Texas Palliative Care Interdisciplinary Advisory Council Recommendations to the 89th Texas Legislature

As Required by
H.B. 1874, 84th Legislature, Regular Session, 2015

October 2024

Revised 2/24/25

About This Report

This report was prepared by members of the Texas Palliative Care Interdisciplinary Advisory Council. The opinions and recommendations expressed in this report are the members' own and do not reflect the views of the Texas Health and Human Services Commission Executive Council or the Texas Health and Human Services Commission.

The information contained in this document was discussed and voted upon at regularly scheduled meetings in accordance with the Texas Open Meetings Act. Information about these meetings is available at https://hhs.texas.gov/about-hhs/leadership/advisory-committees/palliative-care-interdisciplinary-advisory-council.

Report Date
October 2024

Contact Information

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Letter from Chair

To: Governor Abbott, Members of the Legislature, and the HHSC Commissioner:

Palliative Care is patient-centered, family-focused care that provides a patient with relief from the physical, emotional, and spiritual burdens caused by serious and often life limiting illness. Palliative care services are often provided by a specialty interdisciplinary team (IDT) offering an additional layer of support to the patient and family. This type of care is appropriate for patients of various ages and can be beneficial at any stage of a serious illness, including day one of diagnosis. In fact, **Supportive Palliative Care (SPC)** is best provided earlier in the course of serious illness as part of a collaborative and concurrent care team, which includes efforts in disease modification and curative/noncurative therapy. This collaborative effort can help a patient improve their quality of life, while also improving health care fiscal stewardship. Similarly, **Hospice Care** (HC) aides the patient facing a terminal illness at the end of life (a prognosis of six months or less to live) to ease the suffering caused from terminal disease. Hospice care also helps the patient and caregiver team create a treatment plan based on what matters most to the patient. End-of-life care is provided holistically to alleviate physical, emotional, and spiritual symptom burdens, with the utmost focus on patient comfort and support for the family/caregiver team during the most difficult time in a patient's life.

House Bill (HB) 1874 (Zerwas), 84th Texas Legislature, 2015, established the Health and Human Services Commission's (HHSC's) Palliative Care Interdisciplinary Advisory Council (PCIAC). The council was charged to assess and define relevant clinical, system, educational, and policy issues regarding the availability of SPC in Texas. The PCIAC was also expected to educate health professionals and the general public about palliative care to raise awareness and improve access to SPC services. Patients, families, caregiver teams, and health care clinicians should be educated and have access to supportive palliative care specialists who provide evidenced-based specialty care through an interdisciplinary team of healthcare professionals. The PCIAC now submits it's fifth biennial report to provide HHSC and state policy makers with modern, innovative, and fiscally responsible solutions for Texans. The Council's initial 2016 report offered a number of recommendations that became action items and accomplishments:

- Developed and launched the Texas Health and Human Services (HHS) supportive palliative care and hospice care websites as resources for patients, families, and professionals.

- Developed and conducted an annual palliative care interdisciplinary continuing professional education event starting in 2017 and established a repository of education resources linked within the HHS supportive palliative care website.
- Established methods and means to track and report on key measures of supportive palliative care access.
- Advanced a statewide, population-based data collection initiative to assess completion of advance care planning documents in Texas.
- Elevated the profile of serious and life limiting illness care as a significant area of opportunity for raising overall healthcare quality and access in Texas.
- Adapted and collaborated with the national Center to Advance Palliative Care to monitor ongoing Texas metrics pertaining to supportive palliative care.

A cornerstone concept of the first report was the recommendation to refine the language of palliative care by expanding its application beyond end-of-life treatment. This spurred favorable statewide discussion among healthcare professionals and stakeholder groups and positioned Texas as a leader in the palliative care field.

In the second biennial report in 2018, the Council recommended codifying language surrounding the definition of palliative care into law. In addition, the Council continued to emphasize the importance of Advance Care Planning, which is paramount to meeting the needs of patients and families. That report summarized progress of the Council's efforts and presented recommendations for further advancements that were then accomplished:

- Adopted statutory language that defined supportive palliative care from hospice care.
- Prioritized advance care planning.
- Addressed supportive palliative care provider education, workforce, access, and shortages across 254 counties.
- Expanded supportive palliative care programs as a value-based model of specialty care.
- Supported a balanced response to the opioid crisis.

The third biennial report released in 2020 summarized continued efforts and progress over the interim since the previous report, built upon the foundational efforts documented in the first two reports, created a new pediatric sub-committee,

and offered recommendations for further advancements, including the following policy issues:

- Policy Issue: Enhancing Family Caregiver Support.
- Policy Issue: Adoption of a Medicaid Supportive Palliative Care Benefit.
- Policy Issue: Utilizing Telemedicine/Telehealth for Supportive Palliative Care.
- Policy Issue: Amending statutory language to change eligibility requirements for the use of low-THC cannabis for cancer patients.

The fourth report in 2022 focused on specific areas of need and interest in the field of SPC in Texas. Policy issues addressed in the report included:

- Policy Issue: Supportive Palliative Care Regulatory Standards for Home Health Agencies (including licensing needs for home health and hospice agencies providing community based SPC).
- Policy Issue: Adoption of a Texas Medicaid Advance Care Planning Benefit.
- Policy Issue: Child Life Specialists are Essential Members of the Supportive Palliative Care Team
- Policy Issue: Promote Health Care Provider and Health Care Professional Continuing Education Opportunities with specific focus on Supportive Palliative Care topics.
- Policy Issue: Establishment of a Supportive Palliative Care Awareness Day on October 10th.
- Policy Issue: Expanding the Medicaid Hospice Benefit into the Prenatal Period to Improve Care for Children with a Terminal and/or Life-Limiting Illness.

Health care needs in Texas continue to escalate. It's reported that an estimated 1,000 people are moving to Texas daily. The council encourages the Texas Legislature and HHSC to remove non-evidenced-based regulatory barriers to practice and utilize all available human capital to their full extent of education, training, licensure, and certification, thereby increasing access to high quality and affordable health care across settings and the care continuum. Texas has a unique opportunity to improve the quality of life for some of the most vulnerable patients, while also improving fiscal stewardship with the commonsense policies outlined in this report. When provides ensure early access to evidenced-based SPC, it has a direct impact on patients, families, caregivers, care teams, and health systems.

Since the inception of this council, The PCIAC has strived to help bridge the gap of high-quality supportive palliative care for vulnerable Texans suffering from serious

and often life-threatening illness. This Council of experts has truly proven when teams place the needs of patients first, incredible outcomes can be achieved. Texans are now living a better quality of life. Families and clinicians caring for Supportive Palliative Care patients have better tools to care for them and themselves. The ripple legacy of meaningful and impactful health care policy will continue to grow for generations to come.

Texas is known as a bright light shining across the United States and a "pioneer" for supportive palliative care. Texans are helping Texans live better, know better, and do better with evidenced-based SPC and innovative policy guidance. We have come so far, but there is much work to be done in haste for Texans to help Texans with SPC needs.

The recommendations within this report offer good faith solutions to advance supportive palliative care for all Texans facing a serious illness Please contact me for further clarification and discussion on these solutions to help vulnerable Texans in need of supportive palliative care and those who help care for them.

Yours in Service,

Dr. Erin Perez

Erin Perez, DNP, APRN, ANP-C, AGNP-C, ACHPN
Chair, Palliative Care Interdisciplinary Advisory Council

About the Palliative Care Interdisciplinary Advisory Council

House Bill (H.B.) 1874, 84th Legislature, Regular Session, 2015, established the Palliative Care Interdisciplinary Advisory Council (PCIAC). By rule (Texas Administrative Code §351.827) the Council assesses the availability of patient-centered and family-focused interdisciplinary team-based palliative care in Texas for patients and families facing serious illness. The Council works to ensure that relevant, comprehensive, and accurate information and education about palliative care is available to the public, health care providers, and health care facilities. This includes information and education about complex symptom management, care planning, and coordination to address the physical, emotional, social, and spiritual suffering associated with serious illness.

The PCIAC performs the following tasks:

- Consults with and advises the Health and Human Services Commission (HHSC) on matters related to the establishment, maintenance, operation, and outcome evaluation of the palliative care consumer and professional information and education program established under Texas Health and Safety Code §118.011.
- Studies and makes recommendations to remove barriers to appropriate palliative care services for patients and families facing serious illness in Texas of any age and at any stage of illness.
- Pursues other deliverables consistent with its purpose as requested by the Executive Commissioner or adopted into the work plan or bylaws of the Council.
- Hosts regular continuing education (CE) Events. This aim is imperative to the purposes of the PCIAC. Since 2017, CE events have been held annually and developed to award CE credits to interdisciplinary professionals on current topics for palliative care and include ethics credits.
- Implements Senate Bill (SB) 916, 86th Texas Legislature, 2019, requiring an assessment of the potential improvements of supportive palliative care (SPC) on health quality, health outcomes, and cost savings from the availability of SPC services in Medicaid. Additionally, the study will include an evaluation and comparison of other states that provide Medicaid reimbursement for SPC.

Palliative Care Interdisciplinary Advisory Council Members

The PCIAC consists of 18 members appointed by the Health and Human Services Commission (HHSC) Executive Commissioner who are leaders and experts in their fields, including physicians, nurses, a social worker, a pharmacist, a spiritual professional, and advocates. Erin Perez, DNP, APRN, ANP-C, AGNP-C, ACHPN serves as the current chair. The current vice-chair is Hattie Henderson, M.D., CMD. The Council also includes ex officio, non-voting representation from HHSC.

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Executive Summary

A majority of people with a serious, often life limiting illness wish to spend as much time as possible in a non-hospital setting, among loved ones, free from pain and other distressing symptoms. To help achieve this vision, House Bill 1874 (84th Texas Legislature, Regular Session, 2015) established the Palliative Care Interdisciplinary Advisory Council (PCIAC). Through the efforts of the PCIAC, the Palliative Care Information and Education Program was created and helped to cultivate and elevate this specialty care for vulnerable Texans. Through state and national partnerships and collaboration, the Council and HHSC colleagues work together to make Texas a state and national leader for improving awareness, education, and access while advancing high quality specialty supportive palliative care for patients and families.

Supportive Palliative Care (SPC) is not end of life care. SPC offers specialized, multi-disciplinary support to assist in alleviating a patient's symptom burdens and improving the quality of life at any stage of a serious and often life-threatening illness. Hospice care (HC) is a medical election. This specialty helps patients in the terminal stage of serious and life limiting illness with a prognosis of six months or less. Supportive palliative care is most effective when initiated on day one of diagnosis of a serious and/or life limiting illness(es). The evidence is clear, that when specialty supportive palliative care is initiated early in a disease course, this added layer of care improves quality of life not only for the patient but for the family and care team, reduces patient and caregiver burdens, lowers medical costs, and improves system utilization, while focusing health care efforts and interventions patient centered goals of care.

A nine-year review from the inception and from passage of House Bill 1874 (Zerwas) 84th legislative session finds the state advancing in its efforts to increase access to palliative care. Texas has established a central supportive palliative care website resource to provide critical information and education to patients, families, and health care professionals and is monitoring relevant indicators of progress and performance. Awareness of the benefits of specialty supportive palliative care and hospice care are on the rise as is the number of multi-disciplinary specialty professionals and inpatient palliative care programs. A standardized definition of supportive palliative care passed in Senate Bill 916 (Johnson), 86th legislative session, 2019 largely as a result of the work of this Council. However, even with this initial momentum, substantial gaps in awareness and access to supportive palliative care persist. Specialty supportive palliative care teams, professional resources, and patient/family benefits remain below rates found in most other

states. Despite reports of more than 1,000 people moving to Texas daily as of 2023, Texas health care outcomes ranks consistently low. Texas was ranked 48th in the 2023 Commonwealth Fund Scorecard Rankings for health system performance. More than 88% of Texas is considered rural and/or medically underserved. This spans 254 counties and eleven HHSC regions. Texas does not provide a comprehensive community- based SPC benefit line nor does it reimburse for vital and cost-effective complex communication of Advance Care Planning for Medicaid recipients. Since the inception of this Council and the efforts of its experts, slow but consistent progress forward has been seen in health care professionals choosing supportive palliative care specialty, education and awareness. Texas is in vital need and ready to provide high quality and specialty supportive palliative care in community should Texas adopt a new SPC benefit line and modernize the backbone component of complex communication with advance care planning reimbursement.

With this complex and challenging context in mind, the Council releases its fourth biennial report to the Texas Legislature and Executive Commissioner of HHSC with ideas to improve access to patient and family-centered supportive palliative care. The recommendations that follow were adopted without a dissenting vote (with one abstention) and offer good faith and common sense solutions to help the state move forward toward a goal that all Texas patients and families facing serious and often life limiting illnesses have the information and opportunity to choose this specialty care, which is congruent with the patient's desired goals, wishes, and values.

Recommendations

Supportive Palliative Care Standards for Home and Community Support Services Agencies Under the Home and Community Support Services Agencies (HCSSA) License

At a minimum, HHSC should adopt rules to ensure agencies use an interdisciplinary team approach to SPC. Rules would include but are not limited to:

- HHSC should create a Subchapter or separate sections within 26 TAC Chapter 558, Licensing Standards for Home and Community Support Services Agencies, with rules specific to SPC for home health agencies.
- Specific rules for home health agencies providing SPC under the HCSSA license would be developed to include, *at a minimum*:

- The provision of services under the full array of SPC.
- Coordination of care to ensure services and referrals are available to the client and family.
- Minimum recommendation for staffing qualifications.
- Twelve hours of Education and training of staff specific to SPC.
- Guidance on the management of the interdisciplinary team.
- Number of and specific disciplines required for SPC to meet the needs of the client and family.
- Parameters for the referral to hospice, when deemed necessary.
- Plan of care requirements.
- Initial and continuing education.
- Frequency of use patient care conferences and interdisciplinary team meetings.

