Three Stubborn Misconceptions About the Authority of Health Care Agents

By Kathleen M. Burke, Alice Herb and Robert N. Swidler

New York's Health Care Proxy Law empowers an adult to appoint a health care agent to make treatment decisions for the adult in the event the adult loses the capacity to make such decisions personally.[1] Health care providers and the public now have nearly 15 years' experience with the law, and it appears that the law been very successful, in most respects. The process to create a health care proxy has proven to be simple and easy to accomplish, and largely free of technical requirements that can confuse the public or invalidate the document. Clinical staff members are generally pleased and relieved when patients or family members produce health care proxies, because they clarify both who has decision-making authority and the scope of that person's authority. Finally, there appear to have been very few examples of abuse or misuse in connection with the creation or use of health care proxies.

To be sure, problems occasionally arise relating to the use of health care proxies. Probably the most common problems stem from three misconceptions relating to the authority of health care agents. It is the purpose of this article to refute these three stubborn misconceptions:

> **Misconception 1:** *A health care agent cannot have access to protected health information unless the patient signed a HIPAA-compliant authorization*.—This is wrong.
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> **Misconception 2**: *A health care agent can consent to the withdrawal or withholding of artificial nutrition and hydration from a patient only if the patient authorized such decision on the proxy form, or left other clear and convincing evidence that he or she would want artificial nutrition and hydration withdrawn or withheld.*—This is wrong.
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> **Misconception 3**. *A health care agent can override a patient's prior instructions to health care professionals, or a patient's advance directive*.—This is wrong.

1. Unnecessary Evil—Adding a HIPAA Authorization to a Health Care Proxy

The first stubborn misconception is the notion that a HIPAA authorization needs to be added to a health care proxy in order to assure that patient's agent will have access to hospital or physician records.[2] This language, if inserted into the proxy itself, could very well be damaging to the interests of both those who have executed proxies and those who plan to do so.

What can be harmful about adding a simple paragraph about HIPAA to a health care proxy? Briefly stated: At best, the authorization is redundant. At worst, it can potentially delay, if not thwart, implementation of the wishes of the patient and also cause confusion about the validity of other proxies that do not contain HIPAA language. In any event, as explained below, the agent has ample authority to access protected health information without a HIPAA authorization.

The Agent's Authority to Access Information Under the Health Care Proxy Law

Both the New York State Health Care Proxy (HCP) law and federal HIPAA privacy regulations were developed for similar reasons: to protect patients and enhance the exercise of their control—in one instance about medical treatment decisions, in the other about the privacy of their personal health information. Examining the HCP law first, the most striking feature of the statute is its simplicity and clarity. It provides that a person may designate another to make decisions on his or her behalf when and if he or she is unable to do so. The document requirements are few, and the principal (the individual who creates a HCP) may add additional directions to his or her agent if desired. By statute, the agent must have access to all necessary information in order to make an informed decision for the principal. Indeed, Section 2982 of the proxy law, under "Rights and duties of agent," explicitly states:

> 3. Notwithstanding any law to the contrary, the agent shall have the right to receive medical information and medical and clinical records necessary to make informed decisions regarding the principal's health care.[3]

The NYS Department of Health (DOH) provides online a simple HCP form, understandable instructions and commonly asked questions and answers about the statute and the process.[4] In answer to a FAQ, the DOH states:

> All hospitals, nursing homes, doctors and other health care providers are legally required to provide your health care agent with the same information that would be provided to you and to honor

> the decisions by your agent as if they were made by you. . . ."[5]

Moreover, the DOH model HCP form has not been changed to reference the HIPAA regulations even though it has been modified more than once since the promulgation of those regulations. DOH's omission of any HIPAA language in the suggested form—or even in the FAQs material—underscores that in DOH's view no HIPAA language is needed for the agent to have full access.

