



NEW YORK STATE
BAR ASSOCIATION

Report and Recommendations of the New York State Bar Association **Task Force on Medical Aid in Dying**

January 2024

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Association Task Force on Medical Aid in Dying**

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**NEW YORK STATE BAR ASSOCIATION
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I. EXECUTIVE SUMMARY

The New York State Bar Association Task Force on Medical Aid in Dying (MAID) was formed in June 2023 by President Richard Lewis. President Lewis framed the Task Force mission and charge to the Task Force as follows:

The Task Force on Medical Aid in Dying shall review the legal, ethical, health and public health, and broader policy considerations concerning medical aid in dying, including legislative proposals in New York and issues that may be related to the design as well as implementation of any such proposals if enacted by the NYS Legislature. The focus of the Task Force review shall include available research evidence and public health data; risks and benefits; financing; potential inequities and disparities; and the impacts of any such proposal or law if enacted upon families and caregivers; providers and residential and correctional care facilities; professional and informal workforces; and structural vulnerability and social determinants of health across diverse communities. The Task Force may evaluate laws of other states, jurisdictions, and countries, including Canada, as may be relevant to the Task Force inquiry. Through a consultative process with its members and other sections, the Task Force will develop recommendations for submission to the NYSBA Executive Committee and House of Delegates.

The members of the Task Force are leaders in many NYSBA sections and committees with relevant expert knowledge in multiple areas, including disabilities rights; elder law; health and public health law; insurance law; palliative care, hospice, and end-of-life care. President Lewis appointed Mary Beth Morrissey Esq., PhD, MPH, who is chair elect of NYSBA's Health Law Section and an active member of the Committee on Rights of Persons with Disabilities and the Elder Law Section, as Task Force Chair. Dr. Morrissey had chaired NYSBA's Health Law Section Task Force on COVID-19 in 2020,¹ and NYSBA's Emergency Task Force on Mandatory Vaccination and Safeguarding the Public's Health in 2021.² She served on NYSBA's Nursing Homes and Long-Term Care Task Force in 2021,³ chaired by Hermes Fernandez. Dr. Morrissey is a well-known public policy researcher in gerontological health, public health, and social work, and palliative and end-of-life care, and has a strong record of scholarship and policy advocacy in New York, as well as nationally and in the United Nations global health and aging communities. Judith Grimaldi chaired the Task Force's Working Group on Hospice, Palliative, and End-of-Life Care (End-of-Life Working Group), and Hon. Rachel Kretser chaired the Task Force's Legislative Working Group.

The Task Force heard from diverse parties, including individuals, organizations, attorneys, physicians, social workers, and other professionals with relevant expertise. Those who presented testimony included individuals and organizations who support the MAID bill, as well as those who

¹ <https://nysba.org/app/uploads/2021/01/health-Law-Resolutions-and-report-with-cover-approved-November-2020.pdf>.

² <https://nysba.org/app/uploads/2021/08/EC-Approved-Final-Report-on-Emergency-Task-Force-on-Mandatory-Vaccination-and-Safeguarding-the-Publics-Health..-with-appendix-a.pdf>.

³ <https://nysba.org/app/uploads/2021/03/Task-Force-on-Nursing-Home-and-Long-Term-Care-Report-FINAL-approved-6.12.2021.pdf>.

voice serious concerns about it or oppose it. In addition, the Task Force held a five-hour Open Forum on November 17 to afford people outside the legal community an opportunity to offer their ideas and insights.

This report summarizes the comprehensive and methodical review carried out by the Task Force since June 2023.

Section II explains that MAID cannot be created judicially under current controlling authority and reviews the history of certain New York laws relevant to the Task Force's focus of inquiry.

In Section III, the New York MAID bill is framed in the end-of-life spectrum of care options, alongside hospice and palliative care. The need for more information and counseling at the end of life is also addressed.

The MAID laws and the history of their implementation in 10 other U.S. jurisdictions are mapped out in Section IV to provide further context for consideration of the bill currently before the New York State Legislature, which would amend the Public Health Law to provide that certain terminally ill patients could request and use medication for aid in dying.⁴

Sections V and VI of this Report set forth additional comments and recommendations for consideration once MAID is authorized in New York State. The State ought then to draw on its past legislation and regulatory and payment models, and on approaches created in other states, to ensure citizens have equal access to comprehensive end-of-life care including MAID. Comments and recommendations address structural inequities and disparities in health and end-of-life care at the intersectionality of race, ethnicity, gender, disability, age, immigration status, and social determinants of health; additional safeguards for certain special populations; funding for MAID; and development and provision of MAID training.

The Appendices provide summaries of testimony by individuals and organizations who appeared during the Public Forum and before the Legislative Working Group, affiliations of the Task Force Members, and charts comparing MAID laws and reports nationwide.

In order to ensure that all eligible New Yorkers have equitable access to high-quality medical aid in dying as part of a continuum of compassionate end-of-life care options in New York, and further, based on the methodical review conducted by the Task Force pursuant to the charge from New York State Bar Association President Lewis and after serious deliberations:

The Task Force on Medical Aid in Dying recommends the New York State Bar Association adopt a position in support of the pending MAID bill (A995a/S2445); and additional comments and recommendations, and to support similar bills that accomplish this purpose.⁵

⁴ The NY Medical Aid in Dying Act, A995A/S2445A, available at https://nyassembly.gov/leg/?default_fld=&leg_video=&bn=A00995&term=&Summary=Y&Text=Y.

⁵ This report reflects the consensus opinion of the New York State Bar Association Task Force members and does not reflect, unless otherwise stated, the views held by any individual member or the member's clients or employers. Participation in the Task Force by any one member should not be interpreted as an expression of support for the Task Force, this report, or Medical Aid in Dying by the member or the member's client or employer.

INTRODUCTION

To address the experience of some terminally ill people who suffer at the end of life, even with the support of hospice and palliative care, lawmakers have sought for more than 9 years to change the law in New York to allow these people to access an end-of-life option known as “medical aid in dying.”

Medical aid in dying is a medical practice that has now been adopted in 11 U.S. jurisdictions that allow a terminally ill, mentally capable adult with a prognosis of six months or less to live to request from their doctor a prescription for medication they can decide to self-ingest to die peacefully in their sleep.

New York’s Medical Aid in Dying Act was introduced by Senator Diane Savino and Assemblymember Amy Paulin in 2016 and has been amended several times and re-introduced each two-year legislative cycle since then. The bill currently before the legislature (A995a/S2445), carried by Senator Brad Hoylman-Sigal and Assemblymember Amy Paulin, will be considered by the New York State legislature in the 2024 legislative session. At the time this report went to press, the bill was co-sponsored by 84 lawmakers.

The New York bill is modeled after legislation in Oregon and the other 9 states and Washington, D.C., where medical aid in dying has been authorized. The bill would allow a terminally ill adult with mental capacity to request and receive from their physician a prescription for medication that they can take at a time of their own choosing to bring about a peaceful death. The safeguards in the legislation include the following: i) a qualified patient must have a medically confirmed terminal illness that is incurable and irreversible and will likely cause death within 6 months; and the bill states that individuals are not eligible for medical aid in dying because of age or disability; ii) two physicians must confirm that the person is terminally ill with a prognosis of 6 months or less to live, is making an informed health care decision and is not being coerced; iii) the attending physician must inform the requesting individual about all of their end-of-life care options, including palliative care and hospice; iv) there is a mandatory mental health evaluation if either physician has concerns about the person’s mental capacity to make their own healthcare decisions and the mental health provider must confirm in writing the dying person’s capacity before a prescription can be written; v) the individual must make an oral and a written request for aid-in-dying medication, witnessed by two people — neither of whom can be a relative or someone who stands to benefit from the person’s estate; vi) the terminally ill person can withdraw their request for aid-in-dying medication, not take the medication once they have it, or otherwise change their mind at any point in time; vii) the individual must be able to self-ingest the medication; viii) no physician, health provider or pharmacist is required to participate in medical aid in dying and those who do and comply with all aspects of the law receive civil and criminal immunity; ix) anyone attempting to coerce a patient will face criminal prosecution; and x) unused medication must be disposed of as required by state and federal laws.

II. MAID DECISIONS AND SURROGATE DECISION-MAKING LAWS

Because the U.S. Supreme Court and the New York Court of Appeals have not recognized MAID as a fundamental liberty interest, legislation is the pathway available to legalize MAID. In *Washington v. Glucksberg*, 521 US 702 (1997), physicians argued that a Washington state ban on physician-assisted suicide violated the fundamental liberty interest of personal choice by a mentally competent, terminally ill adult to commit physician-assisted suicide. The Supreme Court rejected such argument, grounded in the Due Process Clause of the 14th Amendment, and held that the Washington statute was rationally related to a legitimate state interest. *Id.* at 720–721, 728. *Vacco v. Quill*, 521 US 793 (1997), concerned a challenge by New York physicians to statutes criminalizing physician-assisted suicide as a violation of the Equal Protection Clause. The Supreme Court upheld the prohibition. *Id.* at 806; *see also Myers v. Schneiderman*, 30 NY3d 1 (2017) (upholding ban on MAID in New York’s Penal Law under Due Process and Equal Protection analyses). If a statute legalizing—rather than prohibiting—MAID were enacted, under the applicable rational basis standard, such statute could be expected to withstand a constitutional challenge since such additional end-of-life option could be shown to be rationally related to a legitimate state interest.

History of New York’s Surrogate Decision-Making Laws

In providing the full spectrum of medical, residential, and habilitative care to patients, providers must consider New York’s wide-ranging surrogate decision-making laws and regulations. To be clear, New York’s Medical Aid in Dying Bill does not allow for surrogate decision making. The only person who can request medical aid in dying is a terminally ill patient themselves. This request cannot be made by a physician, guardian, family member, or health care proxy; nor can it be requested by a person in a living will or advance care planning document to be deployed after the person loses the capacity to make their own medical decisions. The bill is explicit: only a terminally ill, decisionally-capable adult can make a request for medical aid in dying.

Despite the complexity of New York State’s surrogate decision-making system, for decisions like executing consents to certain routine medical treatments or screenings, or agreements for admission to rehabilitation or nursing facilities and related matters, the lack of any (in some cases) or even intermediate options leads to situations that are difficult to address. The Legislature should consider directing its attention to remedying the current process of legislating or promulgating regulations that stand alone as patches to the system and should utilize the strengths within current law to bolster MAID if it becomes law. The full spectrum of social, financial, and medical surrogate decision-making law and regulations could fill a report on their own. Still, a brief overview of a few key options that could interact with MAID follows. Readers would be well served by becoming familiar with the various reports issued by New York’s Task Force on Life and the Law. Many of the surrogate decision-making laws and principles we currently follow in New York started with that group’s writings.⁶

⁶ https://www.health.ny.gov/regulations/task_force/.

Prior to the March 16, 2010, signing of the Family Health Care Decisions Act (FHCDA) into law during a ceremony at Albany Memorial Hospital, the law in New York on end-of-life decision making had been relatively stable, but unable to address many real-world situations.⁷ Healthcare providers were caught between a desire to behave in a humanely, respectfully, and medically appropriate way that could be rectified versus harsh caselaw and a patchwork of policies. The law before 2010 was united in its acceptance of the principle that a patient with decision-making capacity had a broad right to consent to or decline treatment: even life-sustaining treatment.⁸ Life-sustaining treatment could be withdrawn or withheld if there was clear and convincing evidence that the patient would want the treatment withdrawn or withheld.⁹ If there was not clear and convincing evidence that the patient would want treatment withdrawn or withheld, life-sustaining treatment was legally required to be provided. Since the 1980s, the Legislature has implemented several changes in law that create other instances where life-sustaining treatment can be withdrawn or withheld. The first is a decision to put in place an order not to resuscitate (DNR).¹⁰ A second option is healthcare proxies (“HCP”), an option for individuals with capacity who want to make sure their wishes are honored when it comes time to make a healthcare decision, but they are no longer able to fully advocate on their own. New York’s HCP system was developed based on recommendations by the Task Force on Life and the Law. In a healthcare proxy, a then-competent adult may appoint a healthcare agent.¹¹ The healthcare agent becomes empowered upon a determination by an attending physician that the principal now lacks capacity to make healthcare decisions.¹² A second type of advance directive that is commonly (and advisably) used in conjunction with a healthcare proxy is a Living Will. A Living Will can provide the agent appointed by the proxy with the clarity they need to fulfill their charge and to be protected while they do so.¹³ Persons with intellectual disabilities who lack decisional capacity can have healthcare decisions made on their behalf, including decisions to withhold or withdraw life-sustaining treatment, by an Article 17-A guardian or by an actively involved family member with specific

⁷ 2010 N.Y. Laws ch. 8, A.7729-D (Gottfried et al.) and S.3164-B. (Duane et al.). Section 2 of Chapter 8 amends N.Y. Public Health Law (PHL) to create “Article 29-CC Family Health Care Decisions Act.”

⁸ 52 N.Y.2d 363, 438 N.Y.S.2d 266, *cert. denied*, 454 U.S. 858 (1981). *See also* 521 U.S. 793 (1997), specifically Justice Stevens’ concurrence, which implies even broader rights.

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

¹⁰ PHL art. 29-B.

¹¹ PHL § 2980–81. NYS Task Force on Life and the Law, *When Others Must Choose: Deciding for Patients Without Capacity* (March 1992) available at <http://www.health.state.ny.us/nysdoh/taskfrce/inforpts.htm>.

¹² A candidate for agent is disqualified if the conditions in PHL § 2981(3) are met. PHL § 2983, PHL § 2982, SCPA § 1750-b(2), PHL § 2985, 2008 N.Y. Laws ch. 210, section 4. Steps were taken to develop a healthcare proxy form for use by individuals with I/DD, including the creation of a workgroup, but their work product was never advanced for approval because the Legislature did not appropriate funds for the required preapproval study of the forms. As a result, OPWDD has not been able to approve the draft form. Individuals with I/DD may be able to use other healthcare proxy forms, but they would not be able to have their proxy commence decision making by proxy immediately and with nearly the same limitations and powers of a proxy acting under the Public Health Law. In these cases, some “extra” requirements include that one witness must be someone who is not “affiliated with” the facility, and the other must be a physician or clinical psychologist with specialized experience.

¹³ Where an advance directive would have been helpful but does not exist you have to examine the past statements of the patient. It is advisable to consult the following case in such an instance: *Matter of O’Connor*, 72 N.Y.2d 517 (NY Court of Appeals, 1988). New York has no statute governing their form, interpretation, or enforcement of Living Wills.

limitations and safeguards under a special law enacted in 2002 applicable to people who are intellectually disabled.¹⁴

In 1985, Governor Mario Cuomo formed the Task Force on Life and the Law, which, in its 1992 report “When Others Must Choose: Deciding for Patients Without Capacity,” called for a number of specific reforms to state law and advanced legislation to enact its suggested reforms.¹⁵ In 1993 the proposal was introduced in the Assembly by Richard Gottfried, Chair of the Assembly Health Committee and formerly the lead sponsor of the Health Care Proxy Act.¹⁶ Bills that the Task Force had previously supported, such as the aforementioned DNR and HCP laws, had been successful, which supported the case for passing the FHCDA. Unfortunately, the bill remained in legislative doldrums until 2003, when various amendments gave some hope the FHCDA would pass. It did not pass until 2010 after Senator Duane’s unity bill weathered the June 2009 Senate “coup”.¹⁷ A Senate bill and Assembly consort were re-introduced in both houses in January 2010 with only one change: a provision stating that a surrogate’s decision was not required if the patient had made a prior decision personally, was amended to attach witnessing requirements to prior oral decisions to forgo life-sustaining treatment. The Assembly passed the FHCDA on January 20 with a nearly unanimous bipartisan vote, and the Senate passed it on February 24, unanimously. On March 16, 2010, 17 years after the FHCDA was first introduced, Governor Paterson signed the FHCDA into law.¹⁸ It is worth mentioning that the FHCDA’s passage also paved the way for the MOLST (Medical Orders for Life-Sustaining Treatment) form’s use in New York.¹⁹

The FHCDA is a sweeping piece of legislation that strains any attempt to summarize it, reaching into the areas of guardianship, civil litigation, patient notification, HCPs, DNRs, and other areas. The FHCDA applies to decisions for incapable patients in general hospitals and residential health care facilities (both are referred to as “hospitals”).²⁰ It sets forth a hospital-based process to determine that a patient lacks decisional capacity, but only for purposes of the FHCDA, and for objections to such determinations.²¹ The statute sets forth, in order of priority, the persons who may act as a surrogate decision maker for the incapable patient. The surrogate has the authority to make all health care decisions for the patient that the adult patient could make for themselves, subject

¹⁴ Surrogate’s Court Procedure Act 1750-b (SCPA). A variety of other guardianship types exist in modern New York law.

¹⁵ NYS Task Force on Life and the Law, *When Others Must Choose: Deciding for Patients Without Capacity* (March 1992) available at <http://www.health.state.ny.us/nysdoh/taskfrce/inforpts.htm>.

¹⁶ The bill was not named the “Family Health Care Decisions Act” until 1995. The bill was introduced in the Senate by Sen. DeFrancisco, and later sponsored by Sen. Hannon, with broad support as S4685 (1995). Assem. Gottfried was also a sponsor of New York’s MAID bill.

¹⁷ S.3164-B (Duane). The “coup” refers to two Democrats voting with Republicans to give the Republican party control of the State Senate. Ken Rudin, *Winners & Losers In New York Coup; Dems Not Giving Up* (Jun 2009) available at https://www.npr.org/sections/politicaljunkie/2009/06/winners_losers_in_new_york_cou.html. This abridged retelling skips over, but is not intended to diminish, the difficult concessions as to the rights of same-sex partners and fetuses made from 2003–2009, and the impasse that resulted.

¹⁸ Enacted at PHL § 2994-d(3)(ii).

¹⁹ NY State Department of Health, MOLST Form, <https://www.health.ny.gov/forms/doh-5003.pdf> (last visited December 29, 2023).

²⁰ PHL § 2994-b and c. The FHCDA does not apply to decisions for incapable patients who have a health care agent; who have a court-appointed guardian under SCPA 1750-b; for whom decisions about life-sustaining treatment may be made by a family member or close friend under SCPA 1750-b; or for whom treatment decisions may be made pursuant to OMH or OMRDD surrogate decision-making regulations.

