



## NEW YORK STATE TASK FORCE ON LIFE & THE LAW

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June 3, 2013

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Dear Senators Klein and Skelos, and Assembly Members Silver and Kolb:

On behalf of the New York State Task Force on Life and the Law (the “Task Force”), we are pleased to submit for your consideration *Recommendations for Extending the Family Health Care Decisions Act to Medicare and/or Medicaid-Certified and State-Licensed Agencies, Programs, and Settings*.

Established by Executive Order in 1985, the Task Force is comprised of 23 Governor-appointed leaders in the fields of religion, philosophy, law, medicine, nursing, and bioethics. The Task Force develops public policy on issues arising at the interface of medicine, law, and ethics, and has issued influential reports on cutting-edge bioethics issues, such as withholding and withdrawing life-sustaining treatment and organ transplantation.

The Family Health Care Decisions Act (“FHCDA”), which was modeled on the Task Force report *When Others Must Choose: Deciding for Patients Without Capacity*, directs the Task Force to examine whether the Act should be amended to allow surrogate decision-making for health care provided in settings outside of hospitals and residential health care facilities. *See* 2010 N.Y. Laws Ch. 8, § 28(2). In December 2010, the Task Force made an initial proposal to the Legislature recommending extension of the FHCDA to include hospice care. *See* New York State Task Force on Life and the Law, *Recommendations Regarding the Extension of the Family Health Care Decisions Act to Include Hospice* (Dec. 22, 2010), available at [http://www.health.ny.gov/regulations/task\\_force/reports\\_publications/](http://www.health.ny.gov/regulations/task_force/reports_publications/). This proposal served as the basis for the amendment passed in July 2011, providing surrogates with authority to make hospice decisions on behalf of patients who lack the capacity to provide first-person consent. *See* 2011 N.Y. Laws Ch. 167.

Although the FHCDA now confers upon surrogates the power to make decisions in hospitals, residential health facilities, and hospice, New Yorkers frequently receive care outside of institutional settings, such as in clinics, physicians’ offices, home care, surgery centers, and adult homes. Similar to patients in institutional settings, patients in community settings also may lack the capacity to make health care decisions for themselves due to a variety of health conditions. Under the FHCDA as currently worded, however, in order for surrogates to have authority to make health care decisions for patients in non-institutional settings, patients would have to be transferred to a hospital, residential health care facility, or hospice. Such transfers may be burdensome, unnecessary, and potentially detrimental to patients’ health and well-being.

In light of these concerns, the Task Force has extensively explored the legal and ethical dimensions of extending the FHCDA beyond institutional settings, including the need for surrogate appointment, as well as the procedural safeguards necessary to ensure proper oversight of health care delivery and protection of patients’ rights. As is set forth in the enclosed statement, the Task Force hereby proposes for the Legislature’s consideration its recommendation that the FHCDA be extended to decisions regarding health care provided by agencies, programs, and settings that are Medicare and/or Medicaid-certified and State-licensed, and that opt to comply with the requirements of the FHCDA. These recommendations may not extend to treatment decisions made in physicians’ offices where such offices do not meet these criteria.

In the coming months, the Task Force will undertake a second project at the direction of the Legislature, convening a Special Advisory Committee to make recommendations about whether the FHCDA should be amended to incorporate procedures, standards, and practices about the withdrawal or withholding of life-sustaining treatment for patients with developmental disabilities and patients in mental health facilities and units. *See* 2010 N.Y. Laws Ch. 8, § 28(1).

Thank you for entrusting the Task Force with these important projects. We look forward to working with you in the future.

Sincerely,

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New York State Task Force on Life and the Law

Valerie Gutmann Koch, J.D.  
Senior Attorney  
New York State Task Force on Life and the Law

On behalf of the New York State Task Force on Life and the Law

Enclosure

cc: Nirav R. Shah, M.D., M.P.H., Commissioner, New York State Department of Health  
Honorable Kemp Hannon, Chair, New York State Senate Health Committee  
Honorable Gustavo Rivera, Ranking Member, New York State Senate Health Committee  
Honorable Richard N. Gottfried, Chair, New York State Assembly Committee on Health  
Honorable Andrew Raia, Ranking Member, New York State Assembly Committee on Health

**Recommendations for Extending the  
Family Health Care Decisions Act to Medicare and/or Medicaid-Certified and  
State-Licensed Agencies, Programs, and Settings**

