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# New York's Family Health Care Decisions Act

## The Legal and Political Background, Key Provisions and Emerging Issues

By Robert N. Swidler

### Introduction

New York's Family Health Care Decisions Act (FHCDA)<sup>1</sup> establishes the authority of a patient's family member or close friend to make health care decisions for the patient in cases where the patient lacks decisional capacity and did not leave prior instructions or appoint a health care agent. This "surrogate" decision maker would also be empowered to direct the withdrawal or withholding of life-sustaining treatment when standards set forth in the statute are satisfied.

On March 16, 2010, Governor Paterson signed the FHCDA into law at a ceremony at Albany Memorial Hospital. The key provisions became effective on June 1, 2010.<sup>2</sup>

### 1. The Legal Background

#### End-of-Life Decision Making

Prior to the FHCDA, the law in New York on end-of-life decision making had been relatively stable for about 25

years – stable, but in the view of many observers, also harsh and unrealistic in its approach to decision making for dying and incapable patients. The long-standing law could be summarized in three broad principles:

**Principle 1.** Patients who have decisional capacity have a broad right to consent to or decline treatment – even life-sustaining treatment. This principle, which has its roots in Justice Cardozo's seminal decision in *Schloendorff v. New York Hospital*,<sup>3</sup> was first explicitly stated by the New York State Court of Appeals decisions in *In re Storar*,<sup>4</sup> and reaffirmed by the Court repeatedly since then, notably in *Fosmire v. Nicoleau*.<sup>5</sup> While New York courts based the right on common law, in 1990 the U.S. Supreme Court, in *Cruzan v. Director, Missouri Department of Health*, found that the right of competent adults to refuse unwanted medical treatment is a liberty interest protected by the Fourteenth Amendment Due Process Clause.<sup>6</sup> Accordingly, in general capable patients can decline life-sustaining treatment, including artificial

nutrition and hydration, without regard to their prognosis or the invasiveness of the treatment.

**Principle 2.** With respect to incapable patients, life-sustaining treatment can be withdrawn or withheld if there is clear and convincing evidence that the patient would want the treatment withdrawn or withheld. The Court of Appeals announced this standard in *In re Storar*.<sup>7</sup> In a later decision, *In re Westchester County Medical Center (O'Connor)*, the Court explained that “clear and convincing evidence” means proof that the patient made “a firm and settled commitment to the termination of life supports under the circumstances like those presented.”<sup>8</sup> The *O'Connor* court also noted that the “ideal situation” is where the patient expressed his or her wishes in writing, such as in a living will.<sup>9</sup>

**Principle 3.** With respect to incapable patients, if there is not clear and convincing evidence that the patient would want treatment withdrawn or withheld, life-sustaining treatment is legally required to be continued or provided. This logical corollary to Principle 2 also arises from *In re Storar*. In that case, the Court refused to allow the mother of a mentally retarded man who was dying from bladder cancer to discontinue his regime of blood transfusions, because of the absence of proof of the patient’s wishes.

In the years since *Storar* and *O'Connor*, the New York State Legislature approved three other principal circumstances in which life-sustaining treatment could be withdrawn or withheld:

**DNR decisions.** Decisions regarding the entry of a do-not-resuscitate (DNR) order can be made by a surrogate decision maker under circumstances defined in New York’s DNR law.<sup>10</sup>

**Health care agent.** When a patient appoints a health care agent pursuant to New York’s Health Care Proxy Law and later loses capacity, the agent can make any health care decision the patient could have made, including a decision to forgo treatment, based on a substituted judgment/best interests standard.<sup>11</sup>

**Mentally retarded patients.** Decisions to withdraw or withhold life-sustaining treatment from patients who have mental retardation or a developmental disability can be made by an Article 17-A guardian under a special state law enacted in 2002, known as the Health Care Decisions Act for Mentally Retarded Persons (HCDA).<sup>12</sup> Significantly, indeed remarkably, the Legislature amended the HCDA in 2007, with little controversy, to provide for the designation of a guardian without a court appointment for the purpose of making end-of-life decisions for a patient with mental retardation or a developmental disability who meets clinical criteria.

In many end-of-life decisions involving incapable patients, the issue concerns a treatment other than resuscitation, there is no health care agent, and the patient is not mentally retarded. In such cases, the legal ability to

withdraw or withhold treatment depends on whether there is “clear and convincing evidence” of the patient’s wish to forgo such treatment.

### Familiar Scenarios

With these legal principles as the backdrop, variations of this scenario have occurred daily in hospitals and nursing homes across New York: An elderly patient is left permanently unconscious after a stroke and is able to breathe only while on a ventilator. After a period of waiting for improvement, the physician tells the family that there is no hope of recovery, and that it would be acceptable from a medical standpoint to discontinue ventilation. The close and loving family members believe their husband and father would not want his death prolonged this way, and favor discontinuing ventilation after making him comfortable.