²¹ PHL § 2994-c(4)(a)-(6).

to certain standards and limitations.²² The surrogate must make decisions based on the wishes of the patient, if known, or based on the patient’s best interests if their wishes are not known.²³

The FHCDA also creates a process for healthcare providers to secure legally valid decisions concerning treatment for “isolated” patients, meaning patients without family, close friends, or any other surrogate recognized by state law.²⁴ Most important to this report, the FHCDA allows a surrogate to make decisions concerning the withholding or withdrawal of life-sustaining treatment if the treatment would be an extraordinary burden to the patient and the patient is terminally or permanently unconscious; or, if the patient has an irreversible or incurable condition and the treatment would involve such pain, suffering, or other burden that it would reasonably be deemed inhumane or excessively burdensome under the circumstances.²⁵ The two standards also apply to decisions regarding artificial nutrition and hydration (e.g., the provision of nutrition or hydration by a tube inserted through the nose, stomach, or vein). Decisions regarding the oral provision of food and drink are not considered health care decisions and are outside the scope of the statute.²⁶

One aspect of the FHCDA that the Workgroup spent a considerable amount of time discussing is the adequacy of the safeguards it put in place and whether those safeguards could provide additional layers of protection for vulnerable patients if MAID is made law. The most significant change made by the FHCDA was that it empowered family members to direct the withdrawal of life-sustaining treatment in the absence of clear and convincing evidence of a patient’s wish to forgo treatment. Surrogates receive this power without going to court (as is the case with certain guardianships), without signing a document (as with a HCP), or appearing before a decision-making body.²⁷ Over ten years on from the FHCDA there is reason to believe its safeguards work, though we must also acknowledge they have room to improve. We have limited empirical confirmation but ample testimony from healthcare professionals, patient advocates, medical ethicists, academics, and others that the safeguards and other provisions are working as intended. Special mention of the FHCDA’s requirement that hospitals and nursing homes implement ethical review committees (ERCs) is warranted because the ERCs seem to be an obvious check on a patient with an intermediate level of capacity, enough perhaps to indicate they would like to avail themselves of MAID without a mental health consultation, but not enough to reassure their attending physician.²⁸ ERCs could be especially helpful in the case of an isolated patient. The Department of Health, as is suggested by other sections of this report, could also support the development of ERC best practices.

²² PHL § 2994-d.

²³ PHL § 2994-d.

²⁴ PHL § 2994-g.

²⁵ PHL § 2994-d.

²⁶ PHL § 2994-a (12).

²⁷ Once again, for the purposes of summary we are simplifying the complexities of the interaction between the FHCDA and the HCDA, Article 17-A, and other laws. Still, the FHCDA undoubtedly filled in gaps and allowed family, friends, and medical professionals into the decision-making process when guardians or the Surrogate Decision Making Committee (SDMC) were not an option. Now housed in the Justice Center for the Protection of People with Special Needs, SDMC provides an alternative to court for individuals who do not have capacity to give informed consent, but who also have no authorized surrogate available. Again, SDMC will only tackle “major” decisions and specifically excludes routine diagnosis and treatment decisions. *See generally* <https://www.justicecenter.ny.gov/services-supports/sdmc>.

²⁸ PHL § 2994-m.

III. HOSPICE, PALLIATIVE CARE, AND MAID

MAID is inextricably tied to hospice and palliative care. As with MAID, a core value of hospice is patient autonomy. Patients are supported in their desire to die in the manner and setting they choose. Some hospice providers have reservations about legalizing MAID. However, many concerns have been addressed in the current bill, which the Hospice and Palliative Care Association of New York State (HPCANYS) does not oppose. HPCANYS is a not-for-profit organization representing hospice and palliative care programs, allied organizations, and individuals in New York that are interested in quality, comprehensive end-of-life services. The Task Force received testimony from HPCANYS President and Chief Executive Officer Jeanne Chirico and Director of Government Relations and Policy Director Cheryl Kraus.

HPCANYS urges that patients must have full autonomy to make informed choices about their end-of-life care. Unfortunately, often patients do not receive relevant information, as further discussed in Section VI, *infra*. Indeed, New York ranks last in the country for hospice utilization.²⁹ The responsibility for this failure rests with providers, as well as regulators, who have not properly incorporated hospice and palliative care services into planning efforts or budget allocation processes. This problem led to the Palliative Care Information Act (PCIA), which requires physicians and nurse practitioners to offer to terminally ill patients information and counseling concerning palliative care and end-of-life options.³⁰ In 2011, this requirement was expanded by the Palliative Care Access Act (PCAA), which provides that (a) such information and counseling must be provided by general hospitals, nursing homes, home care agencies, enhanced assisted living residences, and special needs assisted living residences to individuals with life-limiting conditions or illnesses who might benefit from palliative care, and (b) such entities must facilitate access to such care.³¹ Unfortunately, the requirements of PCIA and PCAA have been routinely ignored by providers. HPCANYS was thus concerned that terminal patients would choose MAID without an adequate understanding of other options.

HPCANYS therefore asked that New York’s MAID legislation be amended to include a mandate that providers inform patients of their hospice and palliative care options prior to prescribing MAID. In response, several provisions were added to the legislation. The bill requires that a patient make an “informed decision.” The definition of “informed decision” includes a requirement that patients be informed about “the feasible alternatives and appropriate treatment options, including but not limited to palliative care and hospice care.”³² The bill includes a separate requirement that the prescribing physician discuss “the feasible alternatives and appropriate treatment options,” offer to refer the patient for such options, and provide:

“[H]ealth literate and culturally appropriate educational material regarding hospice and palliative care that has been prepared by the department [of health] in consultation with representatives of hospice and palliative care providers from all regions of New York State, and that is available on the department’s website for

²⁹ National Hospice and Palliative Care Association, *NHPCO Facts and Figures*, Dec 2022, p 6 (available at [NHPCO-Facts-Figures-2022.pdf](#)).

³⁰ Chapter 332 of the 2010 Laws of NY; *see also* Pub Health Law § 2997-c.

³¹ Chapter 59 of the 2011 Laws of NY; *see also* Pub Health Law § 2997-d.

³² NY State Bill No A995A/S2445A of 2023, § 2, new § 2899-d(7).

access and download, provided, however, an otherwise eligible patient cannot be denied care under this article if these materials are not developed by the effective date of this article.”³³

Moreover, patients requesting MAID must attest to having received such information.³⁴ HPCANYS requested other changes that were made to the bill, including conforming terminology to language in existing statutes regarding healthcare decision making and ensuring that providers can opt out of providing MAID as a matter of conscience. Not all requested changes were made, and concerns remain. The bill includes a provision that “an otherwise eligible patient cannot be denied care under this article if these materials are not developed by the effective date” of the law.³⁵ Despite such provision, HPCANYS does not oppose the legislation, given its implications for patient autonomy.

Another concern involves opt-out provisions. The bill provides broad protection for practitioners who do not wish to participate in MAID³⁶ and allows health care facilities to prohibit the prescribing, dispensing, ordering, or self-administering of MAID if doing so is contrary to a “formally adopted policy of the facility that is expressly based on sincerely held religious beliefs or moral convictions central to the facility's operating principles.”³⁷ However, “health care facility” is defined to include only inpatient hospice care and hospice residences.³⁸ This means that home hospice has no opt-out available, and some hospices might be forced to have multiple, conflicting policies about MAID that depend on the treatment venue. Finally, HPCANYS is concerned that the bill will be effective immediately upon approval by the Governor.³⁹ Thus, providers would have no opportunity to develop and implement policies necessary to support the administration of MAID. Accordingly, HPCANYS seeks a sufficient time between final approval and effectiveness to ensure that providers can administer MAID as expected. Notwithstanding these remaining issues, HPCANYS does not oppose the bill.

HPCANYS has identified other recent State actions that should support the hospice infrastructure and advance patient awareness about hospice and palliative care. Recently, the Governor’s Master Plan on Aging (MPA) Council acknowledged the importance of hospice and palliative care. The MPA Council was created in 2022 to “coordinate existing and new state policy and programs creating a blueprint of strategies to ensure older New Yorkers can live fulfilling lives, in good health, with freedom, dignity and independence to age in place for as long as possible.”⁴⁰ Foundational pillars have been identified to focus ongoing conversations.⁴¹ HPCANYS and other stakeholders in the MPA Council advocated for, and were granted, the inclusion of an additional new central element focused on delivering quality health care services and ensuring that the MPA addresses all aspects of an aging population’s health and well-being.

³³ NY State Bill No A995A/S2445A of 2023, § 2, new § 2899-f(1)(e)-(g).

³⁴ NY State Bill No A995A/S2445A of 2023, § 2, new § 2899-k(1).

³⁵ NY State Bill No A995A/S2445A of 2023, § 2, new § 2899-f(1)(g).

³⁶ NY State Bill No A995A/S2445A of 2023, § 2, new § 2899-m(1).

³⁷ NY State Bill No A995A/S2445A of 2023, § 2, new § 2899-m(2).

³⁸ NY State Bill No A995A/S2445A of 2023, § 2, new § 2899-d(5).

³⁹ NY State Bill No A995A/S2445A of 2023, § 3.

⁴⁰ 9 NYCRR § 9.23(1).

⁴¹ See Preliminary Report of the New York State Master Plan for Aging, August 28, 2023 (available at [MPA Preliminary Report FINAL.pdf \(ny.gov\)](#)).

Similarly, in response to a law promoted by HPCANYS and passed by the Legislature,⁴² in November 2023 the Department of Health (DOH) created a Center for Hospice and Palliative Care Access and Quality in DOH's Office of Aging and Long Term Care. Hospice advocates hope that this legislation and Center will ensure that hospices and palliative care providers and the patients and families they serve are thought of at the front end of all DOH strategic planning, program development, and investment efforts. The Center can also provide a platform for research and innovation in end-of-life care. Among the programs that the Center could administer is a statewide advance care planning campaign established by statute in 2022,⁴³ which could be invaluable in promoting public awareness of hospice and palliative care services. The new Center could also advance efforts to educate the public and train providers on MAID administration.

IV. MAID LEGISLATION NATIONWIDE

MAID in Eleven Jurisdictions

The Task Force's Legislative Working Group researched laws in the 11 U.S. jurisdictions that have legalized MAID; compared those approaches to the New York bill; reviewed reports in those states to determine how well the laws are working; and interviewed relevant experts and individuals, including those with first-hand experience with MAID.

The first MAID law in the United States—the Oregon Death with Dignity Act (DWDA)—was passed through a voter ballot initiative in 1994 and was implemented in 1997.⁴⁴ Since then, nine more states and Washington, D.C. have legalized MAID:

- Washington's Death with Dignity Act, 2008 (ballot initiative),⁴⁵ amended 2023⁴⁶
- Montana Supreme Court ruling, 2009⁴⁷
- Vermont's Patient Choice and Control at the End of Life Act, 2013,⁴⁸ amended 2023⁴⁹
- California's End of Life Option Act, 2015,⁵⁰ amended 2021⁵¹

⁴² A5587/S4858 of 2023.

⁴³ Chapter 406 of the 2022 Laws of NY.

⁴⁴ Oregon Death with Dignity Act, available at

<https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/index.aspx>.

⁴⁵ Washington Death with Dignity Act, Revised Code of Washington, Chapter 70.245, available at <https://app.leg.wa.gov/rcw/default.aspx?cite=70.245>.

⁴⁶ Washington State Legislature, Substitute Senate Bill 5179 (April 6, 2023), available at [https://lawfilesexternal.wa.gov/biennium/2023-24/Pdf/Bills/Session Laws/Senate/5179-S.SL.pdf?q=20230510092955](https://lawfilesexternal.wa.gov/biennium/2023-24/Pdf/Bills/Session%20Laws/Senate/5179-S.SL.pdf?q=20230510092955).

⁴⁷ *Baxter v. Montana*, 224 P.3d 1211, 354 Mont. 234 (2009).

⁴⁸ Vermont Patient Choice at End of Life, Chapter 113, available at

<https://legislature.vermont.gov/statutes/chapter/18/113>.

⁴⁹ Act No. 10, An Act Relating to Removing the Residency Requirement from Vermont's Patient Choice at End of Life Laws, Vermont General Assembly (passed May 2, 2023), available at

<https://legislature.vermont.gov/Documents/2024/Docs/ACTS/ACT010/ACT010%20As%20Enacted.pdf>.

⁵⁰ California End of Life Option Act, California Health and Safety Code, Division 1, Part 1.85, Section 443–443.22, available at https://leginfo.legislature.ca.gov/faces/codes_displayText.xhtml?lawCode=HSC&division=1.&title=&part=1.85.&chapter=&article=

⁵¹ California Senate Bill 380, Chapter 542, End of life (enacted October 5, 2021), available at https://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_id=202120220SB380.

- Colorado’s End-of-Life Options Act, 2016 (ballot initiative)⁵²
- District of Columbia’s Death with Dignity Act, 2017⁵³
- Hawaii’s Our Care, Our Choice Act, 2018,⁵⁴ amended 2023⁵⁵
- Maine’s Death with Dignity Act, 2019⁵⁶
- New Jersey’s Aid in Dying for the Terminally Ill Act, 2019⁵⁷
- New Mexico’s Elizabeth Whitefield End-of-Life Options Act, 2021⁵⁸, amended 2023.⁵⁹

The above statutes (described in Appendix IV, Exhibit A), are modeled after the Oregon DWDA and require a patient to:

- be an adult (aged 18 or older);
- be confirmed by two doctors to be terminally ill;
- have a prognosis of six months or less to live;
- have decision-making capacity;
- be able to self-administer the medication.

Public Support for MAID

In its most recent report, Gallup reveals that 74% of U.S. adults believe that doctors should be allowed to end the life of a patient with an incurable disease “by some painless means” if the patient and the patient’s family request such relief.⁶⁰ While the Gallup poll specifically addressed “doctor-assisted suicide”⁶¹ rather than MAID, it is evident that most Americans have favored some form of MAID since Gallup first asked about it in 1996.⁶² This includes majority support

⁵² Colorado End of Life Options Act, Article 48, available at <https://www.sos.state.co.us/pubs/elections/Initiatives/titleBoard/filings/2015-2016/145Final.pdf>.

⁵³ Death with Dignity Act of 2016, D.C. Law 21-182 (December 19, 2016), available at https://dchealth.dc.gov/sites/default/files/dc/sites/doh/page_content/attachments/Death%20With%20Dignity%20Act_FINAL_.pdf.

⁵⁴ Hawaii Our Care, Our Choice Act, HB 2739 (April 5, 2018), available at <https://health.hawaii.gov/opppd/files/2018/11/OCOC-Act2.pdf>.

⁵⁵ Hawaii House Bill 650 (signed June 1, 2023), available at https://www.capitol.hawaii.gov/session/measure_indiv.aspx?billtype=HB&billnumber=650&year=2023.

⁵⁶ Maine Death with Dignity Act, Public Law Chapter 271, available at https://legislature.maine.gov/legis/bills/bills_129th/chapters/PUBLIC271.asp.

⁵⁷ New Jersey Medical Aid in Dying for the Terminally Ill Act, Chapter 59 (April 12, 2019), available at https://pub.njleg.gov/bills/2018/PL19/59_.HTM

⁵⁸ The Elizabeth Whitefield End-of-Life Options Act (2021), available at <https://www.nmhealth.org/publication/view/general/8382/>.

⁵⁹ New Mexico Senate Bill 471 (2023), available at <https://www.nmlegis.gov/Sessions/23%20Regular/final/SB0471.pdf>.

⁶⁰ Gallup News Service, Gallup Poll Social Series: Values and Beliefs (May 1–13, 2020), available at <https://news.gallup.com/poll/312209/prevalence-living-wills-slightly.aspx>.

⁶¹ The term “doctor-assisted suicide” was in use at the time Gallup initiated its polling. The term “medical aid in dying” is now more commonly used.

⁶² *Id.*

across most demographic groups.⁶³ In addition, 79% of people living with disabilities in the United States opine that MAID should be legal for terminally ill, mentally capable adults.⁶⁴

Fifty-eight percent of New Yorkers support MAID, according to recent Siena College Research Institute poll results.⁶⁵ New York’s MAID Act has been endorsed by nearly 40 organizations including ACT UP- NY, Coalition of Progressive Hindus, Gay Men’s Health Crisis, Inc., Harlem United, Latino Commission on AIDS, Hispanic Health Network, Latino Commission on AIDS, League of Women Voters of New York State, New York Civil Liberties Union, New York State Academy of Family Physicians, New York State Public Health Association, Planned Parenthood Empire State Acts, SADHANA, SAGE, New York Statewide Senior Action Council.⁶⁶ Two New York disability rights organizations have taken supportive or neutral positions on MAID.⁶⁷ The New York Alliance Against Assisted Suicide provides information on certain organizations that may oppose MAID.⁶⁸

In the most recent report of Medscape, 55% of physicians surveyed agreed that “Physician assisted death should be allowed for terminally ill patients.”⁶⁹ In addition, 86% of nurses said that they would care for a patient contemplating MAID.⁷⁰ In 2018, New York doctors showed strong support for MAID:

- By a margin of 56% to 26%, New York physicians support MAID or physician-assisted suicide.⁷¹

⁶³ *Id.*; see also LifeWay Research, American Views on Assisted Suicide (2016), available at

<http://lifewayresearch.com/wp-content/uploads/2016/12/Sept-2016-American-Views-Assisted-Suicide.pdf>.

⁶⁴ US for Autonomy, Nationwide Poll Shows 79% of People with Disabilities Believe Medical Aid in Dying Should Be Legal for Terminally Ill, Mentally Capable Adults, available at <https://www.usforautonomy.org/polling>.

⁶⁵ See Siena College Poll Trends, November 2023, available at

<https://scri.siena.edu/wp-content/uploads/2023/11/SNY-November-2023-Release.pdf> (question 28); see also Marist Poll of 822 New York State Adults, Marist Poll (2021), at https://maristpoll.marist.edu/wp-content/uploads/2021/10/Marist-Poll_NYS-NOS-and-Tables_202110110852.pdf (59% of voters support the bill compared to only 36% who oppose it).

⁶⁶ See Compassion & Choices, New York Organizations that Support Medical Aid in Dying, available at

https://www.compassionandchoices.org/docs/default-source/new-york/ny-orgs-that-support-medical-aid-in-dying-021522.pdf?sfvrsn=7c838bfc_2.

⁶⁷ See The Arc New York Position Statements 2023–2024, position on Medical Aid in Dying, p 40, available at

https://www.thearcny.org/application/files/1917/0008/1445/TheArcNewYorkPositionStatements_2022-24_FINAL11-15-23.pdf; Cision PR Newswire, the Arc New York—One of the Leaders in Supporting New Yorkers with Disabilities—Supports Medical Aid in Dying, Resource Center for Independent Living Neutral on Issue (March 2, 2020), available at <https://www.prnewswire.com/news-releases/the-arc-new-york--one-of-the-leaders-in-supporting-new-yorkers-with-disabilities--supports-medical-aid-in-dying-301014781.html>.

⁶⁸ See New York Alliance Against Assisted Suicide, New York State Organizations Which Oppose Assisted Suicide, available at <https://nosuicideny.org/about>.

⁶⁹ Medscape, Life, Death, and Pain: Ethics Report 2020: available at

<https://www.medscape.com/viewarticle/941104?form=fpf>.

⁷⁰ Nurses’ Values and Perspectives on Medical Aid in Dying: A Survey of Nurses in the United States, Journal of Hospice Palliative Nursing (February 1, 2022), available at

<https://pubmed.ncbi.nlm.nih.gov/34840280>.

