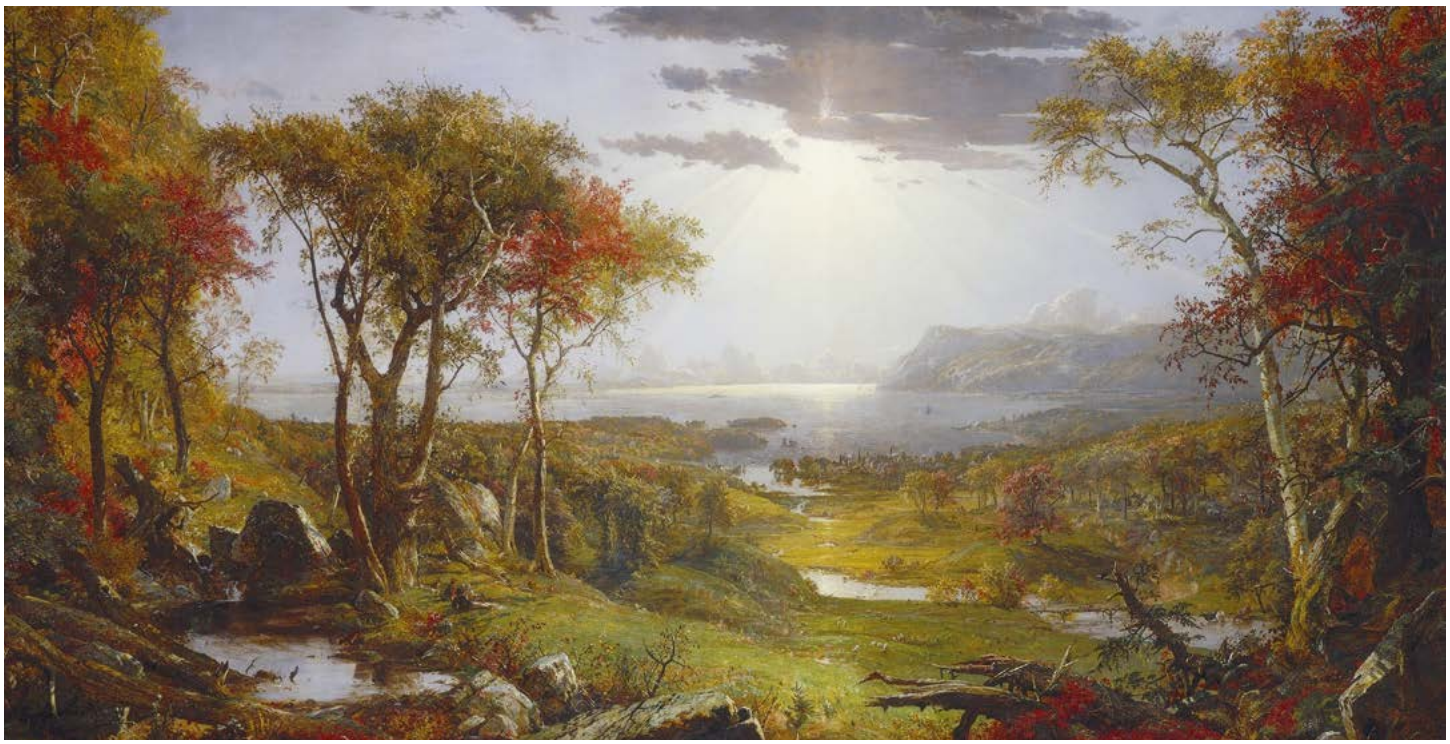
New York's Family Health Care Decisions Act: What Just Changed; What Else Should Be Changed

By Robert N. Swidler



On December 21, 2024, Governor Hochul signed a bill that amended the Family Health Care Decisions Act (FHCDA) and related health care decision-making laws in numerous respects.[1] There was no signing ceremony or fanfare; the bill made only minor technical and clarifying amendments. But the event furnishes the occasion (1) to review what changed and, more importantly, (2) to consider what else should be changed.