NEW YORK STATE TASK FORCE ON LIFE AND THE LAW  
June 3, 2013

The Family Health Care Decisions Act (FHCDA) authorizes persons with certain enumerated relationships to make health care decisions on behalf of patients who lack decisional capacity and who have neither left prior instructions to direct their care nor appointed a health care agent.<sup>1</sup> As originally passed, the FHCDA limited surrogate authority to decisions made about care in general hospitals and residential health care facilities.<sup>2</sup> The Legislature directed the New York State Task Force on Life and the Law (the Task Force) to “consider whether the FHCDA should be amended to apply to health care decisions in [other] settings.”<sup>3</sup> In December 2010, the Task Force submitted to the Legislature a proposal that the FHCDA be extended to allow surrogate decision-making for hospice care,<sup>4</sup> which formed the basis for legislation passed in July 2011.<sup>5</sup>

Recognizing the widespread need to authorize surrogates to make important health care decisions on behalf of adults lacking capacity who receive care outside of general hospitals, nursing homes, and hospice settings, the Task Force has continued to explore the legal and ethical dimensions of extending the FHCDA to home care and other non-institutional settings. As set forth below, the Task Force recommends that a modified form of the surrogate decision-making authority of the FHCDA should be extended to those agencies, programs, and health care settings that are Medicare and/or Medicaid-certified and State-licensed (not including those licensed pursuant to the professional licensure requirements under the New York State Education Law), and that opt to comply with the requirements of the FHCDA.

A. Health Care in the Community

i. Home Care Agencies and Programs in New York State

“Home care” is an umbrella term for a variety of agencies, health and social services, and programs that provide medical, nursing, social, and therapeutic care, and/or assistance with

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<sup>1</sup> N.Y. Pub. Health Law Art. 29-CC.

<sup>2</sup> Under the FHCDA as currently worded, a “general hospital” is defined in Pub. Health Law § 2801(10) and excludes wards, wings, units or other parts of a general hospital operated for the purpose of providing services for persons with mental illness pursuant to an operating certificate issued by the Office of Mental Health. Thus, the surrogate decision-making provisions of the FHCDA do not, at present, apply in psychiatric units of general hospitals. The recommendations contained herein are not intended to modify this definition.

<sup>3</sup> 2010 N.Y. Laws Ch. 8, § 28(2).

<sup>4</sup> New York State Task Force on Life and the Law, *Recommendations Regarding the Extension of the Family Health Care Decisions Act to Include Hospice* (Dec. 22, 2010), available at [http://www.health.state.ny.us/regulations/task\\_force/docs/2010-11-30\\_recommendations\\_regarding\\_the\\_extension\\_of\\_family\\_health\\_care\\_decisions\\_act.pdf](http://www.health.state.ny.us/regulations/task_force/docs/2010-11-30_recommendations_regarding_the_extension_of_family_health_care_decisions_act.pdf).

<sup>5</sup> 2011 N.Y. Laws Ch. 167.

daily living activities. The wide range of home care agencies and programs offer acute, short-term, chronic long-term, and public health preventive care to people of all ages, including the elderly, chronically-ill infants and children, patients who are disabled or recuperating from acute illness, and terminally-ill patients.

New York State has a diverse and integrated home care system, with a majority of home care patients being served by Certified Home Health Agencies (CHHAs), Long Term Home Health Care Programs (LTHHCPs), and Licensed Home Care Services Agencies (LHCSAs). CHHAs offer part-time, intermittent health care and support services to post-acute, extended care, and maternal/child cases.<sup>6</sup> LTHHCPs provide care management and comprehensive services according to a care plan designed to keep nursing home-eligible patients in their homes and are administered jointly by the New York State Department of Social Services and the New York State Department of Health (NYSDOH).<sup>7</sup> LHCSAs subcontract with CHHAs, LTHHCPs, county departments of social services, and other home care settings to assist with the services they offer.

These home care programs are subject to both federal and State oversight and must be licensed by NYSDOH.<sup>8</sup> Specifically, every CHHA, LTHHCP, and LHCSA may be surveyed periodically by NYSDOH to gauge the quality and scope of the medical, nursing, and rehabilitative care they deliver.<sup>9</sup> Although only CHHAs and LTHHCPs are required by law to meet the federal requirements for participation in Medicare and sometimes Medicaid,<sup>10</sup> LHCSAs may contract with CHHAs to provide services to patients with Medicare or Medicaid coverage, and therefore LHCSAs must comply with the same regulatory requirements that apply directly to CHHAs.<sup>11</sup>

In addition to these more formal agencies and programs, home care may also be provided through a variety of other programs that serve specific populations, including the Care at Home Program for Physically Disabled Children, Traumatic Brain Injury Waiver, Managed Long Term

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<sup>6</sup> The Legislature has recognized the significant role that CHHAs play in the State's health care system. N.Y. Pub. Health Law § 3600 ("The certified home health agencies render a coordinated array of services to patients in their homes, thereby avoiding prolonged institutionalization, concomitant high costs and associated adverse social and medical implications.").

<sup>7</sup> N.Y. Pub. Health Law § 3605.