Under New York law, the family had no control – life-sustaining treatment had to be continued indefinitely.

In most states, as a result of statute or caselaw, providers could honor the decision by this family. Under New York law they could not: in this instance there is no clear and convincing evidence and no health care proxy, the decision relates to ventilation, not CPR, and the patient is not mentally retarded. Accordingly, under New York law, the family had no control – life-sustaining treatment had to be continued indefinitely.

In another familiar scenario, an elderly woman who is a nursing home resident is in an advanced stage of Alzheimer’s disease, and stops eating. As an interim measure, staff commences tube feeding by nasogastric (NG) tube, but recognizes that long-term tube feeding will require a surgical gastrostomy. The woman did not appoint a health care proxy or leave clear and convincing evidence of her wishes. The woman’s daughters believe their mother would not want that operation, nor would she want continuous tube feeding for the short remainder of her life. They request that the NG tube be removed, and that she be given comfort care only. Again, in most states their decision could lawfully be honored. In New York, it would have been unlawful to honor their decision.

To be sure, even before the HCDA, many hospitals and nursing homes in New York (or their medical staff) would have given effect to the decisions of these families, believing in each case that it was the humane, respectful and medically appropriate course. They might have tried to support their action by discerning “clear and

convincing evidence” from the family’s recollections of the patient’s statements and values. Or they might have contended that the treatment was “medically futile” or “medically inappropriate,” even though in each case it would likely have been effective in keeping the patient alive a while longer. But it was hard to reconcile those approaches with the harsh letter of the caselaw, particularly as articulated in *O’Connor*. For that reason, other more cautious providers would have declined the family’s decision under these circumstances; they would have kept the patient on the ventilator, or insisted upon the gastrostomy, even though in each case those approaches are inconsistent with the family’s wishes and the patient’s likely wishes.

among other public policies, a New York State regulation recognizing brain death (1986); New York’s do-not-resuscitate law (1987); New York’s Health Care Proxy Law (1990); and a law restricting surrogate mother contracts (1993).

In *When Others Must Choose*, the Task Force examined the absence of authority of family members or friends to make decisions for patients who lack capacity in New York. It reviewed the clinical, ethical and legal aspects of the problem. It recognized that most New Yorkers have not appointed health care agents, and it found there was a need to give family members and others close to the patient some default authority to make health care decisions for those patients who lack capacity, and who did

Prior to the FHCDA, New York law was also deficient in providing family members with authority to consent to beneficial treatment for incapable patients.

### Decisions to Consent to Treatment

Prior to the FHCDA, New York law was also deficient in providing family members with authority to consent to beneficial treatment for incapable patients. A patchwork of laws and regulations provides such authority under certain circumstances, such as where the patient previously appointed a health care agent, or where a court had appointed a guardian.<sup>13</sup> But there was no statute or regulation that generally empowered family members to consent to treatment when the patient could not and scant caselaw support for such authority. To be sure, providers generally turned to family members for consent anyway, and an exception in the New York informed consent statute provided some protection from liability for doing so.<sup>14</sup> But this lacuna in decision-making authority was still problematic in many ways. For example, the absence of clear legal authority on the part of family members to consent to treatment also impaired the ability to secure other decisions relating to treatment, such as authorization for the disclosure of protected health information.<sup>15</sup>

## 2. The Political Background

### When Others Must Choose

In March 1992, the New York State Task Force on Life and the Law addressed this issue in its influential report, *When Others Must Choose: Deciding for Patients Without Capacity*.<sup>16</sup> The Task Force is a multidisciplinary panel that was formed by New York Governor Mario Cuomo in 1985 and charged with studying and making policy recommendations for public policies on issues relating to medical ethics and bioethics. Its earlier reports led to,

not previously make a decision themselves or appoint a health care agent. The Task Force concluded that the absence of such authority resulted in both undertreatment and overtreatment of patients.

The Task Force went beyond just calling for reform. It advanced a specific legislative proposal to address the problem. The proposal (not called the Family Health Care Decisions Act until later) was similar in many respects to the Task Force’s earlier proposal that led to New York’s DNR law. Specifically, it proposed a statute that would set forth requirements for determining incapacity; allow the selection of a surrogate decision maker from a priority list, empower such surrogates to make health care decisions for patients who lack capacity and who could not make the decision themselves or appoint a health care agent; require the surrogate to adhere to the substituted judgment/best interests standard; and limit the circumstances in which a surrogate may authorize the withholding or withdrawal of life-sustaining treatment.