The Agent's Authority to Access Information Under HIPAA

Although the HCP law does not reference HIPAA privacy regulations, those regulations specifically require the "covered entity" (i.e., the provider) to give the principal access to medical information. Moreover, the regulations go on to mandate that the "personal representative" be treated as if he or she were the individual.[6] With respect to adults and emancipated minors who lack capacity, HIPAA regulations define "personal representative" as follows:

> (2) Implementation specification: adults and emancipated minors. If under applicable law a person has authority to act on behalf of an individual who is an adult or an emancipated minor in making decisions related to health care, a covered entity must treat such person as a personal representative under this subchapter, with respect to protected health information relevant to such personal representation.[7]

Accordingly, for purposes of HIPAA an agent is the patient's personal representative.

Furthermore, the Department of Health and Human Services deals directly with this issue in its FAQs. Answers to questions 30 and 95[8] clearly state that the HIPAA Privacy Rule does not affect the way health care representatives are designated nor prevents their access to medical records.[9] In other words, there is no limitation on the authority of the agent other than that specified by the principal. The agent is authorized to obtain all medical information about the principal. The agent "stands in the shoes" of the principal and has authority to make decisions and access all information.

Mougiannis: HIPAA Authorization Unnecessary

In re Mougiannis v. North Shore-Long Island Jewish Health Systems, Inc.[10] is the the only relevant New York State precedent. The court held that HIPAA authorization is *not* necessary to enable a health care agent to have access to the principal's medical information, Judge LaMarca rested his decision on Section 2982(3) stating: ". . . §2982(3) makes the right of a health care agent to medical information clear." The court concluded that the "health care proxy, is deemed a 'qualified person' for the purpose of rquesting access to the subject's health care information."

Proxies with HIPAA Authorizations—An Unnecessary Evil

Since both HIPAA and the HCP law are quite specific about the rights of an agent to access all medical information, the question that remains unanswered is the original one, i.e., how can adding HIPAA authorization language harm the client? But the more appropriate question would be why would attorneys want to append additional language—language that is at once superfluous and can inadvertently sabotage and complicate the process? It should be remembered that HCPs are documents read by non-lawyers—physicians, nurses, etc.—people for whom the familiar form allows them to quickly identify the agent and spot any optional directions. Unnecessary language can confuse, delay or deny the exercise of the principal's rights.[11] Also, what if a change in HIPAA law, regulation or practice affects the acceptable wording of a patient's consent? A HIPAA release form is typically prepared at the time of a patient's visit or hospitalization and, thus, is presumably current with the law. However, an HCP is often prepared years ahead of the time when the principal's illness and incapacity requires its implementation.

The simplicity of the DOH HCP form reflects a compelling public policy goal: to make it easy for anyone, even someone in distress, to execute an HCP, so that in the event of incapacity an authorized agent would be available to make decisions. In fact, the instructions even say that an attorney is not needed. Attempting to "improve" on the form, therefore, is unnecessarily complicating, not protective of the principal. Indeed, it could harm the principal—and defeat the very purpose of the document. If the attorney's rationale for including an authorization is a concern that an uninformed clerk in a record room or in an otherwise non-clinical setting can deny access, pandering to such ignorance only compounds the problem and encourages it. It would be far better to demonstrate with DOH model forms in hand that the agent is entitled to such records and report the refusal to supervisory staff. Attorneys have the obligation to correct a misconception rather than perpetuate it.

For the larger community, it would behoove attorneys to be aware that grafting unnecessary HIPAA language on to an HCP form could lead those unfamiliar with the law

and regulatory interpretation to reject a valid HCP as illegal. Attorneys must avoid creating proxies that become a source of confusion or misinterpretation. Professional ethics demands this.

2. Health Care Agent Decisions Regarding Artificial Nutrition and Hydration

Another stubborn misconception that repeatedly needs to be refuted is the view that a health care agent can consent to the withdrawal or withholding of nutrition and hydration only if the patient provided written authorization for such decision on the proxy form, or if there is clear and convincing evidence that the patient would want artificial nutrition and hydration withdrawn or withheld. This view is inconsistent with the language of the statute, with its legislative history, and with official interpretive guidelines.

