

**WRITTEN TESTIMONY SUBMITTED BY
THE BIOETHICAL ISSUES COMMITTEE, HEALTH LAW COMMITTEE
AND SCIENCE AND LAW COMMITTEE**

**ASSEMBLY COMMITTEE ON HEALTH
HEARING ON MEDICAL AID IN DYING
HELD ON MAY 3, 2018**

This written testimony is submitted jointly by the Bioethical Issues, Health Law, and Science and Law Committees (respectively the “Committees”) of the New York City Bar Association (“City Bar”) concerning the Medical Aid in Dying Act, A.2383-A/S.3151-A NY Leg. Sess. (2018), amending A.2383/S.3151 NY Leg. Sess. (2017).

The City Bar led a process of holding forums in 2016-2017 and reviewing information presented by parties on all sides of the debate concerning Medical Aid in Dying (“AID”) and proposed policy-making in New York State. The City Bar issued a Commentary on the 2017 legislative proposal, which can be found on the City Bar web site.¹ The 2017 Commentary is appended, and we would ask that the 2017 Commentary be incorporated into this City Bar written testimony and made part of the record.

We turn now to the 2018 bill as it has been amended since the submission of our 2017 Commentary (the currently pending bill is referred to herein as the “AID Bill”).

At the outset, the AID Bill addresses certain concerns we identified in our June 2017 Commentary. In particular, we commend the bill sponsors on making changes to the provisions on interpreters, including provisions to ensure:

- that those who require an interpreter due to speech, hearing or vision disabilities have access to medical aid in dying (“AID”), and that interpreters in each category, those who serve as language interpreters and those who serve as interpreters for those living with a disability, have the appropriate qualifications for serving as such. The amendments also strengthen the Interpreter’s Declaration in a number of other critical ways, including adding language to the attestation about “impartial and accurate” translation, and requiring the interpreter to provide an ID number or Agency name, as well as the native language spoken by the interpreter; and

¹ Available online here: http://s3.amazonaws.com/documents.nycbar.org/files/2017130-AidinDyingNY_WhitePaper_FINAL_5.30.17.pdf.

- that an employee or an independent contractor with a health care facility where the patient is receiving treatment can serve as an interpreter only if they are qualified to do so, if it is part of their job description, and if they are requested to do so by the patient.

We also acknowledge several other amendments that strengthen procedural safeguards in the AID Bill, and may help to prevent potential abuse to the extent such type of individual-level safeguards may be effective in reducing risk of abuse, including:

- clarifying that the determination of “capacity” refers to the capacity to make an “informed decision” (as defined) specifically about requesting and obtaining a lethal medication for self-administration;
- requiring a patient to affirmatively request AID “of his or her own volition, and without any coercion,” after being informed about all other appropriate treatment options, including palliative care and hospice;
- defining “terminal illness or condition” as one that has been medically confirmed by two doctors (See also Recommendation 3 herein below, concerning deletion of “or condition” from defined term);
- requiring both doctors to confirm capacity and informed consent;
- requiring referral to a mental health professional if either doctor believes the patient may lack capacity;
- requiring any mental health determination to be forwarded to the consulting physician;
- requiring the doctor to inform the patient that he or she may rescind the request at any time; and
- providing for notification to family members.

I. PROPOSED ADDITIONAL AMENDMENTS TO AID BILL

Although the above-referenced amendments are commendable, we believe that additional amendments can and should be made to improve upon the AID Bill.

a. Section 2899-d. “Definitions.”:

1. Section 2899-d[5] - “Health Care Facility”

Recommendation: Include “Hospice” in the definition of “Health Care Facility.”

Article 40 (“Hospice”) of the New York Public Health Law defines “hospice” as “a coordinated program of home and in-patient care which treats the terminally ill patient and

family as a unit, employing an interdisciplinary team acting under the direction of an autonomous hospice administration.” Public Health § 4002. A hospice must receive a Certification from the New York State Department of Health to operate and provide hospice care, whether in a hospice residence or at the patient’s home.

Proposed Section 2899-d[5] in the AID Bill limits the term “health care facility” to “a general hospital, nursing home or residential health care facility as defined in section twenty-eight one hundred one of this chapter.” We recommend that “hospice” be added to the definition of “health care facility”, for the following reasons.

Proposed Section 2899-k in the AID Bill (“Form of written request and witness attestation”) provides that least one of the witnesses to a patient’s request for medication must attest that he or she is “not ... an owner, operator, employee or independent contractor of a health care facility where the person is receiving treatment or is a resident.” If hospices are excluded from the Bill’s definition of “health care facility,” the witness conflict of interest provision would not apply to protect hospice patients.

There is no reason why general hospital patients and residents of nursing homes and residential health care facilities should receive protection from a witness’ conflict of interest, but not hospice patients. Under New York law, a hospice patient must have a “terminal illness” as defined in Public Health Law § 4002 (“one year or less if the illness runs its course”); hospice patients as a group necessarily include those who would have a “terminal illness or condition” as defined by proposed Section 2899-d[17] in the AID Bill, *i.e.* “an incurable and irreversible illness or condition that has been medically confirmed and will, within reasonable medical judgement, produce death within six months.” It is more likely that hospice patients would have a terminal illness or condition than hospital patients or residents in a nursing home or residential health care facility.

Oregon’s “Death with Dignity Act” (Chapters 127.800 *et seq.* of the Oregon Revised Statutes) uses the term “health care facility” in Section 2.02 (Ch. 127.810), “Form of the Written Request”, in providing that one witness may not be “an owner, operator or employee of a health care facility where the qualified patient is receiving medical treatment or is a resident.” However, the Oregon law does not define “health care facility” and thus does not exclude hospices.²

We recommend that proposed Section 2899-d[5] in the AID Bill be amended to state: “Health care facility means a general hospital, nursing home or residential health care facility as defined in section twenty-eight one hundred of this Chapter or a hospice as defined in section four thousand of the Public Health Law.”

² Under the Oregon Death with Dignity Act, 90.9% of persons requesting aid are hospice patients; *see* Oregon Death With Dignity Act 2017 Data Summary, Oregon Health Authority Public Health Division, Center for Health Statistics, Feb. 8, 2018, <http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf>.

2. Section 2899-d[11] - “Mental Health Professional”

Recommendation: Clarify “Mental Health Professional.”

The AID Bill uses a very broad definition of mental health professional and one that is inconsistent with other parts of New York law, particularly with the Family Health Care Decisions Act (“FHCDA”).³ Patients are referred to mental health professionals by the attending or consulting physician when there is a belief that the patient may lack capacity. Mental health professionals are responsible for evaluating a patient to determine whether the patient has capacity to make an informed decision to request and obtain medication that the patient may self-administer to end the patient’s life.

The definition of mental health professional includes not only a licensed physician or psychologist, but a nurse practitioner and physician assistant as well. Moreover, while we recognize the desire to provide AID options in more rural areas of the state, the AID Bill, in contrast to the FHCDA, does not specify that the attending or consulting physician must be board certified or eligible in the field of psychiatry or list the specific qualifications that any of the other identified professionals would need in order to be able to make such a determination. This vagueness could lead to confusion and inconsistent application of the determination of whether a patient has the capacity to receive medical AID.

Accordingly, we recommend that the AID Bill be amended to elevate the credentials and qualifications of the medical professionals involved in the AID process. Specifically, whenever the attending or consulting physician believes that the patient may lack capacity, then either the physician or mental health professional who reaches a conflicting decision and finds capacity should be required to possess, at a minimum, the FHCDA’s credentialing and qualifications requirements for determining lack of capacity under the FHCDA⁴ -- at the very least, in the case of any patient with a history of mental illness or any developmentally disabled patient.

³ The FHCDA (Public Health Law §§ 2994-a *et seq.*) requires that a physician making the initial determination that a patient lacks mental capacity due to mental illness or developmental disability “have the following qualifications . . . [1] (in the case of mental illness) (i) a diplomate or eligible to be certified by the American Board of Psychiatry and Neurology”, or (ii) “certified by the American Osteopathic Board of Neurology and Psychiatry or . . . eligible to be certified by that board;” and [2] (in the case of a developmental disability) “a physician or clinical psychologist who either is employed by a developmental disabilities services office named in section 13.17 of the mental hygiene law, or who has been employed for a minimum of two years to render care and service in a facility operated or licensed by the office for people with developmental disabilities, or has been approved by the commissioner of developmental disabilities in accordance with regulations promulgated by such commissioner. Such regulations shall require that a physician or clinical psychologist possess specialized training or three years of experience in treating developmental disabilities.” Public Health Law § 2994-c[3](c). If, and only if, such an initial determination of incapacity has been made by a qualified physician is that determination then subject to a concurring determination of incapacity by a “health or social services practitioner,” defined as “a registered professional nurse, nurse practitioner, physician, physician assistant, psychologist or licensed clinical social worker, licensed or certified pursuant to the education law acting within his or her scope of practice.” Public Health Law §§ 2994-c[3](a), 2994-a[17].