<sup>8</sup> CHHAs, LTHHCPs, and LHCSAs must be licensed by the State. *Id.* Moreover, home care agencies may also be accredited by the Joint Commission, Accreditation Commission for Health Care, or Community Health Accreditation Program. Standards for accreditation vary among accrediting bodies. Although accreditation is voluntary and not required for any home care agencies, these accrediting organizations have Medicare-deeming authority, in which private, national accreditation organizations are authorized by the Centers for Medicare & Medicaid Services (CMS) to determine that an organization is compliant with certain Medicare requirements. Alternatively, a home care agency or program may request certification directly from Medicare.

<sup>9</sup> N.Y. Pub. Health Law § 3616-A.

<sup>10</sup> 42 C.F.R. pt. 484. Throughout these recommendations, agencies, or programs determined by CMS or an accrediting agency to meet the federal statutory conditions necessary to participate in Medicare will be referred to as "Medicare-certified."

<sup>11</sup> N.Y. Pub. Health Law § 3605.

Care, AIDS Home Care Program, and Consumer Directed Personal Assistance Program.<sup>12</sup> Some – but notably, not all – of these and other home care programs are subject to State oversight and Medicare and/or Medicaid certification requirements.

ii. Other Non-Institutional Health Care Settings

Many patients receive health care outside of hospitals, nursing homes, hospice, and home care programs. Routine, major medical, and end-of-life decisions are made in community-based settings, such as clinics and physicians' offices, ambulatory care and surgery centers, adult homes (including assisted living residences), ambulances and other emergency medical service (EMS) settings, and in the home (*e.g.*, by relying on private duty nursing pursuant to physicians' orders).

For example, routine or major medical decisions may be made in Enriched Assisted Living Residences (EALRs), a type of assisted living residence that provides aging in place services, including some nursing and health care.<sup>13</sup> Under certain conditions, a patient already residing in an EALR whose health deteriorates to the point of requiring around-the-clock medical or nursing care may remain in the facility.<sup>14</sup> EALRs require NYSDOH licensure both as an adult home<sup>15</sup> and as an assisted living residence,<sup>16</sup> as well as special certification as an EALR.<sup>17</sup> Health care services delivered in an EALR may be provided by a Medicare-certified agency, such as a CHHA.<sup>18</sup>

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<sup>12</sup> See, *e.g.*, New York State Department of Health, *Care at Home Program for Physically Disabled Children*, [http://www.health.ny.gov/publications/0548/care\\_at\\_home\\_physically\\_disabled.htm](http://www.health.ny.gov/publications/0548/care_at_home_physically_disabled.htm) (last visited Oct. 17, 2012); New York State Department of Health, *Traumatic Brain Injury Waiver*, [http://www.health.state.ny.us/health\\_care/medicaid/program/longterm/tbi.htm](http://www.health.state.ny.us/health_care/medicaid/program/longterm/tbi.htm) (last visited Oct. 17, 2012); New York State Department of Health, *Managed Long Term Care Program (MLTC)*, [http://www.health.state.ny.us/health\\_care/medicaid/program/longterm/mltc.htm](http://www.health.state.ny.us/health_care/medicaid/program/longterm/mltc.htm) (last visited Oct. 17, 2012); New York State Department of Health, *Consumer Directed Personal Assistance Program (CDPAP)*, [http://www.health.state.ny.us/health\\_care/medicaid/program/longterm/cdpap.htm](http://www.health.state.ny.us/health_care/medicaid/program/longterm/cdpap.htm) (last visited Oct. 17, 2012).

<sup>13</sup> The range of services that could be provided by a nurse in an EALR is dictated by the resident's health care needs – as described in the resident's individualized service plan – and what the EALR and nurse are each authorized by law to provide.

<sup>14</sup> N.Y. Comp. Code R. & Regs. tit. 10, § 1001.7(e)(2). The patient may remain in the EALR provided the patient's physician decides that his/her care can be safely delivered there and the operator agrees to provide services or arrange for services and is willing to coordinate care.

<sup>15</sup> N.Y. Comp. Code R. & Regs. tit.18, pt. 487.

<sup>16</sup> N.Y. Comp. Code R. & Regs. tit.18, pt. 490. An assisted living residence is defined as an entity that provides or arranges for housing, on-site monitoring, and personal care and/or home care services in a home-like setting to five or more adult residents.

<sup>17</sup> N.Y. Comp. Code R. & Regs. tit. 10, §1001.5.

<sup>18</sup> In assisted living residences, resident care aides perform similar services to those provided by home health aides in home care agencies and programs, and are trained to the same level as home care aides. N.Y. Comp. Code R. & Regs. tit. 10, § 1001.10(j)(3).