The Task Force sent its proposal to Governor Cuomo and to the state Legislature. In 1993 the proposal was introduced in the Assembly by Richard Gottfried (D-Manhattan), Chair of the Assembly Health Committee and formerly the lead sponsor of the Health Care Proxy Act.<sup>17</sup> Assemblyman Gottfried would prove to be a tenacious champion for the FHCDA. The bill was first introduced in the Senate by John A. DeFrancisco (R-Onondaga) in 1995,<sup>18</sup> but in most years thereafter it was sponsored by Senate Health Chair Kemp Hannon (R-Garden City).

At the start, the bill’s prospects were strong. The Task Force had a remarkably successful track record of secur-

ing enactment of its previous proposals, such as the DNR and Health Care Proxy laws. Those policies were generally regarded as successful, and the Task Force made the compelling case that the FHCDA was a necessary and logical extension of the policies and principles it had previously advanced. Soon a large, impressive and diverse list of organizations announced their support for the FHCDA.<sup>19</sup> An umbrella group called the Family Health Care Decisions Coalition emerged to coordinate activities in support of the FHCDA.<sup>20</sup>

But at the same time, other factors impeded the progress of the bill. The New York State Catholic Conference, which was especially influential in the Republican-controlled state Senate, issued a memo opposing the bill. The Conference was concerned that aspects of the bill devalued life and facilitated euthanasia. It emphasized its opposition to a provision that would allow ethics committees to make end-of-life decisions for patients who did not have surrogates and to the termination of life-sustaining treatment for pregnant women patients. The Conference also sought to limit the circumstances in which artificial nutrition and hydration could be stopped, and to protect the conscience rights of health care providers. Other organizations such as Agudath Israel and New York State Right to Life expressed similar concerns.

Over time, the bill was amended to meet some of the Conference's concerns. For example, in 2002 both versions deleted the hospital-based process for making end-of-life decisions for patients without surrogates. But the Conference's opposition generally continued.

It was also significant that those New Yorkers who cared most about end-of-life decisions already had adequate means to protect their interests under law: they could create a health care proxy or living will. In a sense, the FHCDA sought to protect the interests of those who were not concerned enough about the matter to look out for themselves – akin to an intestacy law. Unsurprisingly, legislators did not often hear demands from grass-roots constituents for the bill.

As a result of forces promoting and forces impeding the FHCDA, for many years each spring a ritual was played out in Albany: supporters would meet with legislators and secure an editorial or op-ed piece. Numerous organizations would go on record as supporting the bill, but none would put substantial resources into a lobbying effort. At the same time, the organizations opposed to the bill would make their influential opposition known, especially to the Senate. By the end of each session, the bill had died in committee in one or both houses.

Beginning in 2002, a few developments offered new hope of securing enactment of the FHCDA. For one thing, that year the Legislature enacted the HCDA.<sup>21</sup> FHCDA advocates argued that since the Legislature was

willing to allow surrogate end-of-life decisions for mentally retarded patients, who are less likely to have formed wishes and values, and who are more at risk of being “devalued,” it should be willing to allow surrogate end-of-life decisions for other patients as well.

Also in 2003 the Family Decisions Coalition retained an Albany lobbying firm, Malkin & Ross, which advocated for the FHCDA year after year, mostly on a pro bono basis. Moreover, in 2007, Assemblyman Gottfried managed – rather surprisingly – to secure the support of Right to Life for the FHCDA, largely by adding language to emphasize the duty of providers to respect surrogate decisions that favored the provision of life-sustaining treatment.<sup>22</sup>

Perhaps most important, the attitudes of New Yorkers, including legislators, had gradually changed since 1993. A consensus seemed to emerge that it was often quite reasonable and not eccentric for a patient to want to opt for palliative rather than aggressive care toward the end of life. It also seemed to most New Yorkers that families *should* be able to make these decisions for their dying, incapable loved ones.

All these developments boded well for the prospects of enacting the FHCDA.

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## The Dispute Over “Fetus” and “Domestic Partner”

Despite such developments, the bill was gridlocked for several years by two issues that related more to the battles over abortion and gay/lesbian rights than to end-of-life decisions. First, in 2003 the Senate, at the request of the Catholic Conference, inserted in its version of the FHCDA a requirement that a surrogate, when making a decision about life-sustaining treatment for a pregnant patient, must consider “the impact of the treatment decision on the fetus and on the course and outcome of the pregnancy.” Although it was doubtful that the clause would have any practical effect on surrogate decision making, pro-choice members of the Assembly regarded the insertion of the word “fetus” objectionable for symbolic and political reasons. As a result, for years the Assembly refused to support the FHCDA if it included the fetus clause, while the Senate refused to support the FHCDA without the clause.

Meanwhile, also in 2003, the Assembly introduced a version of the bill that revised the surrogate priority list to make the highest priority relative the “spouse or domestic partner.” It did so both as a result of its growing support for gay/lesbian rights generally, but also because of the strong case for allowing a partner in a same-sex couple to make the health care decisions. However, the Senate indicated that it would not make that change in its version. As a result, for years the Senate refused to support the FHCDA if it included the domestic partner phrase, while the Assembly refused to support the FHCDA without such clause.

