

FY 2025 HEALTH BUDGET TESTIMONY



WRITTEN TESTIMONY OF:
**Hospice and Palliative Care Association of New York State
(HPCANYS)**

PRESENTED TO:
The Joint Health Legislative Budget Hearing

ON THE SUBJECT OF:
**FY 2025 Executive Budget Proposals on Health Care:
Recommendations and Priority Inclusions**

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Executive Summary

The Hospice and Palliative Care Association of New York State (HPCANYS) is the leading association representing New York State's hospice and palliative care programs, allied organizations and individuals that are interested in the development and growth of quality, comprehensive care for all confronted with serious illness and their families. HPCANYS works collaboratively with hospice and palliative care providers, policymakers, community organizations and other stakeholders to ensure access to quality and compassionate care for all New Yorkers with a life-limiting illness.

Underscoring the Association's advocacy and education is a commitment to health equity and personal autonomy. HPCANYS promotes policies and practices to ensure access to quality serious-illness care for all individuals in alignment with their health care goals and wishes, while providing support to families, caregivers and communities.

As the only statewide association exclusively representing New York State's hospice and palliative care industry and its workforce, HPCANYS is uniquely positioned to identify barriers to care and challenges to sustainability, and to propose achievable and measurable solutions.

HPCANYS offers the following commentary on key Executive Budget provisions for your consideration, and proposes additional solutions that will support the state in its endeavors to reform care policies for the rapidly expanding number of New Yorkers with a life-limiting illness. The Association's recommendations, logically building on recent legislative changes, would ensure effective implementation of identified policy initiatives.

Specifically, the Association's FY 2025 testimony will highlight how the state's Certificate of Need (CON) process for Article 40 providers would be subverted if the Executive's proposals are adopted as-written. The Executive's budget proposals, in tandem with loopholes in existing law (PHL 2805-x), and under the most recent 1115 waiver, have significant implications to the public, the health care community, and to New York State's own regulatory structure to detriment of health care consumers.

The status of initiatives mandated by the legislature over the past three years will be provided, and budget recommendations and priority inclusions of the hospice and palliative care community will be offered to operationalize legislative initiatives.

Introduction

Thank you to Chair Krueger, Chair Weinstein, and members of the Committees for providing this opportunity to provide comments and present recommendations from the Hospice and Palliative Care Association of New York State (HPCANYS) on the FY 2025 Budget.

Hospice is an essential part of the health care continuum. It is a team-oriented approach to end-of-life care that offers expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Hospice has long addressed social determinants of health, caregiver wellness, and family participation in the plan of care. Hospice promotes quality care for those with a life-limiting illness, and supports patient choice and informed decision making, allowing patients with a life-limiting illness to make the decisions for themselves that they deem best.

The Executive Chamber, Legislature, and Department of Health have repeatedly stated their commitment to improving and strengthening the State's hospice and palliative care infrastructure. However, policy and financial support has been erratic, as demonstrated by the legislative support of bills to prohibit the establishment of for-profit hospices that the Governor vetoed, and the law signed by Governor Hochul in 2022 to create a statewide Advance Care Planning Campaign that has yet to be implemented. While the support and advocacy the Legislature has provided for the hospice and palliative care industry over the past several years is greatly appreciated, several provisions in the Executive Budget will negatively impact community based hospice care and have a detrimental impact on patient care, patient choice, and health equity.

1. Executive Budget Proposal Impacting CON and Undermining Health Equity ***Recommendation: Intentionally omit language from the Executive's proposed budget to appropriately address complex CON methodology reform***

The most alarming proposals in the Executive Budget are provisions revising or circumventing the State's Certificate of Need (CON) laws, which govern the establishment of health care providers, including hospice. This issue is especially fraught at a time when other states are wrestling with an influx of unscrupulous for-profit providers that prioritize revenue over patient care, prompting some states to impose additional restrictions on the expansion of hospice. New York has not yet faced the fraud and abuse being seen in other states, but the Executive's proposals would expose New York's serious illness care industry to disturbing trends in other states who abolished or carelessly modified their CON process.