Ambulatory care is medical care delivered on an outpatient basis in settings such as clinics and urgent care centers.<sup>19</sup> It includes, for example, blood tests, X-rays, endoscopy, and biopsy procedures. Many of these tests and treatments are performed on an ambulatory basis in ambulatory surgery centers,<sup>20</sup> which are subject to similar State oversight as other Public Health Law Article 28 facilities, such as hospitals and diagnostic and treatment centers.<sup>21</sup> New York State requires the accreditation of ambulatory surgical facilities by one of three agencies: the Joint Commission, the Accreditation Association for Ambulatory Health Care, or the American Association for Accreditation of Ambulatory Surgery Facilities.<sup>22</sup> After an initial licensing inspection, NYSDOH accepts accreditation surveys in lieu of its own re-licensing inspections. NYSDOH has the ability to survey or investigate an ambulatory surgery center at any time. Further, ambulatory surgery centers may participate in Medicare and Medicaid.

Health care decisions also are often made in physicians' offices. Generally, NYSDOH does not regulate the individual, office-based, private practice of medicine outside of Article 28 facilities.<sup>23</sup> However, where a physician's office provides office-based surgery,<sup>24</sup> NYSDOH requires that it: (1) be accredited<sup>25</sup> and (2) report adverse events.<sup>26</sup> Although the law does not set level of equipment requirements, maintenance schedules, or mandatory inspections for physicians' offices that perform office-based surgery,<sup>27</sup> NYSDOH has issued nonbinding guidelines, which are intended to define the appropriate standard of care for such procedures.<sup>28</sup>

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<sup>19</sup> N.Y. Pub. Health Law Art. 28.

<sup>20</sup> N.Y. Comp. Code R. & Regs. tit. 10, pt. 755.

<sup>21</sup> Urgent care centers are facilities in which surgical or invasive procedures using moderate (or deeper) sedation occur. They qualify as either Public Health Law Article 28 facilities or are subject to the office-based surgery law, N.Y. Pub. Health Law § 230-d.

<sup>22</sup> N.Y. Comp. Code R. & Regs. tit. 10, § 755.2(f).

<sup>23</sup> The State Education Department's Office of the Professions licenses the medical profession, including physicians and nurses. N.Y. Educ. Law Art. 131, §§ 6520-6529; Art. 139, §§ 6900-6910. Until the 2007 promulgation of the office-based surgery regulations (N.Y. Pub. Health Law § 230-d), there was almost no NYSDOH oversight of private office-based care, except where a physician became subject to professional misconduct proceedings pursuant to N.Y. Pub. Health Law § 230 or was sued for providing unacceptable care (*e.g.*, medical malpractice or otherwise).

<sup>24</sup> Office-based surgery is defined as "any surgical or other invasive procedure, requiring general anesthesia, moderate sedation, or deep sedation, and any liposuction procedure, where such surgical or other invasive procedure or liposuction is performed by a licensee in a location other than a hospital... excluding minor procedures and procedures requiring minimal sedation." N.Y. Pub. Health Law § 230-d(1)(h).

<sup>25</sup> Although accreditation is not the same as state regulation, NYSDOH noted that it may ensure a level of standardization among office-based surgery practices while assuring quality of care and patient safety. New York State Department of Health, *Office-Based Surgery Practices in New York State*, [http://www.health.state.ny.us/professionals/office-based\\_surgery/practices/](http://www.health.state.ny.us/professionals/office-based_surgery/practices/) (last visited Oct. 17, 2012).

<sup>26</sup> N.Y. Pub. Health Law § 230-d.

<sup>27</sup> N.Y. Pub. Health Law § 230-d(5); New York State Department of Health, *Office-Based Surgery*, [http://www.health.state.ny.us/professionals/office-based\\_surgery/](http://www.health.state.ny.us/professionals/office-based_surgery/) (last visited Apr. 23, 2012).

<sup>28</sup> Committee on Quality Assurance in Office-Based Surgery, *Clinical Guidelines for Office-Based Surgery*, ix (2000), [http://www.auanet.org/content/practice-resources/office-based-surgery/pdfs/NY\\_protocols.pdf](http://www.auanet.org/content/practice-resources/office-based-surgery/pdfs/NY_protocols.pdf). See also New York State Department of Health, *Report of the Committee on Quality Assurance in Office-Based Surgery* (2007), [http://www.health.state.ny.us/professionals/office-based\\_surgery/reports/docs/committee\\_on\\_quality\\_assurance.pdf](http://www.health.state.ny.us/professionals/office-based_surgery/reports/docs/committee_on_quality_assurance.pdf).