FHCDA advocates were frustrated by this impasse and wanted to return the focus of attention to the need to allow humane decisions for dying patients. They repeatedly proposed ideas for compromising or bypassing these disputes, but without success – until 2009.

## Enactment of the FHCDA

As a result of the November 2008 election – the election that brought Barack Obama into the White House – Democrats gained control of the state Senate for the first time in over 40 years. In early 2009 Senator Thomas Duane (D-Manhattan) became Chair of the Senate Health Committee, and shortly thereafter he introduced a version of the FHCDA that tracked the Assembly version: it excluded the “fetus clause” and included the domestic partner clause.<sup>23</sup> The gridlock had ended.

In the spring of 2009, staff from the Governor’s office, the Senate and the Assembly began to meet in the Capitol to scrutinize the language of the bill, and to identify and address technical and policy issues. Among the issues that received particular three-way attention were the need to clarify the settings where the FHCDA would apply and the need to address how the FHCDA would apply to persons who are already subject to the HCDA, or subject to OMH or OMRDD surrogate decision-making regulations.

That three-way review process was nearly complete when the dramatic “coup” in the Senate in June 2009 brought a halt to progress on all legislation, including the FHCDA.<sup>24</sup> Although staff ultimately finished that work and identical bills were introduced in the final days of the 2009 session, both houses adjourned before acting on them.

The bills were re-introduced in both houses in January 2010 with only one change: a long-standing provision stating that a surrogate’s decision was not required if the patient had made a prior decision personally was amended to attach witnessing requirements to prior oral decisions to forgo life-sustaining treatment.<sup>25</sup>

The Assembly passed the FHCDA on January 20 with a nearly unanimous bipartisan vote, and the Senate passed it February 24, unanimously. On March 16, 2010, 17 years after the FHCDA was first introduced, Governor Paterson signed the FHCDA into law. The Governor stated, “After nearly two decades of negotiations, New Yorkers now have the right to make health care decisions on behalf of family members who cannot direct their own care.”<sup>26</sup>

## 3. Key Provisions of the FHCDA

Key provisions of the FHCDA are summarized below. The new law is detailed, however, and this summary does not cover all its provisions.

### Applicability

The FHCDA applies to decisions for incapable patients in general hospitals and residential health care facilities (nursing homes).<sup>27</sup> The statute uses the term “hospital” to apply to both those settings.<sup>28</sup> The FHCDA does not apply to decisions for incapable patients who have a health care agent;<sup>29</sup> who have a court-appointed guardian under SCPA 1750-b;<sup>30</sup> for whom decisions about life-sustaining treatment may be made by a family member or close friend under SCPA 1750-b;<sup>31</sup> or for whom treatment decisions may be made pursuant to OMH or OMRDD surrogate decision-making regulations.<sup>32</sup>

### Determining Incapacity

The FHCDA sets forth a hospital-based process to determine that a patient lacks decisional capacity, but only for purposes of the FHCDA.<sup>33</sup> The process requires special credentials for professionals for determining that a patient lacks capacity as a result of mental retardation or mental illness.<sup>34</sup> It also requires that the patient and prospective surrogate be informed of the determination of incapacity<sup>35</sup> and additional notifications for patients from mental hygiene facilities.<sup>36</sup> Notably, if the patient objects to the determination of incapacity, or the choice of surrogate, or the surrogate’s decision, the patient’s objection prevails unless a court finds that the patient lacks capacity or another legal basis exists for overriding the patient’s decision.<sup>37</sup>

## Decisions for Adult Patients by Surrogates

The statute sets forth, in order of priority, the persons who may act as a surrogate decision maker for the incapable patient, i.e.:<sup>38</sup>

- 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 (as defined in the FHCDA).

The surrogate has the authority to make all health care decisions for the patient that the adult patient could make for himself or herself, subject to certain standards and limitations.<sup>39</sup>

A surrogate's consent is not required if the patient 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 or in writing.<sup>40</sup> But since a surrogate must base his or her decision on the patient's wishes if they are reasonably known, even if a patient's prior oral decision cannot be honored directly, a surrogate will have to give that statement appropriate weight in making a decision.

The FHCDA requires the surrogate to base his or her decisions on the patient's wishes, including the patient's religious and moral beliefs. If the patient's wishes are not reasonably known and cannot with reasonable diligence be ascertained, the surrogate must base decisions on the patient's best interests, a term explained in the statute.<sup>41</sup>

## Surrogate Decisions to Withdraw or Withhold Life-Sustaining Treatment

The FHCDA authorizes surrogate decisions to withhold or withdraw life-sustaining treatment only if one of two standards is met.