Our concerns are multifaceted. Recently, the Department of Health seems to have expanded its interpretation of its authority to waive regulations under the Hospital-Home Care-Physician Collaboration Program, Public Health Law (PHL) §2805-x to include the waiver of statutory obligations. In particular, it has allowed one hospice to waive its obligations under the CON laws, notwithstanding the lack of any authority to waive statutory obligations, and expand its service area to the detriment of its competitors without public notice. This decision has significant implications to the public, the health care community, and to New York State's own regulatory structure. Notification and the opportunity to offer comments into the decision-

making process are critical elements to determining the need and worthiness of any application claiming to meet an unmet or new health care need.

Section 2805-x of the Public Health Law is intended to establish a framework to support voluntary initiatives that improve patient care access and management. The law's purpose is to facilitate innovation in hospital, home care, and physician collaboration, and we are grateful that the Executive Budget has now expanded that to include hospices statutorily. Unfortunately, there is nothing in the budget language to ensure that such collaborations do not violate the otherwise-applicable public need methodology and undercut non-participating providers. For example, given the way the law is now being interpreted, a hospital system could apply to expand their own palliative care program, in partnership with a homecare agency or hospice, and request the hospice organization be allowed to add counties to their current territory without considering the current providers in those regions. This negatively impacts workforce and the economy as hospitals provide 80% of the referral base for hospices currently. In addition, the law does not require the waiver applicant to meet other statutory obligations related to the CON process.

It is particularly concerning that this is occurring at a time when the current hospice public need methodology (established under 10 NYCRR §79.0.16) is being actively reconsidered. While it is not clear whether it will ultimately be revised, it has been recognized by HPCANYS, DOH and the Public Health and Health Planning Council (PHHPC) as being outdated and in need of substantive change. As a result, the DOH convened a workgroup including HPCANYS leaders to examine and make recommendations regarding the CON methodology. The workgroup has made progress on a revised analysis and language that has, as its priority, hospice integrity measures that align with recent Center for Medicare and Medicaid Services (CMMS) concerns with fraud, waste, and abuse in states without significant CON protections.

The need methodology workgroup is also working to assure that any modifications align with the Master Plan for Aging End-of-Life workgroup recommendations, which specifically call for the need for a Certificate of Need Task Force, and the review of a veto memo issued by the Governor in November of 2022 related to the prohibition of for-profit hospices in the state (A.8472/S.9387 of 2022). All of this work is circumvented when providers can be granted expansions without any reference or identification of public need. If the door is opened to avoid the necessary evaluation of PHHPC character and competency background checks as a required part of the CON process, DOH will witness an unprecedented influx of applications from venture backed “health care partners”. Many claim to deliver palliative care and “hospice-like” services at lower costs while avoiding the regulations that are in place for Article 40 providers. These wider networks pillage the existing workforce and operate without appropriate licensure, certification, or surveillance from the Department of Health.

Additionally, the Department of Health has committed to ongoing work and collaboration with stakeholders to establish recommendations for standardization of a palliative care benefit. The goal is not only to improve reimbursement mechanisms via a Medicaid benefit, but to protect the millions of consumers already confused by the variability and quality of “palliative” services delivered by insurance companies, venture-backed groups, and other entities not falling under DOH surveillance. Licensure, registration, and surveillance are components that need to be

established prior to any additional 2805-x application approvals. We need only to look at the fraud and abuses occurring in other states to see that rushing CON reforms or providing pathways to skirt the process results in shocking violations of human rights. We cannot allow our state to ignore the dire warnings.

CON need methodology reform is a policy consideration more appropriately addressed outside of the budget and should not be included in FY 2025 Enacted Budget as the Governor has proposed. Accordingly, we request that the Legislature reject the language found in sections 1-3 of Part V of the Health & Mental Hygiene Article VII bill, and require stakeholder input by the Executive, DOH, and provider advocates on these reforms as part of a larger effort after the budget is finalized. Further, we ask the legislature to support language that would prohibit the recently expanded interpretation of PHL 2805-x which, as discussed, effectively subverts the CON process and its intent to preserve health equity.