Building upon the recommendation of the PCIAC's 2022 legislative report on "SPC Standards for Home Health Agencies":

- HHSC should set *minimum* qualifications for home health employees and/or contracted staff with experience in SPC.
- HHSC should draft rules that require all Texas home health agencies who employ and/or contract providers on the SPC interdisciplinary team to complete at least twelve hours in hospice *and* SPC continuing education topics per year.
  - These topics include pain and symptom management, bereavement, nutritional support, medication management in addition to non-pain symptom management, plan of care, end of life care, spiritual care, complex communication for serious and life limiting illness and advance care planning.
- Texas Home health agencies currently do not have standardized guidance for evidence-based standards of care or quality metrics for SPC that they must report on. Therefore, Texas Home health agencies should develop guidance on evidence-based standards of care and quality metrics for SPC based on the National Quality Forum (NQF) practice guidelines and implement all eight domains. These eight domains of quality SPC care are listed below:
  - Structures and processes of care;

- Physical aspects of care;
- Psychological and psychiatric aspects of care;
- Social aspects of care;
- Spiritual, religious, and existential aspects of care;
- Cultural aspects of care;
- Care of the imminently dying patient; and
- Ethical and legal aspects of care.

- The NQF also recommended that performance measures should be focused on:
  - Assessment and management of symptoms for patients with life limiting illness (e.g., pain, dyspnea, weight loss, weakness, nausea, serious bowel problems, delirium, and depression);
  - Patient and family centered SPC that address psychosocial needs and care transitions; and
  - Patient, caregiver, and family experience of care.

HHSC should review other program areas to determine what rules need to be amended to reflect the use of outside resources and coordination of care SPC. Programs include but are not limited to nursing facilities, assisted living, intermediate care facility for persons with intellectual disabilities and Medicaid and CHIP programs.

Establishing Licensing Standards and Reimbursement for Child Life Specialists in Texas

- The Texas Legislature should establish licensing requirements for child life specialists in both adult and pediatric settings, in hospitals and within the community, that fall within the scope of support for certified child life specialists (CCLSs).
  - A basic license should qualify the CCLS to work in pediatric settings, and additional certification(s) and/or specialized designation licenses should be achievable for those working in adult SPC and/or adult in pediatric hospice, as well as community settings.
  - Initial Basic License fee applications will cost $120 per application. Additionally, initial Specialized Designation (SD) Licenses will cost $90 each. Renewals for a Basic License will cost $90 and renewals for each SD

License will cost $70, to offset the costs incurred to the licensing board for managing and maintaining license applications and renewals.

- Texas Medicaid and other commercial insurance payors should provide reimbursement for licensed CCLS services in all settings, including for services provided via telemedicine.

Request for HHSC to Pursue a Supportive Palliative Care Texas Medicaid Benefit

- HHSC should submit a State Plan Amendment (or other waiver authority) to the Centers for Medicare & Medicaid Services (CMS) to allow for SPC services to become a Texas Medicaid Benefit.
- HHSC should allow for reimbursement for Advance Care Planning (ACP) procedure codes 99497 and 99498 within Texas Medicaid. This will ensure Medicaid providers are compensated for vital and ongoing crucial complex communications on Texas specific ACP legal document discussions in various settings which cover medical power of attorney (MPOA), durable power of attorney (DPOA), disposition of remains, in and out of hospital do not resuscitate, and advance directive forms.

Expanding Access to Medical Cannabis and Research on Psychedelic Microdosing for Patients in Texas

Building upon the PCIAC's previous 2020 recommendation, the PCIAC advocates that:

- The Texas Legislature should further expand the patient eligibility criteria for medical cannabis to include sickle cell disease as well as to treat other conditions that cause severe and/or chronic pain for which a physician would otherwise prescribe an opioid or for conditions leading to severe nausea and/or anxiety.
- The Texas Legislature should expand the compassionate use institutional review board to also evaluate and approve proposed research programs to study the medical use of psychedelic microdosing in treating certain medical conditions, as described in HB 1535, 87th Legislature, Regular Session, 2021.

Request for Paid FMLA for patients and family caregivers facing a serious health condition

The Texas Legislature should explore what family and medical leave insurance benefits could be offered as payable to any covered and qualifying individuals who is caring for a family member with a serious and life-limiting and/or terminal illness or has a serious and/or life-limiting and/or terminal illness that makes the individual unable to perform the functions of their daily living and/or employment, beginning September 1, 2025. Whether taken intermittently or continuously, the weekly benefit shall be up to 80 percent of the covered individual's average weekly wages for up to twelve weeks within a twelve-month period. To establish a minimum paid leave standard for all workers in Texas, employers should be mandated to participate but employees may choose to opt in or out to the family and medical leave benefit.

1. Introduction

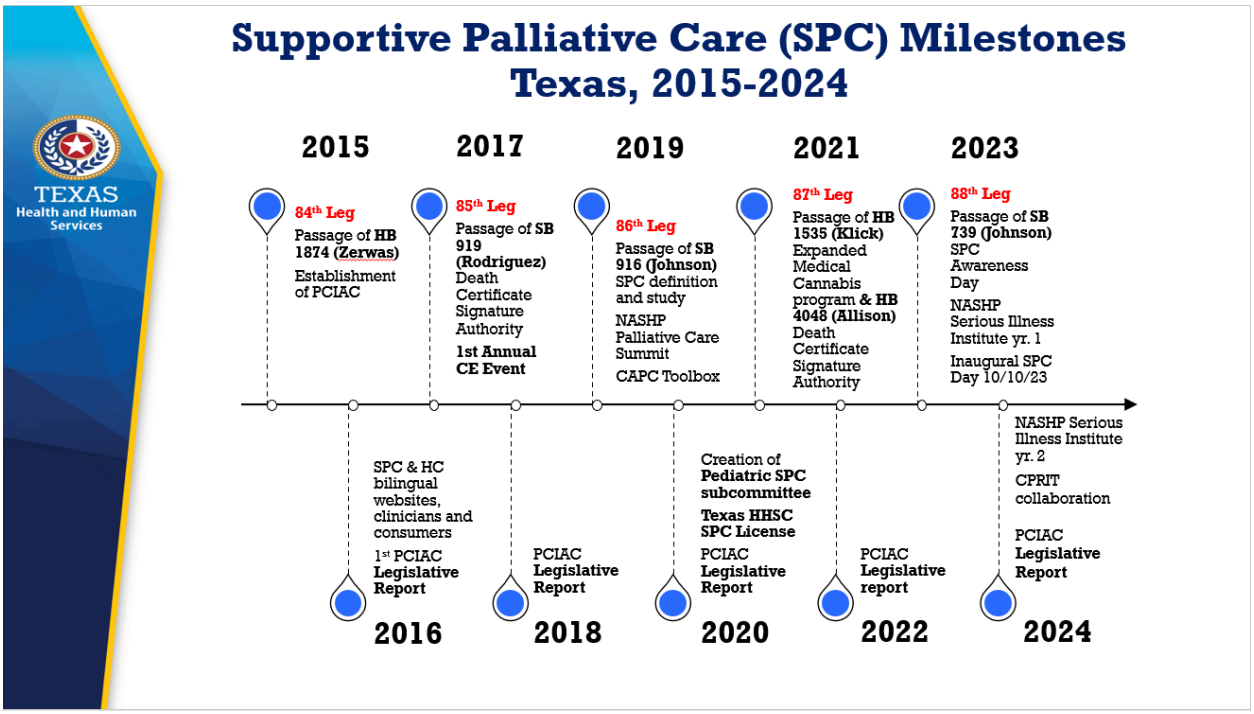
Beginning with its first meeting in February 2016, the Palliative Care Interdisciplinary Advisory Council ("Council") has pursued a mission to increase the awareness and access of patient and family centered specialty supportive palliative care (SPC) in Texas. As part of this charge, every two years, this multi-stakeholder expert committee reports consensus findings and recommendations to the Executive Commissioner of the HHS system and the Texas Legislature. In its first report, the Council addressed the challenges with ongoing misunderstandings by health care clinicians and consumers that SPC is synonymous with end-of-life and hospice care. Supportive Palliative Care is not intended to replace hospice specialists who provide end of life care. SPC offers specialized, multidisciplinary support to relieve physical, emotional, and spiritual burdens for patients at any stage of a life-threatening illness. While hospice helps patients in the terminal stage of serious illness (six months or less prognosis), SPC is most effective when started early as part of an individual's overall collaborative health care plan. A growing body of evidence shows that SPC improves quality of life, reduces patient and caregiver burdens, and improves health care fiscal stewardship. SPC may be combined with attempts of curative and disease modifying treatments to extend life or promote recovery from serious illness. The Council's second report addressed increasing the availability of patient and family focused SPC in Texas with an emphasis on advance care planning. The Council also recommended and was successful in helping to develop statutory language for SPC enacted into law by the Texas Legislature in Senate Bill 916 (Senator Johnson) in the 86th legislative session. The Council's third report included guidance for enhancing caregiver support, proposed the adoption of a Medicaid supportive palliative care benefit, advocated for increasing utilization of tele health/telemedicine for SPC, and promoted a change to eligibility requirements for the use of low-THC cannabis for cancer patients. The fourth report recommended that Texas set SPC standards for home health agencies, advocate for the adoption of a Texas Medicaid advance care planning benefit, endorsed child life specialists as essential members of the SPC team, promoted provider and healthcare professional continuing education opportunities, advocated for the establishment of an SPC awareness day in Texas, and promoted the expansion of the Medicaid hospice benefit into the prenatal period to improve care for children with a terminal or life-limiting illness. This fifth iteration of the report includes recommendations to address SPC standards for home and community supports services agencies, licensing standards and reimbursement for child life specialists, a request to pursue an SPC Texas Medicaid benefit, expanded access to medical cannabis and psychedelic microdosing, and a

request for paid FMLA for patients and family caregivers facing a serious health condition.

Since inception in the 84th legislative session, the Council has provided ongoing education and awareness efforts at the state and national levels to catalyze a sustained quality improvement effort that aims to advance evidenced based SPC across Texas and further endeavors to cultivate Texas as a national leader for providing appropriate, compassionate, and high-quality SPC to patients and families at any stage of serious illness. To date, significant activities and accomplishments from this pursuit include:

- Publishing four legislative reports, and now a fifth report;
- Launching the first Texas Health and Human Services (HHS) system supportive palliative care and hospice website resource for patients, families, and professionals;
- Developing, conducting, and supporting annual supportive palliative care continuing education events starting in 2017, awarding approximately 7,000 continuing education hours to date for interdisciplinary professionals;
- Establishing methods to track and report on key measures of supportive palliative care access;
- Advancing a statewide, population-based data collection initiative to assess completion of advance care planning documents in Texas;[1] and
- Elevating the profile of serious illness care as a significant area of opportunity for raising overall healthcare quality for at risk and vulnerable Texans (see HHSC's Medicaid and CHIP Quality and Efficiency Improvement webpage).

[1] Texas Department of State Health Services. (2018). Texas Behavioral Risk Factor Surveillance System Questionnaire p. 38.



In its initial assessment, the Council concluded that the available evidence supported the Legislature's belief, as described in HB 1874, that broad advances in access to palliative care are possible in Texas. The Council was charged with aiding HHSC in implementing Senate Bill (SB) 916, 86th Texas Legislature, Regular Session, 2019. This bill authorized HHSC to conduct a study to assess the potential improvements of SPC on health quality, health outcomes, and cost savings from the availability of SPC services in Medicaid. Additionally, the Council aided in the development of a study that included an evaluation and comparison of other states that provide Medicaid reimbursement for SPC. Study findings were submitted to the Council on September 1, 2022, and findings from the study are detailed in the report titled Medicaid Reimbursement for Supportive Palliative Care in Texas and Other States.

In 2018, HHSC added two questions to the Behavioral Risk Factor Surveillance System (BRFSS) as part of a statewide, population-based data collection initiative to assess completion of advance care planning documents for adults 65 and older in Texas. Based on analysis of the survey results, we found that the data showed concerning results. Only about half (51%) of Texans aged 65 and older said they had a written an advance directive.[2] This points to a need for greater education and awareness on the importance of completing written advance directives. Fortunately,

[2] Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Questionnaire. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, [2018].

about 83% of respondents reported that a person would have knowledge of their preferences, indicating that a large majority of Texans have at least had conversations with someone they trust about their medical care preferences in the event they are unable to communicate for themselves.[3]

Over the past nine years, indicators of SPC access tracked by the Council have shown improvement. A national leader in SPC, The Center to Advance Palliative Care (CAPC) published national and state level results or "grades" to provide an analysis of whether patients living with a serious illness in the United States are receiving equitable access to palliative care services in hospitals. These CAPC results were only published periodically, so the Council requested that HHSC staff also provide routine monitoring using Texas specific data collected as part of the American Hospital Association (AHA) Annual Survey of Hospitals. The AHA survey, administered for Texas by the Department of State Health Services, is the primary, though not the only source used by CAPC to compile its report card metric. Using only the AHA data, the Texas staff largely corroborated the earlier CAPC results for the state and have followed emerging trends through 2022 to report this "in-house" Texas data (see Figures 1 and 2). The Texas in-house data from Figure 1 shows that the percentage of hospitals with palliative care programs or inpatient units among hospitals with ≥300 staffed beds increased from 71% to 78% between 2014 to 2022, indicating a significant improvement for Texas. Figure 2 also shows significant improvement in the percentage of hospitals with palliative care programs or inpatient units among hospitals with ≥50 staffed beds, with an increase from 42% to 56% between 2014-2022.

[3] Ibid.

