efforts to determine whether paragraphs (a), (b) or (c) of this subdivision are 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 consent for the decision may be provided pursuant to the mental hygiene law or regulations of the office of mental health or the office of mental retardation and developmental disabilities, then the decision shall be governed by such statute or regulations and not by this article.
>
> 4. If, after reasonable efforts, it is determined that a health care decision for the patient cannot be made pursuant to subdivision two or three of this section, then the health care decision shall be made pursuant to this article.

3. The chart review group was convened by Lorraine Ryan, Senior Vice President, Legal, Regulatory and Professional Affairs Greater NY Hospital Association and Sara Kaplan-Levenson, Project Manager, Regulatory and Professional Affairs, Greater NY Hospital Association. Participants included John V. Campano (NY Presbyterian), Joan Hauswald (NY Presbyterian), Deborah Korzenik (Continuum Health Partners); Lynn Hallarman, M.D. (SUNY Stony Brook Health Science Center); Jonathan Karmel (NYS Department of Health); Karen Lipson (NYS Department of Health); Carolyn Wolf (Abrams Fensterman). Paul Kietzman (NYSARC) also commented independently. I am very grateful to these reviewers—their work has improved these charts greatly.

4. It would seem that the designation of a surrogate (whether under SCPA §1750-b, 10 NYCRR §633.11 or the FHCDA) is not necessary if the incapable person, previously when capable, personally consented to the treatment.

5. It would seem that the designation of a surrogate (whether under SCPA §1750-b, 10 NYCRR §633.11 or the FHCDA) is not necessary if the incapable person, previously when capable, left clear and convincing evidence of a wish to forgo treatment under the circumstances presented.
The FHCDA, in PHL §2994-d.3(a)(ii), provides guidance as to the type of evidence that would suffice.

6. NY PHL §2982.

7. NY PHL §2982.

8. NY SCPA §1750-b.1.

9. NY SCPA §1750-b.1.

10. NY SCPA §1750-b is inapplicable because its non-court process for authorizing an involved family member, Consumer Advisory Board or SDMC to act as a "guardian" is limited to decisions to withdraw or withhold life-sustaining treatment. See §1750-b.1(a). When a health care decision for the patient cannot be made pursuant to the SCPA or Mental Hygiene Law or regulations, the FHCDA becomes applicable. NY PHL §2994-b.4. Accordingly, the FHCDA becomes applicable, and a FHCDA surrogate can consent to such treatment per PHL §2994-d.

11. NY SCPA §1750-b(a) applies because its non-court process for authorizing a family member to act as guardian applies to decisions to withdraw or withhold life-sustaining treatment. See §1750-b.1(a). Qualified family members are identified in 14 NYCRR §§633.10(a)(7)(iv)(c).

12. The OPWDD surrogate list promulgated pursuant to NY SCPA §1750-b(a) does not provide for the authorizing of a "close friend" to act as "guardian." See 14 NYCRR §633.10(a)(7)(iv)(c). However, NY SCPA §1750-b.1(a) provides that when no other surrogate is available, the MHL Article 80 SDMC may act as guardian for purposes of making the withdrawal or withholding of treatment decision.

13. Most patients with developmental disabilities and who do not a have a guardian or family will qualify for decisions by an SDMC. See MHL §80.3(b).3 (definition of "patient in need of surrogate decision-making"). Moreover, once a person is eligible for decisions by an SDMC, the person remains eligible regardless of a change in residential status. MHL §80.03(b). As a result, the FHCDA provisions on consent for patients without surrogate generally are not applicable. See §2994-b.3(c). In the relatively rare event where SDMC lacks jurisdiction for a patient, the FHCDA would apply.

14. Per NY SCPA §1750-b.1(a), when no other surrogate is available, the MHL Article 80 SDMC may act as guardian for purposes of making the withdrawal or withholding of treatment decision.

15. 14 NYCRR §633.11 provides surrogate decision-making rules for persons who are "residents of a facility operated or certified by OPWDD." Such persons, when hospitalized, are still residents of OPWDD facilities and subject to this regulation.

16. 14 NYCRR §633.10 implements SCPA 1750-b for residents of OPWDD-licensed and operated facilities.

17. See n.11

18. Per PHL §2994-a.21: "Mental illness" means a mental illness as defined in subdivision twenty of section 1.03 of the mental hygiene law, and does not include dementia, such as Alzheimer's disease, or other disorders related to dementia. Per MHL §1.03(2): "Mental illness" means an affliction with a mental disease or mental condition which is manifested by a disorder or disturbance in behavior, feeling, thinking, or judgment to such an extent that the person afflicted requires care, treatment and rehabilitation.
19. This chart points to the applicable law or regulation, but does not provide a complete summary of the applicable law or regulation.
20. PHL §2994-d.1(a).
21. Id.
22. Id.
23. Id.
24. PHL §2994-b.3(c) provides that if a health care decision can be made pursuant to the Mental Hygiene Law, then the decision is governed by such statute. Accordingly, if the decision can be made pursuant to MHL Art. 80 then the decision is governed by MHL Art. 80. Under MHL Art. 80, a decision can be made by an SDMC for a person who is "a resident of a mental hygiene facility including a resident of housing programs funded by an office of the department [of mental hygiene] or whose federal funding application was approved by an office of the department or for whom such facility maintains legal admission status therefor; or receiving home and community-based services for persons with mental disabilities provided pursuant to section 1915 of the federal social security act; or receiving individualized support services .... " Also, note that MHL Art. 80 and the FHCDA have some differences in the scope of major medical treatments that can be authorized pursuant to their procedures.
25. PHL §2994-b.4 provides that " If, after reasonable efforts, it is determined that a health care decision for the patient cannot be made pursuant to subdivision two or three of this section, then the health care decision shall be made pursuant to this article." Accordingly, if MHL Art 80 is inapplicable, then the FHCDA, and specifically PHL §2994-g, becomes applicable.
26. There is no applicable Mental Hygiene Law or OMH regulation. Accordingly, PHL §2994-g.5 applies.
27. If the patient was discharged from the OMH-regulated facility or unit, then OMH regulations become inapplicable, and the FHCDA applies.
28. If the patient was discharged from the OMH-regulated facility or unit, then OMH regulations become inapplicable, and the FHCDA applies. But even if the patient was not discharged, there still is no applicable Mental Hygiene Law or OMH regulation. (MHL Art. 80 is inapplicable because it does not authorize the SDMC to make decisions to withdraw or withhold life-sustaining treatment). Accordingly, per PHL§2994-b.4, the FHCDA becomes applicable.
29. Both provisions are available as a means to secure consent to treatment.
30. There is no applicable mental hygiene law or regulation. (MHL Art. 80 is inapplicable because it does not authorize the SDMC to make decisions to withdraw or withhold life-sustaining treatment). Accordingly, PHL §2994-g.5 applies.

Robert N. Swidler is General Counsel, Northeast Health, Troy NY. Mr. Swidler is also Editor of the NYSBA *Health Law Journal* and Editor of the NYSBA FHCDA Information Center.

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

By Robert N. Swidler

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

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

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

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

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

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

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

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

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

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

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

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

ROBERT N. SWIDLER is VP Legal Services for St. Peter's Health Partners, a not-for-profit health care system in New York's Capital Region.

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

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

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

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

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

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

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

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

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

Endnotes

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

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

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,

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

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

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

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

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

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

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

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

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

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

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

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

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

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

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

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

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

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

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

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

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

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

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

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

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

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

Informed Consent
Decision-Making Capacity
and
Decisions for Patients
Who Lack Capacity

Robert N. Swidler
General Counsel
St. Peter's Health Partners
St. Joseph's Health

I. Informed consent

II. Decision-making capacity

III. Decisions for patients who lack capacity

The permission voluntarily given by a patient for a medical procedure,

after the practitioner has disclosed the risks, benefits and alternatives, in a manner permitting the patient to make a knowledgeable evaluation

Based on NY PHL 2805-d .1.

Two Components:

Consent — The permission voluntarily given by a patient for a medical procedure …

Informed — after the practitioner has disclosed the risks, benefits and alternatives, in a manner permitting the patient to make a knowledgeable evaluation.

Consent —

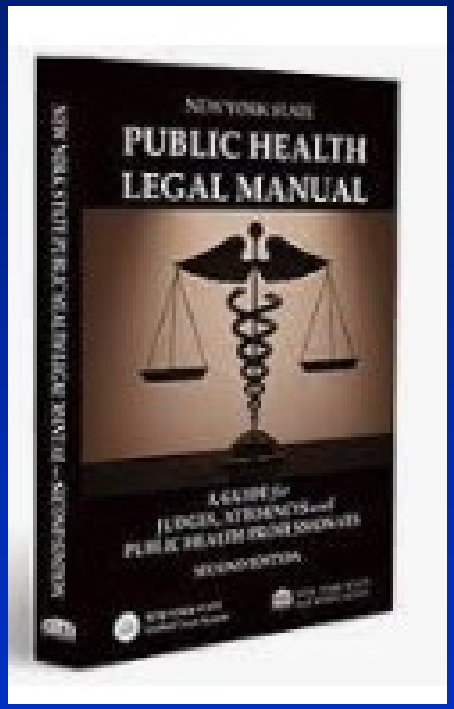
The permission voluntarily given by a patient for a medical procedure.

- Patients have a right not to be treated without their permission.

- "Every human being of adult years and sound mind has the right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages." *Schloendorff v. NY Hospital* (NY 1914)(Cardozo, J)

Exceptions

- Emergency
- Need to protect the public health
- Prisoners
- Lack of capacity



Informed —

For a patient's consent to be valid, it must be based on disclosure of adequate information about the proposed treatment. That disclosure must address:

- Risks
- Benefits
- Alternatives

Moreover, from an ethical standpoint, informed consent is more than a disclosure or a signature on a form. It is a process involving discussion between the provider and the patient.

Source of the legal requirement to obtain informed consent:

- Caselaw
- NYS Public Health Law §2805-d
- DOH Regulations (e.g., §405.7(9) – Patient Rights)
- Medicare Conditions of Participation
  (e.g., 42 CFR § 482.51(b)(2) Surgical Services)
- JCAHO requirements
- Hospital policies

New York's Informed Consent Statute

NY Public Health Law Section 2805-d

Does not require informed consent – It assumes such requirement exists, and lists defenses to an action for lack of informed consent.

§ 2805–d. Limitation of medical, dental or podiatric malpractice action based on lack of informed consent

1. Lack of informed consent means the failure of the person providing the professional treatment or diagnosis to disclose to the patient such alternatives thereto and the reasonably foreseeable risks and benefits involved as a reasonable medical, dental or podiatric practitioner under similar circumstances would have disclosed, in a manner permitting the patient to make a knowledgeable evaluation.

2. The right of action to recover for medical, dental or podiatric malpractice based on a lack of informed consent is limited to those cases involving either (a) non-emergency treatment, procedure or surgery, or (b) a diagnostic procedure which involved invasion or disruption of the integrity of the body.

3. For a cause of action therefor it must also be established that a reasonably prudent person in the patient's position would not have undergone the treatment or diagnosis if he had been fully informed and that the lack of informed consent is a proximate cause of the injury or condition for which recovery is sought.