As the contours of health care delivery continue to change, Accountable Care Organizations (ACOs) and other integrated health care delivery systems will become more commonplace. ACOs are groups of doctors, hospitals, and other health care providers who come together voluntarily to give coordinated high quality care to the patients they serve. In March 2011, New York enacted a law to foster the development of ACOs within the State.<sup>29</sup> ACOs that seek Medicare incentives must meet requirements prescribed by the Centers for Medicare and Medicaid Services.<sup>30</sup>

## B. Analysis

The flexibility essential to the delivery of care in the community, in addition to the variation in oversight, populations, and delivery of care, distinguishes care provided in non-institutional settings from that in hospitals, nursing homes, and sometimes hospice. Importantly, while the provision of health care in the community, including capacity assessments and assessments of health conditions, is “overseen” by a physician,<sup>31</sup> care is commonly provided by nurses, home health aides, and other paraprofessionals.<sup>32</sup> Often, these non-physician clinicians are the individuals who examine and administer care to patients in the community setting.

Regardless of where individuals receive care, they may suffer from a variety of serious conditions or may be terminally-ill. According to the New York State Office for the Aging, 75 % of care recipients over 60 years old who receive care from informal caregivers in the State have Alzheimer’s disease or other forms of dementia.<sup>33</sup> These care recipients may have to rely

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<sup>29</sup> N.Y. Pub. Health Law Art. 29-E. The law establishes a demonstration program that will allow for the evaluation of the viability of ACOs, and authorizes NYSDOH to approve a maximum of seven ACOs between the law’s effective date and December 2015. N.Y. Pub. Health Law § 2999-p (“[T]he demonstration project is intended ‘to test the ability of ACOs to deliver an array of health care services for the purpose of improving the quality, coordination and accountability of services provided to patients in New York.’”).

<sup>30</sup> Centers for Medicare & Medicaid Services, *Accountable Care Organizations (ACOs)*, <http://www.cms.gov/ACO/> (last visited Oct. 17, 2012). The federal Shared Savings Program would require that ACOs that meet certain quality performance standards to be eligible to receive Medicare shared savings payments. Among other requirements, the ACO must demonstrate that it meets patient-centeredness criteria, such as the use of patient and caregiver assessments or the use of individualized care plans.

<sup>31</sup> See N.Y. Comp. Codes R. & Regs. tit. 18, §§ 505.21, 505.23; N.Y. Comp. Codes R. & Regs. tit. 10, § 766.4. At the federal level, the Patient Protection and Affordable Care Act and its related regulations now require a face-to-face encounter when physicians certify eligibility for home health care. However, a nurse practitioner, a certified nurse midwife, or a physician assistant may perform the face-to-face visit instead of a physician. See Pub. L. No. 111-148 § 6407(a); 42 CFR § 424.22(a)(1)(v).

<sup>32</sup> Home health aides must complete State-mandated training classes, and are required to undergo annual physical assessment and meet in-service requirements. See New York State Department of Health, *Home Health Aide Training Program Application*, <http://www.health.ny.gov/forms/doh-4396.pdf> (last visited Oct. 17, 2012).

<sup>33</sup> New York State Office for the Aging, *New York State Family Caregiver Council Report (2009)*, <http://www.aging.ny.gov/Caregiving/Reports/InformalCaregivers/FamilyCaregiverCouncilReport.pdf>. The 2009 Caregiver Support Programs Participants Survey found that caregivers receiving caregiver support program services during fiscal year 2007 were generally at least 18 years of age and were family



on surrogates to make health care decisions – including routine, major medical, and life-sustaining treatment decisions – on their behalf. Proxy decision-making is not limited to elderly patients, however; patients of all ages may lack or lose capacity outside of health care institutions due to, for example, complications from a serious illness or the unexpected deterioration of one’s health. Thus, surrogate appointment and decision-making would benefit individuals being treated outside of a hospital, nursing home, or hospice.

The FHCDA as currently worded does not give authority to family members and loved ones to consent to treatments or object to procedures on behalf of patients in non-institutional settings. In fact, there is little clear legal authority permitting family members or loved ones to make proxy decisions outside of the three categories of settings currently specified by the FHCDA.<sup>34</sup> Instead, in order for a surrogate to have authority to make health care decisions pursuant to the FHCDA, the patient would have to be transferred to a hospital, nursing home, or hospice, even where there is no emergency or clinical need for such a transfer.

Requiring patients to be moved from their residence of choice is often jarring and medically unnecessary, and contravenes the value intrinsic to receiving care outside of institutions: to allow a patient to remain in an environment where he or she is most comfortable. Evidence suggests that transitioning patients to a hospital or nursing home can lead to further deterioration of patients’ health, including their capacity to provide first-person consent to treatment.<sup>35</sup> Enabling surrogate decision-making on behalf of people who cannot provide legally and ethically appropriate consent for themselves – both in the community and across many venues of care – is essential.<sup>36</sup> Moreover, family members, loved ones, health care providers,

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members, friends, or neighbors who help care for an elderly individual (aged 60 or older) who lives at home.