Figure 1. In-House Texas Data, Total Palliative Care Programs Among Hospitals with 300 or more Staffed Beds (Refer to Appendix A, Table A-1)

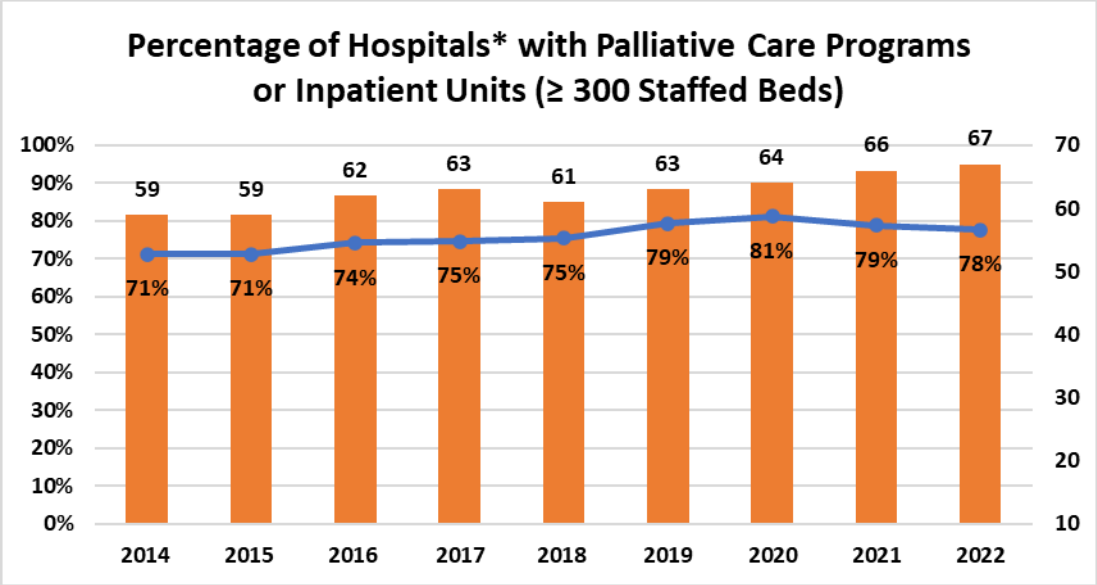
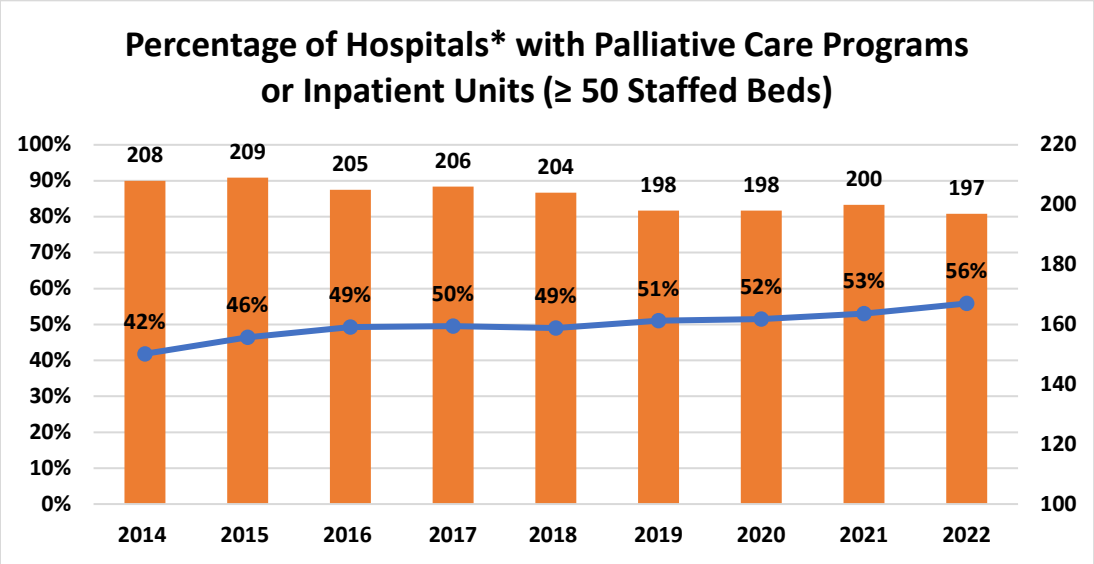


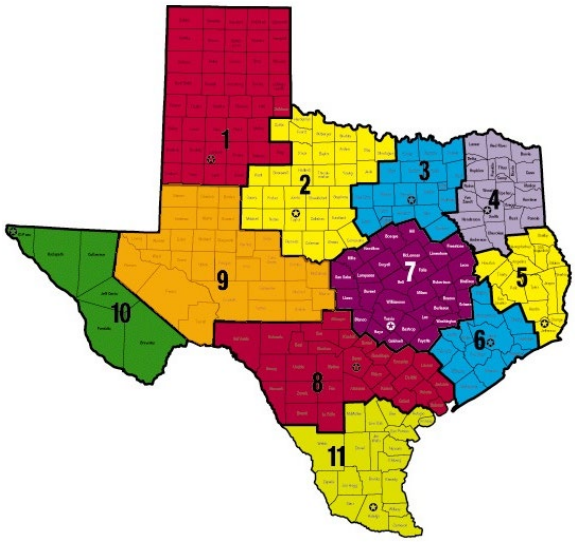
Figure 2. In-House Texas Data, Total Palliative Care Programs Among Hospitals with 50 or more Staffed Beds (Refer to Appendix A, Table A-2)



Note: Results are based on the CAPC defined hospital cohort. Analyses were limited to general medical and surgical, cancer, or heart hospitals with fifty or more licensed beds based on data from the American Hospital Association Annual Survey of Hospitals.[4] Results from previous years of in-house Texas data have slightly changed due to a minor change in methodology of calculating results.

[4] Veterans Administration and Indian Health Service facilities were excluded. CAPC does not clearly distinguish hospital run palliative care programs from contracted services.

Figure 3. Texas Palliative Care Programs by Public Health Region (PHR), 2022 (see data in Table 1)



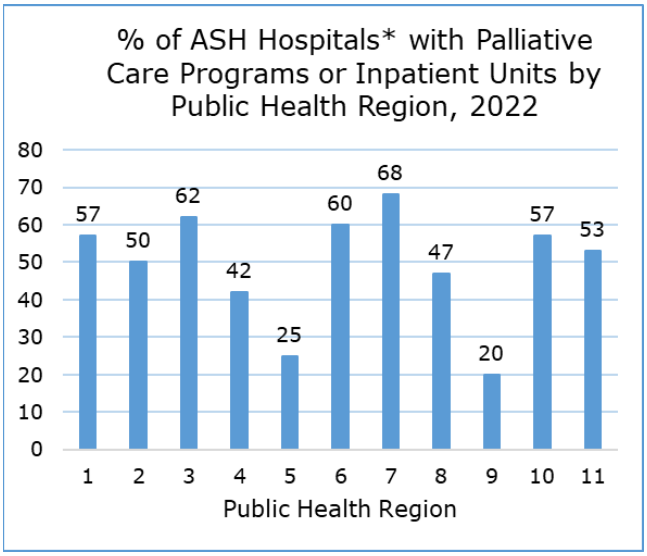


Table 1. Texas Palliative Care Programs by Public Health Region (PHR), 2022[5]

PHR	# Hospitals (50 or more beds)	# with PC Program	% with PC Program
1	7	4	57%
2	4	2	50%
3	60	37**	62%
4	12	5	42%
5	8	2	25%
6	40	24**	60%
7	22	15*	68%
8	17	8	47%
9	5	1	20%
10	7	4*	57%
11	15	8*	53%
Total	197	110	56%

Note: PHRs denoted with one asterisk (*) gained one inpatient palliative care program between 2018 and 2022; PHR 3 and 6 denoted by (**) gained two programs. The number of programs in other regions remained the same.

[5] CAPC state-by-state report card on access to palliative care

HHSC staff also reviewed the AHA data to provide a more granular analysis of the availability of hospital palliative care programs in Texas, which revealed that access to inpatient palliative care services varies significantly from community to community. As shown above (Figure 3 and Table 1), a much lower percentage of hospitals in Public Health Region (PHR) 4 and 5 (East Texas) as well as PHR 9 (West Texas) offer palliative care services than hospitals in other parts of the state. While most regions clearly trail the nation, PHR 7 (Austin/Central Texas) has a rate that is near the national average. Other regions adding programs include PHR 3 (Dallas) and PHR 6 (Houston) adding two programs each and PHR 7 (Austin/Central Texas), PHR 10 (West Texas), and PHR 11 (South Texas) all adding one program each.

As with hospitals, more interdisciplinary professionals are entering the field of palliative care (Table 2). Between 2015 and 2023, Texas physicians with a hospice and palliative medicine (HPM) specialty increased by 58%, including a 104% jump for doctors listing HPM as their primary specialty; certified Advanced Practice Registered Nurses increased from 2015 to 2024 by 174%; Certified Hospice Medical Directors increased from 2015 to 2024 by 395%; and palliative medicine fellows increased from 2015 to 2023 by 132%.

Table 2. Growth by Palliative Care Profession, Texas, 2015

Professional Category	2015	2019	2023 or 2024	% Increase from 2015 – Current Number
Physicians with Palliative Specialty	275	373	434 (2023)	58%
Primary Physician working in Palliative or Hospice as a primary job.	51	89	104 (2023)	104%
Secondary Physician working in Palliative or Hospice as secondary job.	224	284	330 (2023)	47%
Advanced Practice Registered Nurses(APRNs)/Nurse Practitioner(NPs) with Palliative and Hospice Specialty as a Certified ACHPN	46	95	126 (2024)	174%
Certified Hospice Medical Director	19	47	94 (2024)	395%
Palliative Medicine Fellow	19	28	44 (2023)	132%

Note: Palliative Medicine Fellow data for all years has been updated to reflect revised numbers. The table has been updated and reflects the removal of six providers in 2019 with a primary and

secondary palliative medicine specialty who were double counted. Source: Health Professions Resource Center, Center for Health Statistics, DSHS.

There is no available date for Nurse Practitioner, Physician Assistant, Social Work, Chaplain or Registered Nurse who may be in a Palliative and Hospice fellowship at this time.

Table 3. Physicians with Primary or Secondary Specialty in Hospice and Palliative Medicine (HPM), by Public Health Region (PHR), 2015, 2019, 2023

PHR	# HPM Physicians 2015	# HPM Physicians 2019	# HPM Physicians 2023	# per 100,000 population (age 18 years and older), 2021	# per 100,000 population (age 65 years and older), 2022
1	9	11	11	1.83	9.21
2	7	10	10	2.33	9.75
3	62	96	121	1.90	11.09
4	12	13	19	1.99	7.81
5	10	14	12	2.02	8.38
6	74	96	118	1.87	11.08
7	41	50	57	1.82	10.38
8	36	49	52	2.34	11.94
9	11	8	6	1.27	7.36
10	3	5	6	0.91	4.98
11	10	18	18	1.24	6.57
Total	275	373	434	1.86	10.21

Source: Health Professions Resource Center, Center for Health Statistics, DSHS. Note: Only 2022 data was available for the population estimates at the time of this report.

The increase in palliative care workforce is broadly distributed across Texas, as shown in Table 3 above. The rural region of PHR 9 (West Texas) as well as PHR 5 (East Texas) experienced a decline in palliative care physicians. One region with significant needs, PHR 10 (West Texas), saw positive growth in HPM specialists relative to 2019.

Additionally, Table 4 below shows the geographic distribution of the number of Texas Advanced Practice Registered Nurses (APRNs) who have become nationally boarded as advanced certified hospice and palliative nurses (ACHPNs). The national board certification is from the Hospice and Palliative Credentialing Center (HPCC). Overall, the extraordinary growth in certified APRNs seen from 2015-2024 provides

insight that APRNs have recognized the heath care needs for some of the most vulnerable and at-risk Texans and are joining in efforts to help bridge the health care gap for supportive palliative care patients and families in Texas. Barriers remain in: access to education, training, licensure, certification, and regulatory practice for Texas health care providers at this time. In previous legislative reports this Council has supported removing regulatory barriers to practice in efforts to improve access to high quality health care professionals. Removing non evidenced based regulatory barriers helps the patient and the Texas health care system at large improve resource allocation and fiscal stewardship.

Table 4: Number of Hospice and Palliative Credentialing Center (HPCC) certificates for Advanced Practice Registered Nurses (APRNs)/Nurse Practitioner (NPs) with Palliative and Hospice Specialty as an advanced certified hospice and palliative nurses (ACHPNs) in Texas, by Public Health Region (PHR), 2020-2024

Public Health Region	Total number of HPCC certificates May 2020	Total number of HPCC certificates May 2021	Total number of HPCC certificates May 2022	Total number of HPCC certificates May 2023	Total number of HPCC certificates April 2024
1	5	5	5	7	6
2	4	4	6	6	6
3	16	16	17	15	14
4	3	4	4	5	5
5	0	0	0	0	0
6	31	30	33	30	32
7	26	31	35	39	42
8	12	7	7	10	11
9	4	4	4	4	2
10	1	1	1	2	2
11	4	3	4	7	6
Total	106	105	116	125	126

Source: Hospice and Palliative Care Nurses Association

Even with this initial progress, the Council recognizes that substantial gaps in health care persist. Specialty teams, professional resources, and funding for SPC remain below rates found in most other states, and, as leading experts point out, demand for patient-centered and family-focused specialty SPC continues to grow

exponentially.[6] Texas still faces notable challenges to expand the availability of SPC services to the national average. Moreover, within Texas, some communities, such as the Rio Grande Valley, El Paso, and rural areas generally, appear particularly disadvantaged with regard to the availability of SPC infrastructure.

Over the past eight years, the Council has heard from a wide variety of healthcare professionals, subject matter experts, and stakeholders and reviewed a wide array of research and literature to create the recommendations discussed in this report. The report addresses SPC standards for Home and Community Support Services Agencies, Licensing Standards for Child Life Specialists, the pursuit of an SPC Medicaid Benefit, expanding access to Medical Cannabis and research on Psychedelic Microdosing, and paid FMLA for patients and family caregivers.

The recommendations that follow, all adopted with no dissenting votes and one abstention (regarding expanding access to Medical Cannabis and research on Psychedelic Microdosing) and with consensus from the Council's interdisciplinary members, reflect these findings and offer good faith solutions to meet the goals established by the Texas Legislature in HB 1874. The Council looks forward to continuing its service to the state of Texas and to helping ensure that all Texas families facing serious and/or life limiting illness have the information and opportunity to choose specialty care that is most congruent with their patient centered goals of care and values.

