



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

PRESENTED TO:
Senate Finance Committee
Assembly Ways and Means Committee
on the
Proposed 2022-23 Executive Budget for Health

Date:
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SUBMITTED TO:
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PRESENTED BY:
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Introduction

Thank you Chair Krueger, Chair Weinstein, Senator Rivera, Assemblymember Gottfried, and other distinguished members of the Legislature and staff, for providing me with an opportunity to present comments from the Hospice and Palliative Care Association of New York State (HPCANYS) on the 2022-2023 Executive Budget. I am Jeanne Chirico and I serve as President and CEO of HPCANYS. Our Association has engaged in discussions with the Executive Chamber, the Division of Budget and the Department of Health over the fall and winter months and we were pleased to find placeholders for our recommendations embedded within the Governor's budget proposals. We look forward to working with the NYS Legislature to ensure these initiatives are included in the final enacted budget.

HPCANYS is the only statewide association that exclusively represents the state's licensed hospice providers and palliative care providers, as well as individuals and organizations concerned with care for patients at the end of life. Hospice care is a team-oriented approach to expert medical care, pain management, emotional, and spiritual support expressly tailored to the patient's needs and wishes. Hospice has long addressed social determinants of health, caregiver wellness, and patient and family participation in the plan of care.

Since its inception, hospice has been ahead of its time, focusing on delivering high-quality, holistic care to patients and families that are only recently being adopted by the rest of the health care system. National attention is increasingly focused on patient-centered care, social determinants of care and improved care coordination, which have always been key tenets of hospice. National and state policies now aim to reduce unplanned hospital readmissions, excessive emergency visits, and overuse of services – all of which we know contribute to a sharp rise in health care costs. It has been shown since the inception of the hospice benefit that the benefit dramatically reduces these costs.

Hospice and Palliative Care providers serve an important role in health care, providing care and support to the State's most seriously ill, their caregivers, and families. However, New York State has consistently ranked behind the rest of the country for Hospice Medicare utilization, with a current ranking of 51st in the nation (*Hospice Facts and Figures. Alexandria, VA: National Hospice and Palliative Care Organization. August 2020, www.nhpco.org/factsfigures*). New York State has a Medicare Hospice utilization rate of 24.7% as compared to a National utilization rate of 46.7%. As the COVID-19 pandemic has highlighted,

the current health care system in New York State does not support nor promote access to these beneficial Hospice and Palliative Care services.

As HPCANYS and other stakeholder advocates have repeatedly communicated over the past two years, Hospice and Palliative Care providers have been on the frontline alongside our colleagues in health care throughout the ongoing COVID-19 pandemic. However, as has been consistently demonstrated by the State, hospice organizations and their employees were repeatedly left out of significant Department of Health guidance. Two examples include when the State failed to recognize hospice employees as “essential workers” and failed to give hospices access to their patients in nursing homes without considerable time-consuming efforts in the middle of a pandemic when care for the seriously ill was desperately needed.

At a time when we are being called to consider the impact of our actions and decisions on historically underserved and underrepresented populations, it is extremely concerning that of the small number of New Yorkers who utilized Hospice for end-of-life care, only 9% were Black, 3% Latino, and 2% Asian. Racial disparities in utilization of Hospice and Palliative Care persist, with Black and Hispanic populations less likely to receive a referral than White patients according to recent data from the U.S. Agency for Health Care Research and Quality. Overall, Black patients are less likely to receive Hospice care and more likely to receive intensive care — hospitalizations, emergency department visits, and aggressive treatments — at the end of life than their white peers. Regardless of the cause of death, those racial health disparities persist. Analyzing Medicare claims data for 1,212 Black and White study subjects, researchers found that even when referred to Hospice, Black patients were likely to receive Hospice care for a significantly shorter period prior to death.

There are a variety of issues that limit access and widen the gap in health disparities including regulatory, reimbursement, and educational issues (*see attached*). Public perception of Hospice and Palliative Care in general remains a roadblock to access. In communities of color, additional contributing barriers 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

debunking 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.

Given the known benefits of Hospice care as a treatment option, and the lack of education and informed consent that is at odds with patients' rights to access and choice in health care, the State has a moral imperative to address the reforms that are needed in care for seriously ill individuals. As we have endured the challenges of the pandemic with our colleagues, COVID-19 has brought attention to the fragility of life and the reality of death. Health care policy experts agree Hospice care helps improve the quality of life for a terminally ill patient. Our state is at a pivotal and defining moment in history. We must learn from the past and build our future's health care infrastructure, which includes addressing the significant opportunities for reform in the care of the seriously ill.