⁴ *Id.*

3. **Section 2899-d[17] – “Terminal Illness or condition”**

Recommendation: Limit AID to Patients with “Terminal Illness.”

The AID Bill would extend the authority to provide AID to persons who have a “terminal illness or condition” with a life expectancy of 6 months or less. Adding the disjunctive, “or condition”, introduces a disturbing ambiguity as to what condition, other than a “terminal illness”, would then allow a physician to prescribe lethal medication.

We understand that “terminal condition” is also tethered to a life expectancy of 6 months or less. However, “terminal illness” should sufficiently describe a patient’s health status when AID could be appropriately offered. Notably, “terminally ill” is the term used to delineate the authority to provide hospice care to end-of-life patients. Public Health Law § 4002. Moreover, “illness” more aptly denotes disease, sickness and suffering; by contrast, “condition” is vague and amorphous.

If there is no intent to extend the reach of AID beyond the terminally ill, then the addition of “or condition” would be mere surplusage that could only create confusion. If however the intent is instead to somehow broaden the reach, that amendment would not only create confusion, it could also increase the risk of abuse by the unscrupulous purporting to act under the guise of treating a “terminal condition” that is something other than a terminal illness.

Whatever the intent may have been for adding “or condition”, the fact remains that “condition” is not a separately defined term in the AID Bill, leaving medical practitioners with no understanding as to its reach or application. Adding the phrase to the statute would only create confusion and ambiguity on the part of physicians being asked by a patient to prescribe a lethal medication, when the overarching legislative goal should be clarity given the profound consequences of their decisions.

To ensure clarity, we recommend that the AID Bill be amended to revert to the term used in the original bill, “terminal illness,” and to delete the disjunctive, “or condition,” from the definition section and other relevant provisions of the bill.

b. Section 2899-e. “Request Process”

1. Section 2899-e[3](b)(iii) - *the Declarations of Witnesses*

Recommendation: Enhance Protections Against Witness Conflicts.

The AID Bill provides that no more than one of the two individuals required to witness a patient’s written request for AID may be an owner, operator, employee or independent contractor of a “health care facility” where the patient is receiving treatment or resides. As we understand, this provision is designed to prevent both witnesses from having an actual or potential conflict of interest in hastening the patient’s death, for financial or other reasons.

However, “health care facility” as currently defined in the AID Bill is limited to a hospital or nursing home, and does not include any other residential setting such as an assisted living residence or other institution, where the patient may be residing and where similarly a conflict of interest could arise. Nor does it preclude as a second witness someone who may be employed by or affiliated with a managed care or health plan or a home care agency that is caring for the terminally ill patient in a community setting.

At the very least, as noted earlier, the definition of “health care facility” should be amended to include a hospice, a likely setting for the care of the terminally ill. Moreover, the Legislature should consider broadening the protections against witness conflicts of interest to other health care settings or arrangements.

c. Section 2899-q. “Reporting”

1. Recommendation: Strengthen Regulatory Oversight and Reporting.

The AID Bill requires the Department of Health to furnish an annual report on utilization and compliance with the requirements of the AID Bill. In our view, the level of Department of Health oversight is too limited, especially in light of the risk of coercion and abuse, particularly among vulnerable populations. The rationale for more robust oversight is simple: when lives are being foreshortened with AID, however compelling the reasons may be in most cases, it is of vital public interest to ensure that compliance with the statute is broad-based, and that instances of non-compliance - especially when professional abuse or coercion of the terminally ill is evident - do not fall below the radar.

The legislation does require the Department of Health to review a “sample” of AID patient records, and to promulgate regulations establishing a process for physician reporting of utilization and compliance data to the Department on a confidential basis. Yet the AID Bill does not specify how large a sample size of AID records the Department will actually review, or how the Department of Health would go about collecting the sample. As such, there would be no assurance that the sample will be sufficiently robust for the Department to draw any reliable conclusions about compliance with the statute.

More fundamentally, a sample review - whatever the size or parameters - will not identify all instances of non-compliance nor enable the Department to even detect patterns of non-compliance. For instance, a more comprehensive review of AID data may reveal to the Department a concentration of AID being provided by certain physicians or at certain institutional settings, warranting further investigation and possible enforcement action.

Accordingly, in order to better inform the regulatory process, the AID Bill should be amended to require the Department of Health to undertake a rigorous review or analysis of all or substantially all of the deaths associated with AID.

To further enhance oversight, the Department should also be required to directly furnish its annual reports to the Legislature, in addition to the posting requirement included in the AID Bill. In its annual report, the Department should discuss compliance with the AID statute

generally, and specifically identify and address any instances (subject to patient confidentiality) or patterns of non-compliance, especially those involving suspected abuse of the terminally ill.

The Department should also review and address in its annual report, the experience of institutional “ethics review committees” in connection with their role in the AID decision-making process, as we have recommended below. (See Recommendation: “Provide a Role for Institutional Ethics Committee”.)

Likewise, the Legislature should consider providing a sunset provision in the legislation. A sunset clause would require the Legislature -- prior to renewing the AID statute -- to look at New York’s experience with AID and affirm that the statutory safeguards in place are effective, the requirements are being faithfully observed, and AID is not being abused.

II. ADDITIONAL RECOMMENDATIONS

a. Recommendation: *Codify Legislative Intent.*

If the intent is not to authorize a surrogate or guardian to request AID on behalf of a terminally ill individual -- notwithstanding a surrogate or guardian’s otherwise broad powers conferred under the Family Health Care Decisions Act (“FHCDA”) or Article 81 of the Mental Hygiene Law -- the legislation should say so, explicitly, so as to leave no ambiguity or inconsistency. Incorporating this understanding into positive law would also send the loud and clear message to the public that any attempt to use the cover of AID, by unauthorized actors, will not be tolerated.

b. Recommendation: *Maintain Stringent AID Safeguards.*

At a minimum, the AID Bill should incorporate the more robust review processes provided for resolving conflicts in medical decision-making under the FHCDA, in particular, to the extent there is a conflict among the physicians and the mental health professional concerning the patient’s capacity, either in support of or against the patient’s request for AID. In so requesting, we do not believe however that the AID Bill should be structured in “parity” with the FHCDA. Rather, the AID Bill should include appropriate FHCDA protections and provide the additional safeguards noted above.⁵

⁵ Notwithstanding survey data suggesting growing popular support for AID, there does not appear to be consensus that the existing, recognized right to forgo life-support technologies, including artificial nutrition and hydration, is the ethical equivalent of a right to request the assistance of medical professionals to facilitate the termination of one’s life. *See* 2017 Commentary, pp. 7-8. The right to forgo treatment is premised on the notion that the individual has autonomy over his or her body, and should not be forced by others to accept medical treatments, food or hydration, against his or her will. On the other hand, a right to medical assistance to facilitate one’s death is premised on the view that the individual should have the right to have others enable him or her to terminate, and not to preserve, his or her life. The pressure to relax AID regulation and oversight may intensify if society does not allocate the resources necessary to ensure that a terminally ill patient’s choice of AID is both knowing and meaningful - with other options such as palliative and hospice care made available and fully explained - and is free from coercion. The additional AID safeguards are both rational and warranted for the regulation of AID decisions even if not required for decisions to forgo life-sustaining treatments.

c. Recommendation: Mandate Offering Palliative and Hospice Care Counseling.

The AID Bill requires the physician to discuss “the feasible alternatives and appropriate treatment options, including but not limited to (1) information and counseling regarding palliative and hospice care, and end-of-life options appropriate to the patient . . . ; and (2) information regarding treatment options appropriate to the patient, including prognosis, risks and benefits of the various treatment options.” With this amendment, the AID Bill improves upon the original bill, but does not go far enough to ensure that the terminally ill patient is fully informed of the benefits and resources available for hospice or other forms of palliative care, in lieu of AID.