[6] Lupu, D., Quigley, L., Mehfoud, N., & Salsberg, E.S. (2018). The Growing Demand for Hospice and Palliative Medicine Physicians: Will the Supply Keep Up? *Journal of Pain and Symptom Management*. *55*(4), 1216-1223. https://doi.org/10.1016/j.jpainsymman.2018.01.011

2. National Academy for State Health Policy Serious Illness Institute Project with Texas

In March of 2023, Texas applied and was accepted into the prestigious National Academy of State Health Policy's (NASHP) Serious Illness Institute, which is a two-year technical assistance opportunity to improve care for people with serious illness funded by the John A. Hartford Foundation. The NASHP Serious Illness Institute is currently engaging with six teams of state leaders (Texas, Colorado, Maine, Maryland, Ohio, Washington) from March 2023-2025 to develop and/or strengthen state policies and strategies to improve access to supportive palliative care. States will also share best practices and lessons learned from the policy institute's work. Technical support from NASHP staff, state leaders, and national experts and actuarial analysis has aided the Texas team in their efforts to develop an innovative comprehensive supportive palliative care framework that could be implemented as a managed care organization (MCO)-led alternative payment model pilot. Evidence consistently reveals when specialty SPC is initiated early in serious and/or life limiting illness, the patient, caregiver team, family, health care team and health care systems all benefit from improved quality of life and fiscal stewardship.

Project Activities from 2023-2024

- Individual Calls with NASHP staff and Torrie Fields Analytics (TFA) to discuss progress and receive feedback.
- All-State Zoom Calls to hear from state leaders and subject matter experts in the palliative care field.
- Individual outreach to MCOs to identify potential partners for an alternative payment model (APM) or concept in Medicaid managed care to improve access to SPC.
- Research on existing palliative care programs, authorities, and models in other states.
- Identifying suitable eligibility inclusion criteria, services, and billing codes to support a potential supportive palliative care model.
- Completion of actuarial and other analysis to show return on investment (ROI) and potential for improved cost and quality metrics.
- Review of quality measures and benchmarks for SPC model concept.

- Develop quality and health care outcomes monitoring and evaluation strategy.

Lessons Learned from Hawaii

A main outcome of the NASHP Serious Illness Institute is gaining insight from Hawaii's multi-year initiative to create a palliative care benefit. Hawaii received approval from CMS in May 2024 on their State Plan Amendment (SPA) to cover non-hospice palliative care services in non-hospital settings. The SPA categorizes palliative care as a *preventive service*, as defined by the Social Security Act 1905(a) 13(C) and provides details regarding eligibility criteria, palliative care services, the membership of the interdisciplinary team (including the scope of work, minimum qualifications, etc.), and the reimbursement methodology included within the model. Eligibility criteria for beneficiaries focus on cardiac and pulmonary diseases/conditions, complex chronic conditions, cognitive and functional limitations, and other forms of serious illness. Services include, but are not restricted, to care plan development/implementation, clinical services delivered by the interdisciplinary team, comprehensive management, and care coordination. Special attention should be paid to the reimbursement methodology in particular. Hawaii's palliative care benefit relies on a per member per month (PMPM) bundled payment rate developed by the state.[7] Bundled payments are essentially a fixed price for a defined episode of care (defined by CMS as the set of services provided to treat a condition or procedure).[8,9] Bundled payments require participating providers to assume upside and downside risk, based on the difference between the fixed price and the actual costs of providing care.[10] The Hawaii model requires the bundled payment to be tied to at least one service within the benefit for the provider to successfully bill the rate. Medicaid providers can still bill for separate, allowable services not included in the bundle. Palliative care beneficiaries can concurrently receive curative services, which are paid separately. Hawaii's extensive due diligence in evaluating their serious illness population found that introduction of the community based palliative care benefit would not increase total Medicaid spending and would lead to an overall decrease in costs and improved

[7] Ibid.
[8] Bazell, C., Alston, M., Pelizzari, P.M., & Sweatman, B.A. (2023, March 27). *What are bundled payments and how can they be used by healthcare organizations?* Milliman. https://www.milliman.com/en/insight/what-are-bundled-payments-and-how-can-they-be-used-by-healthcare-organizations
[9] Centers for Medicare & Medicaid Services. (n.d.). *2015 Supplemental QRURs and Episode-Based Payment Measurement*. CMS.gov. https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/PhysicianFeedbackProgram/Episode-Costs-and-Medicare-Episode-Grouper
[10] NEJM Catalyst. (2018, February 28*). What Are Bundled Payments?* https://catalyst.nejm.org/doi/full/10.1056/CAT.18.0247

quality outcomes as the new benefit line participation and utilization progressed. As you will read in the upcoming sections, Texas is in urgent need of a community based supportive palliative care benefit in order to help improve the quality of life of those vulnerable Texans enduring a serious and/or life limiting illness and provide the clinicians and systems the standards, quality measures, tools, and resources to care for them.

3. Recommendations

Policy Issue: Supportive Palliative Care Standards for Home and Community Support Services Agencies (HCCSA) Under the HCSSA License

In 2019, Texas established a standardized definition for supportive palliative care (SPC) in SB 916. HHSC regulatory interpretation was published after SB 916 was passed into law. HHSC regulatory interpretation defined supportive palliative care as distinct from hospice care but did not establish a category of licensure for the provision of SPC services, neither standalone nor as a category within an existing care delivery setting until September 15, 2021. On this date, HHSC released a Long-Term Care Regulatory Provider Letter, PL 2021-35, regarding licensing requirements for in-home SPC to individuals who have not elected hospice. The letter established that providers who deliver SPC in the home or community settings must obtain a Home and Community Support Services Agencies (HCSSA) home health license. The letter also highlighted exemptions under Texas Health and Safety Code § 142.003 for physicians, dentists, registered nurses, occupational therapists, or physical therapists who provide home health services to a client only as part of the person's private office practice. However, there are still no standardized rules and regulation on how in-home SPC should be delivered by home health agencies under the HCSSA license to a person with a life limiting or life-threatening illness.

As previously recommended in the PCIAC's 2022 legislative report, Texas home health agencies should employ specialty SPC interdisciplinary teams that include an essential core team composed of at minimum one prescribing clinician (physician [MD or DO], advanced practice provider [advanced practice registered nurse (APRN/Nurse Practitioner) or physician assistant [PA]) and registered nurse, a licensed social worker and a spiritual care provider. Other individuals who can enhance the quality of life for both the SPC patient and family should be employed as part of the team on an as-needed basis and include pharmacists, physical/speech/occupational therapists, child life specialists, nutritionists, psychologists, etc. Texas home health agencies that provide care to only pediatric patients should employ a child life specialist as part of the core SPC team.

Texas home health agencies should encourage that their providers (physicians, physician assistants (PA), and advanced practice registered nurses (APRNs/Nurse Practitioners) be board certified in hospice and palliative medicine and/or have a Hospice Medical Director certification and have at least 12 hours of continuing education in hospice and palliative care related topics in the first year with a minimum of two hours of additional continuing education per year for subsequent years. Other core SPC team members should also be encouraged to have additional certification in hospice and palliative care for their specific discipline and role. While it is a best practice to utilize health care clinicians who are board certified in palliative care or otherwise specialty trained, we recognize that will not be possible in all cases. The work force pipeline for board certification is simply not robust enough to produce the number of board-certified clinicians necessary to provide care to all Texans who need it. Requiring board certification at least at this time would greatly restrict access to care for patients living in all areas of the state and could eliminate access entirely for those in many rural areas in need of specialty SPC.

Recommendation

At a minimum, HHSC should adopt rules that ensure agencies use an interdisciplinary team approach to SPC. Rules would include but are not limited to:

- HHSC should create a Subchapter or separate sections within 26 TAC Chapter 558, Licensing Standards for Home and Community Support Services Agencies, with rules specific to SPC for home health agencies.
- Specific rules for home health agencies providing SPC under the HCSSA license would be developed to include, at a minimum:
  - The provisions of services under the full array of SPC.
  - Coordination of care to ensure services and referrals are available to the client and family.
  - Minimum recommendation for staffing qualifications.
  - Twelve hours of specialty SPC Education and training of staff specific to SPC needs.
  - Guidance on the management of the interdisciplinary team.
  - Number of and specific roles and disciplines required for SPC to meet the needs of the patient and family.
  - Parameters for the referral to hospice, when deemed necessary and patient specific appropriate.

- Comprehensive SPC Plan of Care requirements.
- Initial and continuing education for SPC care needs per role and discipline.
- Frequency of patient case conferences and IDT meetings.

Building upon the recommendation in the PCIAC's 2022 legislative report on "SPC Standards for Home Health Agencies":

- HHSC should set minimum qualifications for home health employees and/or contracted staff with experience in SPC.
- HHSC should draft rules that require all Texas home health agencies who employ and/or contract providers on the SPC interdisciplinary team to complete at minimum twelve hours in hospice and SPC continuing education topics per year.
  - These topics include pain and symptom management, grief and bereavement, nutritional support, medication management in addition to non-pain symptom management, plan of care, end of life care, spiritual care, complex communication for serious and life limiting illness and advance care planning.
- Texas Home health agencies currently do not have standardized guidance for evidence-based standards of care or quality metrics for SPC that they must report on. Therefore, Texas Home health agencies should develop guidance on evidence-based standards of care and quality metrics for SPC based on the National Quality Forum (NQF) practice guidelines and implement all eight domains. These eight domains of quality SPC care are listed below:
  - Structures and processes of care;
  - Physical aspects of care;
  - Psychological and psychiatric aspects of care;
  - Social aspects of care;
  - Spiritual, religious, and existential aspects of care;
  - Cultural aspects of care;
  - Care of the imminently dying patient; and
  - Ethical and legal aspects of care.
- The NQF also recommended that performance measures should be focused on:

- Assessment and management of the relief of pain and non-pain related symptom burdens for patients with serious and/or life limiting illness (e.g., pain, dyspnea, weight loss, weakness, nausea, serious bowel problems, delirium and depression);
- Patient and family centered SPC that address psychosocial needs and care transitions; and
- Patient, caregiver and family experiences of care.

HHSC should review other program areas to determine what rules need to be amended to reflect the use of outside resources and coordination of care for SPC. Programs include but are not limited to nursing facilities, assisted living, intermediate care facility for persons with intellectual disabilities and Medicaid and CHIP programs.

Discussion

The PCIAC, multiple external stakeholders, and HHSC staff have met several times throughout 2024 to address SPC standards as outlined under 26 Texas Administrative Code Chapter 558 Licensing Standards for Home and Community Support Services Agencies (HCSSA). The PCIAC does not recommend any amendments to the Texas Health and Safety Code Chapter 142 Home and Community Support Services and Chapter 142A Supportive Palliative Care Services. With the adoption of additional standards based on the recommendations above, HHSC would be able to appropriately regulate the provision of the health and safety of individuals receiving in home SPC care.

Policy Issue: Establishing Licensing Standards and Reimbursement for Child Life Specialists in Texas

Certified Child Life Specialists (CCLSs) are an integral part of interdisciplinary pediatric and adult supportive palliative care teams and aid in the provision of age-appropriate psychosocial and bereavement care for pediatric patients and family members of patients. The American Academy of Pediatrics states that, "advocating for child life services as an essential part of the interdisciplinary team is a responsibility of health care organizations to ensure it is a standard of pediatric care and should occur on local and national levels as well as in regulatory and

accrediting organizations."[11] CCLSs offer psychosocial support to pediatric patients and to the children of seriously ill adult patients by helping improve a child's coping skills, aiding in the development of holistic pain management and other symptom management strategies, and improving the overall patient experience.[12] In the adult setting, CCLSs help children better understand their parent's or other adult family member's serious illness and help the adult with serious illness communicate in the most effective and developmentally appropriate manner.[13,14] CCLSs provide care based on evidence-based, developmentally-appropriate interventions including therapeutic play, preparation, and education that reduce fear, anxiety, and pain for infants, children, and youth.[15] CCLSs have also been shown to decrease patient and caregiver perceptions of pain, decrease hospital length of stay and readmissions, reduce the need for sedation, and lower overall medical costs.[16,17,18] In addition, the

[11] Romito, B., Jewell, J., Jackson, M., AAP Committee on Hospital Care, Association of Child Life Professionals, Ernst, K., Hill, V., Hsu, B., Lam, V., Mauro-Small, M., & Vinocur, C. (2021). Child Life Services. *Pediatrics, 147*(1). https://doi.org/10.1542/peds.2020-040261

[12] Heckler-Medina., G.A. (2006). The Importance of Child Life and Pain Management During Vascular Access Procedures in Pediatrics. *Journal of the Association for Vascular Access, 11*(3),144–151. https://doi.org/10.2309/java.11-3-10

[13] Taneja., S., Vanstone, M., Lysecki, D.L., McKean, H., Bainbridge, D., Sussman, J., & Molinaro, M. (2023). "There's So Much More Support We Could Have Provided": Child Life Specialists' Stories of the Challenges Working in Adult Oncology. *Qualitative Health Research, 0*(0). https://doi.org/10.1177/10497323231215950

[14] Netzer, G. (Ed.). (2018). *Families in the Intensive Care Unit: A Guide to Understanding, Engaging, and Supporting at the Bedside.* Springer. https://link.springer.com/book/10.1007/978-3-319-94337-4

[15] Brewer, S., Gleditsch, S.L., Syblik, D., Tietjens, M.E., Vacik, H.W. (2006). Pediatric Anxiety: Child Life Intervention in Day Surgery. *Journal of Pediatric Nursing, 21*(1), 13-22. https://doi.org/10.1016/j.pedn.2005.06.004

[16] Dahlquist, L. M., Pendley, J.S., Landtrip, D.S., Jones, C.L., & Steuber, C.P. (2002). Distraction intervention for preschoolers undergoing intramuscular injections and subcutaneous port access. *Health Psychology, 21*(1), 94–99. https://psycnet.apa.org/doi/10.1037/0278-6133.21.1.94

[17] Lerwick, J. L. (2016). Minimizing pediatric healthcare-induced anxiety and trauma. *World Journal of Clinical Pediatrics, 5*(2), 143–150. https://doi.org/10.5409/wjcp.v5.i2.143