<sup>34</sup> For a discussion of reasonable practices in decisions for patients who lack capacity, see Robert N. Swidler & Nina M. Daratsos, *Informed Consent and Decisions for Patients Who Lack Capacity*, in LEGAL MANUAL FOR NEW YORK PHYSICIANS 373-77 (Medical Society State of NY/NYS Bar Association, 3rd ed. 2011).

<sup>35</sup> See, e.g., William J. Ehlenbach et al., *Association Between Acute Care and Critical Illness Hospitalization and Cognitive Function in Older Adults*, 303 JAMA 763 (2010).

<sup>36</sup> Research also has shown that, in comparison to patients who pass away in hospitals or hospice, patients who die at home without nursing services are the least likely to have an advance directive. Specifically, 55.6 % of those whose last place of care was at home, without nursing services, had advance directives, as compared to 70.8 % of those who received care at home with hospice services, 80.8 % of those whose last place of care was at a nursing home, and 62.5 % whose last place of care was in a hospital. Joan M. Teno et al., *Family Perspectives on End-of-Life Care at the Last Place of Care*, 291 JAMA 88, (2004). This finding is perhaps due to the fact that advance care planning conversations are more likely to occur at the time of admission to a nursing home, hospital, or hospice, or because death is more “unexpected” in the home than in other settings (and therefore the patient has not had the opportunity to have such conversations). Dying was “‘extremely’ unexpected” for 65 % of those patients whose last place of care was at home, without nursing services, as compared to 7.1 % of those who received care at home with hospice services, 12 % of those whose last place of care was at a nursing home, and 23.8 % whose last place of care was in a hospital. *Id.*

and clinicians have a clear interest in knowing who can make decisions in such instances and the rules and principles that will apply.<sup>37</sup>

### C. Task Force Recommendations

The Task Force recommends that the surrogate decision-making authority of the FHCDA should be extended, as modified below, on an “opt-in” basis to those agencies, programs, and health care settings that are both Medicare and/or Medicaid-certified and State-licensed, not including those licensed pursuant to the professional licensure requirements under the New York State Education Law. Where an agency, program, or setting has opted in, the Act should authorize surrogate decision-making for all care provided in that setting, including for the creation of a plan of care and for decisions to withhold or withdraw life-sustaining treatment.

In all cases, care should be provided by appropriately-trained clinicians, while focus is maintained on providing the surrogate decision-maker with support and information regarding treatment options. In the community setting, particular emphasis should be placed on ensuring that physicians are responsible for the care of the patient and for working with a surrogate to design a patient’s plan of care.

Where the FHCDA has distinct requirements depending on the setting in which decisions are made, the standards applied should mirror the more stringent requirements currently set forth for nursing homes. Specifically, for surrogate decisions to withhold or withdraw life-sustaining treatment, a surrogate may only have authority to refuse life-sustaining treatment if an Ethics Review Committee (ERC), including at least one physician who is not directly responsible for the patient’s care, or a court of competent jurisdiction, reviews the decision and determines that it meets the standards established in the FHCDA.<sup>38</sup>

#### i. Programs, Agencies, and Settings

The Task Force proposes that the FHCDA be extended to Medicare and/or Medicaid-certified and State-licensed programs, agencies, and settings. The scope of the Task Force’s recommendations is not limited to the entities described in this statement, however. Given the constantly changing health care landscape, these settings are merely representative examples of those that *may* have the potential ability to comply with the FHCDA’s procedural requirements.<sup>39</sup>

Some of the settings discussed herein may not, in fact, be able to abide by the FHCDA’s surrogate decision-making rules. For instance, although this statement refers to the possible

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<sup>37</sup> Under the FHCDA as currently worded, even when a surrogate was previously identified and appointed in an institution covered by the FHCDA, when the patient is transitioned to the community for care (and is not in hospice care), that surrogate will lose the ability to make decisions about on-going care.

<sup>38</sup> N.Y. Pub. Health Law § 2994-d(5).

<sup>39</sup> For example, due to resource sharing agreements and the coordination of care between health care providers and other participants in integrated health care delivery arrangements, ACOs and similar systems may be able to comply with the procedural aspects of the FHCDA, and thus a surrogate appointment may be able to travel with the patient throughout the various ACO participant settings.

capability of some physicians' offices to meet the requirements of the FHCDA,<sup>40</sup> others may not meet the criteria because they are subject to fewer oversight and other legal requirements.<sup>41</sup>

ii. “Opt-In” System

Because not all programs, agencies, and providers will be willing or able to abide by the procedural requirements and oversight mechanisms of the FHCDA, the Task Force recommends an initial expansion of the Act to health care settings that can (and choose to) opt-in to the FHCDA. This proposal will achieve a number of ends. First, and most obviously, it would extend much needed authority for surrogate decision-making for vulnerable populations beyond the hospital, nursing home, and hospice settings. Second, an opt-in system would allow surrogate decision-making authority to be effected without requiring extensive changes to the FHCDA, as many programs may already be equipped to comply with the safeguards enumerated in the Act. Finally, the opt-in process will provide the opportunity to those who are currently unable to comply with the FHCDA to adapt and adjust their procedures and services over time if they so choose, yet will also allow agencies, programs, and settings that do not have the resources or desire to abide by the FHCDA the ability to continue in their current form.