Pursuant to the Palliative Care Access Act (Public Health Law § 2997-d), hospitals, nursing homes, home care agencies, and special needs or enhanced assisted living residences are required to: (1) provide their terminally ill patients with counseling as well as information about options for palliative care, including hospice care, and any associated pain management services; and (2) “facilitate access to appropriate palliative care, consultations and services, including associated pain management consultations and services, including but not limited to referrals consistent with patient needs and preferences.” We submit that all terminally ill patients considering AID -- regardless of their residential setting, be it a congregate setting or a home in the community -- should be offered robust palliative care counseling and access to hospice and palliative care to ensure that AID does not become the “default” option to their continued suffering.

Accordingly, the AID Bill should require physicians and all other health care professionals providing AID to terminally ill patients to furnish information and counseling on palliative care options and facilitate access to such services, at a minimum, to the same extent required of certain health care providers under the Palliative Care Access Act, but optimally to include access to palliative care providers in all settings.

d. Recommendation: Provide a Role for Institutional Ethics Committees.

New York health care facilities -- including hospice agencies -- have ethics review committees (“ERCs”) established pursuant to the FHCDA as amended. The AID Bill should provide a role for ERCs in the AID process.

First, the AID Bill should require each ERC, or a delegate of the ERC, to expeditiously review any request for AID at the point that a prescription for lethal medication is being written. Such a review, however, should be limited to ensuring that the statutory standards for AID have been met, and would not call for a de novo review of the underlying professional medical determinations made before any given prescription is written. To monitor this aspect of the AID statute, we further recommend that the Department of Health be required to address, in its annual report to the Legislature, the experience of ERCs in connection with AID. (See earlier recommendation concerning “Reporting”).

Second, as discussed earlier, the AID Bill should incorporate the more robust review processes provided for resolving conflicts in medical decision-making under the FHCDA, in

particular, to the extent there is a conflict among the physicians and the mental health professional concerning the patient’s capacity. ERCs can play a role in resolving such conflicts. Third, similar to the FHCDA, ERCs should be available whenever an attending or consulting physician or mental health professional requests a consultation with the committee, at any time in the AID process. Having this option may increase support for AID among medical professionals.

Going forward, we stand ready to work collaboratively with the Legislature and assist in an analysis of the ways in which the ERC process could be utilized for the benefit of both medical professionals and patients during the AID process.

e. Recommendation: *Continue the Unfinished Business of Redressing Inequities in End-of-Life Care.*

The AID Bill alone cannot, and does not, resolve all of the concerns raised in our July 2017 Commentary, which we will not repeat in this Statement. However, we highlight below our most important and remaining concerns:

- the inequitable access to health care, and specifically to the other “feasible alternatives and appropriate treatment options, including . . . palliative and hospice care” that a physician would be required to discuss with an end-of-life patient seeking AID;⁶
- the structural barriers to equal treatment, including among more vulnerable, elderly and marginalized dying persons;⁷ and
- the lack of access to mental health services.⁸

If the “alternatives” that a physician is bound to discuss with an end-of-life patient are not viable options to a patient from a medically underserved community, then practically speaking that patient will be faced with only two stark options: continued suffering or a hastened death. As AID advocates have noted, in Oregon most patients who elect aid in dying -- 90.9% -- are hospice patients. If whole swaths of our population do not have meaningful access to hospice care or palliative care,⁹ it is highly unlikely that they will have any meaningful opportunity to choose medical AID either.

⁶ 2017 Commentary, pp. 8-9, 12-13.

⁷ *Id.*, pp. 8-9.

⁸ *Id.*, p. 1.

⁹ For instance, in 2016, 86.5% of the patients receiving the Medicare hospice benefit nationwide was Caucasian. See “Facts and Figures-Hospice Care in America,” National Hospice and Palliative Care Organization (2017 Ed. revised April 2018). Moreover, in New York State, only 30.3% of terminally ill Medicare patients utilized the Medicare hospice benefit, compared with a hospice utilization rate of 45.9% nationwide (based on 2014 Medicare data). See Testimony from the Hospice and Palliative Care Association of New York State, in regards to the 2017-2018 Senate and Assembly Hearing on the Executive Health Budget Proposal (February 16, 2017).

It has been argued that despite societal inequities in health care, AID should still be an additional end-of-life option to those able to access all of the alternatives. However, whatever the rationale being advanced for AID, making another end-of-life option available to a select few does not justify ignoring the persistent and pervasive inequities in access to end of life care brought to the fore with consideration of this legislation. Otherwise, AID will be yet another manifestation of the health care inequality separating the privileged strata among New York citizens from the less fortunate. This is not idle nay-saying: we know from Oregon's experience that those seeking AID are, by and large, white and highly educated. There is no reason to assume that such a disparity would not manifest in New York as well, perhaps even to a greater extent.

Likewise, access to mental health services is critical to ensuring that a terminally ill patient makes any decision to request AID, uncompromised by a mental infirmity that may not be apparent even to the trained eye of a physician.

III. CONCLUSION

In short, there is much unfinished business that needs to be done, regardless of the fate of the AID Bill. We therefore urge the Legislature to work toward ameliorating these inequalities. We would welcome the opportunity to collaborate with lawmakers and other interested stakeholders in exploring ways to address these issues and working to make our State more fair and just in the delivery of and access to end-of-life care.

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Submitted June 4, 2018



**NEW YORK
CITY BAR**

**COMMENTARY ON
NEW YORK MEDICAL AID IN DYING
PROPOSAL**

**BIOETHICAL ISSUES COMMITTEE
HEALTH LAW COMMITTEE
LEGAL PROBLEMS OF THE AGING COMMITTEE
MENTAL HEALTH LAW COMMITTEE
SCIENCE AND THE LAW COMMITTEE**

REISSUED JUNE 2017

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I. INTRODUCTION AND BACKGROUND

The focus of this White Paper by the Bioethical Issues Committee (the “Committee”) of the New York City Bar Association (“City Bar”) is New York’s Medical Aid in Dying proposal. “Medical Aid in Dying” is a medical practice that would allow a physician to prescribe a lethal medication to a mentally competent, terminally ill individual who requests and consents to such lethal medication for the purpose of ending her or his own life.¹

A central issue we identify in this White Paper is that of equitable access to care and the social determinants of health that influence equitable access to care. The issue of equity to which we draw attention here is fundamentally about fairness and just distribution of resources. The aim of this White Paper is to foster more robust debate and deliberation about proposed Medical Aid in Dying in New York and urgent public policy and public health policy issues, including foreseeable and unforeseeable risks to equitable access to care among vulnerable persons and groups, such as the elderly, the poor, racial and ethnic minorities, and the disenfranchised. We voice particular concern about access to appropriate mental health services and qualified mental health professionals.

Medical Aid in Dying is currently being litigated before the New York Court of Appeals (*Myers v. Schneiderman*).² The “Medical Aid in Dying Act” has also been introduced in the New York State Legislature.³ This issue is ripe for review.

a. Other Committees

The City Bar’s Health Law Committee, Legal Problems of the Aging Committee, Mental Health Law Committee and Science and the Law Committee participated in the Bioethical Issues Committee’s review process.

b. Consensus Process

The Bioethical Issues Committee has followed a consensus decision making process in developing this White Paper. Beginning in 2015, the Committee sponsored, co-sponsored and participated in multiple forums on the subject of Medical Aid in Dying (*see* Addendum A), at

¹ The term “physician aid in dying” has also been used to describe physician-aided dying practice, which proponents seek to differentiate from “physician assisted suicide.” The language of “hastening death” or “wish to hasten death” has also been used in this context (Albert Balaguer et al., *An International Consensus Definition of the Wish to Hasten Death and Its Related Factors*, PLOS ONE 11(1): e0146184 (Jan. 4, 2016), <https://doi.org/10.1371/journal.pone.0146184> (last visited May 23, 2017).

² *Myers v. Schneiderman*, 28 N.Y.3d 1131 (N.Y. Jan. 12, 2017). Debevoise & Plimpton LLP represents End of Life Choices in the *Myers v. Schneiderman* litigation. The City Bar President, John Kiernan, a partner at Debevoise, has recused himself from the review and approval of any City Bar reports pertaining to the *Myers v. Schneiderman* case or any related litigation or legislation.

³ Medical Aid in Dying Act, A.2383/S.3151, 240th N.Y. Leg. Sess. (2017). A previous version of the bill (S.7579, 239th N.Y. Leg. Sess.) was voted out of the New York Assembly Health Committee in the 2016 legislative session.

which advocates and ethicists representing diverse views and perspectives have had an opportunity to present arguments, comments, and testimony on the issues in question.