[18] Grissom, S., Boles, J., Bailey, K., Cantrell, K., Kennedy, A., Sykes, A., & Mandrell, B.N. (2016). Play-based procedural preparation and support intervention for cranial radiation. *Supportive Care in Cancer, 24*(6), 2421-2427. https://doi.org/10.1007/s00520-015-3040-y

Center to Advance Palliative Care (CAPC) and the Joint Commission recommend the inclusion of child life specialists as best practice in supportive palliative care.[19,20]

When CCLSs facilitate preparation and procedural support in the hospital setting, they provide cost savings by reducing overall patient length of stay, decreasing the need for anesthesia, sedation, and narcotic pain medication use in pediatric patients, and reducing the risk of medical complications and adverse events. Cost savings have been observed in preoperative settings, with preparation and procedural support interventions demonstrating a 24% shorter length of stay, earlier post-procedural extubation, and a 14% reduction in emergence delirium for those receiving anesthesia.[21,22,23,24] In addition to reducing rates of anesthesia and sedation during procedures, procedural preparation facilitated by CCLSs reduces unnecessary medication use. Preparation has shown to decrease the amount of narcotic pain medications pediatric patients consume by up to 50%, thereby reducing waste, minimizing side effects, and helping prevent medication misuse.[25]

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[19] The Joint Commission Advanced Certification for Hospital Palliative Care Program Needs Assessment. (n.d.). In *Center to Advance Palliative Care*. https://www.capc.org/documents/518/?clickthrough_doc_id=core.cmsdocument.518&clickthrough_req_id=g7sSPWbhS1e3XsWqvmOwAg&clickthrough_query=joint%20commission

[20] Unknown, U. (n.d.). Pediatric Palliative Care: Clinical Models and Staffing Overview. In *Center to Advance Palliative Care*. https://www.capc.org/documents/273/?clickthrough_doc_id=core.cmsdocument.273&clickthrough_req_id=J6jIF6laT860BXV9k68j7w&clickthrough_query=models%20and%20staffing%20overview

[21] Fortier, M.A., Bunzli, E., Walthall, J., Olshansky, E., Saadat, H., Santistevan, R., Mayes, L., & Zeev, K. (2015). Web-based Tailored Intervention for Preparation of Parents and Children for Outpatient Surgery (WebTIPS): Formative Evaluation and Randomized Controlled Trial. *Anesthesia & Analgesia, 120*(4), 915-922. https://doi.org/10.1213/ane.0000000000000632

[22] Seiden, S.C., McMullan, S., Sequera-Ramos, L., De Oliveira Jr, G.S., Roth, A., Rosenblatt, A., Jesdale, B.M., & Suresh, S. (2014). Tablet-based Interactive Distraction (TBID) vs oral midazolam to minimize perioperative anxiety in pediatric patients: a noninferiority randomized trial. *Pediatric Anesthesia, 24*(12), 1217-1223. https://doi.org/10.1111/pan.12475

[23] Stewart, B., Cazzell, M.A., & Pearcy, T. (2019). Single-Blinded Randomized Controlled Study on Use of Interactive Distraction Versus Oral Midazolam to Reduce Pediatric Preoperative Anxiety, Emergence Delirium, and Postanesthesia Length of Stay. *Journal of PeriAnesthesia Nursing, 34*(3), 567-575. https://doi.org/10.1016/j.jopan.2018.08.004

[24] Fraser, C., Gray, S.B., & Boles, J. (2019). Patient Awake While Scanned: Program To Reduce the Need for Anesthesia In Pediatric MRI. *Pediatric Nursing, 45*(6), 283-288. https://www.proquest.com/scholarly-journals/patient-awake-while-scanned-program-reduce-need/docview/2328560238/se-2

[25] Kain, Z.N., Caldwell-Andrews, A.A., Mayes, L.C., Weinberg, M.E., Wang, S-M., MacLaren, J.E., & Blount, R.L. (2007). Family-centered Preparation for Surgery Improves Perioperative

In 2022, the PCIAC developed a policy recommendation advocating for child life specialists to be included as an essential member of all interdisciplinary SPC teams.[26] Unfortunately, barriers still exist for healthcare facilities and community-based settings to employ CCLSs due to a lack of reimbursement pathways by Medicaid or commercial insurance payors. Since there are currently no licensing standards for CCLSs and thus no ability to bill for these services, funding is provided through hospital operational funds, grants, and/or philanthropy. These options are suboptimal for many organizations, rendering them unable to provide this important service. In addition, there is a clear need for standardized educational requirements and quality standards and licensing of CCLSs, if Texas children and the important adults in their life are to receive the best care possible when either the child or the adult is suffering from a serious and/or life limiting illness.

Recommendations

- The Texas Legislature should establish licensing requirements for child life specialists in both adult and pediatric settings, in hospitals and within the community, that fall within the existing scope of support for CCLSs.
  - A basic license should qualify the CCLS to work in pediatric settings, and additional certification(s) and/or specialized designation licenses should be achievable for those working in adult SPC and/or adult or pediatric hospice, as well as community settings.
  - Initial Basic License fee applications will cost $120 per application.[27] Additionally, initial Specialized Designation (SD) Licenses will cost $90 each.[28] Renewals for a Basic License will cost $90 and renewals for each SD License will cost $70, to offset the costs incurred to the licensing board for managing and maintaining license applications and renewals.[29]
- Texas Medicaid and other commercial insurance payors should provide reimbursement for licensed CCLS services in all settings, including for services provided via telemedicine.

Outcomes in Children: A Randomized Controlled Trial. *Anesthesiology, 106*(1), 65-74. https://doi.org/10.1097/00000542-200701000-00013

[26] Texas Palliative Care Interdisciplinary Advisory Council (2022). *Texas Palliative Care Interdisciplinary Advisory Council Recommendations to the 88th Texas Legislature*. https://www.hhs.texas.gov/sites/default/files/documents/txpciac-recs-88th-leg-oct-2022.pdf

[27] This is a projected cost, amount will be subject to change.

[28] This is a projected cost, amount will be subject to change.

[29] These are projected costs, amounts will be subject to change.

Discussion

The PCIAC, multiple external stakeholders, and HHSC staff have met several times throughout 2024 to address the CCLS in the context of evidenced based SPC standards. As of December 2023, there are 605 certified child life specialists in the state of Texas.[30] Since this number is relatively small, the processing of licensing applications and renewals should be manageable by the current licensing board. Additionally, costs for the management and maintenance of the license(s) would be offset by license application and renewal fees and inactivation fees.

The following information details the consensus recommended standards, eligibility criteria, and other important considerations for inclusion in the establishment and management of a license for certified child life specialists (CCLS) in Texas.

Licensure Standards

Licensing standards for CCLSs in Texas should include the following eligibility criteria:

- Be at least 18 years of age.
- Successful completion of an academic program with a baccalaureate degree or higher from an accredited college or university. Coursework can be obtained in one of two ways:
  - Graduated from an Association of Child Life Professionals (ACLP) endorsed academic program or
  - Ten specific college courses (see coursework stipulations noted on the ACLP webpage)[31]:
    - 1 child life course taught by a CCLS
    - 2 child development courses
    - 1 family systems course
    - 1 play course
    - 1 loss/bereavement or death/dying course
    - 1 research course

[30] Association of Child Life Professionals. (2023, December). *CCLS Connection: December 2023.* https://childlife.activehosted.com/index.php?action=social&c=321&m=451
[31] Association of Child Life Professionals. (n.d.). *ACLP Homepage*. https://www.scribbr.com/apa-examples/website/

    - ◊ 3 additional courses in related areas
- Successful completion of a child life internship under the supervision of and verified by a certified child life specialist (CCLS) or a licensed child life specialist who met all requirements of a child life internship supervisor/instructor, as outlined by the Child Life Certification Commission (CLCC).
- Paid work experience as a CCLS. The minimum hour requirement aligns with the ACLP's current internship supervisor/coordinator requirement. i.e., If the ACLP requires internship supervisors/coordinators to have a minimum of 4,000 hours paid experience as a CCLS, Texas licensure will also require 4,000 hours paid experience as a CCLS prior to licensure.
- Get fingerprinted electronically and complete a criminal background check.
- Is not listed on any state employee reportable conduct registry as verified by the interagency reportable conduct search engine.
- Grandfather Clause: The Board may grant initial Basic Licenses to child life specialists who are certified by the CLCC prior to December 31, 2025, and who hold an active CCLS credential at the time of licensure application. As part of this initial license granting, the Board may also grant one initial SD License to the CCLS with verification of a minimum of 24 continuing education units (CEUs) acquired no later than December 31, 2022, that are all specifically relevant to the SD, thus demonstrating competency in the SD area.

Initial and Renewal Information

Initial licenses and renewals shall be valid for two (2) years. Persons licensed as child life specialists are eligible for renewal of their licenses if they:

- Can attest to completion of a minimum of one hundred (100) paid hours of child life service; and
- Have met continuing competency requirements by completing a minimum of twenty-four (24) hours of continuing education every two years related to the practice of child life and other requirements established by rule of the Texas Department of Licensing and Regulation.
- Are currently certified by and in good standing with the CLCC.
- Have in addition to the required 24 CEUs, completed a training course on human trafficking prevention approved by the Texas Health and Human Services Commission.

- Have in addition to the required 24 CEUs, completed the Mandatory Reporting Community Response for Youth and Families course or a course similarly titled for mandated reporters, provided by the Texas Department of Family and Protective Services.

Basic Licenses and Specialized Designation Licenses

A **Basic License** confirms that a CCLS currently meets the standard competencies and requirements as established by the ACLP and CLCC and remains in good standing with the ACLP and CLCC. Additionally, basic licensure raises the educational standards for Texas CCLSs above the minimum requirements established by the CLCC, ensuring public safety, increased knowledge and skills, and clinical credibility. Basic licensees are monitored for compliance, and standards of practice including ethics. The initial **Basic License** application costs $120 and renewal for a **Basic License** costs $90.[32]

Specialized Designation (SD) Licenses are utilized to indicate child life experience and focused continuing education within a specified area of practice, both of which are necessary components for advancing competence in practice. SD licensees must meet the standards and requirements for a **Basic License** and the additional educational requirements for a **SD License**. A **SD License** provides a higher level of assurance and verification that the licensee has committed to advancing their knowledge and skills to support the provision of quality services for the public and the patients and families supported by CCLSs. Acquired SD License(s) will be noted on the **Basic License** certificate to indicate focused continuing education in that area. Specialization is well recognized within professional practice and has become the norm within the health and human services delivery system. An *initial* **Specialized Designation (SD) License** application costs $90.[33] Applications for each additional *initial* **SD License** cost $90.[34] Renewals for **SD License(s)** costs $70 per **SD License.**[35]

Specialized Designation Areas of Recognition

CCLSs with a **Basic License**, may hold one or more **SD License**. Acquiring one **SD License** requires that a minimum of 12 of the 24 required CEUs are specifically relevant to the SD area and requires an additional **SD License** application fee of $90 for each additional initial **SD License**, and $70 for each SD license renewal.[36]

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[32] These are projected costs, amounts will be subject to change.
[33] This is a projected cost, amount will be subject to change.
[34] This is a projected cost, amount will be subject to change.
[35] This is a projected cost, amount will be subject to change.
[36] These are projected costs, amounts will be subject to change.

Application for SD License (s) is only available in combination with the process of application or renewal of a Basic License.

SD licensees may hold more than one **SD License**. A licensee cannot hold a **SD license** without a **Basic License**. For each additional **SD License**, the licensee must pay an additional initial or renewal fee, and obtain an additional 12 CEUs; *i.e., 24 CEUs required for basic licensure, 12 of those hours must be specially relevant to the SD area for one SD license; licensees that seek an additional SD license must complete 12 additional CEUs that are specially relevant to the additional SD license area for a minimum total of 36 hours with at least 12 CEUs for **each** SD license specific area:*

- Supportive Palliative Care and Hospice-Pediatrics
- Supportive Palliative Care and Hospice-Children of Adult Patients
- Neurodiverse Populations
- Trauma-Informed Care
- Grief and Bereavement
- Facility Animal Handler
- Disaster Relief
- Critical Care
- Hematology/Oncology
- Community-based
- Other areas specific to and within the scope of child life will be considered.[37]

Licensure Inactivation, Reactivation, Expiration, and Revocation

- In lieu of renewing a license, a licensee may pay a one-time fee of $70 to *Inactivate* their license(s) indefinitely.[38] Inactivation allows a licensee to be exempt indefinitely from fulfilling the renewal requirements and paying renewal fees for Basic Licensure and SD Licensure. If the licensee holds any SD License(s) in addition to the Basic License, all will be inactivated at the same time, without additional costs. Inactivation must be completed no later than 60 days after licensure renewal deadline. If not placed on *Inactive* status, the license(s) will be permanently revoked on the 61st day after the

[37] Process and procedure for consideration of additional SD license areas to be determined
[38] This is a projected cost, amount will be subject to change.

renewal deadline, and reinstatement requires applicant to meet all initial licensure requirements for the Basic License and for any SD License(s) and apply for new license(s).