2. Advance Care Planning: Development and Implementation of Statewide Campaign

Budget Request: \$2 million to develop and implement a multi-year campaign that was mandated by the Legislature

Funding is requested for the development and implementation of the statewide Advance Care Planning Campaign that was signed into law by Governor Hochul as Chapter 406 of the Laws of 2022. This new law helps to assure that choices regarding one's care during critical moments are honored.

Whether someone is facing an acute illness, a long-term chronic illness or a terminal illness, advance care planning can help alleviate unnecessary suffering, improve quality of life and provide better understanding of the decision-making challenges facing the individual and his or her caregivers. An advance care plan can be used at any stage of life and should be updated as circumstances change.

As COVID-19 highlighted, more individuals recognized that they were not prepared should they become seriously ill. Individuals need to be educated about the options that exist to help keep them comfortable through an illness, how to make informed decisions about what treatments they want to pursue, how to talk with your doctors, and what Hospice is and how to access it. We support empowering the public with the knowledge, so that they can choose what is right for them. Barriers to advance care planning include lack of awareness, denial of death and illness, confusion, and cultural differences. These barriers are best addressed through outreach, education, and discussion.

There are a myriad of issues that limit access and widen the gap in health disparities including regulatory, reimbursement, and educational issues. Public perception of hospice and palliative care remains a roadblock to access. In communities of color, additional challenges include language barriers and culturally-based apprehension regarding cessation of curative treatment. Further, individuals from minority groups are often diagnosed with diseases at late stages and have worse outcomes, leading not only to higher mortality rates, but also affording them less engagement in advance care planning, leading to an under-utilization of hospice care. A

coordinated and comprehensive effort is needed to help address cultural and linguistic barriers to understanding the benefits of hospice and myths about what hospice is and what the benefit is not.

Culturally competent communication and education on advance care planning, hospice, and palliative care, delivered by leveraging the use of community partners and stakeholders will not only improve hospice utilization but help to close the gap in health equity. Despite the benefits offered by hospice, there is still a significant gap in awareness and understanding about this benefit including who is eligible and when it would be appropriate. This gap exists not only with the public, but also with the greater health care community.

There is a critical need to increase this awareness in both the public as well as in the health care system so that more individuals have the option access this end-of-life care. A multiyear financial investment is needed to create a comprehensive stakeholder coalition to develop a public campaign on health care communication and advance care planning. The initiative may include media, social media and material distribution, education of State employees, long-term care facilities, other care providers, and faith-based leaders.

3. The Center for Hospice and Palliative Care Access and Quality

Budget Request: \$1 million for initial funding of the newly created Center for Hospice and Palliative Care Access and Quality

HPCANYS was pleased that a bill to establish the “Office of Hospice and Palliative Care Access and Quality” at the New York State Department of Health was passed unanimously in both houses in 2022 and 2023. Despite broad bipartisan support, the Governor issued a veto both years citing duplicative State efforts and stating that this matter would be more appropriately addressed through the Budget process.

At the same time, the DOH announced the creation of a fully-staffed Center for Hospice and Palliative Care Access and Quality (the Center), responsible for support to and representation of serious-illness care providers. Further, the Center is being tasked to implement long-awaited state health infrastructure projects and forward-thinking initiatives in the hospice and palliative care space. The Center will cement New York as an innovative national leader in serious-illness care policy. However, the Executive has not included dedicated funding for the Center as part of her proposed budget. We certainly recognize the magnitude of the Department’s duty, and do not attribute this failure to any negligence on the part of the Department staff, but without the funding to ensure that someone is involved in decision-making whose sole purpose is to think about the hospice sector, the state will continue to fail in providing support and representation to hospice and palliative care providers. Hospice expertise and insight is essential in the development of end-of-life care policy and regulations. Hospice providers, staff and patients would finally have the representation and support necessary to ensure full and fair access to hospice benefit and reduce disparities in care. We respectfully request the initiative be funded in the FY 2024-25 budget, and that the state affirms its commitment for all people with a serious illness who are nearing the end of life.