The Language of the Statute. PHL § 2982 governs the rights and duties of health care agents. It begins by providing that the agent has the authority to make any decision the principal could make, subject to any express limitations in the health care proxy. It then sets forth the following decision-making standard for agents:

> 2. Decision-making standard. . . . the agent shall make health care decisions: (a) in accordance with the principal's wishes, including the principal's religious and moral beliefs; or (b) if the principal's wishes are not reasonably known and cannot with reasonable diligence be ascertained, in accordance with the principal's best interests; *provided, however, that if the principal's wishes regarding the administration of artificial nutrition and hydration are not reasonably known and cannot with reasonable diligence be ascertained, the agent shall not have the authority to make decisions regarding these measures.*

Elsewhere, the statute sets forth a model health care proxy form which may be used, but is not mandatory. The model form carries this statement:

> NOTE: . . . Unless your agent knows your wishes about artificial nutrition and hydration, your agent will not have the authority to decide about artificial nutrition and hydration. If you choose to state instructions, wishes or limits, please do so below: . . .[12]

Obviously, the statute singles out decisions about artificial nutrition and hydration, and imposes a special restriction on agents with respect to such decisions, i.e.: the agent cannot direct the withdrawal of artificial nutrition and hydration if the principal's wishes "are not reasonably known and cannot with reasonable diligence be ascertained." In other words, the agent cannot base a decision to withdraw artificial nutrition and hydration on the agent's assessment of the principal's best interests. But the agent can make the decision if it is based on patient's wishes that are "reasonably known" or that can "with reasonable diligence be ascertained."

Nothing in the Health Care Proxy Law states that the principal's wishes about artificial nutrition and hydration must be written on the proxy form. The above-mentioned notice in the model form regarding artificial nutrition and hydration is an accurate and helpful statement of the requirement that such wishes must be reasonably known. It is not a cryptic way of warning persons that they must fill in the blank or they will disempower their agent.

Nor does anything in the statute state that there must be "clear and convincing evidence" of the principal's wishes in order for an agent to make a decision about artificial nutrition and hydration. On the contrary, the statute explicitly imposes a lesser evidentiary standard: the principal's wishes need only be "reasonably known" or be ascertainable "with reasonable diligence." The notion that a clear and convincing evidence standard applies to agent decisions about artificial nutrition and hydration presumably is drawn from the Court of Appeals decisions, *In re Storar,*[13] and *In re Westchester County Medical Center [O'Connor].*[14] In those cases, the court held that life-sustaining treatment can be withdrawn or withheld from patients who lack capacity only if there is clear and convincing evidence that the patient would want the treatment withdrawn or withheld under the circumstances. Indeed, that principle still applies, except where, and to the extent the legislature has supplanted it with a different standard—as it did in the Health Care Proxy Law.

Thus, if the Health Care Proxy Law had simply provided that health care agents do not have authority to make decisions about artificial nutrition and hydration, then the *Storar/O'Connor* clear and convincing evidence standard would apply to such decisions. But the Health Care Proxy Law did not do that. Rather, it provided: (1) that agents have the authority to make any decision the principal could make—including decisions about artificial nutrition and hydration; (2) that in general, health care decisions by an agent must be based on the principal's reasonably known or ascertainable wishes or, absent such wishes, on the principal's best interest; but (3) that decisions to withdraw artificial nutrition and hydration can be made by an agent only if based on the principal's reasonably known or ascertainable wishes.

The Legislative History

It should not be necessary to review the legislative history of the Health Care Proxy Law's decision-making standard; its meaning is clear from its plain language. In any event, the legislative history firmly supports the authority of an agent to make decisions about artificial nutrition and hydration based on the patient's wishes, without the need for authorization in the form, and without clear and convincing evidence.