- To reactivate a license(s) after *Inactive* status, applicant must pay renewal fees for the Basic License and each SD License they wish to reactivate and fulfill items #2-5[39] as noted above in the Initial and Renewal Information section. The applicant can choose to reactivate only the Basic License, even if they previously held a SD License(s). SD License(s) can expire without penalty, as long as the Basic License is renewed. Choosing to reactivate *only* the Basic License will result in permanent expiration for the SD License(s). To reinstate one or more SD License(s) at a later time, the applicant can fulfill the requirements for an initial SD License(s) and pay associated costs, at the same time as completion of the renewal process for the Basic License.
- Additionally, to reactivate a license(s) after *Inactive* status, the applicant must demonstrate current competency as a CCLS, and this requirement can be fulfilled in one of two ways:
  - The CCLS can submit a competency checklist from their employer, completed within the previous 6 months during their new employee orientation or their annual competency assessment or
  - The CCLS can attest to completion of a minimum of 360 certified contact hours working as a CCLS (contact hours can include direct patient care and documentation) of which is the equivalent of 9 weeks of full-time work.
- Renewal applications received more than 5 days after the license renewal deadline, incur an additional penalty fee of $35 for each license renewal (Basic License and for each SD License).[40] Inactivation applications received more than 5 days after the license renewal deadline, incur a penalty fee of $35 for *Inactivation* of all licenses.[41] Basic and SD Licenses not renewed or *Inactivated* by the 61st day after the renewal deadline will be permanently revoked and subject to a $35 reinstatement after revocation fee per license (Basic and SD License (s)), in addition to initial application fee, per license.[42] Reinstatement for all revoked license(s) requires applicant to fulfill items #2-5 as noted in the Initial and Renewal Information section, and #3 a or b in

[39] For additional requirements for license reinstatement, see section *Licensure Inactivation, Reactivation, Expiration, and Revocation, #3 a & b.*
[40] This is a projected cost, amount will be subject to change.
[41] This is a projected cost, amount will be subject to change.
[42] This is a projected cost, amount will be subject to change.

the License Inactivation, Reactivation, Expiration and Revocation section, pay renewal fees and an additional $35 reinstatement after revocation fee per license (Basic and each SD License), and apply for new license(s).[43]

- The Board may establish and define the invocation of restrictions in the form of probation as defined by the Board for any licensed CCLS in violation of one or more violations noted in the Disciplinary Actions for CCLSs section. During probation, a CCLS may be entitled to continue to practice as a CCLS, with or without restrictions as deemed appropriate by the Board. Probation may be lifted with rights to practice as a CCLS fully reinstated, after the time period set for probation has elapsed, and as determined by the Board, and during which no additional violations by the CCLS occur. CCLSs whose license(s) are suspended for a specified period of time as determined by the Board, may not practice as a CCLS or as child life assistant, and may not participate in any training or student supervision. Upon the successful completion of the suspension period, the CCLS license(s) may be reinstated upon the licensee successfully meeting all requirements as determined by the Board. A CCLS Basic and SD license(s) may be permanently revoked, and ineligible for renewal upon failure to fulfill the requirements of Board's outlined probation or suspension and/or upon one or more additional violations noted in Disciplinary Actions for CCLSs section. Additionally, in accordance with State and Federal Laws, a CCLS who participates in egregious criminal activities may be subject to criminal charges. A CCLS who has pled guilty to or has been convicted of a felony is ineligible for Texas CCLS licensure, indefinitely.

Disciplinary Actions for CCLSs

The licensure board may reprimand or place on probation any holder of a Child Life Specialist license or suspend or revoke any license issued to a Child Life Specialist who is found in violation of one or more of the following (violations are not limited to those listed below):

- Conviction of a felony or of any offense involving moral turpitude.
- Conviction of, or admission of guilt, or plea of no contest to a felony or misdemeanor.
- Dishonorable or immoral conduct that is likely to deceive, defraud, or harm the public.

[43] This is a projected cost, amount will be subject to change.

- Aiding, abetting, or assisting any other person to violate or circumvent any law, rule or regulation intended to guide the conduct of a Child Life Specialist.
- Procuring, aiding, or abetting a criminal operation.
- Participation in fraud, abuse and/or violation of state or federal laws.
- Fraudulent billing practices and/or violation of Medicare and Medicaid laws or abusive billing practices for self-pay and private insurance clients.
- Improper management of medical records, inaccurate recording, falsifying, or altering of client records.
- Forging prescriptions for medication/drugs or presenting a forged prescription.
- Habitual intemperance or addictive use of any drug, chemical or substance that could result in behavior that interferes with the practice of child life and the responsibilities of the licensee.
- Unauthorized possession or use of illegal or controlled substances or pharmacological agents without lawful authority or prescription by an authorized and licensed independent practitioner.
- While engaged in the care of a client, engaging in conduct with a client, client family member, or significant other that is seductive or sexually demeaning/exploitive in nature.
- Verbally or physically abusing clients or client family members.
- Discriminating in the rendering of client care and/or refusal to provide care.
- Violating HIPAA concerning a client.
- Any conduct which potentially jeopardizes or threatens a client or client family member's life, health, or safety.
- Negligence or providing or performing services outside the scope of licensed CCLS, while in practice of child life or violating the Code of Ethics Principles and/or the Code of Ethics Rules as adopted from the ACLP, managed by the CLCC, and adopted by the licensure Board.
- Determined to be mentally incompetent by a court of competent jurisdiction.
- Failing to make timely application for license renewal.
- Falsifying documents submitted to the ACLP, CLCC, or the Texas State Board of Licensure and Supervision.

- Obtaining or attempting to obtain, by fraud or deception a license, certificate, or documents of any form as a Child Life Specialist.
- Failure to report through proper channels the unsafe, unethical, or illegal practice of any person practicing as a Child Life Specialist.
- Failure to cooperate and/or furnish to the Board, its investigators or representatives, information lawfully requested by the Board.
- Violation of any provision(s) of the Child Life Specialist Act or the rules and regulations of the Board or of an action, stipulation, agreement, or order of the Board.
- Failure to report to the Board any adverse action taken against the licensee by another licensing jurisdiction (United States or foreign), by any governmental agency, by any law enforcement agency, or by any court for acts or conduct similar to acts or conduct that would constitute grounds for action as defined in this section.
- Misrepresenting, misleading, or misinforming about education, credentials, titles, or certifications, to the public, clients, client family members, and/or significant others.
- Failure to maintain certification as a child life specialist through the CLCC.

A Child Life Specialist who knowingly allows or participates with individual(s) who are in violation of the above will be prohibited from supervising other Child Life Specialists, Child Life Practicum and/or Internship Students, and/or Child Life Assistants for so long as the Board deems appropriate and may themselves be subject to disciplinary action pursuant to their conduct, including restricted or fully suspended child life practice. Additionally, a CCLS who knowingly allows or participates with individual(s) who are in violation of any of the above, will be reported to the Child Life Certification Commission Ethics Committee.

All Child Life Specialists are responsible for maintaining and promoting the ethical practice of Child Life. Child Life Specialists shall act in the best interest of the client at every level of practice. All Child Life Specialists shall:

- Demonstrate a concern for the well-being of the recipients of their services. (Beneficence)
- Take reasonable precautions to avoid imposing or inflicting harm upon the recipient of services or to his/her property. (Non-malfeasance)
- Respect the recipient and/or their surrogate(s) as well as the recipient’s rights. (Autonomy, privacy, confidentiality)

- Achieve and continually maintain high standards of competence. (Duties)
- Comply with laws and policies guiding the profession of Child Life. (Justice)
- Provide accurate information about Child Life services. (Veracity)
- Treat colleagues and other professionals with fairness, and discretion. (Integrity)

Referrals to Child Life Services

Referrals to child life services may come from within healthcare organizations, private organizations, and community-based settings, initiated by an adult over the age of 18, a parent or legal guardian, family member, physician, or any other healthcare professional, and referring children ages 0-18 years and their legal guardians to child life services.

Billable Services Provided by CCLSs

Billable services to be provided by CCLSs may include, but are not limited to, the following supports and services:

- **Psychosocial and Emotional Support:** Assess and provide targeted support to reduce anxiety, fear, and stress for patients and families, using evidence-based techniques to enhance positive coping mechanisms.[44,45,46]
- **Developmentally Appropriate Education:** Deliver tailored education to patients and families about medical procedures, diagnoses, and hospital experiences, utilizing age-appropriate methods to promote understanding and alleviate misconceptions.[47]
- **Therapeutic Interventions:** Initiate therapeutic interventions designed to address specific emotional, developmental, or psychosocial needs, facilitating

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[44] Patients refers to a person of any age being treated for a medical condition by licensed medical providers, within or outside of a healthcare facility.
[45] Cristal, N.S., Staab. J., Chatham, R., Ryan, S., Mcnair, B., & Grubenhoff, J.A. (2018). Child Life Reduces Distress and Pain and Improves Family Satisfaction in the Pediatric Emergency Department. *Clinical Pediatrics, 57*(13). https://doi.org/10.1177/0009922818798386
[46] Beickert, K., & Mora, K. (2017). Transforming the Pediatric Experience: The Story of Child Life. *Pediatric Annals, 46*(9), 345-351. https://doi.org/10.3928/19382359-20170810-01
[47] Boles, J., Fraser, C., Bennett, K., Jones, M., Dunbar, J., Woodburn, A., Gill, M.A., Duplechain, A., Munn, E.K., & Hoskins, K. (2020). *The Value of Certified Child Life Specialists: Direct and Downstream Optimization of Pediatric Patient and Family Outcomes.* Association of Child Life Professionals. https://www.childlife.org/docs/default-source/the-child-life-profession/value-of-cclss-full-report.pdf?sfvrsn=5e238d4d_2

normalization and expression of emotions and feelings related to experiences.[48,49]

- **Procedural Preparation and Support:** Facilitate procedural support utilizing developmentally appropriate preparation, and distraction techniques; and coping strategies to minimize distress and promote positive coping mechanisms before, during and after medical interventions.[50, 51, 52]
- **Family Systems Support:** Illness and injury impact the patient, but also impact the family, including children of all relations to the patient, and extended social systems such as church families, sports teams, and schools. CCLSs play a pivotal role toward ensuring family-centered care is at the core of medical care for patients and their families. Their extended support is an adjunct to the family system with a focus on adjustment, normalization, and navigation of medical care:[53]
  - **Parent/Caregivers Support**: Facilitate guidance, education, and psychosocial support to involved adults regarding the understanding, coping, development, stress responses, grieving processes, behavioral changes, at-risk behaviors, scripting support for difficult conversations as well as recommendations for higher-level psychosocial professional support, for the involved children.[54]

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[48] Armington, C. H., Peach, H. E., & Hopkinson, S. (2016). Preparation, education, and procedural support in pediatric cancer. In A. N. Abrams, A. C. Muriel, & L. Wiener (Eds.), *Pediatric psychosocial oncology: Textbook for multidisciplinary care* (pp. 107–117). Springer International Publishing/Springer Nature. https://doi.org/10.1007/978-3-319-21374-3_7

[49] Moore, E.R., Bennett, K.L., Dietrich, M.S., & Well, N. (2015). The Effect of Directed Medical Play on Young Children's Pain and Distress During Burn Wound Care. *Journal of Pediatric Health Care, 29*(3), 265-273. https://doi.org/10.1016/j.pedhc.2014.12.006

[50] Brewer, S., Gleditsch, S.L., Syblik, D., Tietjens, M.E., & Vacik, H.W. (2006). Pediatric Anxiety: Child Life Intervention in Day Surgery. *Journal of Pediatric Nursing, 21*(1), 13-22. https://doi.org/10.1016/j.pedn.2005.06.004

[51] Hall, J.E., Patel, D.P., Thomas, J.W., Richards, C.A., Rogers, P.E., & Pruitt, C.M. (2018). Certified Child Life Specialists Lessen Emotional Distress of Children Undergoing Laceration Repair in the Emergency Department. *Pediatric Emergency Care, 34*(9), 603-606. https://doi.org/10.1097/PEC.0000000000001559

[52] Getchell, K., McCowan, K., Whooley, E., Dumais, C., Rosenstock, A., Cole, A., & DeGrazia, M. (2022). Child Life Specialists Decrease Procedure Time, Improve Experience, and Reduce Fear in an Outpatient Blood Drawing Lab (CLS Decrease Procedure Time). *Journal of Patient Experience, 9*. https://doi.org/10.1177/23743735221105679

[53] Smith, J.G., Desai, P.P., Sira, N., & Engelke, S.C. (2014). Family-Centered Developmentally Supportive Care in the Neonatal Intensive Care Unit: Exploring the Role and Training of Child Life Specialists. *Children's Health Care, 43*(4), 345-368. https://doi.org/10.1080/02739615.2014.880917

[54] Families refers to people related by blood, marriage, adoption, or other ties, who comprise the patient's immediate and extended social group.