What Just Changed: The 2024 Technical and Clarifying Amendments

Chapter 619 of the Laws of 2024 makes minor technical, clarifying and coordinating amendments to the FHCDA,[2] to the Health Care Proxy Law[3] and to the Non-Hospital DNR Law.[4] For instance, the 1990 Health Care Proxy Law still referred in several places, incorrectly, to "a committee of the person" or "a conservator." Those terms were used in statutes that were repealed in 1992 by the Mental Hygiene Law Article 81, New York's Guardianship Law.[5]

Table 1 summarizes the technical amendments made in Chapter 619.

Perhaps the most noticeable change made by the bill is section 10, which directs the commissioner of health to revise the Hospital Patient's Bill of Rights. Currently the statement recites a right to "Receive all the information you need to give informed consent for an order not to resuscitate."[6] That right was added in the wake of the 1997 Do Not Resuscitate Law,[7] which is no longer in effect.[8] The amendment directs the commissioner to replace that clause with a statement that more generally informs patients of their rights with respect to deciding about health care, including appointing a health care agent, consenting to DNR order and making other life-sustaining treatment decisions.

Bills to accomplish these changes and other technical amendments had been introduced repeatedly since 2011, shortly after the FHCDA was enacted.[9] But the 2024 bills sponsored by Senate and Assembly health committee chairs Gustavo Rivera[10] and Amy Paulin[11] were the first versions to pass both houses. The two committee chairs deserve credit for getting this done.

What Else Should Be Changed

The 2024 technical amendments are helpful, indeed overdue. But experience has revealed the need for further changes, e.g., to extend the reach of the FHCDA, and to make certain substantive improvements to these health care decision-making laws. Specifically, here is what else should be changed:

1. Extend the FHCDA to cover all health care decisions for patients with developmental disabilities who lack capacity and did not decide in advance

The FHCDA governs health care decisions for most patients who lack capacity and who did not decide previously or appoint a health care agent. But a separate statute, the Health Care Decisions Act for Persons who are Intellectually Disabled (the HCDA),[12] governs end-of-life decisions for a segment of patients – those with intellectual or developmental disabilities.[13] The principles and procedures in the HCDA are similar to those in the FHCDA, but just different enough to cause confusion, disruption, and delay in the clinical setting. As a matter of principle, a separate statute compels disparate treatment of people with intellectual and developmental disabilities.

The Legislature, in enacting the FHCDA, "carved out" decisions for people with intellectual or developmental disabilities.[14] But at the same time it established a Special Advisory Committee of the New York State Task Force in Life and the Law to study whether the FHCDA should be extended to cover such decisions.[15] In 2016, the committee and the task force issued a report recommending such action.[16] The committee also recommended incorporating into the FHCDA key safeguards from the HCDA, with various adjustments.

A draft bill reflecting these principles is available.[17] The legislature should follow the task force's advice and extend the FHCDA to cover health care decisions for patients with intellectual or developmental disabilities, with safeguards needed for that group of patients. That would advance the goal of simplifying and standardizing decision-making principles and procedures for patients who lack capacity, and reducing disparities in treatment among different classes of incapable patients.

2. Extend the FHCDA to cover all health care decisions (excluding certain psychiatric treatments) for patients in or from psychiatric hospitals and units who lack capacity and did not decide in advance

The FHCDA also "carves out" health care decisions for patients who are in or transferred from Office of Mental Health (OMH) licensed facilities, to the extent that the Mental Hygiene Law or OMH regulations govern such decisions.[18] As a result, the FHCDA does not generally apply in psychiatric hospitals or general hospital psychiatric units, since decisions in those settings are largely governed by OMH regulations.[19]

The task force's Special Advisory Committee studied this issue as well and made several recommendations. First it recommended repealing PHL Article 29-C "Orders Not to Resuscitate in Mental Hygiene Facilities," a remnant of an older, more general DNR Law, and making the FHCDA applicable to such orders.[20] That was accomplished in 2023.[21]

But the amendment did not undo the FHCDA's carve-out of other medical treatment decisions for patients in or from OMH licensed facilities who lack capacity. A bill developed by OMH and introduced in 2024 by Senator Brouk would reduce the carve-out by extending the FHCDA to govern all life-sustaining treatment decisions for such patients.[22] But a strong case can be made for going further and extending the FHCDA to govern all treatment decisions (other than psychiatric treatment decisions)[23] for such patients; i.e., largely eliminating the carve-out. This proposal, like the parallel proposal regarding people with developmental disabilities, would simplify and standardize decision-making principles and procedures for patients who lack capacity, and reduce disparities in treatment among different classes of incapable patients.