Some of these perspectives include those of medical ethicist Dr. Joseph J. Fins, Weill Cornell Medical College, who presented to the committee on December 5, 2016, and addressed the possibility that the Aid in Dying movement may be advancing without thorough consideration of all relevant issues because of some hard cases, such as that of Brittany Maynard.⁴ Still other perspectives aimed to address and discuss issues surrounding palliative care and end-of-life care, as well as end-of-life decisions and end-of-life pain management.⁵

II. FRAMING OF MEDICAL AID IN DYING PUBLIC POLICY ISSUES: PUBLIC HEALTH, HEALTH EQUITY AND HEALTH CARE JUSTICE

Medical Aid in Dying policy and practice raise grave legal and ethical issues for legislators, courts, policy makers, health and social service practitioners, and individuals living with serious illness and their caregivers. These issues center on the humanistic concerns of seriously ill persons and their lived experiences, subjective perspectives and expectations for a meaningful life in the context of their views of full personhood and their experiences in terms of human development over the life-course. These perspectives and contexts have social, cultural and relational significance for seriously ill persons at the end of life.

In this White Paper, we pay particular attention to social and structural determinants of health, mental health and well-being, such as income, education, housing, and food security. We also look at forms of structural discrimination that perpetuate inequities in access to basic health care, hospice and palliative care, and essential medicines that may influence the experience of serious illness and outcomes at the end of life. The public health perspective, and the essential social determinants of health that characterize the public health perspective, have received scant attention, and have perhaps even been marginalized, in debates and deliberations to date about Medical Aid in Dying.

We believe that attaining health care justice for all persons by eliminating inequities is an important public policy goal relevant to serious public discourse and deliberation about proposed Medical Aid in Dying practice. In light of this goal, we call for deeper reflection on unexamined questions of human development, agency and freedom to make meaningful choices at the end of one's life. There is a dearth of empirical evidence about the personal, social and cultural meanings associated with intentionally ending one's own life. In this White Paper, we seek to sharpen the focus on the complex legal and ethical issues embedded in proposed changes to law and policy in New York.

⁴ Dr. Joseph J. Fins, Weill Cornell Medical College, Address at City Bar Bioethical Issues Committee Forum #2 (Dec. 5, 2016). *See also* Addendum A.

⁵ *See* Addendum A.

a. Legal and Ethical Issues

This section addresses the ethical issues that pertain to the governance of a practice commonly referred to as “physician aid in dying” (“PAD”). In the proposed New York bill⁶ and the New York Court of Appeals *Myers v. Schneiderman* litigation, the practice is called “Medical Aid in Dying.” Under either term, the practice involves the prescribing of lethal medication by a physician to end a patient’s life and the self-administration of such medication by a terminally ill, competent patient. (Other practices that involve deliberate steps by a third party to bring a dying person’s life to an end through administration of lethal medication or injection, such as euthanasia, are legally permitted in some countries, but are not legal or under active consideration in the United States at this time and will not be discussed here.)

The topic of PAD rose to prominence in public discussion in the 1990s. Before that, ethical inquiry had been focused on a different issue, namely, decisions to forgo the use of life-sustaining medical technologies and treatments, such as cardiopulmonary resuscitation, mechanical ventilators and artificial nutrition and hydration. As the effectiveness of such technologies increased beginning in the 1960s and 1970s, many patients benefited but many others had their biological function prolonged without corresponding support for their quality of life. Indeed, many suffering from irreversible and progressive chronic disease found such artificial life-extension burdensome: being kept alive on machines was in conflict with their personal wishes and values, and they often were given inadequate palliative care to relieve pain, manage symptoms, and address their suffering and that of their families.

One goal of ethics in the end-of-life care domain is to achieve a proper balance between individual rights and conflicting social interests or cultural values. Over time, an ethical consensus gradually has built around affirming an individual’s right to refuse any and all forms of invasive medical treatment, including life-sustaining medical treatment. This consensus rejected the doctrine of vitalism—the notion that prolonging life was a supreme duty no matter what the consequences—and the so-called technological imperative—the notion that, because artificial life prolongation was now technically possible, it was ethically required, despite patient wishes to the contrary, and should be legally required. Thus, under the dominant views held in 1975, withdrawing the ventilator from Karen Ann Quinlan (a young woman who had suffered severe brain injury and was in a permanent unconscious state) would have been an act of murder.⁷ But between 1975 and 1989, widespread debate and discussion of ethics concerns laid the groundwork for the ruling in the *Cruzan*⁸ decision and recognition of an individual’s legal right to refuse medical treatment as a liberty interest protected by the Fourteenth Amendment.

Over the years, ethical analysis on the right to refuse treatment has included consideration of potentially conflicting and competing social interests, such as public policy concerns about the integrity of the medical profession and the prevention of suicide. However,

⁶ Medical Aid in Dying Act, A.2383/S.3151, 240th N.Y. Leg. Sess. (2017).

⁷ *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

⁸ *Cruzan v. Dir. Mo. Dep’t of Health*, 497 U.S. 261 (1990).

these ethical arguments (many of which have been cited and followed by state courts in these cases) have gradually given way to the conclusion that such interests are not imperiled by respecting the right to refuse life-sustaining treatment.

Thus, the ethical debate on the right to make autonomous decisions to forgo (i.e., refuse before the fact or withdraw after the fact) life-support technologies, including artificial nutrition and hydration, arrived at the more or less consensus view that such refusal is not tantamount to suicide. Such decisions have been deemed to be in a different class altogether from the actions of a person in a self-destructive depressive or psychotic state. As Dr. Fins stated in December 2016,⁹ the reasoning makes sense in that the underlying conditions that can lead to suicide sometimes are controllable or even reversible with medical treatment, whereas this is not the case for a terminally ill patient.

In addition, the common view is that the cause of death where a person refuses life sustaining treatment is the underlying disease itself and, therefore, refusal of treatment that prolongs life (and, in some cases, suffering) but cannot cure the underlying disease is not an act of suicide. Moreover, under the well-established body of law governing advance care planning and shared medical decision making, physicians and other health professionals who offer information to patients about their care and decision options to forgo life-sustaining treatment are not acting in violation of statutes that proscribe actively assisting the commission of suicide. Therefore, the social interests in preventing and/or not promoting acts of suicide simply are not present in cases of refusal of life-sustaining treatment.

This is not to say that ethical analysis has disregarded social and policy interests in the context of medical treatment refusal. On the contrary, these factors have been almost as central to ethical views on end-of-life care as has the importance of patients' rights and autonomy. But the ethical approach to these issues has been largely procedural and has stressed values of equity, protection of vulnerable persons, and safeguards against coercive factors that would taint the autonomy of end-of-life treatment decisions. A tremendous amount of legislative and judicial activity has been undertaken at the state level to set up mechanisms for advance medical directives, durable powers of attorney for health care, Medical Orders for Life Sustaining Treatment (MOLST) in New York (known in other states as Physician Orders for Life Sustaining Treatment or POLST), the establishing of ethics committees and consultation services in hospitals and skilled nursing facilities, and efforts to educate health professionals and the lay public about decision making rights and processes associated with refusal of medical treatment.

The ethical foundation is to respect individual autonomy. However, the patient must be capable of making this decision autonomously, either contemporaneously (when autonomous decision-making capacity and circumstances are still present), or at a prior time when they were present and via an advance directive providing treatment instructions and/or naming an agent or surrogate decision maker to effect the patient's prior wishes and values.

⁹ Dr. Joseph Fins, Weill Cornell, Address at City Bar Bioethical Issues Committee Forum #2 (Dec. 5, 2016).

These considerations have led ethical analysis to stress the importance of safeguards to ensure that social conditions to promote autonomous decision making are optimized in clinical settings and the health care system overall. In particular, the conditions of having the mental and emotional capacity to give rational informed consent or refusal are important, as are environmental conditions that eliminate coercive pressures, fears, or similar constraints on the patient.

When dealing with dying patients who have lost decision-making capacity, the focal ethics question has been: who should speak for the patient and consult with physicians to make treatment plans and decisions? A related issue of central concern to judicial and legislative authorities is the nature of the evidence that an agent or surrogate must show to establish that treatment decisions are in fact in accordance with the authentic and autonomous wishes of the patient. The Supreme Court in the *Cruzan* decision—which affirmed a constitutional right to forgo life-sustaining treatment—gave the states leeway to set different standards of evidence to govern surrogate decision making in their jurisdictions.