- **Sibling Support:** Implement developmentally appropriate psychosocial support, therapeutic interventions, and educational programs for siblings of pediatric patients, addressing their unique needs and concerns related to their sibling's medical condition and/or hospitalization; including diagnoses, treatment plan, end-of-life, and bereavement.[55,56]
- **Children loved by adult patients Support:** Implement developmentally appropriate psychosocial support, therapeutic interventions, and educational programs for children loved by adult patients, addressing their unique needs and concerns related to the adult's medical condition and/or hospitalization; including diagnoses, treatment plan, end-of-life, and bereavement.[57,58,59]
- **Peer Support:** Implement and facilitate support and educational programs for groups of pediatric patients, siblings of pediatric patients, and children loved by adult patients;[60] addressing their unique needs and concerns related to their own, their sibling's and/or their adult patient's medical condition, hospitalization and/or death.
- **Extended Social Systems Support:** Facilitate guidance, and education, with consent from involved child's parent/guardian, for extended social systems of support including church families, sports teams, and schools regarding the understanding, coping, development, stress responses,

[55] Siblings refers to any minor-age child (0-18 years) related to the pediatric patient by blood, marriage, adoption, or other ties, who is or may be impacted by the medical condition of the pediatric patient.
[56] Pearson, L. (1997). Family-centered care and the anticipated death of a newborn. *Pediatric Nursing, 23*(2), 178+. https://go.gale.com/ps/i.do?p=AONE&u=txshracd2570&id=GALE|A19387526&v=2.1&it=r&sid=googleScholar&asid=fe31553b
[57] Children loved by adult patients refers to any minor-age child (0-18 years) related to the adult by blood, marriage, adoption, or other ties, who is or may be impacted by the medical condition of the adult patient.
[58] Lysecki, D., Bainbridge, D., Akitt, T., Georgiou, G., Meyer, R.M., & Sussman, J. (2021). Feasibility of a child life specialist program for oncology patients with minor children at home: Qualitative analysis [Abstract]. *Journal of Clinical Oncology, 39*(28). https://doi.org/10.1200/JCO.2020.39.28_suppl.30
[59] Sutter, C., & Reid, T. (2012). How Do We Talk to the Children? Child Life Consultation To Support the Children of Seriously Ill Adult Inpatients. *Journal of Palliative Medicine, 15*(12). https://doi.org/10.1089/jpm.2012.0019
[60] Boles, J., Fraser, C., Bennett, K., Jones, M., Dunbar, J., Woodburn, A., Gill, M.A., Duplechain, A., Munn, E.K., & Hoskins, K. (2020). *The Value of Certified Child Life Specialists: Direct and Downstream Optimization of Pediatric Patient and Family Outcomes.* Association of Child Life Professionals. https://www.childlife.org/docs/default-source/the-child-life-profession/value-of-cclss-full-report.pdf?sfvrsn=5e238d4d_2

grieving processes, behavioral changes, at-risk behaviors, for the involved children. [61,62]

- **Grief and Bereavement Support:** Initiate anticipatory grief support in response to a family's experience of serious illness or injury, as well as early grief and bereavement support for families experiencing loss, as long as the involved child(ren)'s needs remain in scope for child life services; and provide community organization information including counseling resources, to assist families navigating the grieving process and long-term coping needs when the involved child(ren)'s needs require higher level psychosocial support.[63,64]
- **Orientation and Normalization:** Orient to and normalize the environment and experience in an effort to promote control, comfort, play and understanding.
  - **Environment:** Provide developmentally-appropriate play, expressive play and normalization play opportunities to offer positive and comforting experiences for patient and family.[65]
  - **Facility:** Facilitate tours and familiarization activities for patients and families new to the healthcare facility or setting, aimed at reducing anxiety and increasing comfort with the healthcare environment.[66]

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[61] Trivette, C. M., Deal, A., & Dunst, C. J. (1986). Family Needs, Sources of Support, and Professional Roles: Critical Elements of Family Systems Assessment and Intervention. *Diagnostique, 11*(3-4), 246-267. https://doi.org/10.1177/073724778601100308

[62] Varda, D. M., & Talmi, A. (2018). Social Connectedness in Family Social Support Networks: Strengthening Systems of Care for Children with Special Health Care Needs. *EGEMS*, *6*(1), 23. https://doi.org/10.5334/egems.232

[63] Leigh, K. (2017). Promoting Meaning Making and Spiritual Growth in Bereaved Parents and Siblings Through the use of Legacy Building Interventions. *ResearchGate.* Retrieved July 15, 2024, from https://www.researchgate.net/profile/Korie-Leigh/publication/324585614_Promoting_Meaning_Making_and_Spiritual_Growth_in_Bereaved_Parents_and_Siblings_Through_the_use_of_Legacy_Building_Interventions/links/5ad6cf61a6fdcc293582d191/Promoting-Meaning-Making-and-Spiritual-Growth-in-Bereaved-Parents-and-Siblings-Through-the-use-of-Legacy-Building-Interventions.pdf

[64] Basak, R.B., Momaya, R., Guo, J., & Rathi, P. (2019). Role of Child Life Specialists in Pediatric Palliative Care. *Journal of Pain and Symptom Management, 58*(4), 735-737. https://doi.org/10.1016/j.jpainsymman.2019.05.022

[65] Boles, J., Fraser, C., Bennett, K., Jones, M., Dunbar, J., Woodburn, A., Gill, M.A., Duplechain, A., Munn, E.K., & Hoskins, K. (2020). *The Value of Certified Child Life Specialists: Direct and Downstream Optimization of Pediatric Patient and Family Outcomes.* Association of Child Life Professionals. https://www.childlife.org/docs/default-source/the-child-life-profession/value-of-cclss-full-report.pdf?sfvrsn=5e238d4d_2

[66] Adler, A.C., Leung, S., Lee, B.H., & Dubow, S.R. (2018). Preparing Your Pediatric Patients and Their Families for the Operating Room: Reducing Fear of the Unknown. *Pediatrics in Review, 39*(1), 13-26. http://dx.doi.org/10.1542/pir.2017-0011

- **Provider and Setting/Facility Transitional Support:** Support aimed at lessening distress often resulting from changes in processes, care providers, and settings, including but not limited to-
    - **Age-Focused Care Providers:** Pediatric patient receiving support from pediatric-focused care providers transitioning to being an adult patient receiving support from adult-focused care providers[67,68]
    - **Healthcare Setting/Facility**: Patient and family support for healthcare setting or facility transitions, i.e., transitioning from hospital-based care to rehabilitation, from short-term or long-term nursing care[69]
    - **Transitioning from Curative to Non-Curative Focused Care including Palliative, Hospice and/or Comfort Care:** Initiating education to empower adults supporting involved children; and education to prepare involved children in advance of and during transitions to non-curative focused care.[70,71]

- **Professional Collaboration and Care Planning:** Collaborate with interdisciplinary teams to integrate psychosocial care into the medical treatment plan, participating in patient rounds, care conferences, interdisciplinary team meetings and huddles, etc., to advocate for patient and family needs.[72]
- **Trauma-Informed Care and Resiliency Support:** Initiate support directed by the comprehensive understanding of biological, psychological, and social

[67] White, P.H., Cooley, W.C., Transitions Clinical Report Authoring Group, American Academy of Pediatricians, American Academy of Family Physicians, & American College of Physicians. (2018). Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. *Pediatrics, 142*(5). https://doi.org/10.1542/peds.2018-2587
[68] Got Transition. (n.d.). *Transitioning Youth To An Adult Health Care Clinician: For use by Pediatric, Family Medicine, and Med-Peds Clinicians.* https://gottransition.org/six-core-elements/transitioning-youth-to-adult/
[69] Boles, J., Fraser, C., Bennett, K., Jones, M., Dunbar, J., Woodburn, A., Gill, M.A., Duplechain, A., Munn, E.K., & Hoskins, K. (2020). *The Value of Certified Child Life Specialists: Direct and Downstream Optimization of Pediatric Patient and Family Outcomes.* Association of Child Life Professionals. https://www.childlife.org/docs/default-source/the-child-life-profession/value-of-cclss-full-report.pdf?sfvrsn=5e238d4d_2
[70] Ibid.
[71] Case, C., & Fisher, J.M. (2018). Pediatric Palliative Care-child Life Beyond the Hospital. *Pediatrics, 141*(1), 386. https://doi.org/10.1542/peds.141.1MA4.386
[72] Romito, B., Jewell, J., Jackson, M., AAP Committee on Hospital Care, Association of Child Life Professionals, Ernst, K., Hill, V., Hsu, B., Lam, V., Mauro-Small, M., & Vinocur, C. (2021). Child Life Services. *Pediatrics, 147*(1). https://doi.org/10.1542/peds.2020-040261

effects trauma has on individuals and families- recognizing the needs for safety, connections, and strategies to aid in regulating emotions.[73,74]

Policy Issue: Request for HHSC to Pursue a Supportive Palliative Care Texas Medicaid Benefit & Texas Advance Care Planning Reimbursement

It is estimated that over 13 million patients across the United States qualify for Supportive Palliative Care (SPC) services. Currently, states are exploring and implementing modern and innovative specialty benefits for this vulnerable and high-risk population.[75,76,77]

Through collaboration with national experts through the Serious Illness Institute, Texas was found to have patients with multiple simultaneous complex comorbidities that are serious and/or life limiting illnesses. As part of an actuarial review of one specific population, the Texas Star Plus program, a minimum of 3,000 patients were identified who would use an interdisciplinary SPC service over the course of a year were it available leading to an estimated net of $42 million in cost savings for Medicaid. The same analysis indicated that the upper bound for utilization and savings would be much higher under more optimistic assumptions. The model assumed that an average SPC patient would receive about 7.5 hours total per month in services from a standard core SPC team consisting of one prescribing clinician (MD, DO, APRN, PA), one registered nurse, a social worker, a chaplain, and other professionals. Savings would exceed costs by at least three-fold due to better care coordination and symptom management and reductions in avoidable

[73] Knazik, S.R., Gausche-Hill, M., Dietrich, A.M., Gold, C., Johnson, R.W., Mace, S.E., & Sochor, M.R. (2003). The death of a child in the emergency department. *Annals of Emergency Medicine, 42*(4), 519-529. https://doi.org/10.1067/S0196-0644(03)00424-4
[74] Boles, J., Fraser, C., Bennett, K., Jones, M., Dunbar, J., Woodburn, A., Gill, M.A., Duplechain, A., Munn, E.K., & Hoskins, K. (2020). *The Value of Certified Child Life Specialists: Direct and Downstream Optimization of Pediatric Patient and Family Outcomes.* Association of Child Life Professionals. https://www.childlife.org/docs/default-source/the-child-life-profession/value-of-cclss-full-report.pdf?sfvrsn=5e238d4d_2
[75] Center to Advance Palliative Care. (n.d.). *How States Can Leverage Existing Medicaid Services to Better Meet Palliative Need in the Community*. https://www.capc.org/documents/download/1132/
[76] Hospice News. (2024, March 15). *Palliative Care's Evolving Role in Medicaid. https://hospicenews.com/2024/03/15/palliative-cares-evolving-role-in-medicaid/*
[77] Harvard Public Health. (2024, April 4). *Palliative Care could be a game changer for public health*. https://harvardpublichealth.org/policy-practice/who-pays-for-palliative-care-and-why-we-need-to-change-that/

emergency department, inpatient, and other preventable health care encounters. Under SPC (unlike hospice), patients would continue to receive disease modifying or curative care.

Texas has opportunity to improve the quality of life and reduce the suffering of Texans enduring a serious and/or life limiting illness. Through years of collaboration and partnerships with local, state, and national experts, PCIAC is making a historic request for HHSC to develop and implement with haste through a state plan amendment or other appropriate authority, a new SPC benefit for Medicaid. This new benefit would support patients and families at a difficult time, improve outcomes, and reduce total Medicaid costs. This approach is consistent with recommendations from the Center to Advance Palliative Care and recent actions by other states across the US.[78] [79]

Recommendations

- HHSC should submit a State Plan Amendment (or other waiver authority) to the Centers for Medicare & Medicaid Services (CMS) to allow for SPC services to become a Texas Medicaid Benefit.
- HHSC should allow for reimbursement for Advance Care Planning (ACP) procedure codes 99497 and 99498 within Texas Medicaid. This will ensure Medicaid providers are compensated for vital and ongoing crucial ACP discussions in various settings.

Discussion

There are several state options for establishing a non-hospice palliative care benefit for Texas Medicaid beneficiaries.

- **State Plan Amendment**
  - A Medicaid state plan is an agreement between a state and the Federal government that outlines how that state will administer it's Medicaid program.[80] It ensures that the state will adhere to the Social Security Act

[78] Center to Advance Palliative Care., & National Palliative Care Research Center. (2019). *America's Care of Serious Illness: A State-By-State Report Card on Access to Palliative Care In Our Nation's Hospitals.* https://reportcard.capc.org/
[79] Center to Advance Palliative Care. (n.d.). *Palliative Care State Policy.* https://www.capc.org/toolkits/palliative-care-state-policy/
[80] Centers for Medicare & Medicaid Services. (n.d.) *Medicaid State Plan Amendments.* Medicaid.gov. https://www.medicaid.gov/medicaid/medicaid-state-plan-amendments/index.html

and the guidance of the U.S. Department of Health and Human services.[81] Washington State and Hawaii have successfully implemented palliative care SPC benefit lines for adult and pediatric populations.[82] In the case of Washington, beneficiaries can have up to six care contacts per month from any member of the care team within the home setting.[83] Services include care coordination, counseling, education/training, pain management, and family member/caregiver support.[84]

- 1915(b) waivers
  - 1915(b) waivers allow states to modify their delivery systems by waiving federal requirements for state wideness, comparability, and freedom of choice.[85] Florida delivers pediatric SPC services to Medicaid beneficiaries through their 1915(b) managed care waiver.[86] Services covered under the wavier program include pain/symptom management, counseling, and hospice.[87]
- 1915(c) waivers
  - 1915(c) waiver programs enable states to fund home and community-based services for individuals with disabilities or special health care needs.[88] States like California, Colorado, and North Dakota have relied on 1915(c) waivers to implement programs for pediatric and adult patients with serious illness.[89] Services provided under the waivers include respite

[81] Texas Health and Human Services. (n.d.). *State Plan.* https://www.hhs.texas.gov/services/health/medicaid-chip/about-medicaid-chip/state-plan#:~:text=Essentially%2C%20the%20plan%20is%20the,Services%20as%20state%20plan%20amendments.
[82] Texas Palliative Care Interdisciplinary Advisory Council. (2022). *Medicaid Reimbursement for Supportive Palliative Care in Texas and Other States. https://www.hhs.texas.gov/sites/default/files/documents/senate-bill-916-report-september-2022.pdf*
[83] Ibid.
[84] Ibid.
[85] The Medicaid and CHIP Payment and Access Commission. (2022, May 9). *1915(b) waivers*. https://www.macpac.gov/subtopic/1915b-waivers/
[86] Palliative Care Interdisciplinary Advisory Council. (2022). *Medicaid Reimbursement for Supportive Palliative Care in Texas and Other States. https://www.hhs.texas.gov/sites/default/files/documents/senate-bill-916-report-september-2022.pdf*
[87] Ibid.
[88] Texas Medicaid & Health Partnership. (2024, June 17). *1915(c) Waiver Programs*. https://www.tmhp.com/programs/1915c-waiver-programs
[89] Palliative Care Interdisciplinary Advisory Council. (2022). *Medicaid Reimbursement for Supportive Palliative Care in Texas and Other States. https://www.hhs.texas.gov/sites/default/files/documents/senate-bill-916-report-september-2022.pdf*

care, case management, skilled nursing, bereavement counseling, and expressive therapy.[90]

In addition to establishing a benefit for SPC for services, it's critical to reimburse providers for ACP discussions. ACP is currently not reimbursable under the Texas Medicaid Fee Schedule, specifically Common Procedural Terminology (CPT) codes 99497 and 99498. These codes allow for qualified health professionals to engage in ACP discussions on Texas specific ACP legal documents (medical power of attorney, advance directive, durable power of attorney, out of hospital do not resuscitate, disposition of remains) with patients and their family members.[91] For patients with serious and life limiting illness, early conversations about end-of-life care issues are associated with improved patient health outcomes, including better quality of life, reduced use of undesired and nonbeneficial medical care near end of life, patient health care consistent with patients' values and goals, improved family outcomes, and reduced utilization and costs. [92]

Texas should modernize their reimbursement for vital ACP discussions as it is considered a main component of having patient centered goals of care through comprehensive SPC services. This is an independent need and should not depend on the timing and forward movement for a new SPC benefit. Establishing a Medicaid Benefit and reimbursing providers for ACP codes will enable the full spectrum of services to be delivered to individuals with serious illness across the care continuum.