The Health Care Proxy Law is based on a 1987 proposal by the New York State Task Force on Life and the Law.[15] The Task Force's proposal, and the initial governor's program bill based on the proposal, included a decision-making standard for agents that did not single out decisions about artificial nutrition and hydration for special treatment.[16]

However, the Senate was reluctant to pass the bill unless it was revised to address concerns identified by the NYS Catholic Conference, an influential advocacy organization. The Conference, then represented by its Executive Director J. Alan Davitt, expressed general reservations about empowering agents to authorize the withdrawal of artificial nutrition. But the Conference was particularly critical of the notion that the withdrawal of artificial nutrition and hydration could ever be in a patient's "best interests." Discussions toward the end-of-session in 1990 between officials from the governor's office, the NYS Health Department and the Conference led to a proposed compromise: to eliminate the authority of agents to base such decisions on the patient's best interests. That compromise proposal did not include any amendment to the evidentiary standard applicable to decisions based on patient wishes; the general "reasonably known" standard would remain applicable to all such decisions.[17]

The Senate and Assembly sponsors made the proposed change, and reintroduced the bill. On July 22, 1990, the legislature passed the bill. The governor's approval message addressed the artificial nutrition and hydration decision-making standard, stating as follows:

> Special safeguards apply to decisions about artificial nutrition and hydration: A health care agent can decide against the provision of such measures only when the decision reflects the patient's reasonably known wishes.[18]

The Health Care Proxy Law became effective January 18, 1991.

Post-Enactment Guidelines

Official guidelines and other authoritative materials confirm that an agent does not need written instructions on the proxy form, or other clear and convincing evidence of a patient's wishes in order to direct the withdrawal of artificial nutrition and hydration.

- ***The Health Care Proxy Form and Instructions:***[19] The NYS Department of Health Web site carries a model health care proxy form and instructions that provides this information about the decisions relating to nutrition and hydration:

  > **About the Health Care Proxy Form**: . . . Unless your agent *reasonably knows* your wishes about artificial nutrition and hydration (nourishment and water provided by a feeding tube or intravenous line) he or she will not be allowed to refuse or consent to those measures for you . . . [20]
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  > **Frequently Asked Questions** . . . What decision can my agent make? . . . [Y]our agent can only make decisions about artificial nutrition and hydration (nourishment and water provided by feeding tube or intravenous line) if he or she *knows your wishes from what you have said or what you have written* . . .[21]
  >
  > **Health Care Proxy**: . . . In order for your agent to make health care decisions for you about artificial nutrition and hydration (nourishment and water provided by feeding tube or 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.[22]

- ***The Health Care Proxy Law: A Guideline For Professionals*** (January 1991)—This is a guidebook prepared by the New York State Department of Health and the New York State Task Force on Life and the Law, in consultation with various health care organizations. It provides these two relevant Q & A's:

  > Q: Must the agent have "clear and convincing evidence" of the patient's wishes in order to consent to withdraw or withhold life-sustaining treatment?
  >
  > A: No. Reasonable knowledge of the patient's wishes is sufficient. In addition, if no such evidence is available, the agent can consent to forgo life-sustaining treatment if he or she makes a good faith judgment that forgoing treatment is in the patient's best interests, except for a decision about artificial nutrition and hydration. To decide about artificial

nutrition and hydration, the agent must have reasonable knowledge of the patient's wishes.

Q: Must evidence of the patient's wishes about artificial nutrition and hydration be written on the proxy form?

A: No. There is no requirement that this evidence be written on the proxy form or elsewhere. The agent's knowledge can be based on prior oral statements by the patient and knowledge of the patient's religious, moral and personal belief about health care.[23]

- ***Miller Analysis.*** Shortly after the law's enactment, Tracy E. Miller, who was Executive Director of the Task Force on Life and the Law and was closely involved in both the law's development and enactment, wrote a comprehensive analysis of the law for the *New York Law Journal*.[24] She explained:

> An agent can only decide about artificial nutrition and hydration based on knowledge of the patient's wishes. Clear and convincing evidence is not required; the law expressly displaces that standard by allowing decisions based on reasonable knowledge of the patient's wishes. The patient's wishes about artificial nutrition and hydration may, but need not, be set forth in writing.