Finally, ethics analysis has emphasized the importance of ensuring that those who wish to forgo life-sustaining treatment are not simply abandoned, but are provided with access to resources for continuing palliative, quality of life-sustaining care. It is not surprising that the growth of the hospice movement and the Medicare Hospice Benefit of 1983 went hand in hand with the development of ethical arguments for the autonomous right to refuse burdensome and non-beneficial life-sustaining technological treatments.

It is into this general background of ethical analysis and legal governance that the controversy concerning PAD came to the forefront of public attention in the 1990s. Whereas most of the judicial activity about forgoing life-sustaining treatment had come at the state level, the judicial governance of PAD has been influenced by the federal courts. On the legislative governance side, this issue has often involved recourse to popular referenda, rather than to normal legislative activity. Moreover, the PAD debate has been no less divisive among specialists in ethics than it has been among the general public.

From a conceptual perspective in ethics, PAD has reopened several issues that had been thought settled and has challenged assumptions underlying the ethical consensus on the right to refuse high-tech medical treatment. At the same time, proponents of PAD have made respect for autonomy the principled core of their arguments, thereby drawing on the same taproot value that had prevailed in earlier debates prior to the *Cruzan* decision. Early opponents of recognizing a right to refuse treatment anticipated a time when an individual's right to medical assistance in committing suicide would also be asserted.

And so it has. In the 1990s, two federal circuit courts (the Ninth and the Second)¹⁰ struck down existing state laws against PAD. On appeal, the Supreme Court reversed these lower courts, leaving existing state laws in force; however, the Court did not find PAD to be unconstitutional.¹¹

¹⁰ *Compassion in Dying v. Washington*, 79 F.3d 790, 798 (9th Cir. 1996); *New York v. Operation Rescue Nat'l*, 80 F.3d 64 (2d Cir. 1996).

¹¹ *Washington v. Glucksberg*, 521 U.S. 702 (1997); *Vacco v. Quill*, 521 U.S. 793 (1997).

The Supreme Court's decision left legalization of PAD up to each state to decide. The result since 1997 is that PAD remains clearly illegal in 40 states and ambiguously so in four. It is legally practiced in six states (i.e., California, Colorado, Montana, Oregon, Washington and Vermont) and the District of Columbia¹², which generally follow similar requirements as enumerated below. A grassroots movement in favor of its legalization continues to work for reform in other states, including New York.

Legalization and regulation in some states have made possible some data collection, which provides information concerning how often PAD is used, which physicians take part in it, which patients use it, and under what life circumstances. Of the states that have passed aid in dying laws, only Oregon and Washington publish detailed statistics regarding the number of individuals who receive prescriptions under those laws, the number of individuals who die as a result of using those prescriptions, and the demographic features, health status, and motivations of those individuals. Vermont and Montana do not provide statistics. Laws in Colorado and Washington, D.C., were passed in late 2016 and no records are available from these states at this time.

In all states where PAD is legal, persons using PAD must be legally competent, incurably ill with a life expectancy of six months or less, and be given full information concerning their condition, treatment options, and a cooling off period between consent and the provision of the pharmaceutical prescription. Relatively few persons avail themselves of PAD in states where it is legal. Those who do tend to be white with higher than average incomes and educational levels. In many cases they have had access to, and have utilized, hospice and palliative care prior to their resort to PAD. Many report that it is dignity, integrity, and suffering, rather than pain and symptom management, that is the prime motivating factor in their desire to put a controlled end to their dying process.

A recent *JAMA Oncology* article reported that, in Oregon, "From 1998 through 2013, the number of prescriptions written had an annual average increase of 12.1%...and during 2014 and 2015 it increased by 28% to 41%..."¹³ Oregon Public Health Division Data from 2015 on patient characteristics show that of the 132 Death with Dignity Act deaths during 2015 (as of January 27, 2016), 78.0% were aged 65 years or older (as compared to 80.5% in 2016); median age at death was 73 years; 93.1% of decedents were white (as compared to 96.2% in 2016); and 43.1% had a least a baccalaureate degree (as compared to 50% in 2016).¹⁴ It should be noted here that Oregon's population is not as racially and ethnically

¹² *State-by-State Guide to Physician-Assisted Suicide*, ProCon.org, <http://euthanasia.procon.org/view.resource.php?resourceID=000132> (last updated: Feb. 21, 2017)

¹³ Charles Blanke, et al., Characterizing 18 Years of the Death With Dignity Act in Oregon. *JAMA Oncology* (April 06, 2017), pp. E2-E3.

¹⁴ Oregon Public Health Division, *Oregon Death with Dignity Act: 2015 Data Summary*. Oregon Health Authority (February 4, 2016), <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf> (last visited May 23, 2017).

Oregon Death with Dignity Act: 2016 Data Summary. Oregon Health Authority (February 10, 2017), <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>

diverse or economically segregated as New York. Therefore, issues of population heterogeneity are of greater concern in New York. This is an issue of significance that has been raised by the Public Health Association of New York City in its consideration of the New York Medical Aid in Dying proposal.

From an ethical perspective, the following questions, concerns, and value-orientations are most relevant in evaluating the pros and cons of legalizing PAD.

1. The conceptual distinction between the right to refuse life-sustaining medical technology and the right to choose the exact nature and timing of one's death.

Virtually all moral philosophies and ethical perspectives value human life and contain at least a prima facie prohibition on intentionally causing the death of an innocent person. Over the past 40 years, as noted above, that ethical presumption has been rebutted in the special circumstance of an autonomous patient's right to refuse life-prolonging medical technology and treatment. Some interpret this as ethically privileging the principle of respecting autonomy and the right to bodily integrity over the duty to preserve and prolong life.

Complex arguments have been made concerning the issues of causation and intention. It has been argued that the autonomous patient's decision to forgo life support is not the cause of his or her death – the patient's underlying disease and dysfunction are. It has also been argued that, in this special circumstance, although the patient's death is foreseeable if life-support technology is discontinued (or not initiated), such result is not tantamount to intentionally causing the person's death. Thus, in the limited circumstance of refusal of medical treatment by mentally competent, terminally ill patients, the prima facie ethical duty to prolong life has been overridden. Both American constitutional and common law jurisprudence have supported this conclusion, at times relying on this essentially ethical line of argument.

The question posed in the PAD debate is whether or not prescribing a lethal pharmaceutical so that a dying person can obtain it and ingest it is a practice that also should be exempted from the ethical duty to preserve life. PAD would be ethically supported by demonstrating that it is sufficiently similar to the right to refuse life-sustaining treatment and should be given the same moral status. PAD has been criticized as distinct from, and not logically supported by, ethical arguments in favor of a right to refuse life-sustaining treatment.

Generally speaking, this debate centers on the two prongs of causation and intention. Does the proposition that the patient's underlying pathology, not the act in question, constitutes the morally relevant cause of death hold for PAD as it does for the withholding and withdrawal of treatment? In other words, from the perspective of physicians, does participation in PAD by writing a prescription constitute killing the patient, or is it a way of respecting the right of a patient to determine the timing and manner of her/his own death which may be imminent because of the patient's terminal illness? Answering this question is

perhaps easier when the physician's role is limited to providing access to lethal pharmaceuticals rather than directly administering them, as the former leaves multiple steps in the patient's hands (i.e., whether or not to fill the prescription, whether or not to use the medication, etc.).

The ethical debate has focused on the notion of committing or assisting "suicide" when speaking about intention. Proponents of PAD have argued that the intention of dying patients is misunderstood as suicide. Proponents argue that the dying patient's intention is not to end her or his own life, per se, but to avoid, in the only remaining possible way, a dying process that may be violent, degrading or may prolong their suffering. Avoiding such outcomes is central to all end-of-life medical treatment, including hospice care. Critics of PAD argue the act of knowingly ingesting a lethal substance is, in fact, suicide, an intentional act causing one's own death. They believe that this is, ethically, something that society should prevent and discourage rather than condone. Thus, for critics of PAD, rules and regulations sanctioning physicians who assist with PAD are ethically justified and a reasonable means to curtail intentional self-killing.

Critics of PAD have also argued that PAD is different from the right to refuse life-sustaining treatment because suicide, including PAD, is never an act of rational decision making and, therefore, does not represent the true wishes of the patient, whereas wishing to forgo invasive and burdensome technological interventions may be a rational and autonomous decision. The term "suicide," itself, has connotations that have shaped the debate. In the past, supporters of the legalization of PAD have argued that one class of suicide, "rational suicide," is the result of rational and autonomous decision-making, and that PAD is a form of such rational suicide. More recently, supporters of PAD have avoided the term suicide altogether, having perhaps recognized that the use of the term is stigmatizing and misleading. They also have strived to normalize PAD by arguing that it has become a recognized form of medical practice and as one of many treatment options and care plans that should be available to all terminally ill patients.