⁷¹ New York Physicians Support Medical Aid in Dying (2018), available at

https://www.compassionandchoices.org/docs/default-source/polling-documents/3-2018-medscape_webmd-survey-of-new-york-physicians.pdf?sfvrsn=14dc4566_1.

- When asked whether they support or oppose the bill pending in New York and told about key provisions, doctors supported the legislation 67% to 19%. Ninety percent of the doctors endorsed requiring that patients who request MAID or patient-assisted suicide be offered a referral to hospice if they are not enrolled in hospice when the request is made.⁷²

In 1996, the American College of Legal Medicine (ACLM)—an organization of professionals engaged in issues where the disciplines of medicine and law converge—was “the first such organization to publicly advocate for the elimination of the word “suicide” from the lexicon created by a mentally competent, though terminally ill, person who wishes to be aided in dying.” They filed an amicus brief before the U.S. Supreme Court.⁷³ In 2008, the group issued a position which remains in effect today:

The ACLM recognizes patient autonomy and the right of a mentally competent, though terminally ill, person to hasten what might otherwise be objectively considered a protracted, undignified, or painful death, provided, however, that such person strictly complies with law specifically enacted to regulate and control such a right; and BE IT FURTHER RESOLVED: That the process initiated by a mentally competent, though terminally ill, person who wishes to end his or her suffering and hasten death according to law specifically enacted to regulate and control such a process shall not be described using the word “suicide”, but, rather, as a process intended to hasten the end of life.⁷⁴

In addition, the State Bar Associations in California⁷⁵ and Connecticut⁷⁶ had previously adopted favorable positions on earlier versions of the respective state MAID bills.

The New York City Bar Association submitted testimony in 2018 to the New York State Assembly Committee on Health Hearing on Medical Aid in Dying, making specific recommendations to amend the 2018 bill.⁷⁷ Appended to the 2018 testimony is a full report on Medical Aid in Dying published in 2017.

Six national health care organizations have adopted neutral positions toward MAID: the American Academy of Family Physicians,⁷⁸ American Academy of Neurology,⁷⁹ American

⁷² *Id.*

⁷³ American College of Legal Medicine, ACLM Policy on Aid in Dying, Eff. October 6, 2008, available at <https://www.compassionandchoices.org/docs/default-source/policy/american-college-of-legal-medicine-position-statement.pdf>.

⁷⁴ *Id.*

⁷⁵ The Conference of California Bar Associations, Testimony in Support of ABX2-15 (2015), available at <https://compassionandchoices.org/docs/default-source/california/l-doyle-support-for-abx2-15.pdf>.

⁷⁶ The Connecticut Bar Association, Testimony in Support of HB7015,” (2015), available at <https://www.cga.ct.gov/2015/juddata/tmy/2015HB-07015-R000318-Collins.%20Barbara-TMY.PDF>.

⁷⁷ See New York City Bar Association 2018 testimony to the New York State Assembly Health Committee, available at <https://s3.amazonaws.com/documents.nycbar.org/files/2017371-AidInDyingNYTestimonyMay2018.pdf>.

⁷⁸ American Academy of Family Physicians COD Addresses Medical Aid in Dying, Institutional Racism. (2018), available at <https://www.aafp.org/news/2018-congress-fmx/20181010cod-hops.html>.

⁷⁹ American Academy of Neurology position statement on Lawful Physician-Hastened Death. (2018), available at <http://n.neurology.org/content/90/9/420>.

Academy of Hospice and Palliative Medicine,⁸⁰ American Nurses Association,⁸¹ American Pharmacists Association,⁸² American Society for Health System Pharmacists,⁸³ and National Association of Social Workers.⁸⁴ The American Medical Association (AMA) and the National Hospice and Palliative Care Organization (NHPCO) both have taken positions opposing MAID.⁸⁵ However, they have updated their policies to clarify that it is ethical for a doctor to participate in MAID in an authorized state. The New York State Academy of Family Physicians—which represents more than 6,000 board-certified physicians, residents, and students in family medicine throughout New York—favored MAID in 2017⁸⁶ and currently lists as one of its 2023 priorities the enactment of MAID legislation.⁸⁷ Many state medical associations support MAID, including in Oregon,⁸⁸ California,⁸⁹ Colorado,⁹⁰ Vermont,⁹¹ Hawaii,⁹² Maine,⁹³ New Mexico,⁹⁴ and the District of Columbia.⁹⁵ Neutral stances were taken

⁸⁰ American Academy of Hospice & Palliative Medicine, excerpted from Statement on Physician-Assisted Death (2007), available at <http://aahpm.org/positions/pad>.

⁸¹ American Nurses Association, The Nurse’s Role When a Patient Requests Medical Aid in Dying (2019), revised position statement, available at <https://ojin.nursingworld.org/table-of-contents/volume-24-2019/number-3-september-2019/nurses-role-medical-aid-in-dying/>.

⁸² American Pharmacists Association, 2015 APhA House of Delegates, available at https://docksci.com/report-of-the-2015-apha-house-of-delegates_5a35bf67d64ab2ddfc6de3a7.html.

⁸³ American Society of Health-System Pharmacists, Board Report on the Joint Council Task Force on Pharmacist Participation in Medical Aid in Dying, (2016), available at <https://www.ashp.org/-/media/assets/house-delegates/docs/hod-board-report-on-task-force.ashx>.

⁸⁴ National Association of Social Workers, NASW Standards for Palliative and End of Life Care, available at <https://www.socialworkers.org/LinkClick.aspx?fileticket=xBMd58VwEhk%3D&portalid=0>.

⁸⁵ American Medical Association, Report 2 of the Council on Ethical and Judicial Affairs (2-A-19), Physician Assisted Suicide (Resolution 15-A-16 and Resolution 14-A-17) (2019), available at <https://www.ama-assn.org/system/files/2019-05/a19-ceja2.pdf>.

⁸⁶ New York State Assembly of Family Physicians Position on Medical Aid in Dying, available at <https://www.nysafp.org/2023/02/06/advocates-for-medically-assisted-death-renew-push-for-legalization/>.

⁸⁷ New York State Academy of Family Physicians, 2023 Priorities, available at <https://www.nysafp.org/wp-content/uploads/2023/09/NYSAFP-2023-Broad-Priorities-List.pdf>.

⁸⁸ Oregon Medical Association, excerpted from October 27 Board of Trustees Report, available at <http://bit.ly/2CYT6Dx>.

⁸⁹ California Medical Association Position on Medical Aid in Dying, available at <https://www.cmadoocs.org/newsroom/news/view/ArticleId/27210/California-Medical-Association-removes-opposition-to-physician-aid-in-dying-bill>.

⁹⁰ Colorado Medical Society, Position on Medical Aid in Dying, available at <https://www.compassionandchoices.org/resource/medical-associations-medical-aid-dying>.

⁹¹ Vermont Medical Society, Position on Medical Aid in Dying, (2017), available at <http://www.vtmd.org/sites/default/files/2017End-of-Life-Care.pdf>.

⁹² Hawaii Society of Clinical Oncology, Hawaii Our Care, Our Choice Act Resources (2018), available at <https://www.accc-cancer.org/state-societies/Hawaii/resources/medical-aid-in-dying>.

⁹³ Maine Medical Association (MMA) Position on Medical Aid in Dying, (2017), available at <http://newsmanager.commpartners.com/mainemed/issues/2017-05-01/index.html>.

⁹⁴ New Mexico Medical Society Position on Medical Aid in Dying (2019), available at https://d2zhgehghqjuwb.cloudfront.net/accounts/14766/original/2019_1_5_Council_Minutes_-_PENDING_APPROVAL.pdf?1547577653.

⁹⁵ Robert Lowes, Another State Medical Society Stops Fighting Assisted Death, Medscape (2017), available at https://www.medscape.com/viewarticle/889450?reg=1&icd=login_success_gg_match_norm.

by medical societies in Connecticut,⁹⁶ Maryland,⁹⁷ Massachusetts,⁹⁸ Minnesota,⁹⁹ Delaware,¹⁰⁰ and Virginia.¹⁰¹ While the Medical Society of the State of New York (MSSNY) has taken a position against MAID in the past,¹⁰² the organization has not filed a memorandum in opposition,¹⁰³ nor does it currently maintain a position statement on the New York bill.¹⁰⁴ In addition to the American College of Legal Medicine, five other national health organizations support MAID: American Medical Student Association,¹⁰⁵ American Medical Women's Association,¹⁰⁶ American Public Health Association,¹⁰⁷ GLMA: Health Professionals Advancing LGBT Equality,¹⁰⁸ and the National Student Nurses' Association.¹⁰⁹ In addition, the Coalition for Liberty and Justice, and SAGE¹¹⁰ (a national organization that provides services and advocacy for LGBT elders), have all endorsed MAID on a national level. In addition, these national Latino/a/x organizations support MAID: the Dolores Huerta Foundation,¹¹¹ Hispanic

⁹⁶ Connecticut State Medical Society Position on Medical Aid in Dying (2019), available at <https://www.cga.ct.gov/2019/PHdata/Tmy/2019HB-05898-R000318-Connecticut%20State%20Medical%20Society-TMY.PDF>.

⁹⁷ MEDCHI, The Maryland State Medical Society House of Delegates Position on Medical Aid in Dying (2016), available at <http://www.medchi.org/Portals/18/files/Events/Resolution%2016-16.pdf?ver=2016-08-26-140448-047>.

⁹⁸ Massachusetts Medical Society Position on Medical Aid in Dying (2017), available at <https://www.massmed.org/About/2017-Annual-Report/>.

⁹⁹ Minnesota Medical Association Position on Medical Aid in Dying (2017), available at <https://www.compassionandchoices.org/resource/medical-associations-medical-aid-dying>.

¹⁰⁰ MSD Support of Engaged Neutrality for Medical Aid in Dying (2022), available at <https://files.constantcontact.com/01c210be101/c65122d3-bb72-4b9c-a2f6-8563b3304710.pdf?rdr=true>.

¹⁰¹ The Medical Society of Virginia, 2022-2023 Policy Compendium, available at <https://www.msv.org/wp-content/uploads/2022/11/2022-2023-Policy-Compendium.pdf>.

¹⁰² Medical Society of the State of New York, MSSNY Statement Re: Medical Aid in Dying (May 14, 2019), available at <https://www.mssnynews.org/enews/mssny-statement-re-medical-aid-in-dying>.

¹⁰³ See MSSNY Memos in Support and Opposition, 2019 - present, available at <https://www.mssny.org/take-action/memos-in-support-and-opposition>.

¹⁰⁴ See MSSNY Division of Governmental Affairs, 2023 MSSNY Legislative Program, available at <https://www.mssny.org/wp-content/uploads/2023/01/MSSNY-2023-Legislative-Program.pdf>.

¹⁰⁵ American Medical Student Association, excerpted from Preambles, Purposes, Principles: Principles Regarding Physician Aid in Dying (2008), available at <http://www.amsa.org/wp-content/uploads/2015/03/PPP-2015.pdf>.

¹⁰⁶ American Medical Women's Association, from Position Paper on Aid in Dying, available at <https://www.amwa-doc.org/wp-content/uploads/2018/09/Medical-Aid-in-Dying-Position-Paper.pdf>.

¹⁰⁷ American Public Health Association, excerpted from Patient's Rights to Self-Determination at the End. Policy # 20086 (2008), available at <https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2014/07/29/13/28/patients-rights-to-self-determination-at-the-end-of-life>.

¹⁰⁸ GLMA Letter of Support on AB X2-15, (2015), available at <https://compassionandchoices.org/docs/default-source/california/20151002-glma-letter-in-support-of-ca-eoloa.pdf>.

¹⁰⁹ National Student Nurses' Association, NSNA Resolutions (2018), available at <https://www.dropbox.com/s/8xwq5f827leqriq/NSNA%20Resolutions%202018.pdf?dl=0>.

¹¹⁰ Nation's Largest LGBT Elders Group Endorses Medical Aid-in-Dying Laws (2019), available at <https://www.sageusa.org/news-posts/nations-largest-lgbt-elders-group-endorses-medical-aid-in-dying-laws/>.

¹¹¹ Dolores Huerta Foundation, 2021 Fall WMNL: People Powered Legislative wins, available at <https://www.doloreshuerta.org/2021-fall-wmnl-people-powered-legislative-wins/>.

Health Network,¹¹² Latino Commission on AIDS,¹¹³ Latinos for Healthcare Equity,¹¹⁴ National Hispanic Council on Aging,¹¹⁵ and Nuestra Salud.¹¹⁶

National groups that have taken a position against MAID include the American Association of People with Disabilities, American College of Medical Quality, American Disabled for Attendant Programs Today (ADAPT), American Medical Association, American Medical Directors Association, American Nurses Association, Arc of the United States, Association for Persons with Sever Handicaps (TASH), Disability Rights Education and Defense Funds (DREDF), National Council on Disability, National Council on Independent Living, National Hospice & Palliative Care Organization, National Spinal Cord Injury Association, Not Dead Yet, Patient’s Rights Action Fund, Patient’s Rights Council (PRC), Physicians for Compassionate Care Education Foundation, and the United Spinal Association.¹¹⁷

This report focuses on New York’s proposed law and the laws in MAID jurisdictions in this country and does not examine MAID laws in other countries because of the vast differences in eligibility that have largely been rejected in the United States.¹¹⁸ Unlike in some other countries, U.S. laws require that the patients make their own health care decisions; request the medication themselves, multiple times; and ingest the medication themselves. In addition, U.S. laws do not allow euthanasia, where the medical provider injects the medication through intravenous administration; do not allow a person to make the request in an advance directive; and are restricted to patients with a terminal disease, meaning that they have a prognosis of six months or less to live, and therefore are eligible for hospice care. Other countries permit people who are merely “suffering” to use MAID.¹¹⁹

New York’s Bill and Other MAID Laws

The proposed New York MAID law is similar in many ways to the MAID statutes in the other jurisdictions.¹²⁰ Appendix IV, Exhibit A reveals that 10 jurisdictions have a statutory framework, whereas Montana’s MAID was authorized through a state Supreme Court decision, which found that a competent terminally ill patient had a fundamental right to die with dignity by self-ingesting

¹¹² Latino Health Groups Endorse NY Medical Aid-in-Dying Bill, PR Newswire (February 14, 2018), available at <https://www.prnewswire.com/news-releases/latino-health-groups-endorse-ny-medical-aid-in-dying-bill-300598881.html>.

¹¹³ *Id.*

¹¹⁴ *Id.*

¹¹⁵ Yanira Cruz, All Americans should have access to all end-of-life care options, The Hill (October 28, 2017), available at <https://thehill.com/opinion/healthcare/357575-all-americans-should-have-access-to-all-end-of-life-care-options/>.

¹¹⁶ Jorge L. Otero, President Nuestra Salud, Letter to Governor Lujan Grisham and Members of the New Mexico Legislature (January 1, 2019), available at <https://endoflifeoptionsnm.org/wp-content/uploads/2019/01/Nuestra-Salud-letter-to-EOLO-03JAN19.pdf>.

¹¹⁷ See New York Alliance Against Assisted Suicide, National Organizations in Opposition, available at nosuicideny.org/about.

¹¹⁸ Megan Wright & Cindy L. Cain, Different MAID Laws, Different MAID Outcomes: Expected Rather Than “Disturbing.” The American Journal of Bioethics, 23(11), 92–94 (October 2023), available at <https://doi.org/10.1080/15265161.2023.2256288>.

¹¹⁹ *Id.*

¹²⁰ See Appendix IV to this report, Exhibit A, State-by-State Comparison Chart (November 2023).

medication prescribed by a physician.¹²¹ Consistent with other MAID jurisdictions, the New York legislation requires that an eligible person be an adult aged 18 or older; confirmed by two physicians to be terminally ill; have a prognosis of six months or less to live; be able to self-administer the medication; and be capable of making health care decisions.

One difference in language in New York’s bill as compared to other MAID laws is that here, a person must have “decision making capacity,” whereas most other laws provide that the person must be “mentally capable of making a decision.” This difference in language does not materially change the law; it simply aligns the New York MAID language with the terminology used in other New York public health laws. Like the laws in other states, the New York law also outlines a thorough process for a patient to be able to access the law. This includes requirements that a physician:

- makes the initial determination that a patient has a terminal disease, is capable, and has made the request voluntarily;
- ensures that the patient is making an informed decision;
- refers the patient to a consulting provider who confirms the diagnosis and for a determination that the patient is capable and acting voluntarily;
- counsels the patient about the importance of having another person present when taking the prescription;
- counsels the patient about not taking the prescription in a public place;
- explains that the patient may rescind the request at any time and in any manner;
- verifies, before writing a prescription for medication, that the patient is making an informed decision;
- recommends that the patient notifies their next of kin.

In addition, the New York legislation, like most other MAID statutes:

- requires that an additional request be made in writing, signed, and dated by the patient and witnessed by at least two individuals and neither of whom can benefit from the patient’s estate;
- requires the safe disposal of medication;
- provides immunity for actions in good faith. (“A person is not subject to civil or criminal liability or professional disciplinary action for acting in good faith under this article, which includes being present when a qualified individual self-administers the prescribed MAID medication.”)

In 2023, three states brought constitutional challenges to the residency requirements that prevented out-of-state patients from accessing MAID. Vermont’s legislature approved an amendment eliminating the requirement and became the first state to provide MAID to qualifying out-of-state residents.¹²² Oregon’s legislature removed the residency requirement following a lawsuit.¹²³ An

¹²¹ See *Baxter v. Montana*, 224 P.3d 1211, 354 Mont. 234 (2009).

¹²² Vermont Death With Dignity (2023), available at <https://deathwithdignity.org/states/vermont/>.

¹²³ A Big Step Forward: Oregon Legislature Moves to Remove Residency Requirements (2023), available at <https://deathwithdignity.org/news/2023/06/or-residency-requirement/>.

action in federal court in New Jersey is pending.¹²⁴ Like the Vermont and Oregon laws, the New York bill does not require that a patient prove residency.

MAID Jurisdiction Reports

A summary below sets forth data from nine MAID jurisdictions: Oregon,¹²⁵ Washington,¹²⁶ Vermont,¹²⁷ California,¹²⁸ Colorado,¹²⁹ Hawaii,¹³⁰ the District of Columbia,¹³¹ New Jersey,¹³² and Maine.¹³³ Because Montana's law was authorized by judicial decision, that state's department of health is not required to issue a report to the state legislature; and New Mexico data was not available. Our review of the data is attached as Appendix IV, Exhibit B: Comparing the Reports. Here are noteworthy national trends:

- Less than 1% of the people who die in each jurisdiction use the law each year.¹³⁴ In total, 10,025 MAID prescriptions were written across all jurisdictions. Two-thirds of people (6,378) used the prescription. Seventy-five percent of people who use MAID are 65 or older, split nearly evenly between men (52%) and women (48%).
- The rate at which Asian, Black, Hawaiian/Pacific Islander, Hispanic, Indigenous American/Alaskan Native, Latino/a/x, and multi-race people access and use prescriptions under MAID laws is consistently lower than for white populations.
- Terminal cancer accounts for most qualifying diagnoses, with neurodegenerative diseases following as the second leading diagnosis.