Relevant Case Law

There appears to be only one lower court decision that specifically addresses the evidentiary standard for an agent's decision to withdraw artificial nutrition and hydration. In *Berenstein v. Simonson*,[25] the daughter and health care agent of an 86-year-old woman with advanced heart disease and advanced Alzheimer's Disease, directed hospital staff not to surgically insert a feeding tube into her mother's stomach. The patient's sister petitioned the court to override the daughter/health care agent's decision, alleging that the daughter's decision was contrary to her mother's orthodox Jewish beliefs. After an emergency hearing, the court granted the petition. On the evidentiary point, it stated:

> Mrs. Kahan left no written instructions in said Health Care Proxy regarding the administration of artificial nutrition and hydration, and it is conceded that her wishes in that regard are not reasonably known and cannot with reasonable diligence be ascertained. There is surely no "clear and convincing" evidence on this specific issue. (see *In the Matter of Westchester County Med.Center [O'Connor], supra*). Under these circumstances, the Court finds that, pursuant to Public Health Law Section 2982(2)(b), respondent Joan Simonson, is without authority to make decisions about artificial nutrition and hydration for her mother, Lee Kahan.

The decision is troubling in a number of respects. Once the court found that the patient's wishes were not reasonably known and could not with reasonable diligence be ascertained, that finding provided a legally sufficient basis to cancel the agent's decision. Unfortunately, the court contributed to confusion about the applicable standard by referring to the absence of a writing and, especially, by alluding to the absence of clear and convincing evidence of the patient's wishes. Certainly attorneys should not conclude from the lower court's dicta and superfluous findings that an agent's decision regarding nutrition and hydration requires a writing or clear and convincing evidence.[26]

3. The Authority of Agents to Override the Decisions of Principals

The third misconception is that a health care agent can override a principal's prior instructions to health care professionals, or a principal's advance directive. An agent cannot do so.

N.Y. PHL § 2982 (Rights and duties of agent) gives the agent the authority to make "any and all health care decisions on the principal's behalf that the principal could make." However, it immediately thereafter provides that:

> [T]he agent shall make health care decisions . . . in accordance with the principal's wishes, including the principal's religious and moral beliefs.[26]

This provision reflects the core purpose of creating a health care proxy: to extend patient autonomy beyond the loss of decision-making capacity. Health care agents are appointed to advance the wishes and values of the patient; not to disregard them and substitute their own wishes and values.

Accordingly, in a situation where the principal, prior to losing capacity issued explicit instructions regarding a treatment decision, and there are no exceptional factors (such as those discussed further below) the agent who seeks to override the principal's decision is violating the law's decision-making standard.

Moreover, Section 2989.2 confirms that the principal's prior decision is paramount:

> 2989.2. Nothing in this article creates, expands, diminishes, impairs or supersedes any authority that a principal may have under law to make or express decisions, wishes or instructions regarding health care, including decisions about life-sustaining treatment, whether or not expressed in a health care proxy.

The clause confirms that a patient who, while competent, issued unequivocal instructions regarding treatment has already provided legally sufficient consent to the provision or to the withdrawal/withholding of treatment. Under such circumstances, there is no need, from a purely legal standpoint, to seek a redundant second decision from the health care agent.

Of course, medical staff routinely and understandably consult with, and even seek consent from health care agents, even when the staff may already possess the patient's specific prior decision. That practice is respectful, considerate, and usually advisable from a risk management and customer service perspective. But the fact is, a definitive prior decision by the patient is a sufficient legal basis for staff to act.