First, life-sustaining treatment can be withdrawn or withheld if:

- the surrogate determines<sup>42</sup> that treatment would be an extraordinary burden to the patient, and
- the attending physician and another physician determine that the patient:
  - is terminally ill (i.e., has an illness or injury that can be expected to cause death within six months, whether or not treatment is provided);
  - or
  - is permanently unconscious.

Second, life-sustaining treatment can be withdrawn or withheld if:

- the surrogate determines<sup>43</sup> that treatment would involve such pain, suffering or other burden that it

would reasonably be deemed inhumane or excessively burdensome under the circumstances; and

- the attending physician and another physician determine that the patient has an irreversible or incurable condition.<sup>44</sup>

Significantly, inasmuch as the definition of life-sustaining treatment includes decisions about resuscitation, one of the two standards must be met for surrogate consent to a DNR order as well.<sup>45</sup> As a practical matter, in most of the cases where a DNR order could have been entered under the DNR law, the order can be entered under the FHCDA.

**FHCDA requires the surrogate to base his or her decision on the patient's wishes.**

The two standards also apply to decisions regarding artificial nutrition and hydration (e.g., the provision of nutrition or hydration by a tube inserted through the nose, stomach, or vein). Decisions regarding the provision of food and drink are not considered health care decisions and are outside the scope of the statute.<sup>46</sup>

## Decisions for Minor Patients

The statute authorizes the parent or guardian of a minor patient to decide about life-sustaining treatment under the same two end-of-life standards that apply to surrogate decisions for adults.<sup>47</sup> However, the parent or guardian must make the decision in accordance with the minor's best interests, taking into account the minor's wishes as appropriate under the circumstances.<sup>48</sup>

If the attending physician determines that the minor has the capacity to decide about life-sustaining treatment, the minor's consent is required to withhold or stop treatment.<sup>49</sup> If there is another parent who is unaware of the decision, the law requires an attempt to inform such parent of the decision.<sup>50</sup>

The statute allows a physician to accept a life-sustaining treatment decision by an emancipated minor without parental consent, although a decision by the minor to forgo such treatment requires ethics review committee approval.<sup>51</sup>

## Decisions for Adult Patients Without Surrogates

One of the most significant features of the FHCDA is that it establishes a procedure to secure a decision (it is probably not accurate to call it "consent") to provide needed treatment for incapable patients who have no family members or close friends who could act as the surrogate.<sup>52</sup> Prior to the FHCDA, in such cases the pro-

vider might either go to court for the appointment of a guardian or approval of the treatment, or fashion some legally dubious “administrative consent,” or wait for the patient’s need for the treatment to become so urgent that treatment could be provided under the emergency exception to the informed consent requirement.

The FHCDA addresses the problem first by requiring hospitals, after a patient is admitted, to determine if the patient has a health care agent, guardian, or person who can serve as the patient’s surrogate. If the patient has no such person, and lacks capacity, the hospital must identify, to the extent practical, the patient’s wishes and preferences about pending health care decisions.<sup>53</sup>

**Decisions to withdraw or withhold life-sustaining treatment from isolated incapable patients are strictly limited.**

With respect to routine medical treatment, the statute simply authorizes the attending physician to decide about such treatment for patients without surrogates.<sup>54</sup> For decisions about major medical treatment, the attending physician must consult with other health care professionals directly involved with the patient’s care, and a second physician selected by the hospital or nursing home must concur in the decision.<sup>55</sup> The treatment can then be provided.

In contrast, decisions to withdraw or withhold life-sustaining treatment from isolated incapable patients are strictly limited. Such decision can be made only (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.<sup>56</sup>

### **Ethics Review Committees**

The FHCDA requires hospitals and nursing homes to establish or participate in an ethics review committee (ERC) that has diverse membership, including community participation.<sup>57</sup> The ERC, which can operate through subcommittees, must be available to try to resolve disputes if less formal efforts fail. Its role is strictly advisory, however, except in two respects: ERC approval is required for certain decisions to withdraw or withhold life-sustaining treatment in nursing homes, and to affirm decisions to forgo treatment by emancipated minors.<sup>58</sup>

### **Other FHCDA Provisions**

The FHCDA also

- sets forth the right of private hospitals and individual health care providers to refuse, on grounds of moral or religious conscience, to honor health care decisions made pursuant to the FHCDA, subject to limits and requirements (e.g., the facility must notify patients of its policy prior to admission and promptly transfer responsibility for the patient to another health care professional willing to honor the decision).<sup>59</sup>
- protects surrogates, health care providers and ethics committee members from civil and criminal liability for acts performed in good faith pursuant to the FHCDA.<sup>60</sup>
- provides that liability for the cost of health care provided to an adult patient under the FHCDA is the same as if the patient had consented to treatment.<sup>61</sup>
- establishes that the FHCDA does not:
  - expand or diminish any authority an individual may have to express health care decisions for himself or herself;<sup>62</sup>
  - affect existing law concerning implied consent to health care in an emergency;<sup>63</sup>
  - permit or promote suicide, assisted suicide, or euthanasia;<sup>64</sup>
  - diminish the duty of parents to consent to treatment for minors.<sup>65</sup>
- provides that a hospital or attending physician that refuses to honor a health care decision made by a surrogate in accord with the standards set forth in the FHCDA is not entitled to compensation for treatment provided without the surrogate’s consent, except under specified circumstances.<sup>66</sup>