4. It shall be a defense to any action for medical, dental or podiatric malpractice based upon an alleged failure to obtain such an informed consent that:

(a) the risk not disclosed is too commonly known to warrant disclosure; or

(b) the patient assured the medical, dental or podiatric practitioner he would undergo the treatment, procedure or diagnosis regardless of the risk involved, or the patient assured the medical, dental or podiatric practitioner that he did not want to be informed of the matters to which he would be entitled to be informed; or

(c) consent by or on behalf of the patient was not reasonably possible; or

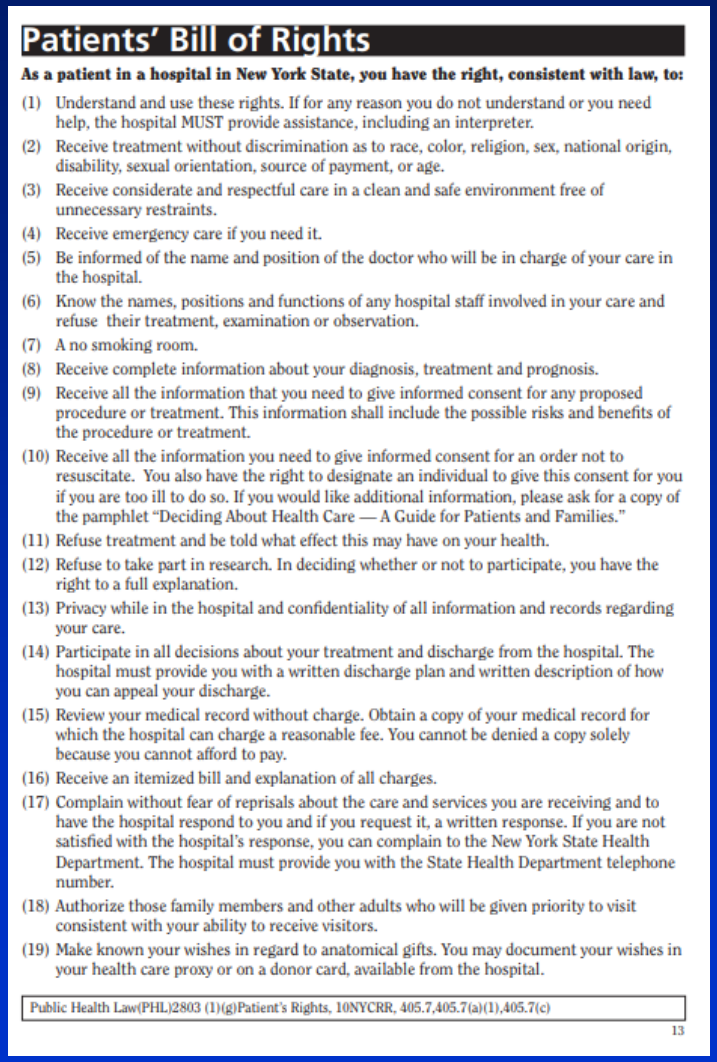
(d) the medical, dental or podiatric practitioner, after considering all of the attendant facts and circumstances, used reasonable discretion as to the manner and extent to which such alternatives or risks were disclosed to the patient because he reasonably believed that the manner and extent of such disclosure could reasonably be expected to adversely and substantially affect the patient's condition.

Hospital Patient Bill of Rights

Ch. 618, Laws of 2022 / Public Health Law §2803.1(g)

Must state that patient has a right to receive

> "all information necessary to give informed consent for any proposed intervention, procedure or treatment, including information regarding the foreseeable and clinically significant risks and benefits of the proposed intervention, procedure, or treatment …."



Patients' Bill of Rights

As a patient in a hospital in New York State, you have the right, consistent with law, to:

(1) Understand and use these rights. If for any reason you do not understand or you need help, the hospital MUST provide assistance, including an interpreter.

(2) Receive treatment without discrimination as to race, color, religion, sex, national origin, disability, sexual orientation, source of payment, or age.

(3) Receive considerate and respectful care in a clean and safe environment free of unnecessary restraints.

(4) Receive emergency care if you need it.

(5) Be informed of the name and position of the doctor who will be in charge of your care in the hospital.

(6) Know the names, positions and functions of any hospital staff involved in your care and refuse their treatment, examination or observation.

(7) A no smoking room.

(8) Receive complete information about your diagnosis, treatment and prognosis.

(9) Receive all the information that you need to give informed consent for any proposed procedure or treatment. This information shall include the possible risks and benefits of the procedure or treatment.

(10) Receive all the information you need to give informed consent for an order not to resuscitate. You also have the right to designate an individual to give this consent for you if you are too ill to do so. If you would like additional information, please ask for a copy of the pamphlet "Deciding About Health Care — A Guide for Patients and Families."

(11) Refuse treatment and be told what effect this may have on your health.

(12) Refuse to take part in research. In deciding whether or not to participate, you have the right to a full explanation.

(13) Privacy while in the hospital and confidentiality of all information and records regarding your care.

(14) Participate in all decisions about your treatment and discharge from the hospital. The hospital must provide you with a written discharge plan and written description of how you can appeal your discharge.

(15) Review your medical record without charge. Obtain a copy of your medical record for which the hospital can charge a reasonable fee. You cannot be denied a copy solely because you cannot afford to pay.

(16) Receive an itemized bill and explanation of all charges.

(17) Complain without fear of reprisals about the care and services you are receiving and to have the hospital respond to you and if you request it, a written response. If you are not satisfied with the hospital's response, you can complain to the New York State Health Department. The hospital must provide you with the State Health Department telephone number.

(18) Authorize those family members and other adults who will be given priority to visit consistent with your ability to receive visitors.

(19) Make known your wishes in regard to anatomical gifts. You may document your wishes in your health care proxy or on a donor card, available from the hospital.

Public Health Law(PHL)2803 (1)(g)Patient's Rights, 10NYCRR, 405.7,405.7(a)(1),405.7(c)

13

Medical Malpractice

A doctor can be held liable if

- the patient is harmed because of the MD's failure, in treating the patient, to exercise the degree of knowledge, care and skill expected of the average physician in the locality. (e.g., fail to diagnose, prescribe the wrong medication, perform a procedure incorrectly); and
- And the doctor's negligence in performing the procedure was the cause of the patient's injury

Treatment without Informed Consent

- A doctor can be held liable ***even if*** the MD, in treating the patient, exercised the degree of knowledge, care and skill expected of the average physician in the locality.
- The claim is based not on the MD's lack of skill, but on the MD's failure to get valid permission from the patient to treat him or her.
- There still must be causation – the failure to get valid permission needs to be the cause of the injury.

Exceptions

- Emergency
- Compelling public health reason
- Prisoners
- Lack of capacity

II. Decision-making Capacity -

The ability to understand the nature and consequence of proposed health care, including the benefits and risks of, and alternatives to proposed health care, and to reach an informed decision.

NY PHL §2994-a NY's Family Health Care Decisions Act – Definition of "decision-making capacity."

II. Capacity -

It determines whether the practitioner seeks consent from the patient, or from someone else on behalf of the patient.

- Incapacity may be clear:
  - Unconsciousness, anesthesia, intoxication, advanced dementia, psychosis, infancy, profound intellectual disability
- Incapacity may be less-than-clear:
  - mild dementia, moderate intellectual disability, depression, bipolar, bad judgment, older child.

II. Decision-making capacity

- Incapacity can long-term or short-term
- Incapacity can be continuous or intermittent.
- Patient can lack capacity for some decisions and not others
- Incapable patient can be passive or assertive

How is incapacity determined (for an adult)?

- Generally, start with presumption that patient has capacity
  - Exception: Patient has a judicial guardian.
- For most health care decision purposes, the determination is a bedside clinical determination, not a judicial determination
  - Exception – Where patient objects to the determination.
- Laws do not specify the clinical tests to determine incapacity.
- However, some NY laws address:
  - The qualifications of the professional; and
  - The level of certainty needed to determine incapacity
  - Documenting the basis for the determination

Key examples:

II. Decision-making capacity

The FHCDA (PHL 29-CC):

- Initial determination by "attending practitioner"
- "To a reasonable degree of medical certainty"
- Concurring by "a health or social services practitioner"
  - in a nursing home
  - for decisions re w/d or w/h of life-sustaining treatment
  - for decisions in re hospice care
- Special qualifications required if the patient lacks capacity due to mental illness or developmental disability

The HCDA (SCPA 1750-B):

- Initial determination by "attending physician"
- "To a reasonable degree of medical certainty"
- Attending must "consult with" another physician or licensed psychologist "to further confirm" the lack of capacity.
- One of the above must either be or was employed by a DDSO or OPWDD licensed program or be approved by OPWDD.

Decisions for Patients Who Lack Capacity

General patient population

Decisions for Patients Who Lack Capacity

1.Patient's Prior Decision

Decisions for Patients Who Lack Capacity

1.Patient's Prior Decision

NY PHL 2994-d.3

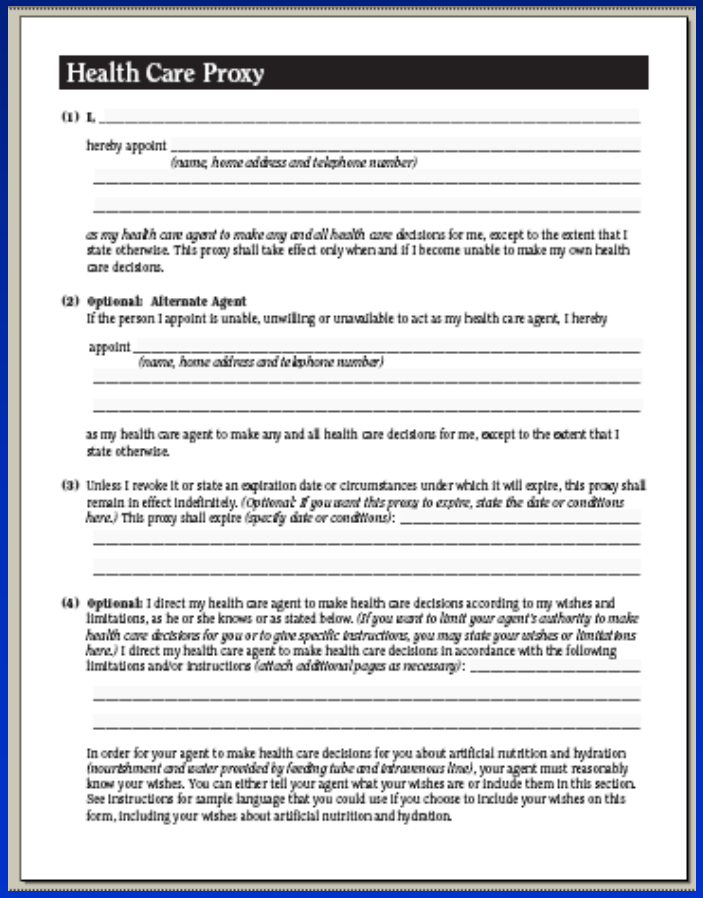
3. Authority and duties of surrogate. (a) Scope of surrogate's authority.

(i) Subject to the standards and limitations of this article, the surrogate shall have the authority to make any and all health care decisions on the adult patient's behalf that the patient could make.

(ii) **Nothing in this article shall obligate health care providers to seek the consent of a surrogate if an adult patient has already made a decision about the proposed health care, expressed orally or in writing or, with respect to a decision to withdraw or withhold life-sustaining treatment expressed either orally during hospitalization in the presence of two witnesses eighteen years of age or older, at least one of whom is a health or social services practitioner affiliated with the hospital, or in writing.** If an

Decisions for Patients Who Lack Capacity

1. Patient's Prior Decision
2. Health Care Agent
   - NY PHL Article 29-C
   - Appoints someone to make decisions if and when the principal becomes incapable
   - In some states the principal can make it take effect immediately
   - Agent can make any decision the principal could have made
   - Agent must base decision on principal's wishes if known, or else the patient's best interests.



Health Care Proxy

(1) I, _____

hereby appoint _____
(name, home address and telephone number)

_____

_____

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. This proxy shall take effect only when and if I become unable to make my own health care decisions.

(2) **Optional: Alternate Agent**
If the person I appoint is unable, unwilling or unavailable to act as my health care agent, I hereby

appoint _____
(name, home address and telephone number)

_____

_____

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise.