2. The role of equality and non-discrimination in regard to autonomy and dignity.

Equal treatment before the law and non-discrimination are also important ethical tenets. They have entered into the PAD debate in two ways. The first is an extension of the discussion above. It has been argued that if we permit patients who require life-supporting technology to refuse it and thereby allow them to die, but deny PAD to similarly situated patients who happen not to require invasive technology, then we are unfairly discriminating against the latter group of patients. The counter argument is that this is not discrimination because patients on life-support require physician assistance to be removed from it, whereas physician assistance is not a necessary component of a patient's autonomous decision to take a lethal dose of medication. Proponents respond that physician assistance and participation are required in order to make this option safe, effective, and humane.

The second prong of the equality and non-discrimination argument asserts that legalizing the practice of PAD would be potentially discriminatory against vulnerable, elderly, and marginalized dying persons because they would face undue pressure and coercion to opt

for PAD, due to structural factors and determinants beyond their control. Such factors include: financial distress, strained relationships with family members, social isolation, or other economic considerations, such as lack of, or inadequate, insurance coverage that might limit their access to palliative care services and thereby exacerbate their fear of pain, suffering or abandonment. These factors not only implicate possible unequal treatment under the law if PAD is legalized, but also undercut a principal ethical rationale of the right to PAD, as well as the decisional competency and autonomy criteria for access to PAD in the first place.

3. The relationship between PAD and the profession of medicine.

One public policy consideration with respect to individual rights in end-of-life care is the effect of permitting PAD on the ethical integrity of the medical profession (and of other clinical professionals as well). This concern ultimately was judged not to be a relevant bar to the ethical permissibility of refusing life-sustaining medical treatment. When it comes to PAD, however, the added consideration is the contention that physicians have an ethical and professional duty to protect and preserve life that is stronger than it is for ordinary persons.

Critics of PAD argue that physicians face too many conflicts of interest, both personal and financial, in decision making with respect to PAD: since physicians are privy to restricted pharmaceuticals and are often in a position of special influence over vulnerable patients, it is too dangerous for society to give them moral permission to assist in the active decision to end a patient's life.

Moreover, critics argue that if physicians are granted this authority and perceived as being facilitators of the deaths of their patients, public trust and confidence in the medical profession as a whole will be compromised. Critics of PAD assert that it is socially important for patients to assume that their physicians are duty bound and motivated to be faithful guardians of their patients' lives and health.

Supporters of PAD counter that equally integral to physicians' professional ethics is the duty to relieve suffering. The American health care system as a whole does not do a good job at providing routine pain and symptom management. In end-of-life care, even palliative care and hospice care facilities and providers encounter cases of intractable pain and suffering that defy available treatment. Physicians have an ethical duty to assist their patients in cases such as these with PAD as an option if palliative care fails. In addition, supporters of PAD argue that, in addition to the duty to relieve suffering, health care professionals also have an ethical duty to respect patient autonomy. These considerations have supplanted older notions of the physician's duty to preserve life and to bear paternalistic burdens in making difficult choices for their patients.

4. Reconsidering the importance of autonomy in ethics.

One of the most important effects that the PAD debate has had on the presuppositions of ethics has been a reconsideration of autonomy in end-of-life care. Ethical analysis was strongly autonomy-oriented during the right to refuse treatment debate, and this emphasis by and large has been carried on by supporters of the movement to legalize PAD.

As clinical experience has developed around the right to forgo life-sustaining treatment, however, it has been found that the central ethical focus on the rights and personal preferences of the individual patient during the decision-making and the care planning process near the end of life has often been impractical and counterproductive. This process is a very complex one comprised of accumulating clinical information, making a series of clinical decisions over time, and communicating and navigating emotional relationships among many individuals—the patient (if competent), agents and surrogates, other family and friends, members of the clinical team, and institutional officials in medical centers and facilities.

In light of this confluence of factors, the assertion and protection of individual rights, while remaining ethically important, becomes less of the central focus, and ultimately gives way to other influencing factors such as good, timely communication, adequate care goal setting and planning, and continuity of care between shifts within one setting and in transfers between different settings. The notion of “individual autonomy,” which treats the person as an isolated, self-contained entity, is giving way to “relational autonomy,” which places respect for the individual into a more complex network of interactions and responsibilities.

Notably, the PAD setting is typically much less complex institutionally and less protracted temporally than end-of-life care in hospitals or nursing facilities, or even hospice home care. By regulation, it always involves a competent patient, and it usually involves only close family, perhaps a few paid care providers, and the attending physician. The process can play out over just a few days, once it is formally initiated.

This setting may fit the picture of individual autonomy more accurately than the setting of a hospital does. However, from a psychosocial viewpoint, it is not clear that we fully understand the interpersonal and family dynamics of the relatively small number of patients and families who have used PAD thus far. Is there any reason to believe that those who have opted for PAD are more self-sufficient or have fewer relationships or familial responsibilities than those who do not opt for PAD? Data collected thus far tend to suggest that persons who use PAD place a very strong value on control over what happens to them. But if legal changes would substantially increase the numbers of persons using PAD, more research and a deeper understanding of the dynamics of the PAD decision-making process are needed. This is important not only socially, scientifically and clinically; it is also important knowledge ethically since so much of the rationale for legalizing PAD relies on the ethical justifications for the practice of PAD—especially our reliance on the supposed rational, voluntary, and well-informed nature of the thinking that goes into making a PAD decision.¹⁵

¹⁵ Neil C. Manson & Onora O’Neill, *Rethinking Informed Consent in Bioethics* (Cambridge UK, Cambridge Univ. Press 2007) (arguing that to be ethically effective, informed consent requires distinctive and relational communicative transactions and settings); Carl E. Schneider, *The Practice of Autonomy: Patients, Doctors, and Medical Decisions* (New York, Oxford Univ. Press 1998) (arguing that ethical and legal ideals of autonomous informed consent are rarely fulfilled in practice and that protecting patients against exploitation requires relationships of care and trust, not unilateral patient empowerment).

5. Is our system capacity sufficient to meet the challenge of ensuring the ethical practice of PAD?

This brings us to a final dimension of the ethical analysis in balancing individual rights and social interests in end-of-life care. This involves the overall social milieu into which the innovation of PAD will be introduced. It also involves the important question of the institutional capacity of our health care system and of authorities in multiple jurisdictions and municipalities across the country to justly, safely, and adequately govern and monitor the practice of PAD if legalized. These are pressing questions to consider in the Medical Aid in Dying debate in New York State in 2017.

Consider first the social context. We are a highly stratified society, separated by many factors including, but not limited to, race, socio-economic status, and cultural and ethnic background. Functional disability is highly stigmatized in prevailing cultural attitudes despite advances made to protect disability rights. Moreover, demographic trends for at least the remainder of the twenty-first century show us to be an aging society where terminal illness and end-of-life care will become more prevalent in our health care system.

Many ethically momentous acts and decisions are performed every day in the health care system which, in turn, pose severe systems and institutional challenges to maintaining high standards of quality assurance and improvement. Legalizing PAD more widely will undoubtedly increase those challenges.

By its very nature, PAD demands a high standard of quality control. This issue has not received as much discussion as other ethical and political aspects of PAD in those states where it has been implemented. But as the movement grows and support for accepting and routinizing the practice spreads, the numbers and diversity of those dying persons and families taking part in it will also increase.

Do we have the institutional and systemic capacity to handle this development? Can we perform research that answers the questions about the dynamics of decision-making posed above? Can we collect reliable and accurate records concerning access to and utilization of PAD? How are capacity determinations made, how adequate are they, and how are they documented? What type of independent auditing and review of such records can be conducted?

We need to conduct more research on the ways in which these questions have been addressed by systems set up in Oregon and in other states that have legalized PAD.

How can the ethical integrity and safeguards of the PAD decision-making process be maintained? Given its practice in the intimacy of the home setting, PAD is an inherently difficult practice to monitor and evaluate in this way. Coercive pressures in a culture that stigmatizes disability and dependency can influence family communication and pressure, and can also color the attitudes of attending physicians. Even subtler is the phenomenon of the internalization of stigma in self-image and self-esteem of the person subjected to it. For dying

persons, even those who retain decision-making capacity, this corrodes the foundational value of autonomy upon which so much of the ethical justification for PAD rests.