### **DNR-Related Provisions**

The statute eliminates much of New York’s DNR law as applied to hospitals and nursing homes, and provides for such decisions to be made in accordance with the standards and procedures in the FHCDA.<sup>67</sup> However, the statute then creates a new PHL Article 29-CCC as a place to retain (with some modifications) existing provisions on nonhospital DNR orders.<sup>68</sup> A helpful revision to the nonhospital provisions obligates home health care agency staff and hospice staff to honor nonhospital DNR orders (previously, nonhospital DNR orders were directed only to emergency medical services and hospital emergency personnel).<sup>69</sup>

The statute also renames the former DNR law, PHL Article 29-B, as “Orders Not to Resuscitate for Residents of Mental Hygiene Facilities,” to preserve existing rules regarding DNR orders in those settings.<sup>70</sup>

## Health Care Proxy Law Amendments

Chapter 8 amends the Health Care Proxy Law to require a provider, when an agent directs the provision of life-sustaining treatment, to provide the treatment, transfer the patient, or seek judicial review.<sup>71</sup> This mirrors a similar provision in the FHCDA. The statute also amends the proxy law to adopt the FHCDA provisions regarding institutional and health care provider conscience.<sup>72</sup>

## Amendments to Guardianship Laws (MHL Article 81 and SCPA 1750-b)

The statute amends New York's guardianship law, MHL Article 81, to authorize a guardian of the person to act as a surrogate under the FHCDA for decisions in hospitals.<sup>73</sup> It also repeals provisions in MHL Article 81 that restricted the authority of a guardian to make life-sustaining treatment decisions.<sup>74</sup>

The statute amends the HCDA (SCPA 1750-b) to insert a definition of "life-sustaining treatment" (because previously it referred to a definition in MHL Article 81 that was repealed).<sup>75</sup>

## Assignments for the Task Force on Life and Law

Chapter 8 directs the Task Force on Life and the Law to create a special committee to provide advice on standards and procedures for surrogate decision making for persons with mental retardation/developmental disability and persons in mental health facilities. The committee must include members appointed by OMRDD and OMH.<sup>76</sup>

Finally the new law also directs the Task Force to make recommendations on extending FHCDA decision-making standards and procedures to other settings, such as physician offices and home care.<sup>77</sup>

## 4. Emerging Issues

Enactment of the FHCDA will direct the attention of health lawyers, policy-makers, patient advocates and health care providers toward several issues. Here are a few:

### The Challenge of Implementation

The FHCDA is not short and simple, and it will take time and considerable effort for health care providers, health lawyers and others to familiarize themselves with its requirements and to implement it in practice. Unexpectedly, the lead time between enactment (March 16, 2010) and the effective date (June 1, 2010) was extremely brief. As a result, providers need to scramble to conduct training and implementation efforts; clearly

those efforts will need to extend well beyond the effective date.

On the positive side, several factors should aid in the prompt implementation of the FHCDA. First, the FHCDA is similar in structure to the DNR law that it supersedes, so providers and others will find its key concepts and procedures familiar. Moreover, statewide hospital and nursing home associations promptly and collectively made available to their members model policies and forms to implement the FHCDA. The developers of MOLST (Medical Orders for Life-Sustaining Treatment) also quickly revised their forms to reflect FHCDA principles. Other educational programs and materials (including this article) are rapidly emerging.

With patience and persistence on the part of providers, and with patience and forbearance on the part of regulators, the FHCDA can be implemented soon and implemented well in facilities across the state.

## The Adequacy of Safeguards

The most significant change made by the FHCDA is that it empowers family members to direct the withdrawal of life-sustaining treatment in the absence of clear and convincing evidence of a patient's wish to forgo treatment. In lieu of the unrealistic and harsh clear and convincing evidence standard, the statute institutes safeguards, including these: it requires the attending physician and another physician to make specific clinical findings; it requires the surrogate to make certain non-clinical findings about the burdens of the treatment; it obligates the surrogate to base his or her decision on the patient's wishes if known, or else the patient's best interests; it allows persons connected with the case to challenge a decision.

There is ample reason to have confidence in the adequacy of these safeguards, and confidence that the

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statute will in fact improve the quality of end-of-life decision making. But it is essential to empirically confirm that expectation. Policymakers, health care professionals, patient advocates, medical ethicists, academics and others need to study the experience under the FHCDA across the state and ensure that the safeguards and other provisions are working as intended.

