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).

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.
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> 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.

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