(3) Unless I revoke it or state an expiration date or circumstances under which it will expire, this proxy shall remain in effect indefinitely. *(Optional: If you want this proxy to expire, state the date or conditions here.)* This proxy shall expire *(specify date or conditions)*: _____

_____

_____

(4) **Optional:** I direct my health care agent to make health care decisions according to my wishes and limitations, as he or she knows or as stated below. *(If you want to limit your agent's authority to make health care decisions for you or to give specific instructions, you may state your wishes or limitations here.)* I direct my health care agent to make health care decisions in accordance with the following limitations and/or instructions *(attach additional pages as necessary)*: _____

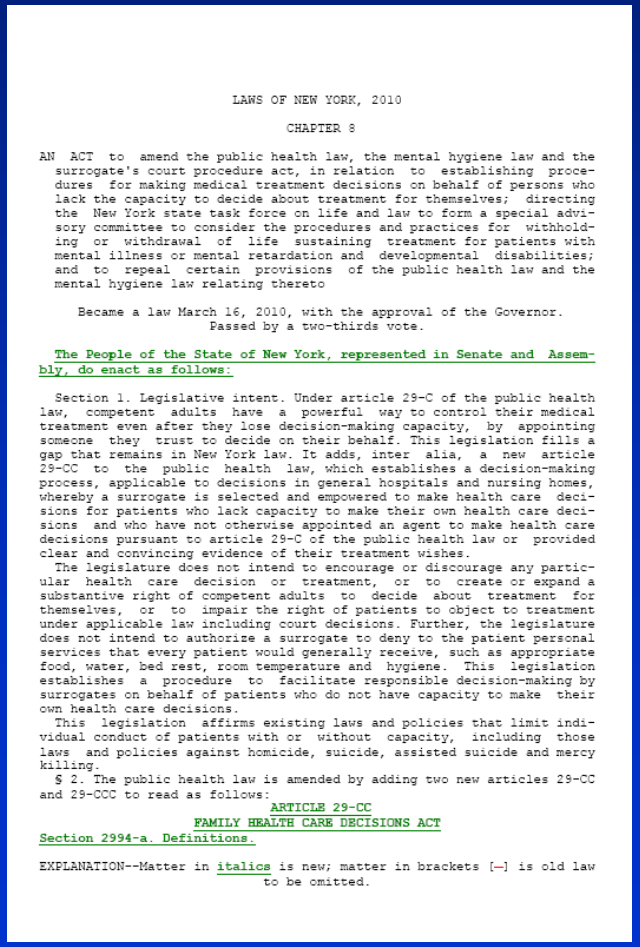
_____

_____

In order for your agent to make health care decisions for you about artificial nutrition and hydration *(nourishment and water provided by feeding tube and intravenous line)*, your agent must reasonably know your wishes. You can either tell your agent what your wishes are or include them in this section. See instructions for sample language that you could use if you choose to include your wishes on this form, including your wishes about artificial nutrition and hydration.

Decisions for Patients Who Lack Capacity

1. Patient's Prior Decision
2. Health Care Agent
3. Family Health Care Decisions Act – Surrogate Decision



LAWS OF NEW YORK, 2010

CHAPTER 8

AN ACT to amend the public health law, the mental hygiene law and the surrogate's court procedure act, in relation to establishing procedures for making medical treatment decisions on behalf of persons who lack the capacity to decide about treatment for themselves; directing the New York state task force on life and law to form a special advisory committee to consider the procedures and practices for withholding or withdrawal of life sustaining treatment for patients with mental illness or mental retardation and developmental disabilities; and to repeal certain provisions of the public health law and the mental hygiene law relating thereto

Became a law March 16, 2010, with the approval of the Governor. Passed by a two-thirds vote.

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

Section 1. Legislative intent. Under article 29-C of the public health law, competent adults have a powerful way to control their medical treatment even after they lose decision-making capacity, by appointing someone they trust to decide on their behalf. This legislation fills a gap that remains in New York law. It adds, inter alia, a new article 29-CC to the public health law, which establishes a decision-making process, applicable to decisions in general hospitals and nursing homes, whereby a surrogate is selected and empowered to make health care decisions for patients who lack capacity to make their own health care decisions and who have not otherwise appointed an agent to make health care decisions pursuant to article 29-C of the public health law or provided clear and convincing evidence of their treatment wishes.

The legislature does not intend to encourage or discourage any particular health care decision or treatment, or to create or expand a substantive right of competent adults to decide about treatment for themselves, or to impair the right of patients to object to treatment under applicable law including court decisions. Further, the legislature does not intend to authorize a surrogate to deny to the patient personal services that every patient would generally receive, such as appropriate food, water, bed rest, room temperature and hygiene. This legislation establishes a procedure to facilitate responsible decision-making by surrogates on behalf of patients who do not have capacity to make their own health care decisions.

This legislation affirms existing laws and policies that limit individual conduct of patients with or without capacity, including those laws and policies against homicide, suicide, assisted suicide and mercy killing.

§ 2. The public health law is amended by adding two new articles 29-CC and 29-CCC to read as follows:

ARTICLE 29-CC

FAMILY HEALTH CARE DECISIONS ACT

Section 2994-a. Definitions.

EXPLANATION--Matter in italics is new; matter in brackets [-] is old law to be omitted.

Family Health Care Decisions Act:

Empowers family member or a close friend to make health care decisions, when the patient

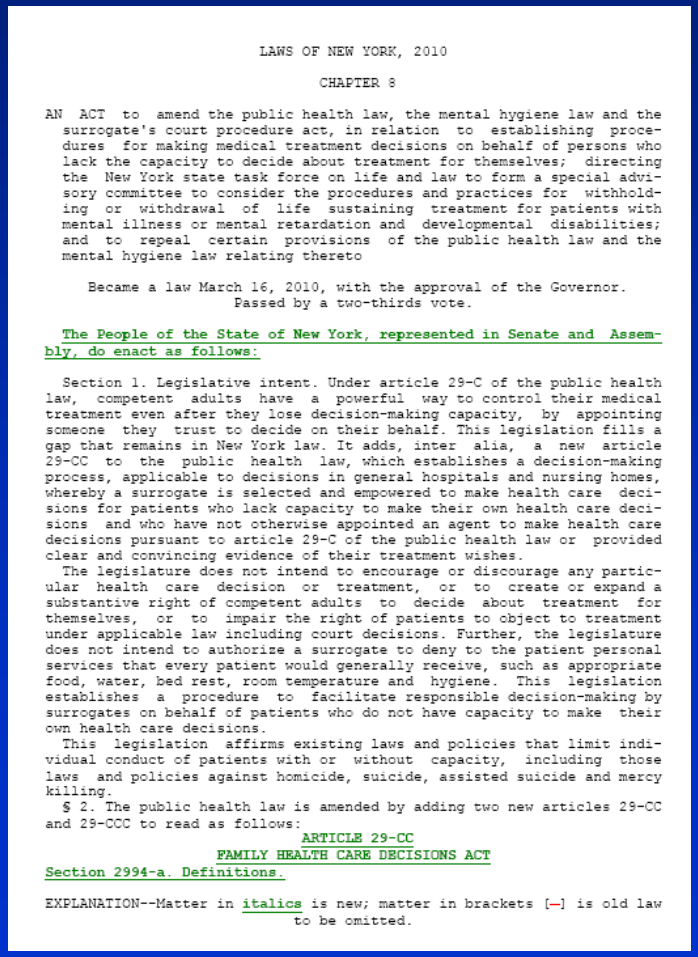
- lacks capacity
- did not previously decide
- did not appoint a health care agent

Includes both:

- consent to treatment
- decisions to w/d or w/h life-sustaining treatment

Does not apply to decisions for persons:

- receiving OPWDD services
- In or transferred from mental health facilities.



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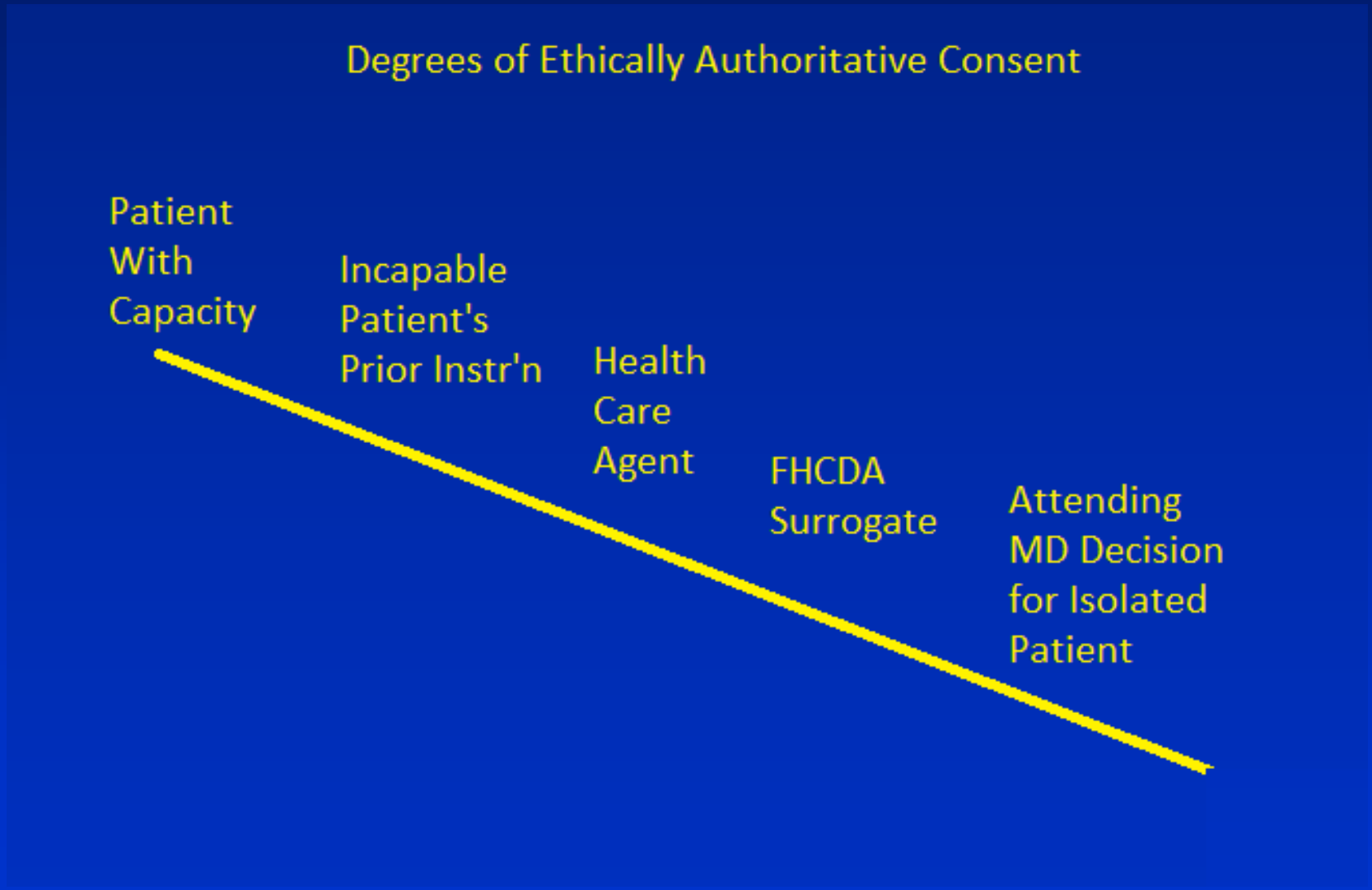
FHCDA Priority List

1. MHL Art 81 Guardian – with health care decisions authority
2. spouse or domestic partner
3. adult son or daughter
4. parent
5. brother or sister
6. close friend

Decisions for Patients Who Lack Capacity

1. Patient's Prior Decision
2. Health Care Agent
3. Family Health Care Decisions Act Surrogate
4. Isolated Patient –
   - Routine: Attending
   - Major Medical: Attending + Concurring
   - W/d or W/h of life-sustaining - basically a futility standard
   - Admission to hospice and hospice care - Attending + Ethics Review Comm

III. Decisions for Incapable Patients



Decisions for Patients Who Lack Capacity

Incapable Patients with I/DD

1. Patient's Prior Decision
2. Health Care Agent
3. Court appointed SCPA 17- A Guardian
4. Surrogate List in OPWDD Reg 14 NYCRR §633.11
   For w/d of life-sustaining treatment, SCPA 1750-B applies
5. Isolated Patients – Surrogate Decision-making Committee (MHL Article 80).