### The Performance of Ethics Review Committees

For the first time, all hospitals and nursing homes in New York will be required to create or participate in ethics review committees.<sup>78</sup> The clear objective of ERCs is to provide a relatively impartial mechanism to resolve disputes and to provide oversight of the most sensitive decisions. But there is no assurance that ERCs will perform these functions well. Moreover, it is unclear how facilities can or will reconcile the role of ERCs with other facility-based ethics initiatives, such as ethics consultation services.<sup>79</sup> Mechanisms must be devised to measure and continually improve the quality of ERCs, and research should be conducted on the merits and demerits of this part of the statute.

### Extending the FHCDA to Other Settings

The FHCDA applies only in hospital and nursing home settings. Yet the need for surrogate decision making can arise in any setting where health care is provided, including a diagnostic and treatment center, physician's office, dentist's office, assisted living residence, or home care situation. Of particular urgency is the need to allow surrogate decisions to elect hospice for an incapable patient, irrespective of where the surrogate makes the decision. But many of the safeguards in the FHCDA are designed for the hospital or nursing home setting, such as concurring opinion requirements and reliance upon ERCs. As a result, extending the FHCDA to other settings is not a simple matter. A key emerging issue for the Task Force on Life and the Law is to devise a way to accomplish this extension in a responsible and practical manner.

### Decision Making for Developmentally Disabled Persons

As noted previously, surrogate decisions are already being made for developmentally disabled persons pursuant to the HCDA. Some advocates believe that the HCDA offers a better approach to surrogate decision making than the FHCA; other advocates favor extending the FHCDA to that population, perhaps with amendments or special provisions. The Task Force was directed to form a subcommittee to address this issue.

### Surrogate Consent to Human Subject Research

The FHCDA has indirectly impacted other laws and regulations that refer to the authorized health care decision maker. Perhaps most significant, federal human

subject research regulations allow a "Legally Authorized Representative" to give consent for incapable patients to be enrolled in research protocols.<sup>80</sup> A "Legally Authorized Representative" includes a person "authorized under applicable law to consent on behalf of a prospective subject to the subject's participation in the procedure(s) involved in the research."<sup>81</sup> Thus the FHCDA would appear to give the surrogate such authority in many cases. This is a positive development in important respects: it expands access by incapable patients to promising clinical trials and facilitates medical advances in the treatment of conditions that cause mental incapacity. But it also poses new ethical concerns. An emerging issue is determining the extent to which the FHCDA has opened the door to surrogate consent for human subject research, and the extent to which the state should seek to regulate such research. This is yet another issue the Task Force on Life and the Law is examining.

### Conclusion

The FHCDA authorizes a family member or close friend to make health care decisions, including end-of-life decisions, for a patient who lacks decisional capacity, subject to substantive and procedural safeguards. Ultimately, the FHCDA is best viewed as an effort to align New York law with sound clinical practice and broadly accepted principles of medical ethics. To be sure, it will be challenging to implement the FHCDA well, and it will be necessary to identify and correct its flaws and gaps, and respond to the issues it raises. But from the outset the FHCDA will provide relief from the harsh aspects of prior law, and over time the law can be expected to enhance the quality of decision making for incapable patients. ■

1. 2010 N.Y. Laws ch. 8, A.7729-D (Gottfried et al.) and S.3164-B. (Duane et al.). Section 2 of Chapter 8 amends N.Y. Public Health Law (PHL) to create "Article 29-CC Family Health Care Decisions Act."

2. 2010 N.Y. Laws ch. 8, § 29.

3. 211 N.Y. 125 (1914).

4. 52 N.Y.2d 363, 438 N.Y.S.2d 266 cert. denied, 454 U.S. 858 (1981).

5. 75 N.Y.2d 218, 551 N.Y.S.2d 876 (1990).

6. 497 U.S. 261 (1990).

7. 52 N.Y.2d 363.

8. 72 N.Y.2d 517, 531, 534 N.Y.S.2d 886 (1988).

9. *Id.*

10. PHL art. 29-B.

11. PHL art. 29-C.

12. Surrogate's Court Procedure Act 1750-b (SCPA).

13. PHL art. 29-C; N.Y. Mental Hygiene Law art. 81 (MHL).

14. PHL § 2805-d(4)(c).

15. See 45 C.F.R. § 164.502(g)(2) (A HIPAA-covered entity must honor decisions about protected health information made by an adult's "personal representative," i.e., a person who has "authority to act on behalf of [the adult] in making decisions related to health care.").

16. NYS Task Force on Life and the Law, *When Others Must Choose: Deciding for Patients Without Capacity* (March 1992) available at <http://www.health.state.ny.us/nysdoh/taskforce/inforpts.htm>.