¹²⁴ NJ Doctors, DE, PA Patients File Lawsuit Challenging Residency Mandate in NJ MAID Law (2023), available at <https://www.compassionandchoices.org/news/nj-residency>.

¹²⁵ Oregon Death with Dignity Act Annual Reports (2022), Year 25 Data, available at <https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx>.

¹²⁶ Washington Death with Dignity Data (2022), available at <https://doh.wa.gov/sites/default/files/2023-10/422-109-DeathWithDignityAct2022.pdf>.

¹²⁷ Vermont Report Concerning Patient Choice at the End of Life. (2022), available at <https://legislature.vermont.gov/assets/Legislative-Reports/2022-Patient-Choice-Legislative-Report.Final.pdf>.

¹²⁸ California End of Life Option Act Annual Report (2022), available at https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/CDPH_End_of_Life%20Option_Act_Report_2022_FINAL.pdf.

¹²⁹ Colorado End of Life Options Act Annual Report (2022), available at <https://drive.google.com/file/d/1DLML5hCvII0Udvt0vCalCziN9g9Lhgf9/>; <https://www.colorado.gov/pacific/cdphe/medical-aid-dying>.

¹³⁰ Hawaii Our Care, Our Choice Act Annual Report (2022), available at <https://health.hawaii.gov/opppd/files/2022/07/corrected-MAID-2021-Annual-Report.pdf>.

¹³¹ District of Columbia Death with Dignity Act Annual Report (2021), available at <https://dchealth.dc.gov/sites/default/files/dc/sites/doh/publication/attachments/2021%20Death%20with%20Dignity%20Annual%20Report.pdf>.

¹³² New Jersey Medical Aid in Dying for the Terminally Ill Act Data Summary (2022), available at <https://www.nj.gov/health/advancedirective/documents/MAID/MAIDAnnualReport2022.pdf>.

¹³³ Maine Patient Directed Care at End of Life Annual Report (2022), available at <https://legislature.maine.gov/doc/10118>.

¹³⁴ According to the Center for Disease Control, in 2019 in jurisdictions that authorized MAID, 427,296 people died in total. In 2019, authorized jurisdictions report 1,027 people died after being provided with a prescription for MAID—less than 0.002% of total deaths in 2019. Center for Disease Control, Deaths: Final Data for 2019, July 26, 2021, available from: https://stacks.cdc.gov/view/cdc/106058/cdc_106058_DS1.pdf.

- More than 87% of terminally ill people who use MAID received hospice services at the time of their deaths in the five states (Oregon, Washington, California, Colorado, and Hawaii) that collect hospice data.¹³⁵
- Just over 90% of people who use MAID can die at home—which is the preference of most Americans, according to various studies.¹³⁶

Since 1997, the Oregon Health Authority (OHA) has published an annual statistical report about its MAID law, the DWDA.¹³⁷ The data is based on mandatory reporting forms and death certificates. Given that Oregon has 25 years of reported data, collects more data than any other state, and has a statutory framework like New York’s bill, the OHA report may provide a meaningful indication of what we can expect if MAID is implemented here. Since the DWDA was passed in 1997, 3,712 people have received prescriptions, and 66% of them (2,454 people) have died from ingesting the medication.¹³⁸ An estimated 0.6% of total deaths were DWDA deaths.¹³⁹ During 2022, 431 people received prescriptions, and 278 people ingested the medication.¹⁴⁰ OHA referred no physicians for failure to comply with the reporting requirements to the Oregon Medical Board.¹⁴¹

As was the case in previous years, most patients were 65 years or older (85%) and white (96%) with a diagnosis of cancer (64%), followed by heart disease (12%) and neurological disease (10%).¹⁴² Nine out of 10 patients died at home (92%) and had enrolled in hospice care (91%).¹⁴³ Excluding unknown cases, all patients had health insurance.¹⁴⁴ The three most common reasons for using MAID were decreasing ability to participate in activities that made life enjoyable (89%), loss of autonomy (86%), and loss of dignity (62%).¹⁴⁵ In 2022, 146 physicians wrote 431 prescriptions.¹⁴⁶ In 2022, 70% of ingestions involved the drug combination DDMAPH, which consists of diazepam, digoxin, morphine sulfate, amitriptyline, and phenobarbital.¹⁴⁷ DDMAPH had a median time until death of 42 minutes.¹⁴⁸ Twenty-eight percent of ingestions used the drug combination DDMA, consisting of diazepam, digoxin, morphine sulfate, and amitriptyline.¹⁴⁹

¹³⁵ See Appendix IV to this report, Exhibit B, Comparing the Reports Chart (November 2023).

¹³⁶ See Kaiser Family Foundation, Views, and Experiences with End-of-Life Medical Care in the U.S. (April 27, 2017) available at <https://www.kff.org/report-section/views-and-experiences-with-end-of-life-medical-care-in-the-us-findings/>.

¹³⁷ See Oregon Health Authority, Death with Dignity Annual Reports, available at <https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx>.

¹³⁸ *Id.*

¹³⁹ *Id.*

¹⁴⁰ *Id.*

¹⁴¹ *Id.*

¹⁴² *Id.*

¹⁴³ *Id.*

¹⁴⁴ *Id.*

¹⁴⁵ *Id.*

¹⁴⁶ *Id.*

¹⁴⁷ *Id.*

¹⁴⁸ *Id.*

¹⁴⁹ *Id.*

DDMA has a median time until death of 49 minutes.¹⁵⁰ Both drugs show longer median times until death than the barbiturates secobarbital and pentobarbital, which are no longer readily available.¹⁵¹

MAID Studies

At the footnotes to this section are citations to selected literature and health and public health data concerning MAID laws. Studies have examined (1) whether these laws ensure that a person who chooses the option of MAID is free from coercion by an agent or agents; and (2) the impact these laws have on families, healthcare providers, nursing homes, and correctional facilities. The evidence confirms what the Task Force heard from experts: even with availability of hospice and palliative care, many patients experience pain at the end of their life.¹⁵² One study found that the prevalence of pain jumps from 26% in the last 24 months of life to 46% in the last four months of life.¹⁵³ Additionally, breakthrough pain—severe pain that erupts even when a patient is already medicated—remains a reality for many patients. In the National Breakthrough Pain Study, among respondents who had cancer, 83.3% reported breakthrough pain.¹⁵⁴ For cancer patients who experienced breakthrough pain, only 24.1% reported that using pain management worked every time.¹⁵⁵

One of the biggest ethical questions that arises with MAID is whether legalization will lead to abuse and/or coercion. With more than 25 years of experience across 11 jurisdictions, to our knowledge there have been no reports of abuse or coercion in a relational or interactional context involving a person or agent being coerced by another person or agent who is doing the coercing. Moving beyond such forms of relational or interactional coercion, consideration of forms of structural or systemic coercion will be addressed later in this report.

Most experts who appeared before the Task Force indicated that they were not aware of any reports of abuse and/or coercion in MAID jurisdictions. A 2015 report from the *Journal of the American Academy of Psychiatry and Law* noted: “There appears to be no evidence to support the fear that assisted suicide [MAID] disproportionately affects vulnerable populations.”¹⁵⁶ However, the authors do note that there is no conclusive evidence about the impact of legalized assisted suicide on vulnerable patients and that such would require more complex studies. As Art Caplan, a renowned bioethicist who originally opposed aid in dying laws, has said:

¹⁵⁰ *Id.*

¹⁵¹ *Id.*

¹⁵² Kate M. Tredgett, Pain Control in Palliative Care, *Medicine*, Volume 50, Issue 12, December 2022, Pages 755–761, available at [https://medicinejournal.co.uk/issue/S1357-3039\(22\)X0012-1](https://medicinejournal.co.uk/issue/S1357-3039(22)X0012-1).

¹⁵³ Alexander K. Smith, et al., The Epidemiology of Pain During the Last 2 Years of Life, *The Annals of Internal Medicine* (2010), available at <http://annals.org/aim/article/746344/epidemiology-pain-during-last-2-years-life>.

¹⁵⁴ Nathaniel P. Katz, et al., Impact of breakthrough pain on community-dwelling cancer patients: results from the National Breakthrough Pain Study. *Postgraduate Medicine*, 129(1), 32–39 (2016), available at <https://pubmed.ncbi.nlm.nih.gov/27846789/>.

¹⁵⁵ *Id.*

¹⁵⁶ Abilash A. Gopal, Physician-Assisted Suicide: Considering the Evidence, Existential Distress, and an Emerging Role for Psychiatry. *Journal of the American Academy of Psychiatry and the Law*. 2015. Vol 43(2): 183–190 (2015), available at <http://jaapl.org/content/43/2/183>.

“Since the time I first opposed physician aid in dying [PAD] more than two decades ago I have closely followed the empirical evidence gathered in Oregon and later in the state of Washington about Death with Dignity legislation. I found no cause for my concerns—none. The police, government officials, families of those who have died, and the citizenry find no cause or basis for changing the laws due to abuse or misapplication. In fact, most critics of PAD do not live in or have first-hand experience of how the legislation has played out. Nor do they present convincing evidence sufficient to undermine official reports and the satisfaction with the way the legislation is working in either state.”¹⁵⁷

The current Oregon model, which laid the foundation for all the other MAID laws, requires a lengthy multistep process.¹⁵⁸ It often takes the dying person several weeks to several months to complete the steps, and many die before doing so. Unfortunately, according to testimony heard by the Task Force, many patients suffer needlessly while navigating the process. Challenges include:

- Late enrollment in hospice. Many terminally ill patients do not receive their six-month prognosis until they have far less than six months to live. One study of patients with advanced cancer found that predictions were accurate in only 41% of cases.¹⁵⁹
- Locating supportive providers. MAID laws allow health care systems and doctors to “opt-out” of providing this care. This restriction means that any patient whose doctor works at an institution that opts out will have to reestablish care in a supportive health system and find two supportive doctors before they can begin the process of qualifying for MAID.
- Providers who do not support MAID. Some doctors who object to the practice believe they should not have to transfer a patient’s medical records.

MAID Law Amendments

After implementing their bills and reviewing their data, five state legislatures (Oregon, Vermont, California, Washington, and Hawaii) amended their laws and streamlined the process, while maintaining strict eligibility criteria. In addition, New Mexico passed a more balanced law from the outset. Some of the improvements made include:

- Waiting Period. The trend is to reduce or eliminate the waiting period. In 2019, the Oregon Legislature amended their law to allow doctors to waive the 15-day waiting period between the two required oral requests and the 48-hour waiting period if they determined and attested that the patient was likely to die while waiting.¹⁶⁰ After the amendment, 21% of

¹⁵⁷ Art Caplan on New York’s Medical Aid in Dying Law, available at https://compassionandchoices.sitefinity.cloud/docs/default-sonource/60-reasons-cc_60reasons_onesheet_artcaplan_01.pdf?sfvrsn=ed04cfe7_1.

¹⁵⁸ See Oregon Death with Dignity Act.

¹⁵⁹ Robert Gramling, et al, Palliative Care Clinician Overestimation of Survival in Advanced Cancer: Disparities and Association with End-of-Life Care, *Journal of Pain and Symptom Management*, 58(4), e19-e20 (2019), available at <https://www.sciencedirect.com/science/article/abs/pii/S0885392418310571>.

¹⁶⁰ Senate Bill 579, 80th Oregon Legislative Assembly—2019 Regular Session, available at <https://olis.oregonlegislature.gov/liz/2019R1/Downloads/MeasureDocument/SB579>.

patients required a physician exemption to make it through the process.¹⁶¹ In 2021, the California legislature amended the California End of Life Option Act to decrease the waiting period between the two oral requests from 15 days to 48 hours. Additionally, the request for the final attestation has been eliminated. The original law required that the form be filled out and executed by the qualified individual within 48 hours prior to the qualified individual choosing to self-administer the drug.¹⁶²

In 2021, the Vermont legislature amended the Vermont Patient Choice and Control at the End of Life Act to remove a waiting period at the end of the request process.¹⁶³ The New Mexico law requires just one written request, so there is no waiting period related to requests. However, the law requires a 48-hour waiting period between receiving and filling a prescription for MAID medication but allows a qualified clinician to waive the waiting period if a person is going to imminently die.¹⁶⁴

In 2023, the Washington legislature amended the Washington Death with Dignity Act (DWDA) to reduce the waiting period between a patient's first and second oral request for the medication from 15 to 7 days.¹⁶⁵ In 2023, the Hawaii legislature amended the Our Choice, Our Care Act to reduce the mandatory waiting period between the two oral requests required for a qualified patient to obtain a prescription for medication from 20 days to five days. It also allows providers to waive the mandatory minimum waiting period for terminally ill qualified patients who are not expected to survive the five-day waiting period.¹⁶⁶

- Qualified Prescribing or Consulting Health Care Providers. New Mexico also expanded its definition of qualified provider to include advanced practice registered nurses (APRNs) and physician assistants (PAs), who may act as either the prescribing or consulting health care provider so long as a physician acts as the other provider.¹⁶⁷ New Mexico does not require confirmation of eligibility for MAID by a consulting provider if the person is enrolled in a Medicare-certified hospice program.¹⁶⁸ In 2023, Washington

¹⁶¹ Oregon Death with Dignity Act, Annual Report (2020), available at <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year23.pdf>; see also Oregon Death with Dignity Act. Annual Report, (2021), available at <https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx>.

¹⁶² California SB 380 End of Life Option Act. Enacted October 2021, available at https://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_id=202120220SB380.

¹⁶³ Vermont S 74 Enacted in 2021, available at https://www.patientchoices.org/uploads/6/1/7/1/61710711/s.74_as_of_2-22-21.pdf.

¹⁶⁴ The Elizabeth Whitefield End-of-Life Options Act (2021), available at <https://www.nmhealth.org/publication/view/general/8382/>.

¹⁶⁵ Washington State Legislature, Engrossed Substitute Senate Bill 5179 (April 6, 2023), available at <https://lawfilesexxt.leg.wa.gov/biennium/2023-24/Pdf/Bills/Session%20Laws/Senate/5179-S.SL.pdf?q=20230510092955>.

¹⁶⁶ Hawaii House Bill 650 (signed June 1, 2023), available at https://www.capitol.hawaii.gov/session/measure_indiv.aspx?billtype=HB&billnumber=650&year=2023.

¹⁶⁷ The Elizabeth Whitefield End-of-Life Options Act (2021), available at <https://www.nmhealth.org/publication/view/general/8382/>.

¹⁶⁸ *Id.*

authorized APRNs and PAs to act as the attending or consulting medical provider for individuals who want to access the DWDA.¹⁶⁹ A physician would still have to be one of the other providers in either case. In 2023, Hawaii authorized qualified APRNs to be attending health care providers.¹⁷⁰

- **Mental Health Capacity.** Most MAID jurisdictions require a mandatory mental health evaluation by a psychiatrist or psychologist if either provider expresses concerns about capacity. In Vermont, New Jersey, and Maine, clinical social workers are also able to make the assessment; and in New Mexico, master social workers, psychiatric nurse practitioners, and professional clinical mental health counselors can make the assessment. In 2023, Hawaii authorized licensed APRNs and clinical nurse specialists with psychiatric or mental health training and licensed marriage and family therapists to provide mental health counseling to qualified patients to determine if they can make an informed decision before they get a prescription.¹⁷¹

Impact on End-of-Life Experience

In one study, Colorado physicians who have supported patients through the MAID process largely reported the experience to be “emotionally fulfilling and professionally rewarding,” despite barriers to offering the end-of-life care option.¹⁷² The finding was confirmed by medical professionals who testified before the Task Force. Several studies concluded that MAID contributes to improvements in other end-of-life care options.¹⁷³ The findings from the studies were likewise confirmed by statements from people who testified before the Task Force. An Oregon survey showed that 30% of responding physicians had increased the number of referrals they provided for hospice care, and 76% made efforts to improve their knowledge of pain management.¹⁷⁴ A 2015 Journal of Palliative Medicine study found that the Oregon DWDA may have contributed to more open conversations between doctors and patients about end-of-life care options, which led to more appropriate hospice use options.¹⁷⁵ Hospice programs across Oregon reported an increase in referrals following passage of the Oregon DWDA.¹⁷⁶ More than 20 years

¹⁶⁹ Washington State Legislature, Engrossed Substitute Senate Bill 5179 (April 6, 2023), available at <https://lawfilesexxt.leg.wa.gov/biennium/2023-24/Pdf/Bills/Session%20Laws/Senate/5179-S.SL.pdf?q=20230510092955>.

¹⁷⁰ Hawaii House Bill 650 (signed June 1, 2023), available at https://www.capitol.hawaii.gov/session/measure_indiv.aspx?billtype=HB&billnumber=650&year=2023.

¹⁷¹ See Appendix IV to this report, Exhibit A, State-by-State Comparison Chart.

¹⁷² Eric G. Campbell, et al., Physicians' Attitudes and Experiences with Medical Aid in Dying in Colorado: a "Hidden Population" Survey, *Journal of General Internal Medicine* 37(13):3310–3317 (October 2022), available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8751472>.

¹⁷³ Melinda A. Lee, MD & Susan W. Tolle, MD., Oregon's Assisted Suicide Vote: The Silver Lining. *Annals of Internal Medicine*, M.A. Lee, S.W. Tolle, (1996), available at https://www.acpjournals.org/doi/10.7326/0003-4819-124-2-199601150-00014?url_ver=Z39.88-2003&rft_id=ori:rid:crossref.org&rft_dat=cr_pub%20%20pubmed.

¹⁷⁴ Linda Ganzini, et al., Oregon Physicians' Attitudes About and Experiences with End-of-Life Care Since Passage of the Oregon Death with Dignity Act, *Journal of the American Medical Association* (2001), available at <https://pubmed.ncbi.nlm.nih.gov/11343484/>.

¹⁷⁵ Shi-Yi Wang, et al., Geographic Variation of Hospice Use Patterns at the End of Life. *Journal of Palliative Medicine*, 18(9), 771–780 (2015), available at <https://doi.org/10.1089/jpm.2014.0425>.

¹⁷⁶ *Id.*

later, about 90% of those who used MAID were receiving hospice services at the time of their death.¹⁷⁷ Data show that the majority of eligible patients involve their family in their decision-making process.¹⁷⁸ Most patients have someone present at some point during their planned death, which sometimes may help to mitigate families' grieving, according to Oregon data.¹⁷⁹

V. INEQUITIES IN ACCESS

Structural Inequities

It is well documented that there are persistent structural inequities in the U.S. health care system based on race, ethnicity, gender, age, disability, and other categories. Importantly, structural racism, ageism, ableism, and a continuum of inequities have a significant influence on the way people live and their health outcomes. These conditions outside the health sector, such as income level; neighborhood or community resources; access to water, housing, food, and transportation; educational attainment and health literacy; language; employment status; and immigration status, are known as social determinants of health. Social determinants of health have an important relationship to health and health outcomes. For example, low income or unemployment; living in an under-resourced community with limited access to nutritious food or clean water; unstable housing or homelessness; low educational attainment and health literacy; incarceration or being detained in jails on account of immigration status; or residing in a highly-regulated and restrictive institutional setting increase risks of marginalization and structural vulnerability and significantly constrain the choices people make in pursuit of a meaningful life. In some cases, such structural and systemic conditions and power inequities may contribute to a coercive environment for persons who are so marginalized and further constrain their freedom in grappling with choices and decisions about end-of-life care.