Some of the FHCDA's procedural requirements may be difficult to apply in community-based agencies and programs because of the Act's institutional focus. For example, under the FHCDA, certain decisions and actions must be reviewed by an ERC.<sup>42</sup> However, having an ERC is not a mandate of community-based agency licensure, and many programs may not have their own such committee. Additionally, the FHCDA has detailed requirements for decisions involving the isolated patient.<sup>43</sup> The requirement that treatment decisions for isolated patients be made by at least one physician may be difficult to follow in home care settings where physicians are often absent.<sup>44</sup>

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<sup>40</sup> Particularly where the doctor is affiliated with a hospital, physicians' offices may be able to meet the FHCDA's technical requirements for routine care decisions on an opt-in basis with additional patient protections. Further, extension clinics are considered part of a general hospital, and therefore physicians providing care in these settings must already meet the FHCDA's technical requirements.

<sup>41</sup> Office-based surgery would generally fall under the FHCDA's classification of “major medical” care. N.Y. Pub. Health Law § 230-d(1)(h); § 2994-g(4).

<sup>42</sup> N.Y. Pub. Health Law § 2994-d(5)(b). The FHCDA requires that ERCs be interdisciplinary, and be composed of at least five members, three of which are health or social service practitioners, and include a physician and a registered nurse. Further, at least one member must be a person without any governance, employment, or contractual relationship with the hospital or nursing home. In nursing homes, the Residents' Council of the facility, or of another facility that participates in the ERC, must be offered the opportunity to appoint up to two individuals, neither of whom may be a resident or a family member of a resident of the facility. N.Y. Pub. Health Law § 2994-m(3).

<sup>43</sup> N.Y. Pub. Health Law § 2994-g. An “isolated patient” is an adult patient who would qualify for surrogate decision-making under the FHCDA but for whom no surrogate is reasonably available.

<sup>44</sup> Under the FHCDA, a single physician can make decisions regarding routine medical care for the isolated patient. When the plan of care, which is established at the time of enrollment, involves major medical care, two physicians would need to be present and independently concur in such decisions. Decisions to withhold or withdraw life-sustaining treatment may be made on behalf of the isolated patient if two physicians determine that the treatment offers the patient no medical benefit because the patient

### iii. Proposed Modifications to the FHCDA

Programs, agencies, and health care settings outside of hospitals, nursing homes, and hospice have varied and distinct practices, oversight, and regulatory requirements as compared to their more institutional counterparts. Accordingly, special safeguards are necessary to protect the interests of the patient. In recognition of these differences and because of the unique nature of health care delivery in the community, the Task Force proposes that the FHCDA be amended for agencies, programs, and settings that are both Medicare and/or Medicaid-certified and State-licensed, as follows:

- (a) Attending physician: The definition of “attending” physician in Section 2994-a(2) should be amended to include a qualified physician as set by the rules and procedures of a qualifying agency, program, or provider, rather than just those defined by “hospital policy.” These policies must ensure that an appropriately-trained physician fulfills the roles and duties of the “attending” physician under the FHCDA, and should focus on the primacy of the role of the physician in patient care.
- (b) Capacity assessments: Before turning to a surrogate for decisions involving major medical care or decisions to withhold or withdraw life-sustaining treatment, a physician must determine that the patient lacks decisional capacity about his or her care. The physician shall assess, monitor, and where appropriate, re-determine capacity in accordance with professional standards.<sup>45</sup> However, for *routine* medical decisions, in order to allow for more flexibility in surrogate decision-making in the community setting, capacity assessments may also be made by a nurse practitioner, in collaboration with a physician.<sup>46</sup>
- (c) Ethics Review Committees: An agency, program, or setting may not have its own internal ERC that meets the FHCDA’s requirements under Section 2994-m for membership and procedures, and may lack the resources to meet the Act’s ERC mandate.<sup>47</sup> Accordingly, the FHCDA should be modified to allow that, where a conflict arises that cannot otherwise be resolved by an ethics consultation or other informal means<sup>48</sup> *or* where a surrogate refuses life-sustaining treatment,<sup>49</sup> the physician and/or surrogate should seek consultative services from its own ERC (if one exists) *or* a hospital, nursing

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will die imminently, even if the treatment is provided, and the provision of the treatment would violate accepted medical standards (or, alternatively, if a court finds that the decision is appropriate). *Id.*

<sup>45</sup> See N.Y. Pub. Health Law § 2994-c(2), (3), and (7).