HPCANYS is grateful for our New York State representatives desire to discuss what can be done to improve the health care of all New Yorkers and to strengthen and sustain the State's hospice and palliative care infrastructure. HPCANYS has identified barriers to care and challenges to sustainability and we are proposing solutions that will support the State in its endeavors to reform care for those with a life-limiting illness.

The recommendations we advance could increase access to Hospice, decrease overall health care expenses, and perhaps more importantly provide information, education, and support to over one hundred thousand New Yorkers that will be facing a serious life-limiting illness this year. The Association's recommendations are consistent with and reinforce Hospice patient rights, which include guarantees of informed consent, provider choice, fair treatment, continuity of care, and autonomy over medical decisions.

The human rights failure of the State in implementing policies and practices to ensure care for our State's most seriously ill and vulnerable can no longer be ignored. As it relates to the work being done by the NYS Legislature and Executive at this time, it is the Association's position that budgets reveal priorities and values, and as a State, they are the primary way that we care for one another, especially the most vulnerable.

Based on the foregoing, we respectfully request the following initiatives be included as critical components of the New York State 2022-23 Enacted Budget:

1. *Create a Director of Hospice and Palliative Care Access and Quality Within the Office of Primary Care and Health Systems Management at the Department of Health*

The lack of a Hospice and Palliative Care Director within the Department of Health is perhaps the most readily identifiable approach to improving Hospice utilization in New York State. Hospice is a unique and highly regulated area of health care service, as it can be carried out in a variety of settings. It focuses on preventing, treating, and eliminating discomfort and pain related to physical, spiritual, and psychosocial distress. As such, it is unlike other forms of health care treatment, yet little consideration is given to the unique impact laws and regulations have on the Hospice programs and patients. Time and again, Hospice is overlooked and not considered in necessary and beneficial programs, nor is Hospice excluded from burdensome unnecessary regulations. The new DOH director should have the authority and jurisdiction to offer insight into all service lines as it relates to the impact on Hospice programs, their patients and their employees. This would include offering “carve-outs”, exemptions, and/or the creation of new beneficial programs that may include Hospice or Palliative Care services. We have developed a concept paper that outlines this important position and the meaningful role the Director could play in advancing hospice and palliative care policies and connectivity in New York.

2. *Advance Care Planning Statewide Campaign* **\$4,000,000**

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 (ACP) 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.

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.

Budget Request: Support an initiative to create a comprehensive stakeholder coalition to develop a New York State Public Campaign on health care communication and advance care planning. The initiative may also include media, social media, material distribution, statewide education of State employees, long-term care facilities, other providers, and faith-based leaders.

Potential Cost Savings of ACP: Taking data on utilization by payer from the 2016 Hospice Facilities report, Hospices in NY served 1,215 Medicaid Hospice patients or 1,435 shy of what the national average would have been. The cost savings for each Medicaid Hospice patient compared to non-Hospice dying patients is \$9,000 nationally. This calculates out to a cost savings as follows:

<i>Cost Savings for Current Use of Hospice in New York</i>	<i>\$10,935,000</i>
<i>Future Cost Savings*</i>	<i>\$12,915,000</i>
<i>Total Cost Savings*</i>	<i>\$23,850,000</i>

** when New York State's Hospice utilization rate is adjusted to be equal to the national average*

3. Advance Care Planning Documents Registry **\$2,500,00**

Patients with advanced progressive diseases are faced with the need to consider the benefits and burdens of important medical interventions. The 1990 federal Patient Self-Determination Act supports individuals' right to accept or refuse medical treatment and to complete advance directives (ADs)—legal documents that allow patients to specify treatment preferences for the future, and to appoint medical decision makers to speak on their behalf should they be unable to do so.

Utilization of health information technology to enhance availability of medical records and other information has increased dramatically in recent years. This is also true for advance care planning documents, especially Medical Orders for Life Sustaining-Treatment (MOLST) forms. Many states have

developed or are considering the development of MOLST registries or other electronic solutions for document completion, storage, and access for health care professionals.

Registry development transforms treatment preferences into actionable medical orders that can be used across treatment settings. One barrier to implementing advance care planning documents is accessing them in a timely manner in emergency medical situations when they are most needed. MOLST orders in particular can be critical to making important determinations. There may be only minutes in which to make these vital decisions. The development of electronic registries of these documents and the wishes or medical orders they contain would alleviate this barrier.