There are also very serious concerns that structural inequities and disparities will be perpetuated and will significantly affect how broadly and equitably people will be able to access MAID if the law is enacted here. Several groups conveyed to the Task Force their concerns about risks MAID would pose to persons of color; persons with disabilities; older adults; persons residing in institutional settings, including carceral facilities, nursing homes, and other long-term care institutions; and immigrants being detained in New York jails or prisons under contract with U.S. Immigration and Customs Enforcement.

One of the primary concerns considered by the Task Force was the impact of structural racism on health care. The Centers for Disease Control and Prevention has predicted that by 2030, the U.S. population will age considerably and become more racially and ethnically diverse.¹⁸⁰ Further, New York has the second largest Black population in the country.¹⁸¹ Income, wealth, and education

¹⁷⁷ *See id.*

¹⁷⁸ *Id.*

¹⁷⁹ *Id.*

¹⁸⁰ Centers for Disease Control and Prevention, *Minority Health*, available at <https://www.cdc.gov/minorityhealth/>.

¹⁸¹ NYSBA Task Force on Racism, Social Equity, and the Law (2023).

affect health care outcomes;¹⁸² and a lack of access to these benefits can harm the minority population's health care.¹⁸³ To ensure equal access to MAID, policymakers must address racial disparities and inequities.¹⁸⁴ In MAID jurisdictions such as Oregon and Washington, data indicate that 95.6% of non-Hispanic whites with higher education and higher income levels are more likely to access MAID than Blacks and Hispanics.¹⁸⁵ Low minority utilization of palliative care and MAID has led to the mistaken assumptions that these populations have no desire to take advantage of such medical options. The reality is that minority populations are severely marginalized by socioeconomic and other barriers.

“Medical deserts” constitute structural barriers to quality end-of-life. Black people and Hispanics are more likely to live in under-resourced neighborhoods.¹⁸⁶ Minorities with lower incomes are more likely to be covered by Medicaid or be uninsured and to lack resources needed to cover high out-of-pocket costs. Since Medicaid has a lower reimbursement rate than private health insurance, minority neighborhoods are less appealing to health care institutions, contributing to the shortage of services in minority neighborhoods.¹⁸⁷ Nursing homes and hospitals serving minority communities are at greater risk of closure and reductions in services compared to those serving white communities.¹⁸⁸ Additionally, minority neighborhoods are less likely to have adequate supplies of opioids.¹⁸⁹ False beliefs concerning the biological differences between Blacks and whites may inform medical judgments. Black people are less satisfied with the quality of end-of-life care and pain management.¹⁹⁰

“People of color are experiencing the dying process differently, in part because of their lack of access and usage of quality of end-of-life care. Informing, educating, and listening to people of color to ensure their decisions fit their priorities and values is critical, particularly during the end-of-life process. Inclusive programs and materials can only help to empower all,”¹⁹¹ according to an organization devoted to expanding end-of-life options. Aside from provider biases and stereotypes, cultural differences contribute to barriers in communication between patients and

¹⁸² Braveman P., Gottlieb L. The social determinants of health: it's time to consider the causes of the causes. *Public Health Rep.* 2014;129 Suppl 2 (Suppl 2):19–31. doi:10.1177/00333549141291S206

¹⁸³ Healthy People 2030, Social Determinants of Health, available at <https://health.gov/healthypeople/priority-areas/social-determinants-health>.

¹⁸⁴ Gardner, D. S., Doherty, M., Bates, G., Koplow, A., & Johnson, S. (2018). Racial and Ethnic Disparities in Palliative Care: A Systematic Scoping Review. *Families in Society*, 99(4), 301–316, available at <https://doi.org/10.1177/1044389418809083>.

¹⁸⁵ Aggregating 23 years of data on MAID in the United States, <https://agsjournals.onlinelibrary.wiley.com/doi/full/10.1111/jgs.17925#:~:text=An%20estimated%2074%20million%20people,is%20on%20the%20legislative%20agenda>.

¹⁸⁶ American Psychological Association, Ethnic and Racial Minorities & Socioeconomic Status <https://www.apa.org/pi/ses/resources/publications/minorities>.

¹⁸⁷ Gaskin, Darrell J et al. “Residential segregation and the availability of primary care physicians.” *Health services research* vol. 47,6 (2012): 2353–76. doi:10.1111/j.1475-6773.2012.01417.x <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3416972/>.

¹⁸⁸ *Id.*

¹⁸⁹ McCleskey, Sara G, and Cindy L Cain. “Improving End-of-Life Care for Diverse Populations: Communication, Competency, and System Supports.” *The American journal of hospice & palliative care* vol. 36,6 (2019): 453–459. doi:10.1177/1049909119827933

¹⁹⁰ Kelly M. Hoffman et al., Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites, available at <https://www.pnas.org/doi/10.1073/pnas.1516047113>.

¹⁹¹ <https://www.compassionandchoices.org/news/people-of-color-need-better-access-to-all-end-of-life-care-options>.

providers. Communication differs by race, which influences the extent to which providers listen and share information with patients. Thus, discussions between patient and provider may be less likely to result in care that reflects preferences of minority patients. Recommendations to address such concerns include patient educational programs to increase knowledge on how to access health care and participate in treatment decisions; cross-cultural training for current and future health care professionals; subsidies that compensate hospitals and medical providers in minority communities for low Medicaid reimbursement rates; and direct governmental investment in adequate health care institutions in minority communities. Some of these solutions are addressed in Section VI, *infra*, on Coverage and Training.

Inequities in the LGBTQ Community

The Task Force also heard testimony about disparities in health care experienced by the LGBTQ community.¹⁹² Structural barriers include stigma and discrimination, health care access and insurance, economic inequities, mental health challenges, violence, and victimization, limited cultural competence in health care, barriers to reproductive health services, and substance use and HIV risk. Certain LGBTQ populations face higher rates of HIV due to several factors, including stigma, lack of comprehensive sex education, and barriers to health care access.¹⁹³

Although new diagnoses of HIV in New York have decreased by 46% from 2011 to 2021, of the 103,900 individuals living with diagnosed HIV, 75% were at least 40 years of age and 57% were 50 years or older.¹⁹⁴ This population includes long-term survivors of HIV/AIDS, or individuals who were diagnosed prior to the advent of antiretroviral therapy in 1996. Many of these individuals are likely to experience consequences from untreated HIV or side effects from other comorbidities of the disease, some of which include cardiovascular disease, cancer, and osteoporosis.¹⁹⁵

There are many reasons for the disparities. First, negative attitudes about LGBTQ individuals may lead to social isolation and discrimination.¹⁹⁶ This discourages individuals from seeking health care or disclosing their sexual orientation or gender identity to providers.¹⁹⁷ Laws and policies that discriminate against LGBTQ individuals can limit access to health care, employment, and housing,

¹⁹² See generally Gary L. Stein et al., Project Respect: experiences of seriously ill LGBTQ+ patients and partners with their health care providers, 1 HEALTH AFFAIRS SCHOLAR 4 (Oct. 2023).

¹⁹³ See *Braidwood Mgmt. v. Becerra*, No. 4:20-cv-00283-O, 2023 WL 2703229 (N.D. Tex. Mar. 30, 2023) (finding that mandating the coverage of medication taken to prevent the spreading of HIV, pre-exposure prophylaxis (PrEP), violates the Religious Freedom Restoration Act).

¹⁹⁴ New York State HIV/AIDS Annual Surveillance Report 2021, 2022.

https://www.health.ny.gov/diseases/aids/general/statistics/annual/2021/2021_annual_surveillance_report.pdf

¹⁹⁵ www.gmhc.org. “Older Adults and Long-Term Survivors of HIV/AIDS - GMHC.” GMHC, August 11, 2020.

¹⁹⁶ See e.g. *303 Creative LLC v. Elenis*, 600 U.S. 570, 637 (2023) (Sotomayor, J. dissenting) (“By issuing this new license to discriminate in a case brought by a company that seeks to deny same-sex couples the full and equal enjoyment of its services, the immediate, symbolic effect of the decision is to mark gays and lesbians for second-class status. In this way, the decision itself inflicts a kind of stigmatic harm, on top of any harm caused by denials of service.”).

¹⁹⁷ *Id.* (“Ask any LGBT person, and you will learn just how often they are forced to navigate life in this way. They must ask themselves: If I reveal my identity to this co-worker, or to this shopkeeper, will they treat me the same way? If I hold the hand of my partner in this setting, will someone stare at me, harass me, or even hurt me? It is an awful way to live.”)

thus contributing to health disparities. Second, some health care systems lack policies that address the needs of LGBTQ individuals, leading to inadequate and culturally insensitive care. Transgender individuals face challenges in accessing gender-affirming care due to bans on that care¹⁹⁸ or insurance exclusions.

Third, LGBTQ individuals experience employment discrimination, leading to higher unemployment and lower income.¹⁹⁹ This results in reduced access to quality health care. Likewise, discrimination in housing leads to homelessness or unstable living conditions. Fourth, LGBTQ individuals experience higher rates of depression, anxiety, and suicide.²⁰⁰ LGBTQ individuals are also more than twice as likely to have a mental health disorder in their lifetime.²⁰¹ Fifth, LGBTQ individuals face higher rates of violence.²⁰² This has profound effects on physical and mental health. Sixth, many providers lack training in LGBTQ cultural competence. LGBTQ individuals frequently avoid seeking health care due to fear of discrimination²⁰³ or lack of understanding from providers. Seventh, LGBTQ individuals may face barriers to reproductive health services, including family planning, fertility treatments, and adoption services.²⁰⁴

Finally, LGBTQ individuals are at a higher risk of substance use. Certain LGBTQ populations face higher rates of HIV due to several factors, including stigma, lack of comprehensive sex education, and barriers to health care access. Individuals living with HIV must receive lifelong treatment to suppress the virus. For an LGBTQ person with a chronic condition like HIV, every health care visit presents a risk of discrimination. Addressing these structural barriers will require comprehensive efforts, including policy changes, cultural competency training for health care providers, stronger antidiscrimination laws, and more societal initiatives to reduce stigma and promote inclusivity.

¹⁹⁸ See *L.W. ex rel. Williams v. Skrmetti*, 83 F.4th 460 (6th Cir. 2023) (upholding bans on gender-affirming care for transgender youth in Tennessee and Kentucky).

¹⁹⁹ But see *Bostock v. Clayton Cnty., Georgia*, 140 S. Ct. 1731, 1741 (2020) (finding that Title VII’s sex discrimination provision also prohibits an employer from discriminating against an individual based on sexual orientation or transgender status).

²⁰⁰ See *303 Creative LLC*, 600 US at 637 (Sotomayor, J. dissenting) (“The truth is, these affronts and denials are intensely human and personal. Sometimes they may harm the physical body, but always they strike at the root of the human spirit, at the very core of human dignity. . . . [I]t reminds LGBT people of a painful feeling that they know all too well: There are some public places where they can be themselves, and some where they cannot” [citations omitted]).

²⁰¹ Am. Psychiatric Assoc., *Mental Health Disparities: LGBTQ* (2017), available at

<https://www.psychiatry.org/File%20Library/Psychiatrists/Cultural-Competency/Mental-Health-Disparities/Mental-Health-Facts-for-LGBTQ.pdf>.

²⁰² *Id.* at 617 (“Rates of violent victimization are still significantly higher for LGBT people, with transgender persons particularly vulnerable to attack” [citation omitted]).

²⁰³ See *Neese v. Becerra*, 640 F Supp 3d 668, 684 (N.D. Tex 2022) (setting aside an official U.S. Department of Health and Human Services interpretation of section 1557 of the Affordable Care Act that covered discrimination based on sexual orientation or gender identity).

²⁰⁴ See *Matter of A.B. v. M.S.*, 77 Misc 3d 1138 (Ulster Co. Family Ct., 2022) (“The [Child Parent Security] Act was born, at least in part, from the acknowledgment that it was time for the laws of this State to provide ‘equality for same-sex parents [and to provide] the opportunity for their children to have the love and support of two committed parents’ regardless of the fact that ‘only one can be biologically related to the child,’” quoting *Matter of Brooke S.B. v. Elizabeth A.C.C.*, 28 NY3d 1 (2016)).

VI. COMMENTS AND RECOMMENDATIONS: SAFEGUARDS FOR SPECIAL POPULATIONS, FUNDING, INSURANCE, AND TRAINING

Protecting Special Populations

While structural and systemic changes are needed to address racial, gender, and other disparities, we call for more specificity in the New York MAID Bill through regulations and implementation oversight when enacted and in the form of additional protections for certain special populations, as follows:

- For persons with intellectual or mental health disabilities who request MAID and who are eligible for representation by the Mental Hygiene Legal Service (MHLS), we recommend that adequate advance notification be given to MHLS which can serve an external oversight role similar to the role it already serves under state law for decisions to withhold or withdraw life-sustaining treatment from people with intellectual disabilities. Also, if the person seeking MAID is eligible for services from the New York State Office for People with Developmental Disabilities or from the New York Office of Mental Health, similar notification to that given to MHLS should also be given to these agencies.
- For persons residing in nursing homes or other residential or long-term care institutions who request MAID, we recommend that adequate advance notification be given to the NYS Office of the Long-Term Care Ombudsman which can serve an external oversight role similar to the role it plays now. We also recommend that nursing home ethics committees be required to review eligible residents' requests for MAID to ensure that the required legal process has been followed.
- For persons in carceral settings who request MAID, due to the structural coercion inherent in such carceral settings, we recommend that adequate advance notification be given to New York State Prisoners' Legal Services which can serve an external oversight role similar to the role it plays now; and further, that such persons in carceral settings who meet MAID eligibility requirements and request MAID be deemed eligible for early parole so that they may have immediate access to counseling, hospice, and palliative care, or MAID.
- For noncitizens held in state jails or prisons under detainer agreements with Immigration and Custom Enforcement (ICE) and who are eligible for MAID, we recommend that adequate advance notification of any request by a noncitizen be given to New York State Prisoners' Legal Services which can serve an external oversight role similar to the role it already serves under state law; and NYC Health and Hospitals/Correctional Health Services.

Funding and Insurance

Though no other state that passed a MAID or Death with Dignity law did so with an appropriation attached, nor is any state currently considering new appropriations measures to support MAID; this report should not be taken to suggest New York must do differently. The Legislature should

recognize that many other states eventually did appropriate monies to support the provision of MAID and other aspects of end-of-life care or altered state law concerning health insurance to achieve a similar goal. Ensuring insurance coverage for MAID's costs and other end-of-life care is within the State's powers. New York should follow the successful examples set by Oregon, Hawai'i, and California, each an example of a state that continues to devote public funds to make MAID an accessible and high-quality aspect of end-of-life care. A failure to act on MAID's affordability, care that could be made affordable if covered by insurance, will limit MAID to only that portion of the population with the means to pay out of pocket, will reduce the number and quality of healthcare providers offering MAID, and will exacerbate the inequities described in this report.²⁰⁵ The Task Force also heard from many healthcare professionals in states with MAID who testified that the industry needs additional end-of-life care training opportunities. The NYS Legislature has a variety of approaches to consider; any combination thereof would allow it to head off quality, access, or affordability issues experienced by patients in other states.

States have the authority to regulate health insurers, referred to as payors in the healthcare industry, but they have less authority to regulate the products those payors offer, that is, the content of the plans we buy with our premiums; however, New York should utilize the powers it does have to ensure that if MAID is made law, that it is accessible to as much of the population as possible. A state can set the terms for a payor to do business in that state, including the shape of their provider network. New York does this via an interplay of the Insurance and Public Health Laws and various state agencies' regulations. Most payors offer multiple product types. A state can regulate certain types of products, in full or to some extent. Different product types fall under different statutes, state or federal.

Despite a complex landscape of applicable federal and state laws, the Legislature can require products to include coverage for MAID and can require payors include providers that offer MAID in their networks. The Task Force heard testimony stating that the cost of accessing care under a state-authorized MAID law is at least \$2,000 per patient. A recent study conducted by researchers at Rutgers University found that “[o]ne major barrier to many would-be users is” paying for MAID's cost.²⁰⁶ The New York State Bar Association's prior studies of healthcare in New York have shown how cost and limited availability of care, particularly end-of-life care, impact patients and their family. We observed these phenomena at play time and time again during the COVID-19 pandemic, and how the underutilization of hospice and palliative care led to patients and their loved ones experiencing worse mental health, less well-controlled symptoms, and lower quality of life near death.

The current state of end-of-life care options in New York, including palliative care and hospice, is an underutilized foundational spectrum of care. Read together, the Palliative Care Information Act

²⁰⁵ Currently, people with low incomes – who historically are disproportionately people of color – may be especially affected by even this relatively minimal cost required to access medical aid in dying, which may put the option out of reach. (See, e.g., Department of Health and Human Services, Office of Disease Prevention and Health Promotion. Access to health services. Washington (DC): HHS; 2021 [cited 2021 Dec 10]. Available from: <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/access-to-health>; Racial and Ethnic Disparities in Medicaid: An Annotated Bibliography; Medicaid and CHIP Payment and Access Commission. Available from: <https://www.macpac.gov/publication/racial-and-ethnic-disparities-in-medicaid-an-annotated-bibliography/>).

²⁰⁶ <https://www.rutgers.edu/news/medical-aid-dying-maid-mostly-used-well-educated-white-patients-cancer>.

(“PCIA”) and Palliative Care Access Act (“PCAA”) patients in a variety of settings have a right to receive information and counseling regarding palliative care, including associated pain management, and access to appropriate palliative care consultations and services.²⁰⁷ Though patients have a right to this information, there has been limited outreach and training by the NYS Department of Health and little to no public funding to allow healthcare providers to gain facility with these difficult conversations. The Task Force heard testimony that the frequency and quality of compliance with the PCIA and PCAA varies. Experienced providers acquired their skills via continuing medical education, time, and sometimes difficult bedside experiences. It is fair to expect professionals to learn new skills during their time in practice. However, the Workgroup also heard that MAID is a “specialty in its infancy” that can take decades to master when deployed within a comprehensive care continuum, and this suggests that the knowledge base to implement MAID needs further development. The Task Force heard testimony from several guests that if the Legislature creates a new end-of-life care option, MAID, they should support grant based training to ensure patients receive care from providers with additional MAID-specific training.²⁰⁸ Alternatively, physician-testifiers suggested that instead of requiring palliative or hospice counseling, the MAID process could require a formal consult with a palliative care physician. That change could be a procedural burden, but it would connect patients with existing information sources they need when deciding about MAID. Though the Workgroup heard a great deal of reassuring testimony about the ability of physicians to learn how to administer MAID on their own and the availability of grand rounds and other continuing medical education opportunities available, the Workgroup also heard from many other members of the allied health community who felt that the focus on physicians was too narrow.²⁰⁹ A publicly supported generalist training program would be beneficial. Various academic institutions, private companies, and regional coalitions already host such programs and could be grown via state funds to meet allied health’s needs. Non-provider professionals help patients and their family navigate the religious, spiritual, and emotional complexities of dying. They are often the ones who doggedly connects the dots in the healthcare continuum for their charges. These professional communities should also be considered for inclusion in any future appropriations or payment streams the Legislature might create, including requirements that payors pay for services such titles offer.