Accordingly, where the patient has made an unequivocal prior decision, it is not legally necessary to seek the agent's subsequent, redundant decision. But if it is sought, or if the agent unilaterally makes such treatment decision, the agent is required by law to make the decision that reflects the principal's wishes, namely, the prior decision.

For example, consider a hospital patient with decisional capacity who firmly tells his physician, "I do not want any more dialysis, even if it means I will die." If and when the patient loses capacity, the agent will acquire the authority to make decisions for the patient. Even so, the hospital need not seek a decision by the agent regarding withholding dialysis—it already has the patient's instructions, and absent exceptional circumstances, the hospital is bound to honor those instructions. But in the event the hospital did seek a decision from the agent regarding dialysis, or in the event the agent asserted a decision-making role, the agent would be obligated to make such decision "in accordance with the principal's wishes, including the principal's religious and moral beliefs." In this example, that would necessarily mean a decision to withhold dialysis.

A similar analysis applies where the principal left an unequivocal written advance directive, e.g., "in the event I lose decisional capacity and my physician determines that there is no reasonable hope that I will recover it, I direct that my physician discontinue my dialysis treatments, even if it means I will die." Later, if the patient loses capacity and the physician makes the required determination, the hospital does not need to seek the agent's decision to discontinue dialysis. If it did seek a decision, the agent would be obligated to consent to discontinuing dialysis.

A variety of exceptional circumstances would change this analysis. For example, the physician and hospital might accept an agent's decision that was contrary to the patient's prior instructions if there was evidence that:

- the patient never actually made the statement, or wrote the document, that he or she was alleged to have stated or written;
- the patient lacked capacity at the time he or she gave the prior instructions;
- the patient's instructions were vague or ambiguous;
- the patient's instructions were made so long ago, or under such different circumstances, as to call into question their currency or applicability;
- the patient issued subsequent instructions that superseded the earlier instructions; or
- the patient subsequently revoked his or her prior instructions.

If a health care agent alleges any of the foregoing exceptional circumstances, the hospital would need to examine such allegations carefully and see if they provide a basis to set aside the patient's instructions, or to refer the matter to court. The provider should not allow a health care agent to override a patient's firm, clear decision based on allegations that are patently pretext or fabricated.

In instances where it is clear that the agent is violating his or her obligation to speak for the patient, the hospital and physician still face a complex question of legal procedure with significant ethical overtones: can the provider simply disregard the agent's *ultra vires* decision and carry out the patient's decision—leaving it to the agent to go to court for injunctive relief if he or she feels so motivated? Or must the provider bear the burden of seeking a court decision before defying the agent?

The Health Care Proxy Law has three provisions that are pertinent here. Section 2984 Provider Obligations, subsection 2, provides that:

> A health care provider shall comply with health care decisions made by an agent in good faith under a health care proxy to the same extent as if such decisions had been made by the principal, subject to any limitations in the health care proxy

> and pursuant to the provisions of [§ 2983.5].[28]

Section 2986—Immunity provides that:

> No health care provider or employee thereof shall be subjected to criminal or civil liability, or be deemed to have engaged in unprofessional conduct, for honoring in good faith a health care decision by an agent, or for other actions taken in good faith pursuant to this article.

Finally, section 2992 authorizes the provider or others to commence a special court proceeding to, among other issues:

> override the agent's decision about health care treatment on the grounds that (a) the decision was made in bad faith or (b) the decision is not in accordance with the standards set forth in [PHL § 2982—the decision-making standard].

Viewed together, these provisions indicate that a provider, faced with a decision by an agent that is contrary to a patient's decision, could commence a special proceeding to override the decision, and abide by whatever the court decides.[29] But that is an option, not a mandate.

On the other hand, it is less clear that the provider could simply comply with the agent's decision pursuant to section 2984 and still expect the immunity under section 2986. The provider's duty and immunity only extend to complying with decisions made by the agent "in good faith." If the provider knows that the agent is violating the decision-making standard, and informs the agent regarding his or her obligations, there is a strong case that the agent's insistence upon a decision in defiance of the standard is not a decision made by the agent "in good faith."