From this point of view, ethical analysis needs to ask whether the track record of the practice of PAD in the United States so far, which many take to be positive on the whole, is a reliable guide to future innovation in other states. The next few years promise turmoil in the health care system, which ultimately will affect the domain of end-of-life care, along with the rest of medicine and nursing. There will be an increasing emphasis on cost-containment and perhaps a decline in the share of health insurance coverage with respect to overall health care expenses for dying patients and their families. Even in the last six months of life, medical and nursing care bills with high out of pocket liabilities can be devastating to most families.

Is this an auspicious moment for a state to embrace the practice of PAD?

Ethics cautions us that the right to die in accordance with one's values may become, instead, a duty to die—for example, to avoid burdening one's family.

On the other hand, for those, however few, who face the prospect of a dying process marked by loss of dignity and suffering, should ethical analysis tell them they must live with a dying process that is less than optimal until society as a whole becomes more just and health systems become better managed? As a counter argument, is it also possible that we as a society do not well understand the experience of suffering – and the social dimensions of suffering – and that each person's experience is necessarily different and influenced by unique factors?

b. Is the Political Climate in 2017 Ripe for Medical Aid in Dying?

This section addresses the current climate surrounding PAD and the impact that may have on the New York Medical Aid in Dying Act. Despite the fact that there has been and still is a high level of controversy surrounding aid in dying legislation, many states have introduced aid in dying bills and legislation this year in an attempt to make it easier for terminally ill patients to make and execute their choice to end their lives with physician assisted death. Currently, five states have a Death with Dignity statute, one state where Death with Dignity is legal, and 19 states where Death with Dignity is being considered. New York State is one in which legislation is being considered, in the form of the Medical Aid in Dying Act. However, regardless of its intentions, the introduction of the Medical Aid in Dying Act may seriously complicate existing end-of-life care currently practiced in New York State. Given a more conservative administration at the federal level and potential cuts to health systems funding, palliative and end-of-life care could suffer.

An ongoing issue of health equity is access to palliative care. The proposed legislation is currently written as an alternative to palliative care, as it says that a physician must inform the patient of all “feasible alternatives or additional treatment opportunities, including but not limited to palliative care and hospice care.”¹⁶ By proposing medical aid in dying as an

¹⁶ Medical Aid in Dying Act, S.3151, 240th N.Y. Leg. Sess. § 2899-F(1)(E)(V) (2017).

alternative to palliative care, the bill, if enacted, may have the unintended consequence of weakening the already insufficient attention given to palliative and hospice care options. In the International Association for Hospice and Palliative Care (IAHPC)'s Position Statement on Euthanasia and Physician Assisted Suicide,¹⁷ the IAHPC asserts that physician aid in dying should not be considered if palliative care options are not universal. One such measure of the adequacy in access to palliative care is the availability of medication, specifically opioids, used to treat severe pain. According to the International Narcotics Control Board as cited by the IAHPC, opioids used to treat severe pain are mostly available in high-income countries, such as the United States; but even in the United States, and certainly globally, legitimate needs for pain-relieving medication used in palliative care are not met. Given this context, the IAHPC believes that proposing policies framing physician assisted suicide as alternatives to policies of palliative care would lead to even less attention given to improving access to palliative care.¹⁸

Another major complication lies in the conflation of withholding treatment and actively acting to end a life. This distinction is important to both the ongoing conversation surrounding physician aid in dying and, more importantly, the conversation around New York's Medical Aid in Dying proposal. Currently in New York, end-of-life options focus on the patient's choice to refuse treatment. The New York Medical Aid in Dying proposal would fall under the other category, with the patient choosing to receive care that would actively end her/his own life. However, the New York Medical Aid in Dying proposal does not seek to clarify this distinction; in fact, as it is written, the distinction is not addressed at all. This conflation poses a serious threat to existing end-of-life options, as it could lead opponents of the bill to not only oppose the bill itself but potentially bring into question other necessary palliative care options that currently ease the suffering of terminally ill patients. Necessary end-of-life and palliative care options that need additional support and funding do not need to be further opposed and disregarded.

In *Myers v. Schneiderman*, examples of existing end-of-life care options practiced in New York State are discussed. Currently, a terminally ill patient who is suffering from extreme physical pain can choose "terminal" sedation as an end-of-life option, which entails the withholding of food and fluid while the patient is placed in continuous deep sedation. The patient may also choose to have ventilators unplugged, feeding tubes withheld, or may even elect to stop consuming food and liquids on their own. These options, while offering similar results, are remarkably distinct from the proposed aid-in-dying bill. With terminal sedation and withholding food and fluids, the intent is not the hastening of the patient's death but, rather, the prevention or removal of continued pain and suffering to the patient. In contrast, the Medical Aid in Dying proposal advocates for the administering of drugs with the intention of ending a patient's life—although the proposal aims to circumvent this distinction by stating

¹⁷ Liliana De Lima, et al. *International Association for Hospice and Palliative Care Position Statement: Euthanasia and Physician-Assisted Suicide*, *J. Palliat. Med.* (Jan. 1, 2017), 20(1): 8–14, <https://doi.org/10.1089/jpm.2016.0290> (last visited May 23, 2017)..

¹⁸ It is also possible that this greater attention to end of life and palliative care may serve to increase conversation surrounding the possible options possible for a terminally ill patient.

that, as in refusal of treatment and terminal sedation cases, the cause of death of the patient would be the underlying disease rather than the administration of life-ending medication.

Finally, while the proposed aid-in-dying legislation does have certain potential safeguards to reduce the risks of coercion at the individual level of decision making (the patient must have an accurate diagnosis and prognosis, must be evaluated by a physician and reevaluated prior to receiving the medication, and must be offered a right to rescind, etc.), concerns have been expressed that the process could be rushed or superficial in some cases. Notably, there are no provisions on a waiting period or second oral request in the New York bill. These safeguards are written into legislation in other states. Affording patients an open and continuous process would be most beneficial to finding the best option for the patient, including intensifying palliative care. The concern remains that the surrounding circumstances of the patient could hasten the decision making process itself, and may lead to a patient being informed of alternatives, such as palliative care, without being educated on all of the palliative and end-of-life care options and the benefits and harms associated with each.

Overall, in light of the current climate that may influence both the conversation surrounding end-of-life care and the political administration, the New York Medical Aid in Dying proposal raises issues that need to be addressed in open public debate to ensure that necessary and adequate end-of-life care is sought and afforded to terminally ill patients.

c. Proposed NY Legislation: Medical Aid in Dying Act¹⁹

The Bioethical Issues Committee identifies the following points of consideration specific to legislation currently pending in the New York State Legislature, A.2383/S.3151. These comments focus on gaps in the proposed bill, as well as provisions that are overly board, inconsistent, vague or not clear.

- Public Policy Gaps:
 - Beneficiaries:²⁰ The bill appears to apply to all possible beneficiaries and therefore as presently written would have universal application. For example, there are no residency requirements. (The six states and the District of Columbia that have legalized aid-in-dying all have residency requirements.) There are also no safeguards for institutionalized persons such as nursing home residents or inmates.
 - Financing: There are no provisions on financing. At forums held throughout the state and at the City Bar, little or no information has been available on financing.
 - Delivery Systems: There are no provisions with respect to delivery systems. At forums held throughout the state and at the City Bar, scant information has been available on delivery systems.

¹⁹ Medical Aid in Dying Act, A.2383/S.3151, 240th N.Y. Leg. Sess. (2017).