Implementing the Family Health Care Decisions Act

Surrogate Decision Making for Incapable Adult Patients with Developmental Disabilities:

A Chart of Applicable Laws and Regulations

	Follow the rules in the first row that applies:	Decisions in Hospitals and Nursing Homes	
		A **Consent to treatment**	**B** **Decision to withdraw or withhold life-sustaining treatment (including entering a DNR Order)**
1	**Patient, previously when capable, left prior written or oral directions**	Follow patient's prior oral or written directions[4]	Follow: (i) patient's prior written directions, or (ii) patient's prior oral directions if made during hospitalization before two witnesses[5]
2	**Patient, previously when capable, appointed health care agent***	Health care agent decides per PHL 29-C[6]	Health care agent decides per PHL 29-C[7]
3	**Patient has a court-appointed guardian per SCPA Art. 17-A***	Guardian decides per SCPA §1750-b[8]	Guardian decides per SCPA §1750-b[9]
4	**Patient resides in community (and not an OPWDD-licensed residence) and has involved family***	Surrogate decides per FHCDA[10]	Involved family member decides per SCPA §1750-b.[11] The prioritized list of qualified family member is set forth in 14 NYCRR §633.10(a)(7)(iv)(c). Note—A domestic partner or close friend would not qualify.[12]
5	**Patient resides in community (and not an OPWDD-licensed residence) but has no involved family***	Surrogate Decision Making Committee (SDMC) decides per MHL Art. 80[13]	SDMC decides per SCPA §1750-b[14]
6	**Patient resides in OPWDD-licensed or operated facility, is temporarily in a hospital or NH, and has involved family***	Involved family member decides per 14 NYCRR §633.11[15]	Involved family member decides per SCPA §1750-b. The prioritized list of qualified family member is set forth in 14 NYCRR §633.10(a)(7)(iv)(c).[16] Note—A domestic partner or close friend would not qualify.
7	**Patient resides in OPWDD-licensed or operated facility, is temporarily in the hospital or NH, but has no involved family***	SDMC decides per 14 NYCRR §633.11	SDMC decides per SCPA §1750-b.[17]

* Applies only if no row above it applies.

End-of-Life decisions for patients with I/DD raises unique issues re:

- Determination of incapacity: focus on special qualifications
- Selection of surrogate: focus on involved family members
- Decision-making standard: focus on best interests
- Need for special protection from being de-valued, and from prejudicial assumptions about quality of life
- Need for greater oversight by state agencies vs. same procedures as in end-of-life decisions for other patients.

III. Decisions for Incapable Patients

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
June 21, 2016

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

By Robert N. Swidler

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

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

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

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

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

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

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

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

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

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

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

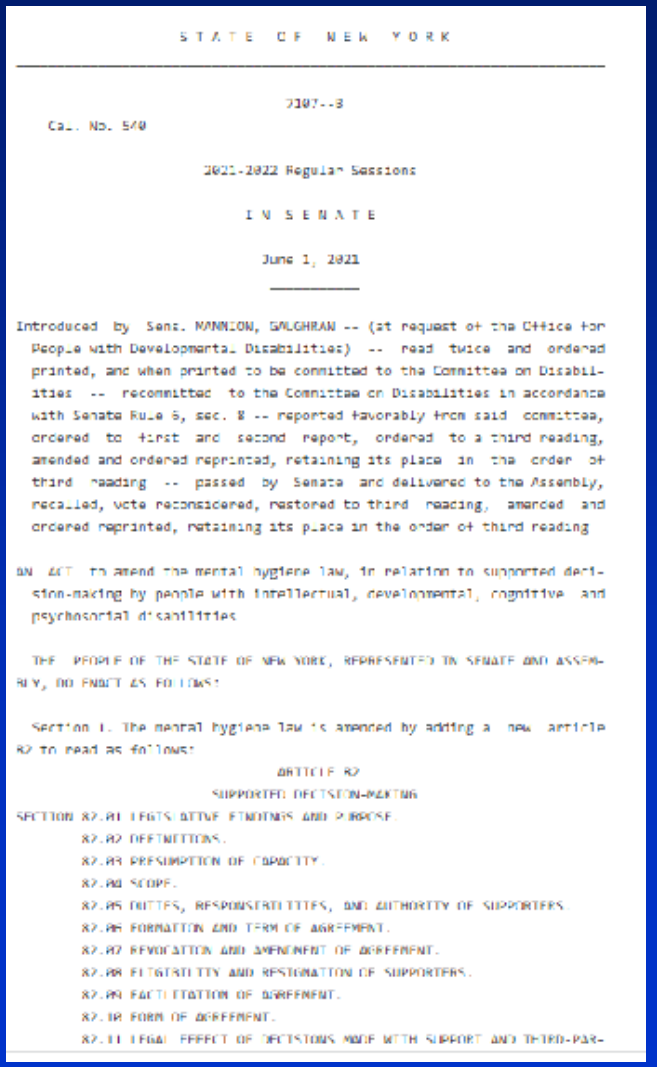
The Task Force's report includes a table that is especially valuable: it is a catalog of the differences among the FHCDA, Section 1750-b, and pertinent OPWDD regulations.[14] Each row includes the SAC's recommendation for a common rule or adaptation. For example, the table notes these slight differences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

ROBERT N. SWIDLER is VP Legal Services for St. Peter's Health Partners, a not-for-profit health care system in New York's Capital Region.

III. Decisions for Incapable Patients

Supported Decisionmaking

- Ch. 486, Laws of 2022
  New NY MHL Article 82
- Helps people with I/DD remain in control of decisions with support
- Applies to decisions beyond treatment
- Reduces need for guardianship and need for a determination that the patient lacks capacty



STATE OF NEW YORK

2107--B

Cal. No. 540

2021-2022 Regular Sessions

IN SENATE

June 1, 2021

Introduced by Sens. MANNION, GALGHRAN -- (at request of the Office for People with Developmental Disabilities) -- read twice and ordered printed, and when printed to be committed to the Committee on Disabilities -- recommitted to the Committee on Disabilities in accordance with Senate Rule 6, sec. 8 -- reported favorably from said committee, ordered to first and second report, ordered to a third reading, amended and ordered reprinted, retaining its place in the order of third reading -- passed by Senate and delivered to the Assembly, recalled, vote reconsidered, restored to third reading, amended and ordered reprinted, retaining its place in the order of third reading

AN ACT to amend the mental hygiene law, in relation to supported decision-making by people with intellectual, developmental, cognitive and psychosocial disabilities

THE PEOPLE OF THE STATE OF NEW YORK, REPRESENTED IN SENATE AND ASSEMBLY, DO ENACT AS FOLLOWS:

Section 1. The mental hygiene law is amended by adding a new article 82 to read as follows:

ARTICLE 82

SUPPORTED DECISION-MAKING

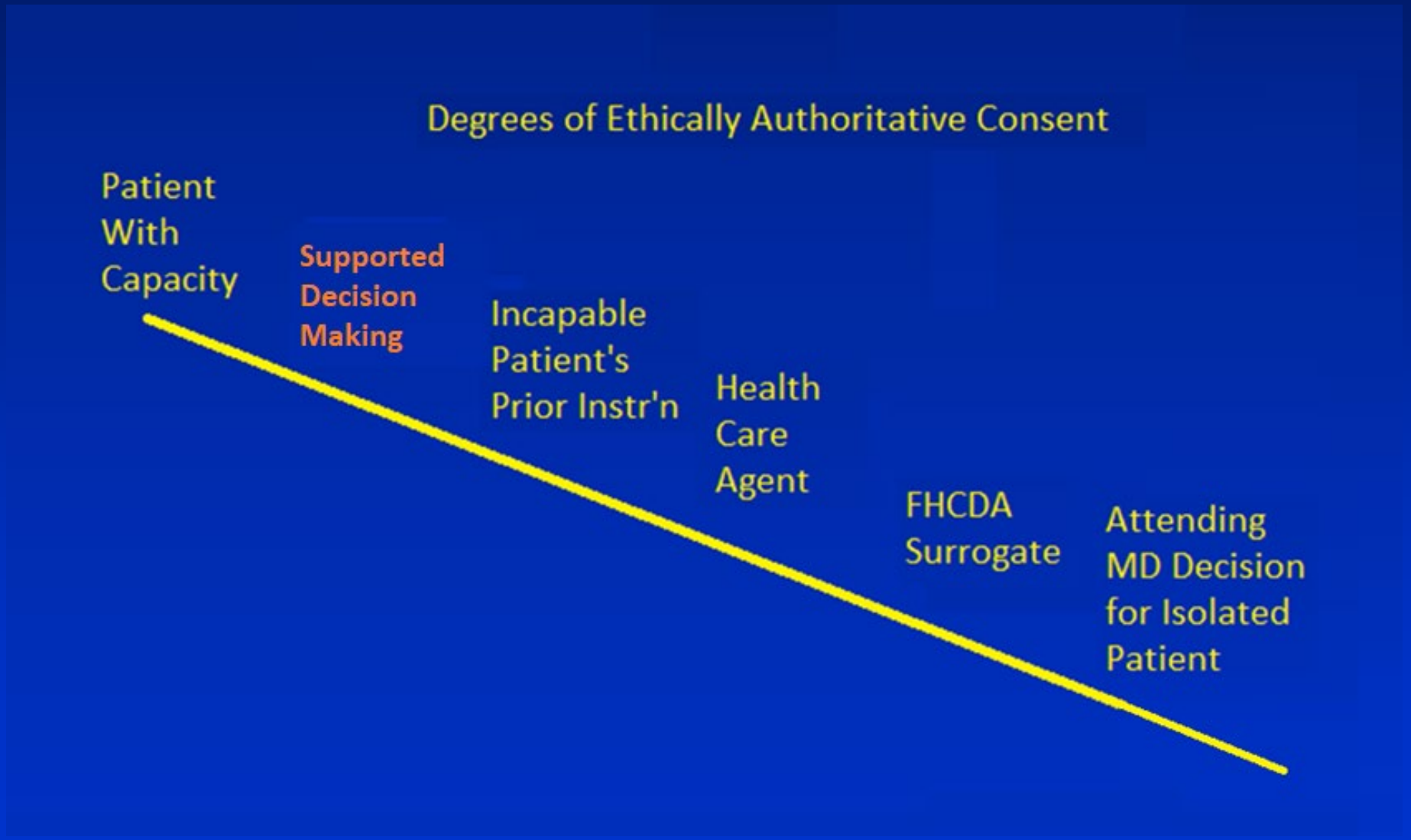
SECTION 82.01 LEGISLATIVE FINDINGS AND PURPOSE.
82.02 DEFINITIONS.
82.03 PRESUMPTION OF CAPACITY.
82.04 SCOPE.
82.05 DUTIES, RESPONSIBILITIES, AND AUTHORITY OF SUPPORTERS.
82.06 FORMATION AND TERM OF AGREEMENT.
82.07 REVOCATION AND AMENDMENT OF AGREEMENT.
82.08 ELIGIBILITY AND RESIGNATION OF SUPPORTERS.
82.09 FACILITATION OF AGREEMENT.
82.10 FORM OF AGREEMENT.
82.11 LEGAL EFFECT OF DECISIONS MADE WITH SUPPORT AND THIRD-PAR-

Supported Decisionmaking

(I) "SUPPORTED DECISION-MAKING" MEANS A WAY BY WHICH A DECISION-MAKER UTILIZES SUPPORT FROM TRUSTED PERSONS IN THEIR LIFE, IN ORDER TO MAKE THEIR OWN DECISIONS ABOUT THEIR LIFE, INCLUDING, BUT NOT LIMITED TO, DECISIONS RELATED TO WHERE AND WITH WHOM THE DECISION-MAKER WANTS TO LIVE; DECISIONS ABOUT FINANCES; THE SERVICES, SUPPORTS, AND HEALTH CARE THE DECISION-MAKER WANTS TO RECEIVE; AND WHERE THE DECISION-MAKER WANTS TO WORK.