3. Expand the list of professionals who are qualified to determine incapacity for people with developmental disabilities

Under the FHCDA, only practitioners with special qualifications are permitted to find that a patient with a developmental disability lacks capacity, which triggers the authority of a surrogate. Specifically, the attending practitioner who makes the determination must be, or must obtain a confirming determination from a physician or clinical psychologist who either:

- is employed by a developmental disabilities services office named in section 13.17 of the mental hygiene law, or
- has been employed for a minimum of two years to render care and service in a facility operated or licensed by the office for people with developmental disabilities, or
- has been approved by the commissioner of developmental disabilities in accordance with regulations promulgated by such commissioner. Such regulations must require that a physician or clinical psychologist possess specialized training or three years' experience in treating developmental disabilities.[24]

The rationale for requiring these qualifications stems from the concern that clinicians who are not experienced in care of patients with developmental disabilities may be apt to underrate or overrate the capacity of such patient. That is a valid rationale. But in practice, hospitals, nursing homes and hospice programs have found it extremely difficult to locate professionals with those unique qualifications. This is especially true in rural hospitals and nursing homes, but it is also true in other hospitals, including major medical centers, during off-hours.

The Special Advisory Committee studied this issue as well, and recommended allowing the determination to be made by a psychiatrist, as an alternative to a practitioner with one of the currently prescribed qualifications.[25] A psychiatrist has advanced training in determining patient capacity, and is more likely to be available than one of the sub-specialists that facilities are currently mandated to find.

Such change would be an improvement, but may still be insufficient to address the problem of securing a determination on an urgent basis in rural hospitals, and in other hospitals on nights, weekends and holidays. An additional change would be to allow a clinician – including a nurse practitioner or physician assistant – who states in the record that they have specialized training or three years' experience in treating developmental disabilities to make the determination, without the need to apply for OPWDD approval. Or, best of all, simply rely upon each facility's medical staff delineation of privileges process to determine which practitioners are qualified to make this determination, just as it determines which practitioners are qualified to perform every other clinical procedure and service at the facility.

4. Revise the standard for end-of-life decisions for socially isolated incapable patients

Sadly, in many instances an end-of-life decision needs to be made for a hospital patient or nursing home resident who lacks capacity and who is socially isolated, that is, who does not have any family member or friend willing and available to act as surrogate decision-maker. In such cases, the FHCDA allows the withdrawal or withholding of life-sustaining treatment in any one of these three circumstances:

1. Judicial approval, based on the court applying the standards that would apply to a surrogate decision;

2. A clinical finding that (i) life-sustaining treatment offers the patient no medical benefit because the patient will die imminently, even if the treatment is provided; and (ii) the provision of life-sustaining treatment would violate accepted medical standards; or

3. The attending practitioner enrolls the patient in hospice, with the approval of an ethics committee, and the decision is part of the hospice plan of care.[26]

In practice, the first standard, judicial approval, is often impractical given the urgency of the decision. And hospice enrollment is not always an available, clinically appropriate, or familiar option.[27]

As a result, the most commonly considered test is the second, "will die imminently" standard, which is essentially a medical futility test. There have been problems in practice in interpreting that clause.[28] In particular, as applied to a DNR order, the clause is often mistakenly read to require a finding that the socially isolated patient "will die imminently" at the time the DNR order is written. But the language and legislative history firmly indicate that the clause allows a DNR order to be written for a socially isolated patient based on a finding that, in the event of cardiac arrest, the patient will die imminently even if resuscitation is attempted.[29]

But the broader problem is that the clause does not allow a humane, ethically supportable decision to opt for comfort care (without hospice enrollment) for a dying socially isolated patient care unless treatment is deemed futile.

Accordingly, the FHCDA should be amended to allow the attending practitioner to decide about life-sustaining treatment in non-futile cases on the same basis that a surrogate could make the decision,[30] but subject to ethics review committee approval. This approach is already used for isolated patients who are enrolled in hospice.[31] There is no great rationale for limiting the approach to hospice patients, who may be clinically indistinguishable from other dying hospital or nursing home patients.