²⁰ *Id.*, § 2899-D(1), (13), (15)

- **Alternative Option:** The proposed bill would position Medical Aid in Dying as an alternative to palliative care. Practically, it is unclear what this would mean and how it would be operationalized. Would New York now require that Medical Aid in Dying be included in palliative and end-of-life options offered to patients under the Palliative Care Information Act and Palliative Care Access Act?²¹ What are the public policy choices and decisions that need to be debated and made about allocation of resources to palliative care and Medical Aid in Dying if they are structured as care alternatives?
- **Inconsistent, Broad and Vague Language:** The bill contains certain inconsistent, vague and broadly defined terms. For example, the definition of “mental health professional” is broad (see more specific comments below). Other inconsistencies include references to “health care professional” and “health care provider” (proposed statute only provides a definition for “health care provider”).²² There are vague references to “or other person,”²³ and a lack of clarity on insurance related provisions.²⁴
- **Provisions on Criminal and Civil Liability:**²⁵ The statutory provisions do not offer protection from negligent or intentional misconduct. This may pose a barrier for physicians and other health care providers should the bill as presently written be enacted.
- **Mental Health Provisions:**²⁶ One of the issues with the proposed bill is the very broad definition of mental health professional and the inconsistency of this definition with other parts of New York law. Patients are referred to mental health professionals by the attending physician when there is a belief that the patient may lack capacity. Mental health professionals are responsible for evaluating a patient to determine whether the patient has capacity to make an informed decision to request and obtain medication that the patient may self-administer to end the patient’s life. The definition of mental health professional includes not just a licensed physician or psychologist, but nurse practitioners and physician assistants as well. The proposed language does not specify whether the physician has to be board certified or eligible in the field of psychiatry or list the specific qualifications that the mental health professional would need in order to be able to make such a determination. This vagueness could lead to confusion and inconsistent application of the determination of whether a patient has the capacity to receive medical aid in dying.

²¹ Palliative Care Patient Information Act, N.Y. Public Health Law § 2997-c(2) (PHL); Palliative Care Access Act, PHL § 2997-d

²² A.2383/S.3151, § 2899-D(6), (13), (15), § 2899-F(3).

²³ *Id.*, § 2899-F(3), § 2899-L(1), § 2899-M(1).

²⁴ *Id.*, § 2899-N(3)(A), § 2899-N(3)(B), § 2899-N(5).

²⁵ *Id.*, § 2899-L(1), § 2899-L(2), § 2899-R(1).

²⁶ *Id.*, § 2899-D(11), § 2899-E(3)(C), § 2899-F(1)(C), § 2899-I, § 2899-K.

Like the proposed bill, the Family Health Care Decisions Act (“FHCDA”)²⁷ also calls for an independent concurring determination that a patient lacks capacity. However, FHCDA separates “health or social practitioner” from physicians who are board certified or board eligible in the field of neurology and psychiatry. “Health or social practitioners” are defined as a “registered professional nurse, nurse practitioner, physician, physician assistant, psychologist or licensed clinical social worker, licensed or certified pursuant to the education law acting within his or her scope of practice.”²⁸ Whether a health or social practitioner makes the concurring determination depends upon whether the attending physician makes an initial determination that a patient lacks decision-making capacity because of a mental illness. If this is the case, then a “physician with the following qualifications must independently determine whether the patient lacks decision-making capacity: a physician licensed to practice medicine in New York state, who is a diplomate or eligible to be certified by the American Board of Psychiatry and Neurology or who is certified by the American Osteopathic Board of Neurology and Psychiatry or is eligible to be certified by that board.”²⁹

Further, FHCDA provides for an ethics review committee when the attending physician and the person giving the concurring determination disagree.³⁰ The proposed bill does not address what happens when the attending physician and the mental health professional disagree and does not provide for an ethics review committee. This leaves no way to resolve potential conflicts. The proposed bill is also silent as to the role of surrogates and guardians in the ability to make this decision.

- **Interpreters:**³¹ Provisions in the bill on interpreters would allow patients not fluent in English to access the Medical Aid in Dying program or benefit. However, the bill does not establish any minimum standards for the qualifications of the interpreter. California, which also allows for the use of an interpreter, does set standards for interpreters.
- **Research:** There is no provision in the bill governing funding of research. There is a dearth of well-designed research studies on the experience of terminally ill patients as they near death, and their desire for Medical Aid in Dying. We urge consideration of a provision in the bill that would fund research that would help to inform public policy in New York.

²⁷ PHL § 2994 *et. seq.*

²⁸ *Id.*, § 2994-a(17).

²⁹ *Id.*, § 2994-c(3).

³⁰ *Id.*, § 2994-c(3)(d).

³¹ A.2383/S.3151, § 2899-K(2)(C)

III. CONCLUSION

As this White Paper has highlighted, there are still many issues surrounding the New York Medical Aid in Dying proposal that have not been thoroughly addressed or explored. We call for more robust debate on important matters of public policy including issues of equity and adequacy of health systems, as well as funding for well-designed research studies.

ADDENDUM A
Bioethical Issues Committee Programs and Forums

December 5, 2016: Committee Forum #2 on Medical Aid in Dying: Dr. Joseph J. Fins. Joseph J. Fins, MD, MACP, is The E. William Davis, Jr. MD Professor of Medical Ethics and Chief of the Division of Medical Ethics at Weill Cornell Medical College where he is a Tenured Professor of Medicine, Professor of Medical Ethics in Neurology, Professor of Health Care Policy and Research, and Professor of Medicine in Psychiatry. The author of over 300 publications, his most recent book is *Rights Come to Mind: Brain Injury, Ethics and The Struggle for Consciousness* (Cambridge University Press, 2015). Dr. Fins is also the author of *A Palliative Ethic of Care: Clinical Wisdom at Life's End* (Jones and Bartlett, 2006) and a co-author of the 2007 Nature paper describing the first use of deep brain stimulation in the minimally conscious state.

September 16, 2016: “Examining Conditions of Confinement in New York’s Correctional Facilities: A Focus on Prisoners’ Rights” – “An Inside Look at the Lived Experiences of Aging and LGBT People and Other Vulnerable Prison Populations” (Tina Maschi, PhD); “Dual Lens of Law and Research: Access to Palliative Care Among Aging and Seriously Ill Prisoners” (Mary Beth Morrissey, PhD). Tina Maschi, PhD, LCSW, ACSW, is an Associate Professor, Fordham University Graduate School of Social Service.

June 13, 2016: Committee Forum #1 on Medical Aid in Dying: David Leven, Corinne Carey Nina Rothschild and Peter J. Strauss. David C. Leven, JD, has served as Executive Director of End of Life Choices New York since 2002. An advocate for patients and an expert on advance care planning, patient rights, palliative care and end-of-life issues, including aid in dying, Mr. Leven has played a leadership role in having legislation enacted in New York to improve pain, palliative and end-of-life care. He initiated the Palliative Care Education and Training Act, the Palliative Care Information Act and laws pertaining to health care proxies. Mr. Leven has lectured or debated on aid in dying at every area law school as well as at Rutgers, Syracuse and Yale Law Schools. Corinne Carey, JD, serves as New York State Campaign Director for Compassion & Choices, New York. Nina Rothschild, DrPH, MPH, serves as President of the Public Health Association of New York City. Peter J. Strauss, JD, is a nationally recognized elder law attorney. His special expertise lies in the legal problems of the aging and persons with disabilities. He is a co-founder of the National Academy of Elder Law Attorneys and the National Association of Professional Geriatric Care Managers. He is currently a partner in the law firm Epstein Becker & Green, P.C., where his practice area is personal planning and his areas of focus are elder law, guardianship, estate planning, and trusts and estates law.

December 16, 2015: Co-sponsored NYSBA Program, New York, NY: “Aid in Dying: A Terminally Ill Patient’s Right to Choose and What Practitioners Need to Know.”

November 12, 2011: NYS Task Force on Life and the Law 30th Anniversary (Bioethical Issues Committee co-sponsor); “Directions in Field of Bioethics: Palliative Ethic of Care” (Mary Beth Morrissey & Bruce Jennings). Bruce Jennings is a nationally recognized ethicist, trained in political science and philosophy at Yale and Princeton Universities, who developed his career in the interdisciplinary field of bioethics over a period of 26 years. He has written

and edited 27 books and has published approximately 200 articles on bioethics and public policy issues. Overall, during the last decade his work has attempted to bridge the domains of biomedical ethics, environmental ethics, and public health ethics. He is currently a Senior Fellow at the Center for Humans and Nature, a Fellow and Senior Advisor at The Hastings Center, and serves as Adjunct Associate Professor on the faculty at Vanderbilt University. In 2011, he was named Editor-in-Chief of the new 4th edition of Bioethics (formerly the Encyclopedia of Bioethics) 6 vols. (Macmillan Reference, 2014), a standard reference work in the field of bioethics, and is currently an Associate Editor of The Encyclopedia of the Anthropocene 5 vols. (Elsevier, forthcoming 2017).

June 15, 2015: “Radically New Approaches to Public Health Emergency Planning: Palliative Care Essentials.”

March 20, 2014: “Palliative Care & Ethics Committees.”

April 1, 2013: “Can I Go Forward with Pain Management After I-STOP?”

April 24, 2012: “Family Health Care Decisions Act & Surrogate Decision Making.”