(J) "SUPPORTED DECISION-MAKING AGREEMENT" IS AN AGREEMENT A DECISION-MAKER ENTERS INTO WITH ONE OR MORE SUPPORTERS UNDER THIS SECTION THAT DESCRIBES HOW THE DECISION-MAKER USES SUPPORTED DECISION-MAKING TO MAKE THEIR OWN DECISIONS. SUPPORTED DECISION-MAKING AGREEMENTS CAN EITHER BE AN INFORMAL ARRANGEMENT BETWEEN THE DECISION-MAKER AND HIS OR HER SUPPORTER OR SUPPORTERS, OR ONE THAT IS IN ACCORDANCE WITH SECTION 82.11 OF THIS ARTICLE, WHICH HAS BEEN REVIEWED AND SIGNED BY A FACILITATOR.

III. Decisions for Incapable Patients



NEW YORK STATE OF OPPORTUNITY.

Office for People With Developmental Disabilities

Supported Decision-Making

Mental Hygiene Law Article 82

Haldan Blecher
Senior Attorney, NYS Office for People With Developmental Disabilities (OPWDD)

What is Supported Decision-Making (SDM)?

- SDM is often viewed exclusively as an alternative to legal guardianship, but that's only one of its applications.
- It's something almost everyone does : **we ask friends or family for advice when we're faced with important decisions.**

What is Supported Decision-Making (SDM)?

- Under the formal model, SDM takes the form of a written agreement, a **Supported Decision-Making Agreement** (SDMA)
  - made at the direction of the individual (the "decision-maker" or DM)
  - with the participation of "supporters," who will assist the individual in making decisions in designated areas of the individual's life
  - Under the model proposed in NYS, generally with the assistance of a "facilitator."

Who can SDM help?

- ***Everyone who wants it!***
- Particularly, people with I/DD who want or need support in:
  - Signing plans of service
  - Consenting to medical treatment or behavioral treatment
  - Providing other routine consent or assent (transportation, banks, landlords, county clerks, etc.)
  - Deciding where and with whom they'd like to live
- People in certified residential settings who want to transition to the community/independent settings with more decision-making supports.

The SDM Act (MHL Article 82)

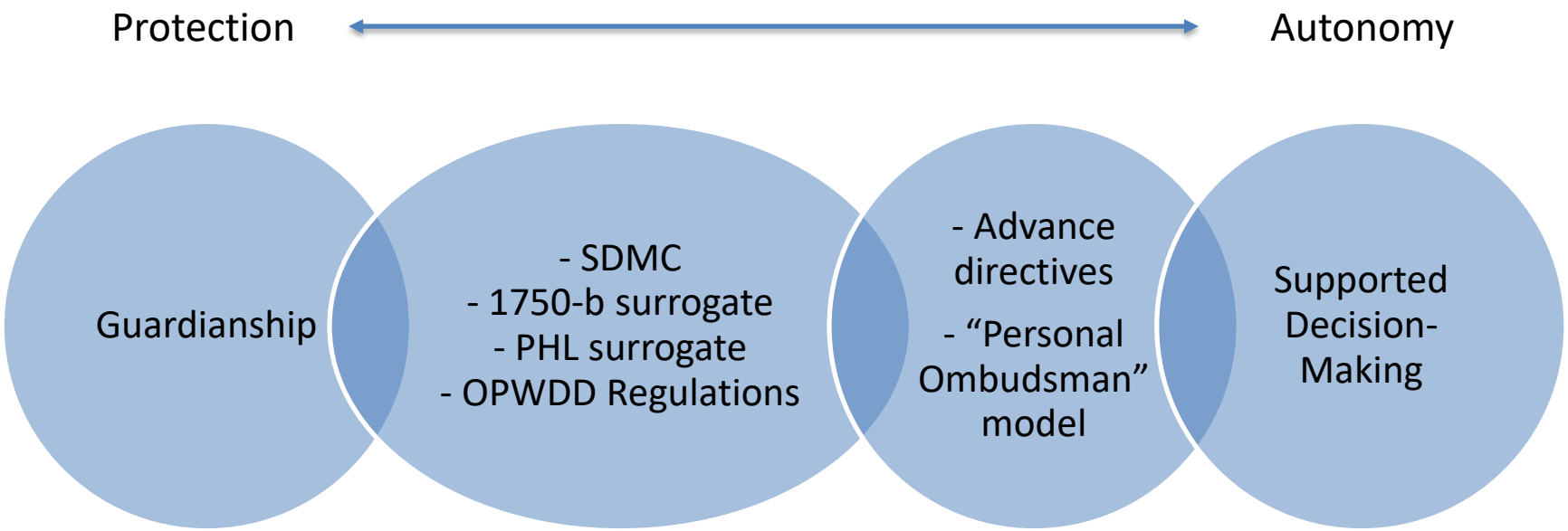
- Recognizes SDM as a *less restrictive alternative* to guardianship
- Presumes capacity to explore SDM. No explicit capacity standard.
- Recognizes SDM facilitation as central to ensuring SDMAs are well-considered
- Requires third parties to honor or recognize a decision made in accordance with a facilitated SDMA
- Grants liability protections to those third parties
- Allows for informal SDM (i.e., without an SDMA), but without third-party obligations and liability protections
- *Regulations will be proposed Summer 2023*

- *Supported* decision-making can allow people to avoid guardianship or other situations where they would lose the power to make decisions for themselves.
- People who have difficulty making decisions may currently become subject to various forms of *substituted* decision-making.

What currently fills this gap?

Examples of *substituted* decision making:

- Guardianship
- SCPA 1750-b for major medical and end-of-life decisions
- Surrogate Decision Making Committee (MHL Art. 80, for major medical and end-of-life decisions)
- OPWDD regulations that allow actively-involved family members to provide consent in some circumstances (e.g., 14 NYCRR 633.11, 633.16)
- Advance directives (e.g., health care proxies or power of attorney)


Protection
Autonomy
Guardianship
- SDMC
- 1750-b surrogate
- PHL surrogate
- OPWDD Regulations
- Advance directives
- "Personal Ombudsman" model
Supported Decision-Making

Historical Context

1. Historically, people with developmental disabilties were subjected to terrible conditions in institutions (such as the Willowbrook State School), experimentation and eugenics.

2. Patients were undertreated due to bias that people with developmental disabilities had a diminished quality of life, or overtreated because of the restrictions of the common law (*Matter of Storar*)

People with Developmental Disabilities Who Lack Capacity

- ★ **If a person with a developmental disability who previously had capacity - executed a health care proxy -**
  - **the agent can make decisions within the parameters of the power given to them.**
- ★ **But what if there is no agent?**
  - **no HCP or agent not available**
  - **or individual never had the capacity to appoint an agent**

Surrogate (as Opposed to Supported) Decision Making -----Legal Framework

1. "Health Care Decisions Act" (for persons who are intellectually disabled)

2. Codified at Surrogate's Court Procedure Act 1750-b; Effective March 16, 2003;

3. Reformed law to relax strict *common law* rules;

4. Legally authorized surrogates may make decisions to withhold or withdraw life sustaining treatment for patients with developmental disabilties who lack capacity.

Review - Legally Authorized 1750b Surrogates

1. **Court appointed guardians with authority to make healthcare decisions.**
2. **Actively involved spouse.**
3. **Actively involved parent.**
4. **Actively involved adult child, sibling, family member.**
5. **Consumer Advisory Board (Willowbrook Class).**
6. **Surrogate Decision Making Committees (Art 80 MHL).* applies to patients without family members or other legally authorized surrogates**

Review - Responsibility of Surrogates

1. **Advocate for efficacious treatment.**

2. **Base decisions on <u>best interests</u>, and when known, the <u>person's wishes</u> including moral and religious beliefs.**

3. **Statutory best interest considerations include - <u>dignity and uniqueness of the person</u>, <u>preserve, improve or restore health</u>; <u>relief from suffering</u>.**

SCPA 1750-b (2) & (4)

Life Sustaining Treatment (LST)

Medical treatment which is sustaining life functions and without which, according to reasonable medical judgment, the patient will die within a relatively short time period. Includes CPR, mechanical ventilation, hemodialysis, and artificial nutrition and hydration.

SCPA 1750-b(1)

Surrogate Decision Making -Role of Physician in Determining Capacity

1. **Attending physician determines if patient has capacity.**

2. **Arranges for a concurring determination of by a clinician with specific credential approved by OPWDD - includes licensed psychologist.**

Surrogate Decision Making - Role of Physician Medical Criteria

Attending/concurring physician determines;

1. patient has a terminal condition; OR

2. is permanently unconscious; OR

3. *has a medical condition other (other than a developmental disability) that is irreversible and will continue indefinitely; (COPD, dementia, for example)*

4. AND, the proposed treatment would impose an extraordinary burden to the individual.

SCPA 1750-b(4)(b)

Surrogate Decision Making - Extraordinary Burden Considerations

1. The person's overall medical condition, other than the person's developmental disability;

2. The expected outcome of treatment; notwithstanding the person's developmental disability

SCPA 1750-b(4)(b)

Artificial Nutrition and Hydration

Additional requirement of finding that ANH itself poses an extraordinary burden to the person

OR

There is no reasonable hope of maintaining life

SCPA 1750-b(4)(b)

Surrogate Decision Making -- Oversight

1. If a patient with a developmental disability is a *resident of a facility* operated or licensed by OPWDD, SCPA 1750-b LST decisions are subject to oversight by the facility director and MHLS;

2. For patients with developmental disabilties who d*o not reside in a certified setting*, SCPA LST decisions are subject to oversight by OPWDD;

3. Oversight exercised by providing notice of LST decisions to facility director and MHLS or OPWDD Commissioner, as appropriate

4. In practice, notice often provided by MOLST form and OPWDD legal requirements checklist

Notice requirements

- **At least 48 hours before *withdrawing* LST (example, terminal/compassionate extubation)**

OR

- **As soon as possible if *withholding* LST (example, DNR/DNI, chemotherapy, dialysis)**

- **<u>Patient should be given notice of decision</u> *unless* therapeutic exception applies**

OPWDD Checklist - criteria, notice

NEW YORK STATE OF OPPORTUNITY. | Office for People With Developmental Disabilities

MOLST Legal Requirements Checklist For People With Developmental Disabilities

_____ _____
LAST NAME/FIRST NAME DATE OF BIRTH

_____
ADDRESS

Note: Actual orders should be placed on the MOLST form with this completed checklist attached. Use of this checklist is required for individuals with developmental disabilities (DD) who lack the capacity to make their own health care decisions and do not have a health care proxy. Medical decisions which involve the withholding or withdrawing of life sustaining treatment (LST) for individuals with DD who lack capacity and do not have a health care proxy must comply with the process set forth in the Health Care Decisions Act for persons with MR (HCDA) [SCPA § 1750-b (4)]. Effective June 1, 2010, this includes the issuance of DNR orders.

Step 1 – Identification of Appropriate 1750-b Surrogate from Prioritized List. Check appropriate category and add name of surrogate.