Alternatively, NYSDOH has a long history of bringing healthcare providers together to share materials, best practices, and policies. This repository of information and center for dialogue could spawn the kinds of collaboration and development described above with minimal investment by the state. NYSDOH’s Center for Hospice and Palliative Care Access and Quality could lead the way in creating this nexus.²¹⁰ COVID demonstrated the efficiencies and quick gains that can be

²⁰⁷ The PCIA, Chapter 331 of the Laws of 2010, is codified as PHL § 2997-c. The PCAA is PHL § 2997-d.

²⁰⁸ Physicians noted that the connection between a patient and an appropriately experienced physician often came too late in their dying process, so MAID might be the only viable option left to a patient who, after learning more, wished palliative care of hospice was something they knew about sooner.

²⁰⁹ Maria Buchbinder et al., Health Care Providers Experiences with Implementing Medical Aid-in-Dying in Vermont: A Qualitative Study, *J of General Internal Medicine*, Vol. 34, No. 4, 636–644 (2019), at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6445925/> (at 641 discuss the “critical, yet under-recognized role” of nurses and social workers in supporting physicians and patients); *see also* Jonathan Singer, et al., Assessment of Oncology Advanced Practice Professional Willingness to Participate in Medical Aid in Dying, *JAMA Network Open*, Vol. 5, No. 10, 1–11 (2022) available at <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2797711>. (at 7 reports study finding that fewer than a third of advance practice professionals (physician assistants and nurse practitioners) “feel knowledgeable or very knowledgeable” about MAID).

²¹⁰ [NY State Senate Bill 2023-S4858 \(nysenate.gov\)](https://www.nysenate.gov/legislation/bills/2023/S4858). Vetoed, but established by NYSDOH on its own accord.

made when regional providers are brought together to share and problem-solve alongside NYSDOH. The Department was at its best during the pandemic when it was a facilitator first, a regulator when needed, and a partner filling roles only it could.

Even in an educated, high-quality care ecosystem, inadequate health insurance coverage is one of the most significant barriers to health care access, and insufficient coverage fuels disparities in health.²¹¹ Currently, coverage for end-of-life care is a minefield of policies and exemptions that the Legislature should rectify. Some of the payment code descriptions used by existing New York payors that cover palliative care or hospice are broad enough to accommodate MAID, or parts of the process included in the MAID bill. For federally underwritten programs, no state Medicaid program offers a comprehensive or “stand-alone” palliative care benefit.²¹²

Gaps in Medicare and Medicaid coverage of end-of-life care, or more specifically MAID, will impact the majority of patients in New York because those funding streams provide the majority of all healthcare dollars spent in the country. The 1997 Assisted Suicide Funding Restriction Act (ASFRA), a federal law, bars the use of federal funds for medical aid in dying. This restriction means that people solely reliant on government healthcare programs do not receive the same options for medical care as those who can afford private supplemental medical insurance or pay for services directly, including MAID and MAID-related services. Suppose a patient wishes to access Since almost all healthcare providers in the country participate in a federally supported payment stream, a patient receiving care in a facility that receives federal funds must find a supportive provider outside the federal healthcare network or an alternative payment method for all MAID-related services and medication. CMS has recognized but not yet fully embraced wider choice in end-of-life care for enrollees with its MCCM model.²¹³

Data from other states indicate that the legalization of MAID, if palliative care and hospice are also covered by insurance along with MAID, does not decrease the use of palliative care and hospice. Instead, most states observed an increase in demand for all forms of end-of-life care.²¹⁴ Models exist for New York to follow if it wishes to have as many products as possible cover hospice, palliative care, and MAID to the maximum extent possible. In **California**, care costs related to medical aid in dying are directly accounted for in the state budget and paid through the state’s Medicaid program, called Medi-cal. This structure avoids the prohibition on the use of federal funds for MAID. In **Hawai’i**, costs are identified through Medicaid billing codes; the state’s fiscal agent also reviews and identifies claims. None of the claims are processed through state health plans. Instead, costs are carved out from the state health plan coverage and covered and reimbursed by the state’s fee-for-service program. Because all costs related to MAID are covered by state funds only, they are not required to be included in reporting to CMS, and no federal match dollars are claimed. In **Oregon**, the State Health Authority issues a “prioritized list” of diagnosis and treatment pairings used to determine if a diagnosis or service is considered to be part of the

²¹¹ [Access to Health Services - Healthy People 2030 | health.gov Limited Access: Poverty and Barriers to Accessible Health Care - National Health Council.](#)

²¹² Medicare Part A will cover some inpatient palliative care but limited home care (that is covered by Part C, aka Medicare Advantage). Part B covers outpatient services (small premium), and D would cover some medications.

²¹³ [Medicare Care Choices Model | CMS Medicare Care Choices Model Improved End-Of-Life Care, Lowered Medicare Expenditures, And Increased Hospice Use | Health Affairs.](#)

²¹⁴ [AID-brief-may2016.pdf \(ucla.edu\).](#)

state Medicaid benefit package. Palliative care is always on the prioritized list. To ensure coverage, the State Health Authority includes MAID under palliative care. Given these successful examples from other states, New York state could easily develop its own model. The Legislature has already passed bills that could be used as a template for a MAID coverage law.²¹⁵

If the Legislature does not mandate MAID to be covered, then it could set up grants to study it and define a standard of care based on New York’s MAID process, thereafter leaving it up to the private and professional organizations, and the civil liability system, to self-regulate. These grants would have a triple aim of improving the overall administration quality of end-of-life care, reducing the risk of a meritless lawsuit against a MAID provider and increasing the chances MAID would ultimately be covered regardless of New York law. Where not mandated or defined as “effective and proven” and not “unnecessary or experimental” (i.e., where MAID is not a standard of care), payors have valid grounds to resist paying for it. Where MAID is established in professional guidelines, plus research, as meeting those standards, it is typically covered as at least a permissible off-label use of the component drugs. The drugs used in MAID, when used in the MAID combination, arguably are an impermissible off-label use of those drugs; however, the grants described above could prevent this outcome. Though liability protection for prescribers and process participants could help address this concern, funding research supporting MAID could also help cut off the risk of an off-label use objection or liability.

To ensure equitable access to end-of-life care states that authorize MAID, a group of states that New York might enter, ought to draw on its past legislation, regulatory and payment models, and approaches created in other states to ensure citizens have equal access to comprehensive end-of-life care. For some, their needs will include MAID. The Workgroup recognizes that the current bill does not and is unlikely to be amended to address funding or the other issues outlined in this section. Adding funding or a fiscal impact to New York’s Medical Aid in Dying Act would make the bill very likely not pass. The Workgroup heard from several guests who wholeheartedly believe that every year that New York’s MAID bill does not pass, more New Yorkers experience unnecessary suffering at the end of life. No New Yorker should suffer through their final days, and perhaps MAID is a way to bring peace and control to that time. While palliative care and hospice certainly provide that peace and control, if New York state does not address issues of quality, access, and affordability at some point it will leave MAID a privileged form of care available to few.

Training

If MAID is enacted in New York, health care professionals providing MAID will need new training opportunities. As explored in Section III, *supra*, the end-of-life spectrum of care is underutilized in New York. Since 2011, the Palliative Care Information Act (PCIA) has required physicians and nurse practitioners to offer terminally ill patients with information and counseling concerning palliative care and end-of-life care options. (Palliative care can be accessed by patients with any serious illness, regardless of prognosis.) The PCIA was expanded later in 2011 by the Palliative

²¹⁵ [NY State Senate Bill 2023-S1196A \(nysenate.gov\)](#). On December 12, 2023, the Legislature delivered A1637A/S1196A to Governor Hochul, who will hopefully sign it into law. That bill requires health insurance policies and Medicaid to cover biomarker testing under certain circumstances; it could be repurposed to meet New Yorkers’ needs for expanded end-of-life care coverage.

Care Access Act (PCAA). Read together, these laws apply to a variety of facilities. Patients in many facilities or in home care are not receiving information and counseling regarding palliative care due to the limited outreach and training by the State Department of Health and the lack of funding.

The End-of-Life Working Group heard testimony that compliance with the PCIA and PCAA varies in frequency and quality and that providers acquired their skills via continuing medical education, time, and bedside experiences. Further, witnesses observed that MAID is a “specialty in its infancy” that can take years to master. Several guests observed that, if MAID is legalized in New York, providers should have additional MAID training. Small independent hospices may not be able to accommodate these training costs. Funding for training programs could require multiple providers to cooperate in MAID training and research and providing of quality, timely information.²¹⁶ Alternatively, physician-testifiers suggested that, instead of requiring palliative or hospice counseling, the MAID process could require a consult with a palliative care physician.

Training is needed not only for physicians, but also for social workers, chaplains, and other health professionals who may regularly interact with patients facing end-of-life decisions. Various academic institutions, private companies, and regional coalitions already host such programs and could be expanded via state funds. Non-provider professionals also help patients and their family navigate the religious, spiritual, and emotional complexities of dying. These communities should be considered for inclusion in any future appropriations. The State Department of Health’s (DOH’s) Center for Hospice and Palliative Care Access and Quality could lead the way as a facilitator with only a small appropriation, as noted in Section III, *supra*.²¹⁷

Clinicians in MAID states have noted the inadequacy of training opportunities.²¹⁸ There have been few studies on MAID training.²¹⁹ Articles have focused on the educational needs of physicians,²²⁰ not nurse practitioners, physician assistants, social workers, pharmacists, mental health providers, and other medical professionals.²²¹ When polled, health care practitioners in MAID states have

²¹⁶ Physicians noted that the connection between a patient and an experienced physician often came too late in their dying process, when MAID was the only viable option left. If the patients had known sooner about palliative services available in a hospice, they might have opted for such care.

²¹⁷ [NY State Senate Bill 2023-S4858 \(nysenate.gov\)](https://nysenate.gov/legislation/bills/2023/S4858). Vetoed, but established by NYSDOH.

²¹⁸ Buchbinder, *supra*, note 208.

²¹⁹ Gina Bravo, et al., *Social Workers’ Experiences With Medical Assistance in Dying: Survey Findings from Quebec, Canada*, *Social Work in Health Care*, Vol. 62, No. 5, 193–205 (2023), abstract at <https://pubmed.ncbi.nlm.nih.gov/37183409/>; see also Jamie K. Fujioka et al., *Implementation of Medical Assistance in Dying: A Scoping Review of Health Care Providers’ Perspectives*, *Journal of Pain and Symptom Management*, Vol. 55, No. 6, 1564–1576(2018)m, available at [https://www.jpmsjournal.com/article/S0885-3924\(18\)30077-0/pdf](https://www.jpmsjournal.com/article/S0885-3924(18)30077-0/pdf).

²²⁰ Bravo, *supra*, at 200 (“the small body of literature addressing the educational needs of healthcare professionals in this area [MAID] of practice has focused on physicians.”), Fujioka, *supra*, at 1572: “This scoping article is one of the first attempts to consolidate evidence exploring the roles and challenges of diverse health care professionals in the implementation of MAID.”); see also Sarah LeBlanc, et al., *Development of Learning Objectives for a Medical Assistance in Dying Program for Family Medical Residency*, *BMC Medical Education*, Vol. 22, No. 167, 1–5 (2022), available at <https://bmcmededuc.biomedcentral.com/articles/10.1186/s12909-022-03204-1> (concludes at 5 that “little is known about the most effective strategies for providing MAID education . . .”).

²²¹ Fujioka, *supra*, note 218 at 1572 (discusses lack of knowledge about work of “nurses, mental health providers, pharmacists, social workers, and medical examiners [who are] integral to the in the execution of MAID in tandem with physicians . . .”).

consistently requested additional training.²²² They are unsure of what they are legally allowed to do and need clinical assistance in the practical bedside provision of MAID.²²³ When adequate learning opportunities are not provided, clinicians are less willing to offer MAID to their patients.²²⁴ If fewer practitioners participate, access to MAID could be limited, especially for patients from marginalized populations²²⁵ who have historically had unequal access to health care.²²⁶ Providing opportunities to meet clinician’s training needs will improve access to MAID and promote broad and equitable access. New York can learn from the academic literature about effective MAID training—including conferences, practice guidelines, mentorship, and role-playing exercises.²²⁷ Other articles note that the participation of other health care professionals has been under-recognized, leading to a lack of training opportunities for them tailored to their professional needs.²²⁸ A multidisciplinary approach should be taken since MAID involves collaborative practice by various health professionals.²²⁹

As in other MAID states, New York could provide MAID training as part of continuing education required by licensing authorities. Training could include a review of the history of MAID, an overview of New York’s law including eligibility standards and safeguards, as well as include

²²² Maria Buchbinder et al., Health Care Providers Experiences with Implementing Medical Aid-in-Dying in Vermont: A Qualitative Study, *J of General Internal Medicine*, Vol. 34, No. 4, 636–644 (2019), at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6445925/> (at 641 discuss the “critical, yet under-recognized role” of nurses and social workers in supporting physicians and patients); *see also* Jonathan Singer, et al., Assessment of Oncology Advanced Practice Professional Willingness to Participate in Medical Aid in Dying, *JAMA Network Open*, Vol. 5, No. 10, 1–11 (2022), available at <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2797711>. (at 7 reports study finding that fewer than a third of advance practice professionals (physician assistants and nurse practitioners) “feel knowledgeable or very knowledgeable” about MAID).

²²³ Buchbinder, *supra*, note 208; *see also* Fujioka, *supra*, note 1 (at 1571—articles surveying clinicians in states with MAID found that “legislative criteria of eligibility, in addition to capacity to consent to MAID, were often vague or ambiguous and thus subject to interpretation by varying practitioners, with examples being clinician confusion about the clinical meaning of terms such as “irremediable” and “intolerable suffering”).

²²⁴ Singer, *supra*, note 208 (reports result of study in which advanced practice professionals who reported higher knowledge and comfort scores with MAID were more willing to participate in providing it); *see also* Bravo, *supra*, note 218, at 200 (surveys articles that recommend course-based, conference, practice guidelines, role playing and mentorship training); *see also* Buchbinder, *supra*, note 208 (discusses clinician concerns about the law and its clinical application and lack of education and training opportunities, leading clinicians to reach out to knowledgeable clinicians and self-educate about MAID).

²²⁵ Tina Sikka, Barriers to Access: A Feminist Analysis of Medically Assisted Dying and the Experience of Marginalized Groups, *Omega Journal of Death and Dying* Vol. 84, Issue 1, abstract at <https://journals.sagepub.com/doi/10.1177/0030222819873770>.

²²⁶ Depesh P. Gopal, et al., Implicit Bias in Healthcare: Clinical Practice, Research and Decision Making, *Future Healthcare Journal*, Vol. 8, No. 1, 40–48, available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8004354/> (implicit bias in health care and that it leads to restricted access to health care and poorer outcomes for people from historically excluded or marginalized groups).

²²⁷ Buchbinder, *supra*, note 208; *see also* Bravo, *supra*, note 218, at 200 (surveys articles that recommend course-based, conference, practice guidelines, role playing and mentorship training).

²²⁸ Buchbinder, *supra*, note 208) (at 641, in article surveying Vermont clinicians after Vermont enacted MAID legislation, note notes that nurses and social workers “play a critical, yet under-recognized role in supporting patients to navigate access and in alleviating some of the practical burden on physicians.”); *see also* Singer, *supra*, note 208 (based on survey of physician assistants and nurse practitioners involved in MAID, article recommends “additional education and training about MAID); *see also* Fujioka, *supra*, (notes need for training of nurses, mental health providers, social workers, pharmacists and medical examiners).

²²⁹ Fujioka, *supra* (recommends additional training, with a “multidisciplinary approach . . . in tandem with physicians . . . of nurses, mental health providers, social workers, pharmacists, and medical examiners.”)

simulations and role-playing exercises to increase clinician familiarity with the clinical aspects of MAID.²³⁰ Existing training staffs and various medical facilities could provide MAID training. Finally, some medical schools and medical residency programs have prepared materials for teaching students and residents about MAID, and such materials could be used for various health care professionals.²³¹ Also, there will likely be many physicians and MAID advocacy groups available to provide free training about MAID.²³² Finally, perhaps DOH could offer MAID training using funding allocated in 2023 for end-of-life care training, though additional state funding may be needed. Upon enactment of MAID, these steps should be considered:

- MAID should be part of health care professionals' continuing education and include elements set forth above.
- Physicians who will provide MAID prescriptions should receive additional required training, which should cover patient selection; medical record requirements; medications used; legal administration of medications; and ongoing communication with patients and/or families.
- Health care facilities with training departments should be mandated to provide MAID training to their employees.
- Physician professional groups and MAID advocacy groups should organize training opportunities and create educational resources.
- Palliative care providers should offer training opportunities to clinicians. This can include knowledgeable practitioner-volunteers from other MAID states.²³³
- MAID should be covered at conferences of health care specialty groups.
- Training opportunities should be expanded at medical schools and medical residency.
- New York should provide a hotline to answer providers' medical and legal questions.

CONCLUSION

The New York State Bar Association Task Force on Medical Aid in Dying, appointed in June 2023, has completed a rigorous process of inquiry pursuant to the charge given to it by President Lewis to examine a range of legal, ethical, health and public health, and workforce issues regarding the provisions of the New York MAID Bill. The Task Force recommends the New York State Bar Association adopt a position in support of the New York MAID Bill; and additional comments and

²³⁰ Based on recommendations made by palliative care physician Judy Setla, MD, MPH in November, 2023 communications.

²³¹ Sarah LeBlanc, et al., Development of Learning Objectives for a Medical Assistance in Dying Curriculum for Family Medicine Residency, BMC Medical Education, 22:167 (2022), at <https://bmcomeduc.biomedcentral.com/articles/10.1186/s12909-022-03204-1>.

²³² Buchbinder, *supra*, note 208 (recounts stories about physicians knowledgeable about MAID providing informal training to other physicians who needed assistance in specific clinical situations).

²³³ Based on conversation with Heather Paladine, MD, on November 10, 2023. She advised that there is a wealth of materials “of curricula, protocols, and other educational resources which have been developed and refined as a result of the experience of clinicians in complying with [their states’] laws.” She recommended that this training be made broadly available as online CME and observed that physicians in other states have been willing to volunteer their time to educate clinicians.

recommendations addressing: i) Safeguards for special populations; ii) Funding and insurance; and iii) Training.