The ethics review committee would play a critical oversight role in this decision. Accordingly, before any such change is made, there is a compelling need to study FHCDA ethics review committees, and include recommended changes to ensure the quality of their services.[32] One such study, limited to hospital ethics review committees, is underway now.[33]

5. Recognize MOLST in statute and support eMOLST

Medical Orders for Life-Sustaining Treatment (MOLST) is "a program designed to improve the quality of care patients receive at the end of life by translating patient goals for care and preferences into medical orders."[34] It is a set of medical orders generally for patients with advanced illness who require long-term care services or who might die within 1-2 years. MOLST may also be used for individuals who wish to avoid or receive specific life-sustaining treatments.

Numerous health care facilities and practitioners throughout New York opt to use the MOLST process and its associated paper or electronic forms and checklists. MOLST forms are familiar to clinicians, use terms that they understand and can apply, and guide them through compliance with the FHCDA and related laws. The forms are also portable, that is, they remain effective as patients transition from one facility or service to another. Such portability is particularly effective when the form is entered into the NYS eMOLST registry.[35]

The use of MOLST is voluntary, and there is no call here to change that. However, it would greatly benefit patients and practitioners to recognize MOLST in statute, and to direct the commissioner of health to approve an official, statutory

compliant model MOLST form and update it as necessary.[36] This would provide assurance to all that a completed MOLST form must be honored. Department of Health (DOH) guidance could also provide that the order needs to be reviewed and modified if needed, if the patient has a major change in health status or the patient changes their mind, or at least every 90 days.

Official recognition of MOLST may also facilitate a body of consistent answers to questions about the meaning of language in the form. And it would reduce the use of nonstandard MOLST checklists, which may not reflect current legal requirements.

Finally, the state should make funds available to support eMOLST (NYSeMOLSTregistry.com). A well-funded eMOLST program would help ensure that patient wishes and interests are consistently identified and honored statewide. It would also provide a reliable, easily accessible source of information for policy review and improvement.

6. Secure DOH cooperation in further studies

Notwithstanding the recommendations for change in this article, the FHCDA appears to be achieving its purpose: facilitating ethically sound, clinically practical decisions for incapable patients. But frankly, that is an impression: there is a dearth of data to back it up.

A major ethical/policy initiative such as the FHCDA, which affects so many lives on a daily basis, deserves serious study: Is the public largely satisfied with the FHCDA's standards and procedures? Do clinicians understand the requirements well? What provisions do patients, family members and clinicians find problematic, and what changes would they call for? Are ethics committees trained and doing their job well? Do the standards need to be revised for specific care settings, specific categories of patients, specific medical conditions or specific treatments? Is the DOH enforcing the law in a fair, measured manner?

At the moment, it seems that academic and health care association researchers would be more willing than government to pursue such studies. But the health commissioner should be encouraged – or possibly directed – to provide reasonable assistance to credible privately funded studies. For example, it could make available relevant governmental data (provided the data is either de-identified or disclosed under the HIPAA exception for IRB-approved disclosures).[37] And as noted previously, eMOLST may be a valuable source of information for such studies. Finally, it could send Dear CEO or Dear Administrator letters encouraging facilities to respond to valuable research surveys. Public policies, like health care services, require continuous quality improvement, which in turn requires data.

Conclusion

The recent law that made minor technical and clarifying amendments to the FHCDA and related laws was helpful. Now comes the harder part – addressing the need for more substantive changes. This article calls for these changes:

1. Extend the FHCDA to cover all health care decisions for patients with intellectual or developmental disabilities who lack capacity and did not decide in advance.

2. Extend the FHCDA to cover all health care decisions (excluding certain psychiatric treatments) for patients in or from psychiatric hospitals and units who lack capacity and did not decide in advance.

3. Expand the list of professionals who are qualified to determine incapacity for people with developmental disabilities.

4. Revise the standard for end-of-life decisions for socially isolated incapable patients.

5. Recognize MOLST in statute and support eMOLST.

6. Secure DOH cooperation in further studies.

By addressing these issues, the Legislature and DOH would demonstrate a commitment to ensuring that the FHCDA and related health care decision-making policies work well for patients and are continually improved based on experience and data.