<sup>46</sup> This modification does not apply to decisions regarding major medical care or decisions to withhold/withdrawal life-sustaining treatment.

<sup>47</sup> See N.Y. Pub. Health Law §§ 2994-c, d, m.

<sup>48</sup> For example, where the physician objects to a surrogate’s decision or where there is a conflict between an initial and a concurring determination of incapacity.

<sup>49</sup> N.Y. Pub. Health Law § 2994-d(5)(b).

home, or hospice-based ERC. A program, agency, or provider's internal policy must include identification of the ERC with whom it will consult if conflicts arise.

#### iv. Advance Care Planning

The Task Force strongly encourages advance care planning prior to or upon entering community-based care by patients who have capacity.<sup>50</sup> Advance care planning may include guidance regarding the types of care a person may wish to have – or avoid – in the event that the patient can no longer indicate his or her preferences, and/or the selection of a surrogate decision-maker if the patient loses capacity to make first-person decisions. Advance care planning promotes respect for the patient as an autonomous decision-maker,<sup>51</sup> alleviates stresses on surrogates who may face enormous emotional burdens when making certain types of medical decisions, particularly regarding end-of-life care,<sup>52</sup> and increases the likelihood that the individual patient receives care consistent with his or her preferences.<sup>53</sup>

When a patient enters certain care settings, such as CHHAs, LTHHCPs, and EALRs,<sup>54</sup> opportunities exist to engage in advance care planning. However, when a plan of care is created, often the primary focus is on identifying appropriate services and medical equipment for the patient.<sup>55</sup> Such plans of care do not necessarily include patient preferences or directions for the initiation, continuation, withholding, or withdrawal of care, although some home care agencies are required to conduct discussions of advance directives upon entrance.<sup>56</sup> Further, in other more

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<sup>50</sup> Some, but not all, programs and agencies require a discussion of advance directives and applicable State law upon admission. 42 C.F.R. § 484.10(c)(2)(ii) (“Medicare Certified Home Health Agencies require that the HHA must inform and distribute written information to the patient, in advance, concerning its policies on advance directives, including a description of applicable State law.”). *See also* Rebecca L. Sudore & Terri R. Fried, *Redefining the “Planning” in Advance Care Planning: Preparing for End-of-Life Decision Making*, 153 ANN. INTERN. MED. 256 (2010) (concluding that the objective for advance care planning ought to be the preparation of patients and surrogates to participate with clinicians in making the best possible in-the-moment medical decisions, and recommending steps for clinicians to follow to prepare patients and surrogates in the outpatient setting).

<sup>51</sup> *See, e.g.*, Peter H. Ditto et al., *Advance Directives as Acts of Communication: A Randomized Controlled Trial*, 161 ARCH. INTERN. MED. 421 (2001).

<sup>52</sup> *See, e.g.*, Karen M. Detering et al., *The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial*, 340 BMJ c1345 (2010).

<sup>53</sup> *See generally* N.Y. Pub. Health Law Art. 29-C; New York State Department of Health, *Medical Orders for Life-Sustaining Treatment (MOLST)*, <http://www.health.state.ny.us/forms/doh-5003.pdf> (last visited Oct. 17, 2012) (NYSDOH-approved physician order form, intended to aid physicians and other health care providers to discuss and convey a patient's wishes regarding cardiopulmonary resuscitation (CPR) and other life-sustaining treatment).

<sup>54</sup> Assisted living residences must develop an individualized service plan for each applicant that includes a medical, functional, and mental health assessment based on the results of a physical exam within 30 days prior to admission. The plan describes the services that need to be provided to the resident, and how and by whom those services will be provided, and must be reviewed and revised as medical, nutritional, social, and everyday life needs change, but at least every six months. N.Y. Comp. Code R. & Regs. tit. 10, § 1001.7(k).

<sup>55</sup> *See* N.Y. Comp. Codes R. & Regs. tit. 10, § 763.6; 42 C.F.R. § 484.18.

<sup>56</sup> 42 C.F.R. § 484.10(c)(2)(ii).

informal care settings and programs, there is little if any emphasis placed on advance care planning.

Regardless of the care setting, discussions of end-of-life care preferences and consideration of individuals who may serve as surrogate decision-makers in the event that a patient loses capacity should be promoted to the greatest extent possible.

#### D. Conclusion

In summary, the Task Force recommends that the surrogate decision-making authority of the FHCDA be extended, with the modifications discussed above, to apply to health care decisions in those Medicare and/or Medicaid-certified and State-licensed agencies, programs, and health care settings that opt-in to the FHCDA requirements.

Should the Legislature adopt these recommendations, the Task Force intends to evaluate the ability and success of the programs that have opted in, in order to assess the effectiveness of extending the FHCDA. In the future, the Task Force may issue additional statements or recommendations on related issues.

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