_____ a. 17-A guardian _____
_____ b. actively involved spouse _____
_____ c. actively involved parent _____
_____ d. actively involved adult child _____
_____ e. actively involved adult sibling _____
_____ f. actively involved family member _____
_____ g. Willowbrook CAB (full representation)
_____ h. Surrogate Decision Making Committee (MHL Article 80)

Step 2 – 1750-b surrogate has a conversation or a series of conversations with the treating physician regarding possible treatment options and goals for care. Following these discussions, the 1750-b surrogate makes a decision to withhold or withdraw LST, either orally or in writing.

Specify the LST that is requested to be withdrawn or withheld: _____

_____

_____

_____ Decision made orally

_____ _____
Witness – Attending Physician Second Witness

_____ Decision made in writing (must be dated, signed by surrogate, signed by 1 witness and given to attending physician).

_____ _____
LAST NAME/FIRST NAME DATE OF BIRTH

Step 3 – Confirm individual's lack of capacity to make health care decisions. Either the attending physician or the concurring physician or licensed psychologist must: (a) be employed by a DDSO; or (b) have been employed for at least 2 years in a facility or program operated, licensed or authorized by OPWDD; or (c) have been approved by the commissioner of OPWDD as either possessing specialized training or have 3 years experience in providing services to individuals with DD.

_____ _____
Attending Physician Concurring Physician or Licensed Psychologist

Step 4– Determination of Necessary Medical Criteria.

We have determined to a reasonable degree of medical certainty that **both** of the following conditions are met:

(1) the individual has one of the following medical conditions:

_____ a. a terminal condition; (briefly describe _____
_____);
or
_____ b. permanent unconsciousness; or
_____ c. a medical condition other than DD which requires LST, is irreversible and which will continue indefinitely (briefly describe_____
_____)

AND

(2) the LST would impose an extraordinary burden on the individual in light of:

_____ a. the person's medical condition other than DD (briefly explain _____
_____) and

_____ b. the expected outcome of the LST, notwithstanding the person's DD (briefly explain _____
_____)

If the 1750-b surrogate has requested that artificially provided nutrition or hydration be withdrawn or withheld, one of the following additional factors must also be met:

_____ a. there is no reasonable hope of maintaining life (explain_____
_____); or

_____ b. the artificially provided nutrition or hydration poses an extraordinary burden (explain: _____
_____
_____)

_____ _____
Attending Physician Concurring Physician

_____ _____
LAST NAME/FIRST NAME DATE OF BIRTH

Step 5 – Notifications. At least 48 hours prior to the implementation of a decision to withdraw LST, or at the earliest possible time prior to a decision to withhold LST, the attending physician must notify the following parties:

_____ the person with DD, unless therapeutic exception applies

notified on ___/___/___

_____ if the person is in or was transferred from an OPWDD residential facility

_____ Facility Director notified on ___/___/___

_____ MHLS notified on ___/___/___

_____ if the person is not in and was not transferred from an OPWDD residential facility

_____ the director of the local DDSO notified on ___/___/___

Step 6 - I certify that the 1750-b process has been complied with, the appropriate parties have been notified and no objection to the surrogate's decision remains unresolved.

_____ _____
Attending Physician Date

Note: The MOLST form may ONLY be completed with the 1750-b surrogate after all 6 steps on this checklist have been completed.

NEW YORK STATE DEPARTMENT OF HEALTH

Medical Orders for Life-Sustaining Treatment (MOLST)

THE PATIENT KEEPS THE ORIGINAL MOLST FORM DURING TRAVEL TO DIFFERENT CARE SETTINGS. THE PHYSICIAN/NURSE PRACTITIONER/PHYSICIAN ASSISTANT KEEPS A COPY.

LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT

ADDRESS

CITY/STATE/ZIP

DATE OF BIRTH (MM/DD/YYYY) ☐ Male ☐ Female eMOLST NUMBER (THIS IS NOT AN eMOLST FORM)

Do-Not-Resuscitate (DNR) and Other Life-Sustaining Treatment (LST)

This is a medical order form that tells others the patient's wishes for life-sustaining treatment. A health care professional must complete or change the MOLST form based on the patient's current medical condition, values, wishes, and MOLST Instructions. If the patient is unable to make medical decisions, the orders should reflect patient wishes, as best understood by the health care agent or surrogate. A physician/nurse practitioner/physician assistant must sign the MOLST form. All health care professionals must follow these medical orders as the patient moves from one location to another, unless a physician/nurse practitioner/physician assistant examines the patient, reviews the orders, and changes them.

MOLST is generally for patients with serious health conditions. The patient or other decision-maker should work with the physician/nurse practitioner/physician assistant and consider asking the physician/nurse practitioner/physician assistant to fill out a MOLST form if the patient:

- Wants to avoid or receive any or all life-sustaining treatment.
- Resides in a long-term care facility or requires long-term care services.
- Might die within the next year.

If the patient has an intellectual or developmental disability (I/DD) and lacks the capacity to decide, the physician (not a nurse practitioner or physician assistant) must follow special procedures and attach the completed Office for People with Developmental Disabilities (OPWDD) legal requirements checklist before signing the MOLST. See page 4.

SECTION A Resuscitation Instructions When the Patient Has No Pulse and/or Is Not Breathing

Check **one**:

☐ **CPR Order: Attempt Cardio-Pulmonary Resuscitation**
CPR involves artificial breathing and forceful pressure on the chest to try to restart the heart. It usually involves electric shock (defibrillation) and a plastic tube down the throat into the windpipe to assist breathing (intubation). It means that all medical treatments will be done to prolong life when the heart stops or breathing stops, including being placed on a breathing machine and being transferred to the hospital.

☐ **DNR Order: Do Not Attempt Resuscitation (Allow Natural Death)**
This means do not begin CPR, as defined above, to make the heart or breathing start again if either stops.

SECTION B Consent for Resuscitation Instructions (Section A)

The patient can make a decision about resuscitation if he or she has the ability to decide about resuscitation. If the patient does NOT have the ability to decide about resuscitation and has a health care proxy, the health care agent makes this decision. If there is no health care proxy, another person will decide, chosen from a list based on NYS law. Individuals with I/DD who do not have capacity and do not have a health care proxy must follow SCPA 1750-b.

SIGNATURE ☐ Check if verbal consent (Leave signature line blank) DATE/TIME

PRINT NAME OF DECISION-MAKER

PRINT FIRST WITNESS NAME PRINT SECOND WITNESS NAME

Who made the decisions? ☐ Patient ☐ Health Care Agent ☐ Public Health Law Surrogate ☐ Minor's Parent/Guardian ☐ §1750-b Surrogate*

SECTION C Physician/Nurse Practitioner/Physician Assistant Signature for Sections A and B

PHYSICIAN/NURSE PRACTITIONER/PHYSICIAN ASSISTANT SIGNATURE* PHYSICIAN/NURSE PRACTITIONER/PHYSICIAN ASSISTANT NAME DATE/TIME

PHYSICIAN/NURSE PRACTITIONER/PHYSICIAN ASSISTANT LICENSE NUMBER PHYSICIAN/NURSE PRACTITIONER/PHYSICIAN ASSISTANT PHONE/PAGER NUMBER

SECTION D Advance Directives

Check all advance directives known to have been completed:

☐ Health Care Proxy ☐ Living Will ☐ Organ Donation ☐ Documentation of Oral Advance Directive

***If this decision is being made by a 1750-b surrogate, a physician must sign the MOLST.**

THE PATIENT KEEPS THE ORIGINAL MOLST FORM DURING TRAVEL TO DIFFERENT CARE SETTINGS. THE PHYSICIAN/NURSE PRACTITIONER/PHYSICIAN ASSISTANT KEEPS A COPY.

LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT DATE OF BIRTH (MM/DD/YYYY)

SECTION E Orders For Other Life-Sustaining Treatment and Future Hospitalization When the Patient has a Pulse and the Patient is Breathing

Life-sustaining treatment may be ordered for a trial period to determine if there is benefit to the patient. **If a life-sustaining treatment is started, but turns out not to be helpful, the treatment can be stopped. Before stopping treatment, additional procedures may be needed as indicated on page 4.**

Treatment Guidelines No matter what else is chosen, the patient will be treated with dignity and respect, and health care providers will offer comfort measures. *Check one:*

☐ **Comfort measures only** Comfort measures are medical care and treatment provided with the primary goal of relieving pain and other symptoms and reducing suffering. Reasonable measures will be made to offer food and fluids by mouth. Medication, turning in bed, wound care and other measures will be used to relieve pain and suffering. Oxygen, suctioning and manual treatment of airway obstruction will be used as needed for comfort.

☐ **Limited medical interventions** The patient will receive medication by mouth or through a vein, heart monitoring and all other necessary treatment, based on MOLST orders.

☐ **No limitations on medical interventions** The patient will receive all needed treatments.

Instructions for Intubation and Mechanical Ventilation *Check one:*

☐ **Do not intubate (DNI)** Do not place a tube down the patient's throat or connect to a breathing machine that pumps air into and out of lungs. Treatments are available for symptoms of shortness of breath, such as oxygen and morphine. (This box should not be checked if full CPR is checked in Section A.)

☐ **A trial period** *Check one or both:*
- ☐ **Intubation and mechanical ventilation**
- ☐ **Noninvasive ventilation (e.g. BIPAP), if the health care professional agrees that it is appropriate**

☐ **Intubation and long-term mechanical ventilation, if needed** Place a tube down the patient's throat and connect to a breathing machine as long as it is medically needed.

Future Hospitalization/Transfer *Check one:*

☐ **Do not send to the hospital unless pain or severe symptoms cannot be otherwise controlled.**

☐ **Send to the hospital, if necessary, based on MOLST orders.**

Artificially Administered Fluids and Nutrition When a patient can no longer eat or drink, liquid food or fluids can be given by a tube inserted in the stomach or fluids can be given by a small plastic tube (catheter) inserted directly into the vein. If a patient chooses not to have either a feeding tube or IV fluids, food and fluids are offered as tolerated using careful hand feeding. **Additional procedures may be needed as indicated on page 4.**
Check one each for feeding tube and IV fluids:

☐ **No feeding tube** ☐ **No IV fluids**
☐ **A trial period of feeding tube** ☐ **A trial period of IV fluids**
☐ **Long-term feeding tube, if needed**

Antibiotics *Check one:*

☐ **Do not use antibiotics.** Use other comfort measures to relieve symptoms.

☐ **Determine use or limitation of antibiotics when infection occurs.**

☐ **Use antibiotics** to treat infections, if medically indicated.

Other Instructions about starting or stopping treatments discussed with the physician/nurse practitioner/physician assistant or about other treatments not listed above (dialysis, transfusions, etc.).

Consent for Life-Sustaining Treatment Orders (Section E) (Same as Section B, which is the consent for Section A)

SIGNATURE ☐ Check if verbal consent (Leave signature line blank) DATE/TIME

PRINT NAME OF DECISION-MAKER

PRINT FIRST WITNESS NAME PRINT SECOND WITNESS NAME

Who made the decisions? ☐ Patient ☐ Health Care Agent ☐ Based on clear and convincing evidence of patient's wishes ☐ Public Health Law Surrogate ☐ Minor's Parent/Guardian ☐ §1750-b Surrogate*

Physician/Nurse Practitioner/Physician Assistant Signature for Section E

PHYSICIAN/NURSE PRACTITIONER/PHYSICIAN ASSISTANT SIGNATURE* PRINT PHYSICIAN/NURSE PRACTITIONER/PHYSICIAN ASSISTANT NAME DATE/TIME

***If this decision is being made by a 1750-b surrogate, a physician must sign the MOLST.**

 This MOLST form has been approved by the NYSDOH for use in all settings.