Table 1

Chapter 619, Laws of 2024

1. Amends the Health Care Proxy Law to

- replace references to "a committee of the person" and "a conservator" with references to a "guardian of the person" under MHL Article 81 (Bill §§ 1, 3 and 4).
- add physician assistant and nurse practitioner to the list of professionals who a health care agent can consult with before making a decision. Those professionals already have significant authority under the FHCDA. (Bill § 2).
- replace "the commissioner or health" with "the commissioner" (Bill §§4, 5).
- correct cross-references to the definition of "a close friend" (Bill § 4).

2. Amends the Family Health Care Decisions Act to

- replace the definition of the term "health or social service practitioner" with the term "health or social services practitioner," (adding an "s" to "services") to be consistent with the rest of the FHCDA. (Bill § 6).
- add "licensed master social worker" to the list of professionals in the definition of "health or social services practitioner," to be consistent with the Health Care Proxy Law list of professionals who an agent can consult before making a decision (Bill § 6).
- replace "attending physician" with "attending practitioner" in the definition section, to be consistent with terminology in the rest of the FHCDA (Bill § 6).
- require the attending physician to document the basis for finding that a minor is an emancipated minor (Bill § 7).
- amend the requirement that a hospital must notify the parents or guardian of an emancipated minor prior to withdrawing or withholding life-sustaining treatment to clarify that the hospital must make and document diligent efforts to notify such persons (Bill § 7).
- amend the requirement that, following ethics review committee consideration of a case concerning the withdrawal or withholding of life-sustaining treatment, treatment shall not be withdrawn or withheld until the hospital makes notifies specific persons involved in the case, to clarify that the hospital must make and document diligent efforts to notify all such persons (Bill § 8).
- Directs the commissioner of health to revise the statement of rights that hospitals are required to post (known as the Patient's Bill of Rights) per PHL § 2803.1(g) to replace the clause regarding DNR order rights with a statement that more generally informs patients of their rights with respect to deciding about health care, including appointing a health care agent, consenting to DNR order and making other life-sustaining treatment decisions. This change would make the statement in the Bill of Rights consistent with DOH publications about patient rights. (Bill § 10).

3. Amends PHL Article 29-ccc - Non-hospital DNR Orders to

- delete a no longer applicable reference to "office for people with developmental disabilities" (Bill § 11).
- add "home care services agency personnel" to the list of professionals who must honor a nonhospital DNR order (Bill § 11).
- eliminate the responsibility of the Commissioner of Health to approve a DNR bracelet, while recognizing the use of such bracelets or other articles to indicate a nonhospital DNR status (Bill § 12).
- permit an alternative nonhospital DNR form in a developmental disabilities services office (Bill § 12).
- in the provision relating to immunity, substitute "pursuant to this article" for "pursuant to this section" (Bill § 13).

Robert N. Swidler, MA, JD, a health law attorney, co-teaches Law and Bioethics in the Columbia University Bioethics Program. For more information see his Orcid page. https://orcid.org/0000-0002-2476-0464

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Endnotes

1. Chapter 619, NY Laws of 2024, enacting Assembly Bill 7194-A(Paulin)/Senate Bill 3283-A (Rivera).
2. NY Public Health Law (PHL) Article 29-CC.
3. PHL Article 29-C.
4. PHL Article 29-CCC.
5. Chapter 698, NY Laws of 1992, creating Mental Hygiene Law Article 81 - Proceedings for Appointment of a Guardian for Personal Needs or Property Management.
6. NYS Hospital Patient's Bill of Rights, available at https://www.health.ny.gov/publications/1500/ (visited 1/16/2025).
7. NY Public Health Law Article 29-B.
8. Chapter 742, NY Laws of 2023. *See* R. N. Swidler, "The Repeal of New York's Do Not Resuscitate Law: A Technical Clean Up Bill – and an Occasion for Reflection," *NYSBA Health Law Journal,* 2023 Vol. 28 No. 3. P. 36.

