

Palliative Care Interdisciplinary Advisory Council

Response to Act 351 for the
2019 Regular Legislative Session

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Annual Report

Health Standards

Office of Aging and Adult Services

February 2021



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Executive Summary

Act 351, enacted in the 2019 legislative session, created the Palliative Care Interdisciplinary Advisory Council (hereafter referred to as the Council) within the Louisiana Department of Health (LDH). The legislation charged the Council with assessing the availability of patient-centered and family-focused palliative care in Louisiana and making recommendations to the LDH Secretary and to the legislature. Council members shall have at least two years of experience providing individual or interdisciplinary palliative care to pediatric, youth, or adult populations in inpatient, outpatient, or community settings.

The Council is charged with consulting with and advising the Secretary on matters related to the establishment, maintenance, operation, and outcomes of palliative care as well as on consumer and professional information and education.

The Council meets quarterly and provides an annual report to the House of Representatives and the Senate's Committees of Health and Welfare by February 1st 2020 through 2022.

The Council held quarterly meetings throughout 2020 as set forth in the legislation. Council members are very supportive of the effort and have been active in the development of the Palliative Care Policy Priorities contained in this document.

The Council will meet with policymakers, legislators and stakeholders to introduce the council and provide information. The Council will also discuss identified priorities in an effort to create an action plan for the implementation of said priorities.

In addition, the Palliative Care Interdisciplinary Advisory Council web page on the LDH website has been completed in accordance with specification as required by the legislation.

Meetings for 2021 are currently being scheduled.

A list of appointed members is included on page 9 of this report.

Advisory Council Charge

The Act states that the Council shall perform the following tasks:

- (1) Conduct an analysis and submit a report of its findings to the senate and house committees on health and welfare annually on February 1st through 2022, to include the following:
 - (a) Availability of palliative care, including palliative care for children in Louisiana for patients in the early stages of serious illness.
 - (b) Barriers to greater access to palliative care.
 - (c) Policies, practices, and protocols in this state concerning patient's rights related to palliative care, including the following:
 - (i) Whether a palliative care team member may introduce palliative care options to a patient without the consent of the patient's attending physician.
 - (ii) The practices and protocols for discussions between a palliative care team member and a patient regarding life-sustaining treatment or advance directives decisions.
 - (iii) The practices and protocols on informed consent and disclosure requirements for palliative care services.
- (2) Establish a statewide palliative care consumer and professional information and education program, in consultation with the department, to ensure that comprehensive, accurate information and education about palliative care are available to the public, healthcare providers, and healthcare facilities.

Additional Resources Available to Council

The Act provides that the Council may engage and solicit recommendations, and guidance pertaining to palliative care from interested parties and stakeholders including but not limited to the following:

- (a) The Louisiana-Mississippi Hospice and Palliative Care Organization,
- (b) The American Cancer Society Cancer Action Network,
- (c) The HomeCare Association of Louisiana,
- (d) Hospice of Acadiana,
- (e) Hospice of Baton Rouge,
- (f) The Louisiana Nursing Home Association,
- (g) The Louisiana Department of Health, Office for Citizens with Developmental Disabilities,
- (h) The Louisiana Department of Health, Office of Behavioral Health,
- (i) AARP Louisiana,
- (j) The Alzheimer's Association,
- (k) Louisiana State Medical Society, and
- (l) ALS Association Louisiana-Mississippi Chapter.

The Council identified the Louisiana Hospital Association as additional resource.

LDH Responsibilities

The legislation states that LDH will provide staff support to the Council and create a Palliative Care Interdisciplinary Advisory Council web page on the LDH website (link listed below). The web page

should have meeting dates and times, minutes from meetings, and any reports or data considered by the Council.

The LDH web page also includes the following information and resources regarding palliative care in accordance with the legislation:

- (1) Links to external resources regarding palliative care.
- (2) Continuing education opportunities on palliative care for healthcare providers.
- (3) Information about palliative care delivery in the home, primary, secondary, and tertiary environments.
- (4) Consumer educational materials regarding palliative care, including hospice care.

The web page can be found at:

<http://ldh.la.gov/PalliativeCare-Adult-Pediatric>

Council Committees

The following committees have been established:

- Pediatric Palliative Care,
- Practice Issues,
- Workforce Development,
- Diversity and Equity,
- Education,
- Reimbursement, Funding and Incentives,
- Availability and Barriers,
- Non-Traditional and Extended Care, and
- Patient Advocacy.

Palliative Care Advisory Council Policy Priorities

Pediatric

Funding for High Quality Home-Based Palliative Care in partnership with hospitals throughout Louisiana that includes:

- Pediatric trained interdisciplinary team (child life, chaplains, nursing, social work, and physicians).
- Two arms of care: hospice and palliative care.
- Transition to hospice arm without disruption of care teams as patients develop trust and rapport with the care team, especially children. This will help assure continuity.
- Improve access and usage of pediatric palliative care within Louisiana.
- Continue to develop telehealth opportunities for rural areas of Louisiana.
- Create incentives for pediatric healthcare providers to receive training in pediatric palliative care with a focus on rural areas.