A third option for the provider is to inform the agent that it intends to carry out the patient's decision, and leave it to the agent to commence a proceeding if the agent so wishes. The provider who takes this course assumes some risk that a court or regulator will find that it has violated the provider's obligation to comply with an agent's decision under section 2984. In a case where it is clear that the provider is disregarding the agent's decision in order to give effect to the patient's paramount decision, the provider should avoid civil or regulatory liability. In fact, it should even be able to avail itself of immunity under section 2986, which gives it immunity for "actions taken in good faith pursuant to this article."

Of course, shifting the burden of commencing a court proceeding to the agent could impose a substantial hardship on the agent—the party that is probably less able to bear that burden, both from a cost and knowledge/experience standpoint. Moreover, in a situation where the provider intends to carry out the patient's wish to withdraw or withhold treatment, its action may be irrevocable before the agent can place the matter before the court.

Accordingly, providers faced with an agent who is seeking to override a patient's unequivocal prior decision must consider various factors in deciding whether to commence a proceeding or simply disregard the agent and implement the patient's decision. On one end of the spectrum is the case where the patient's decision was recent, absolutely clear and unequivocal, and reasonable under the circumstances; where the agent's rationale for overriding the patient's decision is basically "because I say so"; and where the agent will have sufficient time to seek a court order to restrain the provider's action if he or she decides to do so (for example, where a feeding tube is withdrawn). In such case, the provider should feel secure in notifying the agent that it intends to disregard his or her decision and carry out the patient's decision.

However, as those elements weaken—e.g., in a case where the patient's decision is less recent or clear; where the agent's rationale is more plausible ("Dad told me he changed his mind"); and where the provider's action might become irrevocable before the agent could contest it (for example, where mechanical ventilation is discontinued)—it becomes more advisable and prudent for the provider to commence the court proceeding.

Another article in this edition addresses other legal, clinical, and institutional concerns that arise when family members attempt to override the clear decisions of patients.[30]

Endnotes

1. N.Y. Public Health Law (PHL) Article 29-C, L.1990, Ch. 752. Under the statute, the term "health care proxy" refers to the document; the term "health care agent" refers to the person appointed. PHL § 2980.5, § 2980.9.
2. HIPAA privacy regulations provide, in general, that covered entities may not use or disclose protected health information except (i) to the individual or the individual's personal representative; (ii) for treatment, payment and health care operations purposes; (iii) to others, pursuant to a HIPAA-compliant authorization from the individual; or (iv) for other limited and specified purposes. 45 CFR § 164.502(a).
3. PHL § 2982.3.
4. NYS Department of Health, *Health Care Proxy: Appointing Your Health Care Agent in New York State* (2005), *available at* http://www.health.state.ny.us/nysdoh/hospital/healthcareproxy/1430.pdf.