9. *E.g.*, Assembly Bill A.7343 (2011).
10. S.3283-A (Rivera).
11. A.7184-A (Paulin).
12. NY Surrogate's Court Procedure Act §1750-b.
13. The term "intellectual disability" is not defined in either the Surrogate's Court Procedure Act or the Mental Hygiene Law. The closest to a definition for HCDA purposes appears in SCPA 1750-a Guardianship of persons who are developmentally disabled, which states in relevant part:

> [F]or the purposes of . . . [the HCDA] "a person who is intellectually disabled and his or her guardian" shall also mean a person . . . (i) having an intellectual disability, or (ii) having a developmental disability, as defined in section 1.03 of the mental hygiene law, which (A) includes intellectual disability, or (B) results in a similar impairment of general intellectual functioning or adaptive behavior so that such person is incapable of managing himself or herself, and/or his or her affairs by reason of such developmental disability.
>
> "Developmental disability" is defined in Mental Hygiene Law §1.03 as follows:
>
> 22. "Developmental disability" means a disability of a person which:
>
> (a)(1) is attributable to intellectual disability, cerebral palsy, epilepsy, neurological impairment, familial dysautonomia, Prader-Willi syndrome or autism;
>
> (2) is attributable to any other condition of a person found to be closely related to intellectual disability because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of intellectually disabled persons or requires treatment and services similar to those required for such person; or
>
> (3) is attributable to dyslexia resulting from a disability described in subparagraph one or two of this paragraph;
>
> (b) originates before such person attains age twenty-two;
>
> (c) has continued or can be expected to continue indefinitely; and
>
> (d) constitutes a substantial handicap to such person's ability to function normally in society.

14. NY PHL § 2994-b.3.
15. Chapter 8 of the Laws of 2010 § 28.
16. 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.empirestatebioethics.org/reports.
17. Draft bill to extend FHCDA to people with developmental disabilities. https://docs.google.com/document/d/1R4X6Tdi_fQG1PTwyDgFTczNHiXdGc4dq/edit?usp=drive_link&ouid=114443777586833931683&rtpof=true&sd=true. Last accessed 1/16/2025.
18. NY PHL §2994-b.3.
19. E.g., 14 NYCRR §§ 27.9, 527.8.
20. TF/SAC Recommendations at p.26.
21. See *supra*, note 8 above.
22. Senate Bill 7507-A (2023).
23. Policies regarding surrogate consent to psychiatric treatments to persons in or from OMH-licensed psychiatric hospitals and units fall squarely within the expertise and responsibility of OMH, and should remain governed by OMH regulations. Psychiatric treatments would include psychoactive medications, electroconvulsive therapy (ECT), and other treatments to be determined jointly by OMH and DOH. As an aside, the FHCDA provision that allows attending physician-led approval of major medical decisions for patients without surrogates already excludes psychoactive medications from that approval process. PHL § 2994-g.4(v).
24. NY PHL § 2994-c.
25. TF/SAC Recommendations p.23-24.
26. NY PHL § 2994-g.5, 5-a.
27. Notably, New York is ranked last among states in hospice enrolment, with only 24.7% of decedents in hospice. See National Hospice and Palliative Care Organization (NHPCO), accessed at https://www.americashealthrankings.org/explore/measures/hospice_care_sr_a.
28. See R.N. Swidler, *End of Life Decisions for Isolated Patients*, Voices in Bioethics, 10. https://doi.org/10.52214/vib.v10i.12989 (2024).
29. *Id*. Another policy recommendation is for either DOH or, if necessary, the Legislature to confirm this interpretation.
30. See NY PHL §2994-d.5 (Standards that must be met for a surrogate to direct the withdrawal or withholding of life-sustaining treatment).
31. NY PHL § 2994-g.5-a.
32. R.N.Swidler, *End of Life Decisions for Isolated Patients*, supra, note 8.
33. The study is being conduced by the Empire State Bioethics Consortium under an IRB exemption from University of Rochester Medical Center. The author of this article is a member of the study team.
34. P.A. Bomba and K. Orem, *eMOLST and Electronic Health Records,* NYSBA Health Law Journal, Spring 2012, Vol.17, No, 2.
35. *Id*.
36. DOH is empowered to authorize the use of forms for nonhospital DNR orders, NY PHL § 2977.13, and has so authorized MOLST for that limited purpose. It also published a MOLST form and checklists on its website. See https://www.health.ny.gov/professionals/patients/patient_rights/molst/ But the form has no official status beyond its use as a nonhospital DNR order, and there is no mandate for DOH to update it to be consistent with current law.
37. 45 CFR § 164.512(i).