A8586B / S7107B

AN ACT to amend the mental hygiene law

The People of the State of New York, represented in the Senate and Assembly, do enact as follows:

§1. The mental hygiene law is amended by adding a new article 82 to read as follows:

ARTICLE 82
SUPPORTED DECISION-MAKING

NY MENT HYG §82.01

82.01 – Legislative findings and purpose

(a) The legislature finds that a person's right to make their own decisions is critical to their autonomy and self-determination. People with intellectual, developmental, cognitive and psychosocial disabilities are often denied that right because of stigma and outdated beliefs about their capability. This right is denied, despite the reality that very few people make decisions entirely on their own. Everyone uses supports, as do people with disabilities; who may just need more or different kinds of supports.

(b) The legislature further finds that the, now well recognized, practice of supported decision-making is a way in which many people with disabilities can make their own decisions with the support they need from trusted persons in their lives, and that supported decision-making can be a less restrictive alternative to guardianship. Recognizing that supported decision-making can take a variety of forms, the legislature finds that a more formal process, resulting in a supported decision-making agreement between the person with a disability (the decision-maker) and their supporter(s), can provide the basis for requiring third parties, who might otherwise question a person's legal capacity because of their disability, to recognize their decisions on the same basis as others. When this more formal process is followed, people with disabilities can make choices confident that they will be respected by others, and knowing they will be solely responsible for their own decisions.

(c) The legislature further finds that supported decision-making and supported decision-making agreements should be encouraged when appropriate for persons with disabilities, and that the execution of a supported decision-making agreement should not detrimentally impact the eligibility of a person for other services, including adult protective services.

(d) The legislature also strongly urges relevant state agencies and civil society to research and develop appropriate and effective means of support for older persons with cognitive decline, persons with traumatic brain injuries, and persons with psychosocial disabilities, so that full legislative recognition can also be accorded to the decisions made with supported decision-making agreements by persons with such conditions, based on a consensus about what kinds of support are most effective and how they can best be delivered.

NY MENT HYG § 82.02

82.02 – Definitions

When used in this article, the following terms shall have the following meaning, unless the context or subject matter requires a different interpretation:

(a) "abuse" encompasses physical abuse, sexual abuse, and emotional abuse, as defined in section 473 of the social services law.
(b) "adult" means an individual 18 years of age or older.
(c) "advance directive" means a legally recognized written or oral instruction by an adult relating to the provision of health care to the adult if and when they become incapacitated, including but not limited to a health care proxy, a consent to the issuance of an order not to resuscitate or other orders for life-sustaining treatment recorded in a patient's medical record, or other legally recognized statements of wishes or beliefs.
(d) "decision-maker" means an adult who has executed, or seeks to execute, a supported decision-making agreement.
(e) "financial exploitation" has the meaning given in section 473 of the social services law.
(f) "good faith" means honest in fact and in the observance of reasonable standards of fair dealing.
(g) "neglect" has the meaning defined in paragraph (d) of subdivision (1) of section 473 of the social services law.
(h) "physical coercion" means to place under duress, menace, or threaten physical violence or imprisonment.
(i) "supported decision-making" means a way by which a decision-maker utilizes support from trusted persons in their life, in order to make their own decisions about their life, including, but not limited to, decisions related to where and with whom the decision-maker wants to live; decisions about finances; the services, supports, and health care the decision-maker wants to receive; and where the decision-maker wants to work.
(j) "supported decision-making agreement" is an agreement a decision-maker enters into with one or more supporters under this section that describes how the decision-maker uses supported decision-making to make their own decisions. Supported decision-making agreements can either be an informal arrangement between the decision-maker and his or her supporter(s), or one that is in accordance with section 82.11 of the mental hygiene law, which has been reviewed and signed by a facilitator.
(k) "supporter" means an adult who has voluntarily entered into a supported decision-making agreement with a decision-maker, agreeing to assist the decision-maker in making their own

decisions as prescribed by the supported decision-making agreement, and who is not ineligible under section 82.08 of this article.

(l) "undue influence" means moral or mental coercion that leads someone to carry out the wishes of another instead of their own because they are unable to refuse or resist.

(m) "facilitator" means an individual or entity authorized by the office for people with developmental disabilities that works with and educates the decision maker and his or her supporter(s) about supported decision-making and supported decision-making agreements authorized under this article.

NY MENT HYG § 82.03

82.03 – Presumption of capacity

(a) For the purposes of this article, every adult shall be presumed to have the capacity to enter into a supported decision-making agreement, unless that adult has a legal guardian, appointed by a court of competent jurisdiction, whose granted authority is in conflict with the proposed supported decision-making agreement. This presumption may be rebutted only by clear and convincing evidence.

(b) Capacity shall include capacity with decision-making support and/or accommodations.

(c) A diagnosis of a developmental, or other disability or condition shall not constitute evidence of incapacity.

(d) The manner in which an adult communicates with others shall not constitute evidence of incapacity.

(e) Neither the execution of a supported decision-making agreement by an individual, nor the interest in or wish to execute a supported decision-making agreement by an individual, nor the failure of an individual to execute a supported decision-making agreement may be used or considered as evidence that the individual lacks capacity, or to deny the decision-maker benefits to which they are otherwise entitled, including adult protective services.

(f) A decision-maker may make and execute a supported decision-making agreement, if the decision-maker understands that they are making and executing an agreement with their chosen supporters and that they are doing so voluntarily.

NY MENT HYG § 82.04

82.04 – Scope

(a) If a decision-maker voluntarily enters into a supported decision-making agreement with one or more supporters, the decision-maker may, in the agreement, authorize the supporter to provide support to them in making their own decisions in areas they choose, including, but not limited to: gathering information, understanding and interpreting information, weighing options and alternatives to a decision, considering the consequences of making a decision or not making it, participating in conversations with third parties if the decision-maker is present and requests their participation, communicating the decision-maker's decision to third parties if the decision-maker is present and requests their participation, and providing the decision-maker support in implementing the decision-maker's decision.

(b) Nothing in this article, nor the existence of an executed supported decision-making agreement, shall preclude the decision-maker from acting independently of the supported

decision-making agreement or executing, with or without the assistance of supporters under a supported decision-making agreement, a power of attorney under title 15 of the general obligations law, health care proxy under article 29-C of the public health law, or other advance directive.

(c) Notwithstanding the existence of a supported decision-making agreement, a decision-maker shall continue to have unrestricted access to their personal information without the assistance of a supporter.

(d) Notwithstanding the existence of a supported decision-making agreement, a decision-maker may request and receive assistance in making any decision that is not covered under the supported decision-making agreement at any time and from any person, regardless of whether that person is designated as a supporter in the supported decision-making agreement.

(e) A supported decision-making agreement made pursuant to this article may be evidence that the decision-maker has a less restrictive alternative to guardianship in place.

(f) The availability of supported decision-making agreements is not intended to limit the informal use of supported decision-making, or to preclude judicial consideration of such informal arrangements as less restrictive alternatives to guardianship.

(g) Execution of a supported decision-making agreement may not be a condition of participation in any activity, service, or program.

(h) If a decision-maker seeks from any person professional advice that would be otherwise covered by evidentiary privilege in accordance with sections 4503, 4504, 4507, 4508, and 4510 of the civil practice law and rules, the inclusion in the conversation of a supporter authorized by the supported decision-making agreement to provide support in the area in which the decision-maker seeks the professional advice shall not constitute a waiver of that privilege.

(i) Notwithstanding any other provision of law to the contrary, nothing within this article shall be construed to prohibit eligibility of a decision-maker for receipt of services or supports that they would have otherwise been entitled, including adult protective services, absent entering into a supported decision-making agreement under the provisions of this article.

(j) A supported decision-making agreement made between a decision-maker and his or her supporter(s) after consultation and education, which is signed by a facilitator shall have the legal force and effect authorized under section 82.11 of this article.

NY MENT HYG § 82.05

82.05 – Duties, responsibilities, and authority of supporters

(a) A supporter must:

1. respect the decision-maker's right to make a decision, even when the supporter disagrees with the decision or believes it is not in the decision-maker’s best interests;
2. act honestly, diligently, and in good faith;
3. act within the scope set forth in the executed supported decision-making agreement;
4. avoid conflicts of interest; and
5. notify the decision-maker in writing, and in a manner the decision-maker can understand, of the supporter’s intent to resign as a supporter.
6. participate in facilitation and/or education programs developed under regulations promulgated by the office for people with developmental disabilities in order to enter a formal supported decision-making agreement.

(b) A supporter is prohibited from:

1. making decisions for the decision-maker, except to the extent otherwise granted in an advance directive;
2. exerting undue influence upon the decision-maker;
3. physically coercing the decision-maker;
4. obtaining, without the consent of the decision-maker, information acquired for a purpose other than assisting the decision-maker in making a decision authorized by the supported decision-making agreement;
5. obtaining, without the consent of the decision-maker, or as expressly granted by the supported decision-making agreement, and accompanied by an appropriate release, nonpublic personal information as defined in 15 U.S.C. § 6809(4)(A), or clinical records or information under subdivision (c) of section of 33.13 of the mental hygiene law;
6. communicating a decision-maker's decision to a third party without the participation and presence of the decision-maker; and

(c) The relationship between a decision-maker and a supporter is one of trust and confidence and serves to preserve the decision-making authority of the decision-maker.

(d) A supporter shall not be considered a surrogate or substitute decision maker for the decision-maker and shall not have the authority to sign legal documents on behalf of the decision-maker or bind the decision-maker to a legal agreement, but may, if such authority is expressly granted in the supported decision-making agreement, provide co-signature together with the decision-maker acknowledging the receipt of statements of rights and responsibilities in order to permit participation in such programs or activities that the decision-maker has communicated a choice to participate in.

(e) If expressly granted by the supported decision-making agreement, and the decision-maker has signed an appropriate release, the supporter may assist the decision-maker in obtaining educational records under the Family Educational Rights and Privacy Act of 1974 (20 U.S.C. § 1232g), protected health information under the Health Insurance Portability and Accountability Act of 1996 (45 CFR §§ 164.502, 164.508), clinical records and information under subdivision (c) of section 33.13 of the mental hygiene law, or patient information under subdivisions (2) and (3) of section 18 of the public health law.

(f) A supporter shall ensure the information obtained under subdivision (e) of this section is kept privileged and confidential, as applicable, and is not subject to unauthorized access, use, or disclosure.

NY MENT HYG § 82.06

82.06 – Formation and term of agreement

(a) An adult may enter into a supported decision-making agreement at any time if the adult enters into the agreement voluntarily.

(b) A decision-maker may sign a supported decision-making agreement in any manner, including electronic signatures permitted under article 3 of the state technology law.

(c) A supported decision-making agreement formed under the provisions of this article shall remain in effect unless and until revoked by the decision-maker.

NY MENT HYG § 82.07

82.07 – Revocation and amendment of agreement

(a) The decision-maker may revoke all or part of a supported decision-making agreement by notifying the supporters orally or in writing, or by any other act evincing a specific intent to revoke the agreement. The failure of the decision-maker to notify supporters shall not invalidate the revocation of all or part of the supported decision-making agreement.
(b) A decision-maker may amend a supported decision-making agreement at any time for any reason, subject to the requirements of this section. The decision-maker shall notify all supporters of any amendment made to the supported decision-making agreement, but the failure to do so shall not invalidate the amendment.