The Task Force is available to respond to any questions about the Report and the comments and recommendations made.

**APPENDIX I:
OPEN FORUM TESTIMONY
NOV. 17, 2023**

	Attendees	Attendee Organization	Written testimony received
8:10	Nadia Arginteanu	NYSARC, Inc. Trust Services	
8:20	David N. Hoffman, Esq.	Claxton Hepburn Medical Center	X
8:30	Stacey Gibson		
8:40	Daren Eilert		
8:50	Dr. Sonja Richmond		
9:00	Geri Barish	One in Nine Breast Cancer Association	
9:10	Diane Coleman		X
9:20	Prof. Christopher Riddle	Utica University	
9:30	Anita Cameron		
9:40	Scott Barraco		
9:50	Laura Kelly		
10:00	Melissa Milch		
10:10	Nina Miller		
10:20	Nancy Murphy		
10:30	Gail Myers		
10:40	Dr. Jules Netherland		
10:50	Barry Perlman, MD		
11:00	Rachel Rimmel		
11:10	Yale Rosen		
11:20	Cassandra Johnston	Compassion and Choices	
11:30	Myra Shulman		
11:40	Rachel Strauber		
11:50	Barbara K. Koeppicus Thomas	League of Women Voters of NYS	
12:00	Alex Thompson		
12:10	Dr. Lindsay Wright		
12:30	Tim Hoppe		

APPENDIX II: OPEN FORUM TESTIMONY SUMMARIES

The summaries below strive to capsulize key points made by persons appearing in the open forum.

Nadia Argentino

Assistant General Counsel, The ARC New York

Nadia Argentino spoke about the mission of The ARC, which supports persons with intellectual, developmental, and other disabilities. The ARC endorses the concept of MAID but emphasizes the need for additional protections to ensure safe access for individuals with developmental disabilities. The wishes of mentally competent adults with developmental disabilities regarding end-of-life choices should be respected.

Geri Barish

President, One in Nine Breast Cancer Coalition

Executive director of Long Island's Hewlett House

Geri Barish testified in favor of the MAID Act. In part based on her own son's harrowing battle with Hodgkin's disease, Barish strongly supports an individual's right to choose the manner of one's own death. She underscored the need for compassion and the importance of personal autonomy and the right to make choices about one's own life and urged the Bar Association to support MAID legislation.

Scott Barroco from Rochester spoke in favor of MAID and shared the experience of his late girlfriend, Kathy Quinn, who died nine years ago from tongue cancer. She faced her cancer with intelligence and determination, making choices to extend her life. As Kathy's condition worsened, she realized that there were no more options for the long life she desired. Kathy wanted to die peacefully at home but did not have access to MAID in New York. Her attempt to end her life was unsuccessful, and Barroco endured the trauma of finding her alive but suffering and of calling an ambulance in defiance of her wish to die. He urged the Task Force to support the MAID law to allow for a compassionate and dignified choice for those facing terminal illnesses.

Anita Cameron

Director of Minority Outreach, Not Dead Yet

Anita Cameron expressed concerns about so-called "assisted suicide" laws and raised concerns about misdiagnoses. She contended that assisted suicide laws affect vulnerable groups disproportionately, particularly seniors and disabled individuals and noted that Black patients have less access to palliative care than other patients. Cameron warned that assisted-suicide laws may become cost-cutting measures when access to health care is lost and commented further that disability-related issues can be addressed through home care, support services, and effective pain control. She conveyed that there are no safety measures that will make assisted suicide laws safe. The only safety measure is that these laws not exist. She urged the Task Force to oppose assisted suicide laws.

Diane Coleman

President and CEO of Not Dead Yet

Diane Coleman, the president and CEO of Not Dead Yet, a disability group that has a position against assisted suicide, told the Task Force that she is a two-time cancer survivor with a neuromuscular disability. She spoke about the organization Not Dead Yet's opposition to assisted suicide, that they are a part of the New York Alliance Against Assisted Suicide, and join with other national disability groups in opposing these laws.

Coleman said that assisted suicide disproportionately affects people with disabilities, leading to a major lawsuit against California's law. She disputed the claim of no documented abuse, citing several articles and argued that these laws lack mechanisms to detect or report problems. Her concerns include the short duration of physician-patient relationships, elder abuse risks, the absence of independent witnesses during drug ingestion, and the bill's provision of legal immunity based on a claim of good faith. Coleman cited the data from Oregon, which show that psychosocial issues related to disability, not pain, drive assisted suicide requests.

She warned about the possible normalization of assisted suicide and its impact on marginalized communities.

Referencing developments in Canada, Coleman underscored the risk of a slippery slope, stating that although disability alone is purportedly not enough for eligibility in the United States, it could be if the United States follows the Canadian model. She emphasized her advocacy for social justice, and the need for equality in suicide prevention rather than assisted suicide, and urged the Task Force to reject the discrimination against older and disabled persons inherent in the medical aid in dying legislation.

Daren Eilert recounted the story of his daughter, Ayla Rain Eilert, who faced unbearable suffering and pain due to cancer. She wanted MAID, which was not available in New York. She was discharged to home hospice care, but within two weeks, Eilert had to take her back to the hospital because providers could not control her pain. He asked the Bar Association to support the MAID bill to prevent needless suffering experienced by terminally ill individuals.

Stacey Gibson has supported MAID since 2014. Her husband Sid died a horrific death from a progressive neurological disease. He asked Gibson to help him end his life, and she said no, a decision that haunts her. He chose to voluntarily stop eating and drinking to end his suffering. It took 12 days for him to die—a cruel end because of the absence of MAID as an option. A cancer patient herself, she said that it is important that people like her be allowed to access as many options as possible when they face their final days. She asked the Task Force to support this bill so that everyone can have control and autonomy over their own body at the end of life.

David N. Hoffman, Esq.

See summary of testimony to the Legislative Working Group.

Tim Hoppe testified in honor of his sister, Bernadette Hoppe, who was an advocate for this bill. When she was diagnosed with anal cancer, Hoppe thought that she would survive it. But the disease won, she lost. He asked the Task Force: “Death is never easy, why don’t we try to make it

a little less bad?” He noted that we can plan for weddings and funerals and asked: “Once we know we are dying, why can’t we decide when we have had enough?” Hoppe spoke about the celebration of his sister held at Buffalo church, and said that he wished that his sister could have enjoyed that outpouring of love. He urged the Task Force to support the bill.

Cassandra Johnston told the Task Force that she is a resident of New York with firsthand knowledge of what it feels like to be told you are dying. Last year, she learned that she had stage 3 breast cancer. Her entire family lives in NY, and she bought a house in this state just before her diagnosis. She was once proud to be a New Yorker who would spend the rest of her life here but was now “terrified to live here.” Her pain during treatment was unbearable. If she had the financial means to do so, she would have left New York to live in a MAID state. New York’s failure to enact a MAID law caused her anxiety, dread, and heartbreak. Opposing MAID because of the availability of palliative care was misguided. Many terminally ill patients receiving such care starved themselves to death to end their pain. Such forced suffering was barbaric, in her view.

Laura Kelly, a self-employed editor, and writer from Mount Kisco, shared the story of her father, Larry Kelly, a lawyer. Diagnosed with stage 4 colon cancer, he soon faced the end of his life and considered moving to Vermont for MAID options, but timing constraints prevented it. Terminal agitation set in, causing suffering and loss of control. The last days at home were harrowing, traumatic, and absurd. She emphasized the importance of MAID laws to expand end-of-life options. Kelly urged NYSBA to support the proposed law on MAID, asserting that individuals with terminal illnesses deserve the right to choose a peaceful and dignified end.

Ari Klein, junior at the University of Albany, spoke to the Task Force in honor of his grandfather, Dr. Robert Milch, a fierce advocate for MAID, who passed away in 2021 of terminal cancer. Klein read from a letter that his grandfather wrote on his deathbed to New York lawmakers: “The inaction by the Legislature to make MAID available to New Yorkers has become punitive. We have all the data we need from decades of experience in other states. Legislators, you need not endorse this end-of-life care option, but for goodness’ sake, don’t prohibit it. And by not acting on it, that’s exactly what you’re doing.”

Nina Miller, a former executive director of the hospice in Tompkins County, said her perspective on MAID has evolved. She once believed that hospice care could address all the needs of dying patients, but then realized that some patients experience uncontrolled pain that can only be alleviated by keeping them in a state of unconsciousness. She has watched patients who wept with frustration, begging to be released from a position of intolerable existence. Some chose to stop taking nutrition and hydration, which can be a lengthy and uncomfortable way to depart. She urged support for MAID as a compassionate choice for those facing unbearable suffering at the end of life.

Nancy Murphy

See summary of testimony to the Legislative Working Group.

Gail Myers

Deputy Director, New York Statewide Senior Action

Gail Myers said that the mission of her organization is to achieve dignity, well-being, and security for older New Yorkers. Myers stated that the group supports the MAID bill. Drawing upon her decades of legislative experience as a former staffer and a lobbyist, she expressed awe at the level of detail in the bill, including safeguards to assure that those concerned with process that their voices have been heard, to provide patient autonomy, ensure informed decision-making, and protect against coercion. Myers's husband recently received a terminal diagnosis. They would like to be able to make an end-of-life decision that would allow him to be surrounded by loved ones at the time of his death.

Jules Netherland

Director of Research and Academic Engagement, Drug Policy Alliance

Jules Netherland told the Task Force that she received a diagnosis of stage 3 breast cancer in November 2019. Brutal treatment and a mastectomy ensued. In December 2022, she learned that her cancer had spread, and she had surgery to remove tumors from her abdomen. In January 2023, her doctor told her that her treatment would be palliative, not curative. She told the Task Force that the possibility of a terrible dying process scares her. After so much traumatic treatment, autonomy at the end of life is critical. NYSBA should stand up for the option of a good death, she said.

Dr. Barry Perlman graduated from Yale Medical School in 1971 and was the director of psychiatry at St. Joseph's Medical Center in Yonkers for 34 years. During his career he served as president of the New York State Psychiatric Association (NYSPA), which has taken no position on New York's pending MAID bill but was involved in assisting the sponsors of the bill in strengthening its mental health provisions. In Dr. Perlman's opinion, the bill contains adequate safeguards to protect patients. He has been treated for cancer and would welcome the possibility of MAID relief himself.

Rachel Rimmel, a professor from Rochester, told the Task Force that her brother faced a terminal diagnosis and endured unmanageable pain. He found solace that MAID was available to him in Washington. Her brother peacefully passed away at home, surrounded by loved ones, maintaining control and dignity. She stressed that MAID is not suicide. The trauma caused by the lack of legalized MAID in New York causes anguish not only to patients but also to first responders, medical professionals, and families. The MAID bill would honor the choices of persons with terminal illnesses and end persistent suffering.

Dr. Sonja Richmond

Medical Director, Washington, D.C., Vitas Health Care Corporation

See summary of testimony to the Legislative Working Group.

Professor Christopher Riddle

Chair of Philosophy, Utica University

Professor Christopher Riddle support MAID. He has found no evidence of a decrease in the quality of care for people with disabilities due to MAID legalization in other states. He emphasized that

MAID legislation does not devalue lives, but instead grants autonomy for individuals to make choices, including people with disabilities. He urged NYSBA to endorse MAID.

Dr. Yale Rosen

Medical doctor, Long Island

Dr. Yale Rosen supports the MAID bill. He testified that numerous terminally ill people are enduring unbearable pain and suffering despite palliative and hospice care, which are not always effective. Even patients who do not use the MAID medication provided, benefit from peace of mind knowing that the option is available. Dr. Rosen has witnessed the agony of many terminally ill patients. He encouraged Task Force members to watch the documentary *How to Die in Oregon*. He urged that MAID is not physician-assisted suicide. MAID is not a choice between life and death, but rather a choice between the manner of death when death is imminent.

Myra Shulman of Ithaca shared the story of her mother, Beverly Shulman, who died at age 89 from incurable metastatic colon cancer in 2017. A California resident, she had access to MAID and took advantage of such relief. Two weeks after receiving the prescription, she decided it was time, and her family gathered to celebrate their love for her. Shulman described the peaceful and beautiful process as Beverly swallowed the life-ending prescription at home. Beverly slipped into unconsciousness, and her family spent the next five hours at her side, creating a gentle and serene end to her life. Shulman urged NYSBA to support the bill.

Rachel Stauber supports the MAID bill. She recounted her mother's last day. A nurse offered morphine without explicit communication about its consequences, and her mother died alone. Stauber regretted leaving her mother's room during that time. If her mother had had access to MAID, she could have planned the time of her death. It was distressing that the burden of restricted access to MAID fell on the poor, marginalized, and those unable to travel.

Barbara Thomas

MAID Issue Specialist, League of Women Voters of New York State

Thomas supports MAID in New York. In 2018, the NY League of Women Voters decided to support MAID after extensive study. The current bill contains safeguards and protections for both patients and medical personnel, while giving terminally ill patients access to comprehensive end-of-life options. Thomas's husband suffered immensely from his terminal condition and expressed a desire to end his life and urged her to end his life. She is haunted by the fact that she could not do so. Thomas urged NYSBA to support the MAID bill.

Alex Thompson

Director of Advocacy at New York Association on Independent Living

Alex Thompson urged the Task Force to consider that laws in other countries have been expanded to include people living with disabilities and facing mental illness. As a person who has a spinal cord injury and is a quadriplegic, he was concerned about what could happen to him if he ended up on a ventilator. He echoed the concerns of Diane Coleman and Anita Cameron, questioned whether NYSBA should take a stance on the bill, and objected to the idea of the Task Force itself.

Lindsay Wright from Manhattan emphasized that MAID offers comfort to those facing pain and suffering; that people are willing to relocate for autonomy; and that the lack of MAID in New York

creates health care inequities. Her husband, Youssef Cohen, was diagnosed with mesothelioma, wanted a peaceful death at home, and traveled to Oregon for MAID relief—which required overcoming various logistical challenges. Wright stated that most New Yorkers desire better end-of-life options, fewer interventions, and more choices when facing a terminal diagnosis. She urged the Bar Association to support the MAID bill.

APPENDIX III: LEGISLATIVE WORKING GROUP TESTIMONY SUMMARIES

The summaries below highlight key points made by persons appearing before the Task Force's Legislative Working Group.

Art Caplan, PhD

Professor of Bioethics, NYU's Langone Medical Center

Founding Director of NYULMC's Division of Medical Ethics

Dr. Caplan is the Drs. William F. and Virginia Connolly Mitty Professor and founding head of the Division of Medical Ethics at NYU's School of Medicine with extensive expertise in the medical and psychosocial care of the terminally ill and Physician Aid in Dying. Dr. Caplan favors legalization of MAID in New York and other states that are considering legalization and is not persuaded by objections raised. Dr. Caplan does not believe MAID should be called suicide. MAID occurs in a medical situation with external supervision. While it is a form of accelerating one's death, he would not place it in the same category as a suicide by a mentally despondent person. Dr. Caplan argues that MAID is a form of suicide prevention, because in other states where it has not been legalized, people with a terminal diagnosis may end their lives violently because they do not have a MAID option. He believes people would rather live as long as they can, but that the option to use MAID is like having a parachute and provides peace of mind.

Maggie Carpenter, MD

Medical Director at Hudson Valley Hospice

Dr. Carpenter is a family doctor and medical director at Hudson Valley Hospice, as well as faculty at the Mid-Hudson Family Practice Residency. She has specialized in palliative and hospice care for the last ten years. For years she had been a silent supporter of MAID, but that changed this past year with the death of her father from pancreatic cancer. She hears requests for MAID frequently with her hospice patients. For many patients, the anxiety associated with their impending death can be all consuming. Dr. Carpenter reports overwhelming support of MAID by her colleagues, while acknowledging some opposition, primarily for religious reasons. She reported that hospice referrals increase with the availability of MAID. The law should not require medical visits in person. Telemedicine would allow for greater access for homebound patients and those in rural communities. Dr. Carpenter believes that MAID can allow people to end their lives in a more dignified and humane fashion than the current legal options of voluntary stopping eating and drinking or palliative sedation.

Ann Jackson

Former CEO of Oregon Hospice Association

Ann Jackson served as the CEO of the Oregon Hospice Association and the executive director and chief executive officer of the Oregon Hospice Association (OHA). She originally opposed the Oregon Death with Dignity Act (DWDA) because she believed that hospice care could deliver everything that people needed. She now realizes that hospice and the DWDA complement each other and noted that 98% of people who have used the DWDA were in hospice. Jackson also described how a fiancé died peacefully thanks to the DWDA after having suffered unimaginable

pain and terrifying psychotic episodes. Primarily college-educated white people use the DWDA. About one-third of those who requested a prescription pursuant to the DWDA did not ingest the medication, but they had a sense of control over the end of their life. According to Oregon's data, there has been no abuse or coercion in the implementation of the DWDA.

David N. Hoffman, Esq.

Assistant Professor of Professional Practice in Bioethics at Columbia University

Clinical Assistant Professor at Albert Einstein College of Medicine

Chief Compliance Officer at Carthage Area Hospital

David N. Hoffman, a health care lawyer and clinical ethicist in New York, has 40 years of experience in the health care delivery system. He is an Assistant Professor of Bioethics at Columbia University and a Clinical Assistant Professor at the Albert Einstein College of Medicine. Hoffman opined that real-life experience belies rationales to oppose MAID in New York. A patient would never be deemed eligible for MAID based solely on a clinician's determination that the patient would likely expire in six months. Under the law, clinicians can make their own professional judgments about whether MAID is appropriate. Doctors have the duty to ensure that patients are free of coercion. Medical training regarding the capacity to make end-of-life care decisions is available. Palliative sedation does not negate the importance of MAID. He did not see a need for funding or training to implement MAID. The patient advocacy community can provide education, and the Office of Professional Medical Conduct (OPMC) can enforce compliance with laws. Hospital medical staffs and medical schools are ready to develop policies and training programs.

Seth Morgan, MD

Board-Certified Fellow of the American Academy of Neurology

Seth Morgan is a Board-Certified Fellow of the American Academy of Neurology, an advocate for people with disabilities, and a person living with a disability. He supports New York's MAID Act, which provides rigorous safeguards and is modeled after existing MAID laws. Compelling proof belies fears of coercion of people with disabilities. In the 26 years since the enactment of the Oregon Death with Dignity Act, there have been no complaints of coercion of people with disabilities. Under New York's bill, people with a cognitive disability are not eligible for MAID. The bill also contains protections that prevent improper influence by potential heirs. In contrast, there are no such safeguards for palliative sedation. The disability rights and end-of-life care movements share core values of self-determination and personal autonomy. Seventy-nine percent of U.S. residents who self-identify as having a disability agree that MAID should be legal, according to a 2023 survey. The American Medical Association has concluded that physicians can provide MAID according to the dictates of their conscience, and most doctors surveyed in 2020 favored MAID. He did not discern a need for funding or training to implement MAID. All physicians look to their own professional association and institutions to alert them to changes in relevant laws, which routinely occur without funding or training.