5. *Id.* (emphasis added).
6. 45 C.F.R. § 164.502(g)(1).
7. *Id.*, § 502(g)(2).
8. http://healthprivacy.answers.hhs.gov/cgi-bin/hipaa.cfg/php/enduser/prnt_adp.php?p_faqid=220&p_created =1040315553&p_sid=-n4ZuaLh
9. *See* 45 CFR § 164.524. HIPAA provides for two exceptions to treating a "personal representative" as the "individual." Neither is relevant to the typical proxy situation. One involves unemancipated minors (45 CFR 164.502(3)(i)) and the other involves suspicion that the person claiming to be the personal representative is responsible for domestic violence, abuse or neglect of the individual and treating him or her as such would endanger the individual. (45 CFR 164.502(5)).
10. N.Y.L.J., Volume 231, May 19, 2004 (LaMarca, J.).
11. Another article in this edition, and one in a recent edition, of the *NYSBA Health Law Journal* further discuss how clinical staff are susceptible to "HIPAA scare," and become anxious about disclosing information even in permissible situations. See C. Levine, *Family Caregivers Out in the Cold: HIPAA's Chilling Effect on Communication*, NYSBA Health Law J., 10(3):71-74 (Summer/Fall 2005); R. Senska, *Mitigating the 'HIPAA Scare': A closer look at provider disclosures to patient representatives under the Health Portability and Accountability Act (HIPAA)*, NYSBA Health Law J., 10(1):38-47 (Spring 2004).
12. PHL § 29815(d).
13. 52 N.Y.2d 363 (1981).
14. 72 N.Y.2d 517 (1986).
15. *NYS Task Force on Life and the Law, Life-Sustaining Treatment: Making Decisions and Appointing a Health Care Agent* (July 1987). Task Force reports are available from the NYS Department of Health, *available at* http://www.health.state.ny.us/nysdoh/taskfce/inforpts.htm.
16. *Id.*; S.6967 (1988), A.8955 (1988).
17. One of the authors, Robert N. Swidler, was Assistant Counsel to Governor Cuomo at the time, and represented the governor in discussions on this provision. This paragraph is based on his personal knowledge and recollection.
18. *Approval Message of Governor Mario M. Cuomo*, Ch. 752, L. 1990 (July 22, 1990).
19. NYS Department of Health, *Health Care Proxy: Appointing Your Health Care Agent in New York State* (2005), *available at* http://www.health.state.ny.us/nysdoh/hospital/healthcareproxy/1430.pdf.
20. *Id.* at 2, emphasis added.
21. *Id.* at 3, emphasis added.
22. *Id.* at 7, emphasis added.
23. NYS Dept. of Health, NYS Task Force on Life and the Law, *The Health Care Proxy Law: A Guidebook for Health Care Professionals* (January 1991) at 17.
24. T.E. Miller, *New York State's Health Care Proxy Law*, N.Y.L.J., August 16, 1990, at 1.
25. N.Y.L.J., April 12, 2005.
26. The court's opinion is troubling in other respects as well: first, the court wrote its decision after an emergency hearing at which the daughter appeared *pro se* and by telephone, so the court did not have the benefit of legal analysis and advocacy in support of the daughter's case, or even the ability to assess the daughter's sincerity. Second, the opinion sets forth a history of the Health Care Proxy Law which, in important respects, is incomplete and misleading—such as its incorrect view that the provision on artificial nutrition and hydration stemmed from criticisms of the law by the Health Care Facilities Association.

    Most problematic, however, is that the opinion includes a lengthy discourse on Orthodox Jewish law (Halacha) with the rationale that the patient would have wanted whatever treatment decision Halacha commanded. That course of reasoning compelled the court to wade deeply and inappropriately into ascertaining religious tenets and resolving internal religious doctrinal debates. Moreover, the court started down that troubling path based on a faulty assumption: that because the patient allegedly was an Orthodox Jew, she would accept Halacha teachings, whatever they may be. Ultimately, that exercise in determining a patient's wishes by studying religious doctrines seems far less likely to arrive at an accurate indication of what the patient would have wanted than simply relying upon her daughter/health care agent's judgment.
27. PHL § 2982(2)(a). If the patient's wishes are not known, and cannot with reasonable diligence be ascertained, the agent must base a decision on his or her assessment of the patient's best interests. *Id.*, § 2982(2)(b).
28. PHL § 2984.2. The section referred to therein, PHL § 2983.5, is not directly applicable here: it relates to the priority of a principal's decision if the principal actually expresses his or her objection to determination of incapacity or to an agent's decision. This article analyzes situations where the principal is not able to express his or her objection to the agent's decision. The section does, however, confirm again the law's premise that the principal's decision is paramount.
29. PHL § 2992.3(b).
30. R. Swidler, *When a Patient's Prior Decision to Forgo Treatment Conflicts With a Family's Current Decision to Provide Treatment*, NYSBA Health Law J., 10(3):75-82 (Summer/Fall 2005).

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