A state-wide administered registry would offer patients with frailty or advanced progressive illness an important means of helping to ensure that their wishes for medical treatment will be known and honored in times of crisis. New York State MOLST electronic forms are currently contained in a registry maintained and administered by a health insurance company independent of the Department of Health. This benevolent action is admirable but leads to HIPAA concerns from health systems who refuse to use electronic MOLST forms thus preventing community EMS, hospital ER doctors and others from quickly and easily accessing the physician orders for life sustaining treatment.

It is time for New York State's health informatics infrastructure to be assigned the responsibility for assuring the proper access and regulatory upkeep of these critical end-of-life medical orders.

4. *Center for Community Health Care Workforce Innovation, Delivery, Excellence and Access (IDEA)*

\$3,800,000

Only through a comprehensive long term multifaceted workforce development plan with a significant commitment of Medicaid and non-Medicaid dollars will New York begin to see a rise in the number of direct care workers. It is with this commitment that those being asked to give the most care can themselves receive the care needed to have their own health care needs addressed.

Budget Request: To create a coalition of organizations and individuals that can provide significant contributions to education, data, information, and stakeholder support on workforce initiatives. Suggested members may include: *State DOH, PHI, Center for Health Workforce Studies (CHWS) at SUNY Albany, Office for the Aging, Hospice and Palliative Care Association and other Associations representing*

home care, Hospice, DD/ID, 1199 and other applicable Unions, Hospice and home care Providers, Educational Representatives. This coalition could work to advance:

- Recommendations and pilot projects related to regulatory modifications/changes (i.e. Public Assistance reductions in the “countable Income” for essential workers);
- *Pilot Projects or initiatives related to transportation barriers, career paths within the community health care arena, social-environmental support programs for the workforce, etc.; and*
- Regional alliances to study and determine the current workforce “deserts” with the most critical needs. Members of the regional alliances may include: *Local DSS, Local Public Health, Regional OFA, Providers, Educational Institutions, and various Associations.*

5. Serious Illness Demonstration Program

\$4,500,000

The demographics of our aging population, the epidemiology of many serious, life-limiting illnesses, and the improvements in treatments of these diseases have significantly increased the absolute number and proportion of patients who have Palliative Care needs. Some illnesses which were previously untreatable, are now diseases that patients live with for years or even more extended periods of time. Children with medical complexity are a unique population who may survive to adulthood. Their life course frequently includes both life-threatening and life limiting illnesses.

Seriously ill individuals need and deserve care that is interdisciplinary, whole-person and family-centered, with 24-hour access to supports that can reduce anxiety and alleviate suffering that can also prevent unnecessary hospitalizations or emergency department use. Palliative Care ensures all care is patient- and family-centered, optimizes quality of life by anticipating, preventing, and alleviating suffering and follows the patient throughout the continuum of a person’s illness regardless of the illness trajectory. Palliative Care also addresses the physical, intellectual, emotional, social, and spiritual needs of the individual helping to elicit the patients’ goals and preferences for treatment and care by facilitating and supporting patient autonomy, access to information, and choice.

Article 40 of the New York State Public Health Law defines "Palliative Care" to mean health care treatment, including *interdisciplinary* end-of-life care, and consultation with patients and family members, to prevent or relieve pain and suffering and to enhance the patient's quality of life, including Hospice care. Unfortunately, in New York there is no payment mechanism for community-based Palliative Care. These services are only available during a hospitalization or in a few out-patient Palliative Care clinics that

bill Medicare for Physician/Nurse Practitioner visits only. In addition, New York State has not defined what services need to be included when a provider claims to be offering Palliative Care and for some New Yorkers this has meant receiving telephonic contact from an RN. HPCANYS and its members are seeking not only a benefit but also a standardization of Palliative Care that could then be used for monitoring by the Department of Health to assure the comprehensive inter-disciplinary, in-home services that are crucial to quality Palliative Care.

The proposed serious illness demonstration project follows a Palliative Care case management model that would require the following community-based services: Physician and/or Nurse Practitioner, Social Work, Nursing, and Chaplain. Approved Hospice and Palliative Care providers would assure pain and symptom management via home visits, remote monitoring, tele visits, and 24-hr on-call access.

Conclusion

Our requests represent a bold, comprehensive set of proposals that will help advance and improve the quality, access, and delivery of health care for all New Yorker's, especially the seriously ill and dying in the community and congregate care setting. HPCANYS looks forward to continuing our work with the New York State Legislature to improve the utilization of Hospice and Palliative Care services and to provide more cost effective, coordinated and quality care to New Yorkers at end of life.

HPCANYS - Mission Statement

To promote the availability and accessibility of quality Hospice and Palliative Care for all persons in New York State confronted with life-limiting illness.