NY MENT HYG § 82.08

82.08 – Eligibility and resignation of supporters

(a) A supporter shall be any adult chosen by the decision-maker; if the supporter chosen by the decision-maker is an employee of a provider from whom the decision-maker receives services, the employee and the provider must follow the requirements set out in regulations promulgated by the office for people with developmental disabilities, or other appropriate regulatory body which address those circumstances, with attention paid to relative labor law and employment obligations and possible conflicts of interest or the appearance of a conflict of interest.
(b) An individual who has been chosen by the decision-maker to be a supporter, or who has entered into a supported decision-making agreement as a supporter, shall be deemed ineligible to act or continue to serve as supporter upon the occurrence of any of the following:
    1. a court authorizes a protective order or restraining order against the supporter on request of or on behalf of the decision-maker; or
    2. the local department of social services has found that the supporter has committed abuse, neglect, financial exploitation, or physical coercion against the decision-maker as such terms are defined in section 82.02 of this article.
(c) A supporter may resign as supporter by written or oral notice to the decision-maker and the remaining supporters.
(d) If the supported decision-making agreement includes more than one supporter, or is amended to replace the supporter who is ineligible under subdivision (b) of this section or resigns under subdivision (c) of this section, the supported decision-making agreement shall survive for the remaining supporters, unless it is otherwise revoked under section 82.07 of this article.
(e) If the supported decision-making agreement does not include more than one supporter, and is not amended to replace the supporter who becomes ineligible under subdivision (b) of this section or resigns under subdivision (c) of this section, the supported decision-making agreement shall be considered terminated.

NY MENT HYG § 82.09

82.09 – Facilitation of agreement

(a) The provisions of section 82.11 and subdivisions (b) through (d) of section 82.12 of this article shall only apply in circumstances where a decision is made by a decision-maker, pursuant to a supported decision-making agreement created in accordance with this article where such decision-maker and supporter(s) have worked with a facilitator, such supporter has and followed

a recognized supported decision-making facilitation or education process as defined and prescribed by regulations promulgated by the office for people with developmental disabilities and such facilitator has signed such agreement.

NY MENT HYG § 82.10

82.10 – Form of agreement

(a) A supported decision-making agreement may be in any form consistent with the requirements set forth in this article.
(b) A supported decision-making agreement must:
    1. be in writing;
    2. be dated;
    3. designate the decision-maker, and at least one supporter;
    4. list the categories of decisions with which a supporter is authorized to assist the decision-maker;
    5. list the kinds of support that each supporter may give for each area in which they are designated as a supporter;
    6. contain an attestation that the supporters agree to honor the right of the decision-maker to make their own decisions in the ways and areas specified in the agreement, respect the decision-maker's decisions, and, further, that they will not make decisions for the decision-maker;
    7. state that the decision-maker may change, amend, or revoke the supported decision-making agreement at any time for any reason, subject to the requirements of section 82.06 of this article;
    8. be signed by all designated supporters; and
    9. be executed or endorsed by the decision-maker in the presence of at least two adult witnesses who are not also designated as supporters, or with the attestation of a notary public.
(c) A supported decision-making agreement may:
    1. appoint more than one supporter;
    2. authorize a supporter to obtain personal information as described in subdivision (e) of section 82.05 of this article;
    3. authorize a supporter to share information with any other supporter or others named in the agreement; or
    4. detail any other limitations on the scope of a supporter's role that the decision-maker deems important.
(d) In order to be subject to the provisions of section 82.11 and subdivisions (b) through (d) of section 82.12 of this article, a supported decision-making agreement must also:
    1. be signed by a facilitator or educator;
    2. include a statement that the supported decision-making agreement was made in accordance with a recognized facilitation and/or education process; and
    3. include an attached attestation by the decision-maker that a particular decision has been made in accordance with the support described in the supported decision-making agreement.

NY MENT HYG § 82.11

82.11 – Legal effect of decisions made with support and third-party obligations

(a) This section shall apply only to decisions made pursuant to supported decision-making agreements created in accordance with this article and following a recognized supported decision-making facilitation or education process, as prescribed by regulations governing the facilitation and education processes promulgated by the office for people with developmental disabilities. Additionally, such decisions shall be signed by a facilitator.
(b) A decision or request made or communicated by a decision-maker with the assistance of a supporter in accordance with the provisions of a supported decision-making agreement must, notwithstanding any other provision of law, be recognized as the decision or request of the decision-maker and may be enforced by the decision-maker in law or equity on the same basis as all others.
(c) A person, entity, or agency required to recognize and honor a decision made pursuant to a supported decision-making agreement authorized by this section may require the decision-maker to execute or endorse an attestation, as provided in paragraph three of subdivision (d) of section 82.10 of this article, as a condition of recognizing and honoring the decision.
(d) A person, entity, or agency that receives a supported decision-making agreement must honor a decision made in accordance with the agreement, unless the person, entity, or agency has substantial cause to believe the supported decision-making agreement has been revoked, or the decision-maker is being abused, coerced, unduly influenced, or financially exploited by the supporter, or that the decision will cause the decision-maker substantial and imminent physical or financial harm.

NY MENT HYG § 82.12

82.12– Limitations on liability

(a) Subdivisions (b) through (d) of this section shall apply only to decisions made pursuant to supported decision-making agreements created in accordance with this article signed by a facilitator and following a recognized supported decision-making facilitation or education process, as prescribed by regulations governing the facilitation and education processes promulgated by the office for people with developmental disabilities.
(b) A person shall not be subject to criminal or civil liability and shall not be determined to have engaged in professional misconduct for an act or omission if the act or omission is done in good faith and in reliance on a decision made by a decision-maker pursuant to a duly executed supported decision-making agreement created in accordance with this article.
(c) Any health care provider that provides health care based on the consent of a decision-maker, given with support or assistance provided through a duly executed supported decision-making agreement created in accordance with this article, shall be immune from any action alleging that the decision-maker lacked capacity to provide informed consent, unless the entity, custodian, or organization had actual knowledge or notice that the decision-maker had revoked the supported decision-making agreement, or that the supporter had committed abuse, physical coercion, undue influence, or financial exploitation with respect to the decision to grant consent.

(d) Any public or private entity, custodian, or organization that discloses personal information about a decision-maker in reliance on the terms of a duly executed supported decision-making agreement created in accordance with this article, to a supporter authorized by the terms of the supported decision-making agreement to assist the decision-maker in accessing, collecting, or obtaining that information under subdivision (e) of section 82.05 of this article, shall be immune from any action alleging that it improperly or unlawfully disclosed such information to the supporter unless the entity, custodian, or organization had actual knowledge that decision-maker had revoked such authorization.

(e) This section may not be construed to provide immunity from actions alleging that a health care provider, or other third party, has done any of the following:
    1. caused personal injury as a result of a negligent, reckless, or intentional act;
    2. acted inconsistently with the expressed wishes of a decision-maker;
    3. failed to provide information to either decision-maker or their supporter that would be necessary for informed consent; or
    4. otherwise acted inconsistently with applicable law.

(f) The existence or availability of a supported decision-making agreement does not relieve a health care provider, or other third party, of any legal obligation to provide services to individuals with disabilities, including the obligation to provide reasonable accommodations or auxiliary aids and services, including, but not limited to, interpretation services and communication supports to individuals with disabilities under the federal Americans with Disabilities Act (42 U.S.C. § 12101).

NY MENT HYG § 82.13

82.13– Supporter notice

(a) If any state or municipal law requires that an agency, entity, or person provide a prescribed notice to a decision-maker, and the agency, entity, or person required to provide such notice has received a supported decision-making agreement from a decision-maker that specifies that a supporter is also to receive a copy of any such notice, then the agency, entity, or person in possession of the supported decision-making agreement shall also provide the specified supporter with a copy of such notice.

(b) Notwithstanding the provisions of this subsection, if any state or municipal law requires that an agency, entity, or person provide a prescribed notice to a decision-maker and such notice includes protected information, including private health information or educational records protected by state or federal law, such notice shall not be provided to the specified supporter unless the supported decision-making agreement is accompanied by a release authorizing the specified supporter to obtain the protected information.

NY MENT HYG § 82.14

82.14 – Reporting abuse, coercion, undue influence, or financial exploitation

(a) Any person who receives a copy of or an original supported decision-making agreement and has cause to believe the decision-maker is being abused, physically coerced, or financially exploited

by a supporter, may report the alleged abuse, physical coercion, or financial exploitation to adult protective services pursuant to section 473 of the social services law.

(b) Nothing in this section may be construed as eliminating or limiting a person's duty or requirement to report under any other statute or regulation.

NY MENT HYG § 82.15

82.15 – Rules and regulations

(a) The commissioner of the office for people with developmental disabilities shall promulgate within one year of the passage of this act the rules and regulations necessary to implement this article for adults who receive or are eligible to receive services that are operated, certified, funded or approved by the office for people with developmental disabilities.

(b) Additional regulations related to this article may be promulgated by state agencies whose service populations may benefit from the implementation of supported decision-making.

§2. This act shall take effect ninety days from the date that the regulations issued in accordance with this act appear in the New York State Register, or the date such regulations are adopted, whichever is later; and provided that the commissioner of mental hygiene shall notify the legislative bill drafting commission upon the occurrence of the appearance of the regulations in the New Yok State Register or the date such regulations are adopted, whichever is later, in order that the commission may maintain an accurate and timely effective data base of the official text of laws of the state of New York in furtherance of effecting the provisions of section 44 of the legislative law and section 70-b of the public officers law.

Civil Rights and Individuals with Developmental Disabilities
Government Law Center at Albany Law School

Consent in Health Care Decisions—February 9, 2023

Resources

Statutes

New York Mental Hygiene Health Law, Article 80 - Surrogate Decision-Making for Medical Care and Treatment, https://law.justia.com/codes/new-york/2021/mhy/title-e/article-80/

New York Mental Hygiene Law, Article 82, Supported Decision-making, https://www.nysenate.gov/legislation/laws/MHY/TEA82

New York Public Health Law, Article 29-C - Health Care Agents and Proxies, https://law.justia.com/codes/new-york/2021/pbh/article-29-c/

New York Public Health Law, Article 29-CC - Family Health Care Decisions Act, https://law.justia.com/codes/new-york/2021/pbh/article-29-cc/

New York Surrogate's Court Procedure Act, Section 1750-B - Health care decisions for persons who are intellectually disabled, https://codes.findlaw.com/ny/surrogates-court-procedure-act/scp-sect-1750-b.html

Chapter 618, 2022 Laws of New York, amending section 2803 of the public health law, relating to informed consent,

https://assembly.state.ny.us/leg/?default_fld=&bn=S01172&term=2021&Summary=Y&Actions=Y&Text=Y&Committee%26nbspVotes=Y&Floor%26nbspVotes=Y

Regulations

N.Y. Comp. Codes R. & Regs. Tit. 14 § 633.11 - Medical treatment of Individuals Receiving Services in Facilities and Services Operated and/or Certified by OPWDD, https://www.law.cornell.edu/regulations/new-york/14-NYCRR-633.11

Articles and Reports

Natalie M. Chin and Jasmine Harris, Bazelon Center, Lawyers Committee for Civil Rights Under Law, The ARC, Justice in Aging, etc., *Examining How Crisis Standards of Care May Lead to Intersectional Medical Discrimination Against COVID-19 Patients* (Feb. 11, 2021), https://secureservercdn.net/198.71.233.254/d25.2ac.myftpupload.com/wp-content/uploads/2021/02/FINAL-Intersectional-Guide-Crisis-Care-PDF.pdf.

Christy A. Coe, *Beyond Being Mortal, Safeguarding the Rights of People with Developmental Disabilities to Efficacious Treatment and Dignity at the End of Life*, 88 New York State Bar Journal 9 (2016)

Joseph J. Fins, *The Complicated Legacy of Terry Wallis and His Brain Injury*, 39 Issues in Science and Technology (2023), https://issues.org/terry-wallis-brain-injury-neuroscience-care-fins/

Paul Kietzman, Esq., *Act Now Health Care Proxies* (Albany Law School Government Law Center January 27, 2020), https://www.albanylaw.edu/government-law-center/act-now-healthcare-proxies

New York Task Force on Life and the Law, *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 2016) (PDF), https://www.health.ny.gov/regulations/task_force/

Robert N. Swidler, *Informed Consent and Decisions for Patients Who Lack Capacity,* LEGAL MANUAL FOR NEW YORK PHYSICIANS (6TH ED. 2020)