Nancy Murphy, sister used Vermont's MAID law

Nancy's sister, Joan Kline, took advantage of the Vermont MAID law after being diagnosed with terminal ovarian cancer, with months or possibly weeks to live. Joan described her sister's death with dignity. On the day of Joan's choosing, surrounded by many family members, a close friend, and a hospice nurse, Joan drank the medicine, and her loved ones held her hands as she slowly

drifted into a deep sleep. She died two hours later. Nancy indicated that the loving, beautiful, peaceful, and chosen transition allowed them to bond with her and she with them in a way that was “beyond description.” She testified that their grieving was mixed with admiration for Joan’s courage, and with pride that they as a family came together to support her decision.

Deborah Pasik, MD

FACR, Founder of Atlantic Rheumatology and Osteoporosis

Founder New Jersey Death With Dignity

Dr. Deborah Pasik, a rheumatologist from 1985 until her retirement in 2020, was part of the advocacy group that helped enact MAID in New Jersey. While generally New Jersey doctors do not oppose MAID, many are not willing to provide prescriptions for their patients—a situation which is improving. Dr. Pasik’s organization, New Jersey Death with Dignity, also provides physician mentoring. She has evaluated 182 new patients who requested the prescription and had provided it for all but the few who lacked the capacity to make the decision—sometimes losing competency during the statutory 15-day waiting period. The two required visits are virtual, which expands access. In the first visit, patients often seek to justify their desire to use the MAID, whereas in the second one, they are relaxed and grateful. Dr. Pasik is not aware of any coercion problems in New Jersey; it is the loved ones who need to be gently persuaded. People who seek MAID relief are very involved in their own health care. About 30% of New Jersey MAID patients opt not to use the prescription, but having it eliminates fears and improves the quality of their final days. About 85% of New Jersey patients seeking a MAID prescription are already in hospice care. Hospice care and MAID complement each other. Dr. Pasik participates in a national group that has refined the medication combination used nationwide. The group has also devised creative, legal ways to allow patients who cannot swallow to self-administer the medication. Dr. Pasik is a plaintiff in a lawsuit challenging New Jersey’s residency requirement, which will likely be resolved via settlement. Many New Yorkers establish residency in New Jersey to get a MAID prescription.

Benny Pollack, Disability Rights Advocate

Benny Pollack is a staunch supporter of MAID legislation, independent of his personal condition, and believes in personal freedom, and the right to choose. Pollack became a quadriplegic after a car accident when he was 21 and has been dependent on a wheelchair for the last 43 years. Despite these formidable challenges, he has adapted and gone on to live a happy life with a career as a professional software engineer. Pollack spoke of his experience with the biases that exist in the disability community. He believes people without disabilities tend to view those with disabilities from their subjective perspective. Since they would never wish to live with a disability, this creates a bias towards both the expectations they have of those who become disabled, as well as their view of how people with disabilities should be protected. This bias affects the way that access to MAID is considered for the disability community. Pollack addressed the issue that medication must be self-administered, and how this is unjust for those with disabilities who cannot physically do so. The American with Disabilities Act stance toward the legislation would appear to be protecting people with disabilities. Pollack argues that the whole purpose of the ADA is to empower, not to cradle.

Sue Porter**Board Chair and Founding Director, End Of Life Choices Oregon**

Sue Porter is the Board Chair and Founding Director of End of Life Choices Oregon, the only organization in the state that implements the law. She has a Master of Science degree in Bioethics and a master's in business administration. Since 2001, Ms. Porter has worked with hundreds of terminally ill people availing themselves of Oregon's Death with Dignity Act. She is also a Volunteer Client Advisor for Washington. Ms. Porter has attended many deaths as a volunteer. She was a participant in *How to Die in Oregon*, a documentary. Porter works closely with hospices and has seen an increased use of hospice because of MAID. Porter is not aware of any residential hospice prohibiting MAID. A lack of funding had not been a problem in implementing the DWDA. Doctors in Oregon receive extensive training. While it was initially challenging to find a doctor, today they are much more accessible. Since those who use MAID are already dying, its use is not suicide. Having been at hundreds of bedsides of those who have used MAID, she describes the event as peaceful; patients find relief knowing they have the option to control how they are going to leave this world.

David S. Pratt, MD**Pulmonologist, Board Certified in Internal Medicine, and Pulmonary Disease**

David S. Pratt, a licensed New York physician, has provided primary, specialty, and palliative care in New York for more than 40 years. He is board-certified in internal, pulmonary, and preventive medicine. Dr. Pratt testified that, while palliative and hospice care offers seriously ill patients an extra layer of support, such care has its limits. When patients experience pain, loss of autonomy, and humiliation, practitioners may resort to higher doses of opioids and sedatives, and the patient may become a shadow of their prior self. Family members suffer greatly as well. The states that have MAID have proven that society can show compassion to such patients by allowing these competent suffering adults near the end of life to die at the time and place they choose. He stated that there has been no proof of discrimination against people with disabilities in the many years that Oregon has allowed MAID. Physicians who object to MAID need not participate.

Sonja Richmond, MD**Washington D.C. Medical Director for Vitas Health Care Corporation**

Dr. Sonja Richmond is the Medical Director of the Washington, D.C. area for Vitas Health care Corporation, a hospice provider. She noted no funding was associated with the D.C. statute and contended that physicians already have the necessary information and education. Lack of utilization of MAID, and of hospice services in general, by underserved and disadvantaged populations is less a function of MAID than it is representative of trends in overall health care. Dr. Richmond also spoke to the history of physician reactions to MAID and noted that in D.C., like in New York, the medical society initially tended to be opposed, but over time has become more accepting, and is now formally neutral. She highlighted the formal protections in the D.C. bill intended to protect patients from coercion and noted that they have worked. In D.C., MAID is mostly utilized by hospice patients and seems to have resulted in an increase in hospice enrollment. Access to MAID is impacted by varying rules tied to the setting in which a patient resides, and sometimes a patient's setting must change for that patient to have access to MAID.

Mitsuo Tomita, MD

Co-Chair of San Diego County Medical Society's Bioethics Commission

Co-Chair of Compassion and Choices AANHPI Leadership Council

Dr. Mitsuo Tomita attended medical school at UCSF and did his internship and residency in family medicine at UCSF Fresno before working worked at Kaiser Permanente San Diego in a full-time family practice. Upon retirement, he continued to work part-time in community health centers. Dr. Tomita has been a consulting physician on MAID cases and said supported MAID when it was proposed in California. After the implementation of CA's End of Life Option Act, the 15-day waiting period was reduced to two days, which has made a difference to many patients who would not have survived the original period. California also eliminated requirements for a final attestation requirement for a physician's documentation that the patient requested MAID, even if the physician was not going to be involved. A telemedicine option has allowed access to many MAID for many patients. There are enough organizations in California to help interested patients navigate the MAID process.

Exhibit A: State-by-State Comparison Chart

	OR	WA	MT*	VT	CA	CO	DC	HI	NJ	ME	NM	NY (proposed)
Effective Date	27-Oct-97	5-March-19	31-Dec-09	20-May-13	9-Jun-16	6-Jun-17	18-Feb-17	5-Apr-18	12-Apr-19	19-Sep-19	18-Jun-21	N/A
Name of the Act	Death with Dignity Act	Washington Death with Dignity Act	Montana Supreme Court Decision	Patient Choice and Control at End of Life	California End of Life Option Act	Colorado End of-Life Options Act	Death with Dignity Act of 2016	Our Care Our Choice Act	MAID for the Terminally Ill Act	Death with Dignity Act	End of Life Options Act	
Provides a "Form Request" template for the prescription	Yes	Yes		No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Residency Requirement?	No	Yes		No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
"Physician" means a doctor of medicine or osteopathy licensed to practice medicine by the Board of Medical Examiners for that state	Yes	Yes		Yes	Yes	Yes	Yes	Yes	"physician" is licensed pursuant to Title 45 of the Revised Statutes	Yes	physician licensed pursuant to the Medical Practice Act	Yes
Patient Requirements:												
An adult (aged 18 or older);	Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Terminally ill, confirmed by 2 doctors	Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Prognosis of 6 months or less to live	Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mentally capable of making their own healthcare decisions;	Yes			Yes	Yes	Yes	Yes	Yes	Yes	Yes (uses 'competent' instead of 'capable')	Yes	Yes (uses 'decision making capacity' instead of 'capable')
Able to self-ingest/Self-administer the medication.	Didn't specify the words "self-ingest/administer"	Yes		Yes	Yes	Yes	Didn't specify the words "self-ingest/administer"	Yes	Yes	Yes	Yes	Yes
Physician Requirements:												
Make the initial determination of whether a patient has a terminal disease	yes	yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Make the initial determination of whether a patient is capable	yes	yes		Yes	yes	yes	yes	yes	yes	yes	Yes	Yes
Make the initial determination of whether a patient has made the request for the prescription voluntarily	yes	yes		Yes	yes	yes	yes	yes	yes	yes	Yes	Yes
Require that the patient demonstrate residency	Yes	Yes		No	Yes	Yes	Yes	Yes	Yes	Yes	No	No
Ensure that the patient is making an informed decision	Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Refer the patient to a consulting provider for medical confirmation of the diagnosis , and for a determination that the patient is capable and acting voluntarily	Yes	Yes		Yes								
Refer the patient for counseling	Yes	Yes		No	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes****
Must suggest the patient notify their next of kin	Yes	Yes		No	Yes		Yes	Yes	Yes	Yes	No	Yes

	OR	WA	MT*	VT	CA	CO	DC	HI	NJ	ME	NM	NY (proposed)
Counsel the patient about the importance of having another person present when the patient takes the prescription prescribed	Yes	Yes		No	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Counsel the patient about the importance of not taking the prescription in a public place	Yes	Yes		No	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Counsel the patient about the importance of safe- keeping and disposal of unused medical aid-in dying medication	No	No		No	No	Yes	No	No	No	No	No	No
Inform the patient that a qualified patient may rescind the request at any time and in any manner	yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Verify, immediately before writing the prescription for medication under this Act, that the patient is making an informed decision	Yes	yes		Yes	Yes	Yes	Yes	Yes	Yes, but not "immediately"	Yes	Yes, but not "immediately"	Yes but not "immediately"
Form of the Written Request:												
Request needs to be in writing	Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
signed and dated by the patient	Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
witnessed by at least two individuals	Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Other:												
Law addresses safe disposal of unused medication	No	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes

	OR	WA	MT*	VT	CA	CO	DC	HI	NJ	ME	NM	NY (proposed)
Immunities for Actions in Good Faith: A person is not subject to civil or criminal liability or professional disciplinary action for acting in good faith under this article, which includes being present when a qualified individual self-administers the prescribed medical aid-in-dying medication.	Yes	Yes		Yes	Yes	Yes	Specified differently***	Yes	Yes	Specific information, see below.**	Yes	Yes
Patient is Required to make two oral requests at least 15 days apart	Yes	Yes		Yes	Yes, only 48 hours apart*****	Yes	Yes	Yes, but 20 days	Yes	Yes	oral requests are not required, just in writing	No, just one written and one oral request
	OR	WA	MT*	VT	CA	CO	DC	HI	NJ	ME	NM	NY (proposed)

* The case does not explicitly lay out the requirements. It just comes to the conclusion that a patient has the fundamental right of a competent terminally ill patient to die with dignity, by self-ingesting medication prescribed by a physician. These seem to be similar requirements as other states, just not laid out as explicitly. See snippet of conclusion at bottom of table.

** Willful alteration or forgery; coercion or undue influence; penalties; civil damages; other penalties not precluded. The following provisions govern criminal and other penalties for certain violations of this Act. A. A person who, without authorization of the patient, willfully alters or forges a request for medication or conceals or destroys a rescission of that request with the intent or effect of causing a patient's death commits a Class A crime. B. A person who coerces or exerts undue influence on a patient to request medication to end the patient's life or to destroy a rescission of a request commits a Class A crime. C. This Act does not limit liability for civil damages resulting from negligent conduct or intentional misconduct by a person.

D. The penalties in this Act do not preclude criminal penalties applicable under other law for conduct that is inconsistent with this Act.

***Yes, no person shall be subject to civil or criminal liability or professional disciplinary action for (1) Participating in good faith compliance with this act; (2) Refusing to participate in providing a covered medication under this act; or (3) Being present when a qualified patient takes a covered medication.

**** The attending physician only needs "refer the patient to a mental health professional pursuant to section twenty-eight hundred ninety-nine-i of this article if the attending physician believes that the patient may lack decision-making capacity to make an informed decision."

***** "This bill would allow . . . an individual to qualify for aid-in-dying medication by making 2 oral requests a minimum of 48 hours apart." California Senate Bill No. 380 CHAPTER 542, https://leginfo.ca.gov/faces/billTextClient.xhtml?bill_id=20210220SB380, passed on October 5, 2021.

Exhibit B: Comparing the Reports

	OR	WA	MT*	VT (2021)	CA	CO	DC (2021)	HI (2021)	NJ	ME	NM (2021)
Effective Date	27-Oct-97	5-March-19	31-Dec-09	20-May-13	9-Jun-16	6-Jun-17	18-Feb-17	5-Apr-18	12-Apr-19	19-Sep-19	18-Jun-21
Data Period	1/1/22 to 12/31/22	1/1/22 to 12/31/22	N/A	7/1/19 to 6/30/21	1/1/22 to 12/31/22	1/1/22 to 12/31/22	1/1/21 to 12/31/21	1/1/21 to 12/31/21	1/1/22 to 12/31/22	1/1/22 to 12/31/22	-
Number of patients who received the prescription	431	452		29	1,270	316	7	70	91	58	
Number of patients who took the prescription (including those who requested the medication in the year prior)	278 (32 people received it in prior year)	363		17	853 (50 people received it in prior year)	-	6	29	-	40	
Number of patients who requested medication but died without ingesting the medication.	84 (19%)	44		10	173	-	1	20	9	13	
Number deaths caused by prescription out of total deaths in the state	0.06%	-		-	-	-	-	-	-	-	-
Number of patients who outlived their prognosis (lived more than six months after their prescription date)	16 (6%)	-	-	-	-	-	-	-	-	-	-
Demographics	<i>N= 278</i>	<i>N=444</i>		<i>N= 29</i>	<i>N=853</i>	<i>N=316</i>	<i>N= 7</i>	<i>N= 29</i>	<i>N= 91</i>	<i>N= 58</i>	
Aged 65 or older at death	235 (84.5%)	365 (82.3%)		-	91.9% (>60 yrs)	190 (78.2%)	2	20	75 (83%)	43	
Median age at death	75	74		-	78	74		75	79	-	
Male Patients	138 (49.6%)	234 (53%)		-	440 (51.6%)	109 (44.9%)	3	16	47 (52%)	29	
Female Patients	140 (50.4%)	210 (47%)		-	413 (48.4%)	134 (55.1%)	4	12	44 (48%)	29	
White	267 (96%)	93%		-	759 (89%)	226 (93%)	7	18	82 (90%)	-	
African American	1 (0.4%)	-		-	4 (0.5%)	1 (0.4%)	-	-	2 (2%)	-	
American Indian	2 (0.7%)	-		-	4 (0.5%)	1 (0.4%)	-	-	-	-	
Asian / Pacific Islander	5 (1.8%)	4%		-	54 (6.3%)	5 (2.1%)	-	8	6 (7%)	-	
Hispanic (any race)	2 (0.7%)	-		-	24 (2.8%)	7 (2.9%)	-	1	1 (1%)	-	
Native Hawaiian	-	-		-	0	-	-	3	-	-	
Underlying Illness:											
Cancer	64%	73%		21 (72%)	563 (66%)	184 (58.1%)	4		44 (48%)	38 (70%)	
Heart Disease/ Cardiovascular	12%	6%		-	101 (11.8%)	24 (7.6%)	1		13 (14%)	3 (6%)	
Neurodegenerative Disorders	27 (9.7%)	8%		3 (10%)	73 (8.6%)	45 (14.2%)	1		22 (24%)	-	
Amyotrophic lateral sclerosis (ALS)	-	-		2 (7%)	45 (61.6%)	23 (7.3%)	-		-	4 (7%)	

Respiratory disease	27 (9.7%)	7%		-	58 (6.8%)	34 (10.7%)	-		6 (7%)	6 (11%)	
Location of Patient's Death											
Home (patient, family or friend)	255 (91.7%)	76%		-	88.30%	198 (81.5%)	-	-	83 (92%)	-	
Assisted living or foster care facility	18 (6.5%)	-		-	8%	-	-	-	-	-	
Nursing home	0	-		-	1.20%	20 (8.2%)	-	-	2 (2%)	-	
Hospital	1 (0.4%)	-		-	0.40%	4 (1.6%)	-	-	-	-	
Hospice facility	1 (0.4%)	-		-	1.40%	13 (5.3%)	-	-	3 (3%)	-	
End of Life Care											
Enrolled in Hospice Care	91.40%	82%		-	95.4% (hospice and/or palliative care)	195 (80.2%)	-		-	-	

	OR	WA	MT*	VT (2021)	CA	CO	DC (2021)	HI (2021)	NJ	ME	NM (2021)
Insurance											
Number of patients with health insurance		394 (91%)		-	0.981	-	6		-	-	
Private Insurance	43 (20.5%)	-		-	0.107	-	4	6	-	-	
Medicare, Medicaid or Other Govt. Insurance	167 (79.5%)	-		-	2.70%	-	2	1	-	-	
Medicare/private								8			
No Insurance	0	-		-	0.60%	-	-		-	-	
Unknown								14			
Education											
Some high school/high school degree		85 (22%)					-	4			
8th grade or less	5 (1.8%)					1 (0.4%)	-		-		
9th-12th grade, no diploma	8 (2.9%)					5 (2.1%)	-		-	2%	
High school graduate/GED	59 (21.3%)					50 (16.5%)	-		11 (22%)	22%	
Some college/college degree		300 (77.5%)			76.40%		-				
Some college	51 (18.4%)					24 (9.9%)	-	1	4 (8%)	14%	
Associate degree	18 (6.5%)					23 (9.5%)	-		2 (4%)	3%	
Bachelor's degree	61 (22%)					77 (31.7%)	-	4	17 (34%)	27%	
Master's degree	58 (20.9%)					50 (20.6%)	4	6	10 (20%)	24%	
Doctorate or professional degree	17 (6.1%)					22 (9.1%)	1	2	6 (12%)	8%	
Unknown	1	2 (0.5%)				1 (0.4%)	1	12	-		
Other:											
Number of patients referred for psychological or psychiatric evaluation.	3			-	-	-	-	-	-	-	
Non-Residents- Number of out of State Patients who used prescription	3 (1.1%)	N/A		-	-	-	-	-	-	-	
Number of physicians who prescribed medications	146	207		-	341	74	4	21	-	-	

**APPENDIX IV:
TASK FORCE MEMBER AFFILIATIONS**

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