4. The Hospice and Palliative Care Workforce

Budget Request: Specific allocation for hospice in any workforce and related caregiver initiatives that are advanced by the Legislature

The workforce crisis remains the single largest obstacle to patient access to quality hospice and palliative care services. The recommendations we advance could increase access to hospice, decrease overall health care expenses, and perhaps more importantly provide information, education, and support to hundreds of thousands of New Yorkers who will be facing a serious life-limiting illness this year. However, in order to meet the demands of caring for an aging and seriously ill population there must be an adequate workforce.

In December we testified at the joint legislative hearing on the Health Care Workforce. Our detailed comments can be found in our written testimony submitted at that time. Our Association has written and presented numerous advocacy documents outlining how the State has consistently failed to consider palliative care and hospice in policy decisions and regulatory oversight. We respectfully assert our ongoing need for time-sensitive inclusion, and request workforce dollars to meet the immediate needs of seriously-ill New Yorkers. We respectfully ask the Committees to utilize our proposals while finalizing the budget. It is critical that serious illness care providers be included in all conversations regarding the workforce and wages.

We ask the Legislature to remember that workforce initiatives with funding streams tied to Medicaid dollars exclude the hospice workforce, as hospices are primarily reimbursed through Medicare. Further, while the state has received millions of dollars to support its health care workforce, hospice providers received nothing – not one cent in available funding that went to every other workforce sector on the care continuum was provided to the hospice workforce.

While time constraints limit the depth of our discussion, our Association eagerly anticipates the opportunity to engage in a more detailed review of our recommendations and implementation strategies. It is important to recognize that the workforce crisis in hospice and palliative care has far-reaching implications, particularly for the individuals most in need of these time-sensitive specialized services and their dedicated caregivers.

The consideration of policies and regulatory relief that would alleviate some of the identified barriers to access to quality care and supports needed by seriously-ill individuals, their families and caregivers throughout disease progression must become a priority as our population continues to age.

Conclusion

Our recommendations and priority inclusions represent a well-reasoned, comprehensive yet cost-conscious set of proposals that will help advance and improve the quality, access, and delivery of serious illness care for all New Yorkers, especially the seriously-ill and dying in our community and congregate care settings. Our 2024-2025 budget requests complement our ongoing advocacy priorities, save the State Medicaid dollars, and would decrease the out-of-pocket costs to families in an individual's final stage of a life-limiting illness.

The data overwhelming shows that hospice utilization results in significant savings to the state in health care expenditures. Utilization of the hospice Medicare benefit directly translates to savings of Medicaid dollars and family out-of-pocket spending at the end of life. The estimated one-month out-of-pocket savings associated with hospice is \$670, which represents roughly 20% of the monthly income of the lowest third of older adults in the United States. Further, the \$670 estimated savings represents an almost 75% reduction in out-of-pocket costs compared with older adults who did not receive hospice care. ¹

Building on the historic progress made over the last two years within our state to care for the seriously ill and dying, HPCANYS looks forward to continuing our work with the Legislature, Executive Chamber, the Division of Budget, and the Department of Health to improve the utilization of hospice and palliative care services as the State continues to develop a sustainable health care infrastructure. The research and data points consistently show that when hospice is appropriately funded and regulated, hospice represents the best of health care. Moreover, our goals are aligned with the state's obligations to provide more cost-effective, coordinated, and quality care to New Yorkers at end of life. Such goals must be met as the State moves forward with other end-of life care initiatives.

Thank you for your unwavering attention to the critical issues impacting the serious illness care industry and consideration of recommendations to alleviate some of the identified barriers to care. The Association and its dedicated members stand ready to assist in your efforts to address the critical needs of our state and build a sustainable system of care along the health continuum.

Respectfully Submitted on Behalf of the Hospice and Palliative Care Association of New York State by:

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¹ Aldridge MD, Moreno J, McKendrick K, Li L, Brody A, May P. Association Between Hospice Enrollment and Total Health Care Costs for Insurers and Families, 2002-2018. JAMA Health Forum. 2022;3(2):e215104. doi:10.1001/jamahealthforum.2021.5104