17. A.7166 (1993). The bill was not named the “Family Health Care Decisions Act” until 1995.
18. S.4685 (1995).
19. Among the supporting organizations were: AARP; American College of Physicians; Association of the Bar of the City of New York; Friends of the Institutional Elderly; Gay Men’s Health Crisis; Greater New York Hospital Association; Medical Society of New York State; Healthcare Association of New York State; Nurses Association of New York State; NYS Association of Homes and Services for the Aging; NYS Health Care Facilities Association; NYS Bar Association; NY Civil Liberties Union; NYS Hospice and Palliative Care Association; SEIU Local 1199; StateWide Senior Action Council.
20. See Family Decisions Coalition, <http://www.familydecisions.org>.
21. 2002 N.Y. Laws ch. 500.
22. Enacted at PHL §§ 2984(5), 2994-f(3).
23. S.3164-B (Duane).
24. *Republicans Seize Control of State Senate*, <http://cityroom.blogs.nytimes.com/2009/06/08/revolt-could-imperil-democratic-control-of-senate> (June 8, 2009, 15:50 EST).
25. Enacted at PHL § 2994-d(3)(ii).
26. Press Release, Office of Governor Paterson, *Governor Paterson Signs Family Health Care Decisions Act into Law* (Mar. 16, 2010), available at <http://www.state.ny.us/governor/press/031610FHCDA.html>.
27. PHL § 2994-b(1).
28. PHL § 2994-a(18).
29. PHL § 2994-b(2).
30. PHL § 2994-b(3)(a).
31. PHL § 2994-b(3)(b).
32. PHL § 2994-b(3)(c).
33. PHL § 2994-c.
34. PHL § 2994-c(3)(c).
35. PHL § 2994-c(4)(a), (b).
36. PHL § 2994-c(4)(c).
37. PHL § 2994-c(6).
38. PHL § 2994-d(1).
39. PHL § 2994-d(3)(i).
40. PHL § 2994-d(3)(ii).
41. PHL § 2994-d(4).
42. The statute does not explicitly give this responsibility to the surrogate, but it is implicit in the structure of the clause.
43. See PHL § 2994-c(6).
44. PHL § 2994-d(5).
45. PHL § 2994-a(19).
46. PHL § 2994-a(12).
47. PHL § 2994-e(1).
48. PHL § 2994-e(2)(a).
49. PHL § 2994-e(2)(b).
50. PHL § 2994-e(2)(c).
51. PHL § 2994-e(3).
52. PHL § 2994-g.
53. PHL § 2994-g(1).
54. PHL § 2994-g(3).
55. PHL § 2994-g(4).
56. PHL § 2994-g(5).
57. PHL § 2994-m.
58. PHL § 2994-m(2).
59. PHL § 2994-n.
60. PHL § 2994-o.
61. PHL § 2994-p.
62. PHL § 2994-q(1).
63. PHL § 2994-q(2).
64. PHL § 2994-q(3).
65. PHL § 2994-q(4).
66. PHL § 2994-s.
67. See 2010 N.Y. Laws ch. 8, § 4, which amends PHL art. 29-B – the DNR law – to make it applicable only to mental hygiene facilities. See also new PHL § 2994-a(19) (defining “life-sustaining treatment” to include cardiopulmonary resuscitation).
68. 2010 N.Y. Laws ch. 8, § 2, adding PHL art. 29-CCC Nonhospital Orders Not to Resuscitate.
69. PHL § 2994-ee.
70. PHL art. 29-B.
71. 2010 N.Y. Laws ch. 8, § 23, amending PHL § 2984(3).
72. 2010 N.Y. Laws ch. 8, § 23, adding PHL § 2984(5).
73. 2010 N.Y. Laws ch. 8, § 25, amending MHL § 81.22.8.
74. 2010 N.Y. Laws ch. 8, § 25, repealing MHL § 81.22.9(e).
75. 2010 N.Y. Laws ch. 8, § 27, amending SCPA 1750-b.
76. 2010 N.Y. Laws ch. 8, § 28(1).
77. 2010 N.Y. Laws ch. 8, § 28(2).
78. PHL § 2994-m. Since 1992, the Joint Commission on the Accreditation of Healthcare Organizations has required hospitals to have a mechanism to address ethical issue, but it has never specifically mandated ethics committees. Similarly, since 1997, New York’s DNR law has required facilities to have a dispute mediation system, but does not require ethics committees for that purpose. PHL § 2972.
79. The statute helpfully notes that the ERC requirement does not “bar [providers] from first striving to resolve disputes through less formal means, including the informal solicitation of ethical advice from any source.” PHL § 2994-m. Accordingly, a hospital’s ethics consultation service or chaplain’s office could still serve as a first line of guidance or attempted resolution of a dispute.
80. 45 C.F.R. § 46.116.
81. 45 C.F.R. § 46.102.

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