Practice Issues

- Ensure that palliative care and hospice experts are represented on opioid crisis committees.
- Experts will represent seriously ill adults and children who may be harmed by policy changes intended to help communities.
- Allow the use of ketamine outside the ICU for adults and children receiving palliative and hospice care:
 - Safely administered via low-dose infusion,
 - Allow use for adults and pediatrics facing end-of-life in order to avoid ICU placement/readmission, and
 - Consider usage with Risk Evaluation and Mitigation Strategy (REMS) training (due to state board of nursing classification of ketamine as “anesthetic” with regard to package insert).
- Create and disseminate standardized adult and pediatric transitional hospital to home checklist by 2025.
- Primary palliative care skills with rural pediatricians, neonatologists, nursing chaplains, child life specialists, social workers, etc.

Workforce Development

- Develop and sustain a resilient adult and pediatric palliative care workforce.
- Develop workforce recruitment tools to improve access.
- Increase pediatric in-home nursing workforce.
- Develop tools to mitigate workforce burnout.

Diversity

- Educate the palliative care workforce on the following issues: justice, diversity, inclusion and equity.
- Improve access and quality of palliative care provided to diverse underserved communities.
- Diversify the hospice and palliative care workforce to reflect the population served.

Education

- Develop workforce training to improve access.
- Develop annual pediatric hospice and palliative care conference by 2027.
- Require palliative care training in medical, nursing and allied health schools.

Reimbursement, Funding and Incentives

- Obtain funding for pediatric palliative care in the state budget.
- Incentivize Hospitals to invest in sustainable pediatric palliative care programs through training and education for primary palliative care skills.
- Incentivize Pediatric Palliative Care training and education for pediatric healthcare professionals.
- Increase reimbursement for Outpatient and Home-Based Pediatric Palliative Care.
- Increase reimbursement for perinatal palliative and hospice care.
- Obtain funding for Pediatric Palliative Home Transports.
- Permanently allow reimbursement for Telemedicine.
- Reimbursement for Bereavement Services.
- Create funding opportunities for highly trained professionals to continue to train others.
- Obtain funding to expand pediatric palliative care research in the Gulf States.
- Obtain funding for hospital-based home visit programs.
- Obtain funding to prioritize workforce resiliency and mitigate workforce burnout.
- Obtain funding to build a workforce that can sustainably care for pediatric patients.

Availability and Barriers

- Update LaPOST for adults and children:
 - replace 6-month prognosis with a clear definition of life-limiting illness for both adults and pediatric patients, and
 - allow nurse practitioners and physician's assistants to sign LaPOST (requires statute change).
- Remove the following requirements for advance care planning for pediatric patients:
 - Two physicians to "certify" that a patient has a "terminal and irreversible condition",
 - Two witnesses, and
 - Family to sign do not resuscitate (DNR).
- Hospice Considerations:
 - Revise hospice eligibility for pediatric patients to 12-24 months instead of 6-month prognosis.
 - Continue to support efforts to improve concurrent care utilization for children with serious illness.
 - Create a Medicaid staff position specifically dedicated to concurrent care hospice cases.
 - Encourage hospice houses to admit pediatric patients in order to increase family choice of settings.
 - Improve access to interpreter services for all hospice providers.

Council Members

Appointing Entities Specified in Act 351	Profession	Additional Credentials Required	Appointee
LA State Board of Medical Examiners	Physician	Board Certified in hospice and palliative medicine	Mary Raven, MD
LA State Board of Medical Examiners	Physician	Board Certified in hospice and palliative medicine	Sonia Malhotra, MD
LA State Board of Medical Examiners	Physician	Board Certified in pain management	Mordecai Potash, MD
LA State Board of Medical Examiners	Physician	Board Certified in pediatric palliative medicine	Cori Morrison, MD
LA State Board of Nursing	Registered nurse	Board Certified in hospice and palliative care	Christine Guidry, RN
LA State Board of Nursing	Advanced practice RN	Board Certified in hospice and palliative care	Deborah Bourgeois, APRN
LA State Board of Nursing	Advanced practice RN	Board Certified in hospice and palliative care	Robin Rome, APRN
LA Board of Pharmacy	Pharmacist	Experience providing palliative care	Carl Aron
LA State Board of Social Work Examiners	Social Worker	Experience providing palliative care	Edgar Guedry, MSW
LDH (non-voting)			Helen Prett
LDH (non-voting)			Cecile Castello
LDH (non-voting)			Allison Vuljoin
Governor	Palliative Care Provider Administrator or Director	Current operational experience managing a palliative care program	Susan Nelson, MD
Governor	Spiritual care professional	Experience with providing palliative care	Fr. John “Cary” Bani
Governor	Insurance plan administrator	Experience in reimbursement coverage and claims processing for palliative care	
Governor	Patient/family advocate	Must be independent of a hospital or other healthcare facility	Janet Pugh Foret
Governor	Patient/family advocate	Must be independent of a hospital or other healthcare facility	Trey Gibson
Governor	Patient/family advocate	Must be independent of a hospital or other healthcare facility	Pati Capdevielle

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