Policy Issue: Expanding Access to Medical Cannabis and Research on Psychedelic Microdosing for Patients in Texas

Individuals with a serious illness most often desire to be cared for in their home by family members and to have their pain and symptom burden managed to better improve their quality of life. Medical cannabis is a relatively new treatment option that is increasingly being utilized for pain and symptom management. Medical

[90] Ibid.
[91] Centers for Medicare & Medicaid Services. (2023, November 1). *Billing and Coding: Advance Care Planning.* CMS.gov. https://www.cms.gov/medicare-coverage-database/view/article.aspx?articleid=58664
[92] Texas Palliative Care Interdisciplinary Advisory Council (2022). *Texas Palliative Care Interdisciplinary Advisory Council Recommendations to the 88th Texas Legislature*. https://www.hhs.texas.gov/sites/default/files/documents/txpciac-recs-88th-leg-oct-2022.pdf

cannabis has been shown to improve cancer patient pain and symptom burden as well as reduce opioid and other analgesic use.[93]

In 2020, the PCIAC developed a legislative recommendation to amend the language around House Bill 3703, 86th Legislature, Regular Session, 2019 to expand patient eligibility for the use of low-THC cannabis to all cancer patients.[94] During the following legislative session in 2021, House Bill 1535, 87th Legislature, Regular Session, 2021 was passed, which closely followed the PCIAC's recommendation to expand the list of medical conditions and patients that qualify for low-THC medical cannabis as well as established institutional review boards (IRBs) to evaluate and approve proposed research programs to study the medical use of low-THC cannabis in treating a medical condition.

Another emerging area of research for pain and symptom management is the utilization of psychedelic microdosing, which has shown clinically significant effects in the treatment of psychological distress in patients with advanced-stage cancer.[95] However, there is currently very little research being conducted in Texas to explore its utilization as a pain and symptom management treatment option.

Recommendations

Building upon the PCIAC's previous 2020 recommendation, the PCIAC advocates that:

- The Texas Legislature should further expand the patient eligibility criteria for medical cannabis to include sickle cell disease as well as to treat other conditions that cause severe and/or chronic pain for which a physician would otherwise prescribe an opioid or for conditions leading to severe nausea and/or anxiety.

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[93] Aviram, J., Lewitus, G. M., Vysotski, Y., Amna, M. A., Ouryvaev, A., Procaccia, S., Cohen, I., Leibovici, A., Akria, L., Goncharov, D., Mativ, N., Kauffman, A., Shai, A., Bar-Sela, G., & Meiri, D. (2022). The Effectiveness and Safety of Medical Cannabis for Treating Cancer Related Symptoms in Oncology Patients. *Frontiers in Pain Research, 3*, 861037. https://doi.org/10.3389/fpain.2022.861037

[94] Texas Palliative Care Interdisciplinary Advisory Council (2020). *Texas Palliative Care Interdisciplinary Advisory Council Recommendations to the 87th Texas Legislature*. https://www.hhs.texas.gov/sites/default/files/documents/laws-regulations/reports-presentations/2020/txpciac-recs-86th-leg-oct-2020.pdf

[95] Wells, A., Muthukumaraswamy, A.P.S., Morunga, E., Evans, W., Cavadino, A., Bansal, M., Lawrence, N.J., Ashley, A., Hoeh, N.R., Sundram, F., Applebaum, A., Parkinson, H., & Reynolds, L. (2024). PAM trial protocol: a randomised feasibility study of psychedelic microdosing-assisted meaning-centred psychotherapy in advanced stage cancer patients. *Pilot and Feasibility Studies, 10*(1), 29. https://doi.org/10.1186/s40814-024-01449-9

- The Texas Legislature should expand the compassionate use institutional review board to also evaluate and approve proposed research programs to study the medical use of psychedelic microdosing in treating certain medical conditions, as described in HB 1535, 87th Legislature, Regular Session, 2021.

Discussion

Patients with sickle cell disease (SCD) experience significant pain, which can be both acute and chronic. Untreated pain in patients with SCD can lead to preventable hospital admissions and reduce their quality of life.[96] Pain management for these patients is primarily reliant on opioid medications, which are often insufficient in easing pain and symptom burden. Opioids can also contribute to adverse side effects when prescribed in high dosages, which is standard for SCD patients.[97,98] Due to the potential side effects and provider hesitancy[99] associated with opioids, there is a need for alternative strategies to treat SCD. Medical cannabis has been identified as an option for individuals with chronic pain.[100,101] Cannabis has exhibited signs of being well-tolerated for adults with SCD.[102]

[96] Argueta, D.A., Aich, A., Muqolli, F., Cherukury, H., Sagi, V., DiPatrizio, N.V., & Gupta, K. (2020). Considerations for Cannabis Use to Treat Pain in Sickle Cell Disease. J*ournal of Clinical Medicine, 9(*12), 3902. https://doi.org/10.3390/jcm9123902
[97] Ibid.
[98] Paulsingth, C.N., Mohammed, M.B., Elhaj, M.S., Mohamed, N., Singh, T., Mohammed, Z., & Khan, S. (2022). The Efficacy of Marijuana Use for Pain Relief in Adults With Sickle Cell Disease: A Systematic Review. *Cureus, 14*(5), e24962. https://doi.org/10.7759%2Fcureus.24962
[99] Owens, B. (2019). Opioid prescriptions down but some patients fear doctors now too strict. *Canadian Medical Association Journal, 191*(19), E546-E547. https://doi.org/10.1503/cmaj.109-5748
[100] Argueta, D.A., Aich, A., Muqolli, F., Cherukury, H., Sagi, V., DiPatrizio, N.V., & Gupta, K. (2020). Considerations for Cannabis Use to Treat Pain in Sickle Cell Disease. J*ournal of Clinical Medicine, 9(*12), 3902. https://doi.org/10.3390/jcm9123902
[101] Paulsingth, C.N., Mohammed, M.B., Elhaj, M.S., Mohamed, N., Singh, T., Mohammed, Z., & Khan, S. (2022). The Efficacy of Marijuana Use for Pain Relief in Adults With Sickle Cell Disease: A Systematic Review. *Cureus, 14*(5), e24962. https://doi.org/10.7759%2Fcureus.24962
[102] Argueta, D.A., Aich, A., Muqolli, F., Cherukury, H., Sagi, V., DiPatrizio, N.V., & Gupta, K. (2020). Considerations for Cannabis Use to Treat Pain in Sickle Cell Disease. J*ournal of Clinical Medicine, 9(*12), 3902. https://doi.org/10.3390/jcm9123902

While the potential efficacy of medical cannabis for treating SCD is promising[103,104], there are issues concerning the regulatory environment.[105] On the state level, the Compassionate Use Act allows physicians to prescribe low-THC cannabis to patients with certain medical conditions. The current eligibility criteria restricts usage to individuals diagnosed with epilepsy, seizure disorders, multiple sclerosis, spasticity, terminal cancer, autism, or incurable neurodegenerative disease. Expanding the eligibility to include a broader net of people with chronic pain would allow patients with SCD to access medical cannabis.

Federal policy shifts may also warrant an expansion of eligible conditions within Texas. The Department of Justice recently released a proposed rule to reschedule cannabis from a Schedule 1 to a Schedule 3 drug on the Controlled Substances Act Scheduling List. Schedule 1 drugs are defined as drugs with no accepted medical use and a high potential for abuse.[106,107] Schedule 3 drugs have a moderate to low potential for physical and psychological dependence, and a much lower abuse potential than schedule 1 or schedule 2 drugs.[108] If approved, this rule could serve as supplemental support for the expansion of patient eligibility criteria for medical cannabis treatment.

In addition to medical cannabis, public interest has increased in the use of Psychedelics as a non-conventional treatment for pain management.[109] Expanding the compassionate use IRB to study the use of psychedelic microdosing would help researchers further analyze the risks and benefits of this treatment. Conditions that should be considered within the IRB expansion include:

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[103] Ibid.
[104] Abrams, D.I., Couey, P., & Dixit, N. (2020). Effect of Inhaled Cannabis for Pain in Adults with Sickle Cell Disease: A Randized Clinical Trial. JAMA Network Open, 3(7), e2010874. https://doi.org/10.1001/jamanetworkopen.2020.10874
[105] Argueta, D.A., Aich, A., Muqolli, F., Cherukury, H., Sagi, V., DiPatrizio, N.V., & Gupta, K. (2020). Considerations for Cannabis Use to Treat Pain in Sickle Cell Disease. J*ournal of Clinical Medicine, 9(*12), 3902. https://doi.org/10.3390/jcm9123902
[106] United States Drug Enforcement Administration. (n.d.). *Drug Scheduling*. https://www.dea.gov/drug-information/drug-scheduling
[107] United States Department of Justice. (2024, May 16). *Press Release: Justice Department Submits Proposed Regulation to Reschedule Marijuana*. https://www.justice.gov/opa/pr/justice-department-submits-proposed-regulation-reschedule-marijuana
[108] United States Drug Enforcement Administration. (n.d.). *Drug Scheduling*. https://www.dea.gov/drug-information/drug-scheduling
[109] Bornemann, J., Close, J.B., Spriggs, M.J., Carhart-Harris, R., & Roseman, L. (2021). Self-Medication for Chronic Pain Using Classic Psychedelics: A Qualitative Investigation to Inform Future Research. *Frontiers in Psychiatry, 12*, 735427. https://doi.org/10.3389%2Ffpsyt.2021.735427

- Refractory anxiety: When standard anxiety treatments have been delivered and found to be either completely ineffective or only modestly effective.[110]
- Intractable nausea: Nausea and vomiting that is not adequately controlled after multiple antiemetics are used in series and/or in combination.[111]
- Other forms of chronic pain that are resistant to traditional treatment options.

Expanding the use of medical cannabis and research opportunities for psychedelic microdosing will help improve access to pain and symptom management treatments in Texas.

Policy Issue: Request for Paid FMLA for patients and family caregivers facing a serious health condition

In 2021, about 3.1 million Texans provided an estimated 2.9 billion hours of care to adults with limitations in daily activities. The estimated economic value of their unpaid contributions was approximately $41 billion.[112] Due to the time commitment required to care for loved ones with a serious health condition,[113] family caregivers often struggle to perform at optimal levels in their jobs. In fact, 70% of working caregivers suffer work-related difficulties due to their dual roles and 69% report having to rearrange their work schedule, decrease their hours, or take unpaid leave to meet their caregiving responsibilities.[114] Additionally, family caregivers who don't take time for themselves have been found to develop chronic health problems at

[110] Roy-Byrne, P. (2015). Treatment-refractory anxiety; definition, risk factors, and treatment challenges*. Dialogues in Clinical Neuroscience, 17*(2), 191-206. https://doi.org/10.31887/DCNS.2015.17.2/proybyrne
[111] Wood, G.J., Shega, J.W., Lynch, B., & Von Roenn, J.H. (2007). Management of Intractable Nausea and Vomiting in Patients at the End of Life. *JAMA, 298*(10), 1196-1207. https://doi.org/10.1001/jama.298.10.1196
[112] Reinhard, S.C., Caldera, S., Houser, A., & Choula, R.B. (2023). *Valuing the Invaluable: 2023 Update. Strengthening Supports for Family Caregivers*. AARP Public Policy Institute. https://www.aarp.org/content/dam/aarp/ppi/2023/3/valuing-the-invaluable-2023-update.doi.10.26419-2Fppi.00082.006.pdf
[113] The FMLA defines a "serious health condition" as an illness, injury, impairment, or physical or mental condition that involves either inpatient care or continuing treatment by a health care provider. Retrieved from: U.S. Department of Labor. (n.d.). *Fact Sheet #28P: Taking Leave from Work When You or Your Family Member Has a Serious Health Condition under the FMLA.* https://www.dol.gov/agencies/whd/fact-sheets/28p-taking-leave-when-you-or-family-has-health-condition
[114] Family Caregiver Alliance. (n.d.). *Caregiving Statistics: Work and Caregiving*. https://www.caregiver.org/resource/caregiver-statistics-work-and-caregiving/

nearly twice the rate of non-caregivers. A survey of Texans aged 45 or older found that one in six caregivers report being emotionally stressed.[115] Family caregivers also consistently report more stress than non-caregivers. Chronic stress is associated with adverse health outcomes such as high blood pressure, poorer immune status, and mortality.[116] This illustrates a clear need for reimbursement of family caregivers who care for individuals with a serious illness to not only improve the health outcomes of the care recipient and the caregiver but also to reduce overall health care costs.

In 2020, the PCIAC developed a legislative report recommendation advocating for family caregivers of patients with a serious and/or life limiting illness to be screened, assessed, and provided with additional supports.[117] The report also advocated that a system of reimbursement be developed for family members who provide in-home respite services to their loved ones facing a serious or terminal illness. While the Family and Medical Leave Act allows eligible employees to take up to 12 weeks of unpaid leave annually to care for themselves or their family members[118] with a serious health condition, the federal government does not require private employers to offer any paid family leave. However, there is movement across the United States which have passed paid family leave laws to provide paid leave for caregiving and other family responsibilities.

Recommendation

The Texas Legislature should explore what family and medical leave insurance benefits could be offered as payable to any covered and qualifying individual who is caring for a family member with a serious and life-limiting and/or terminal illness or has a serious and life-limiting and/or terminal illness that makes the individual

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[115] AARP Research. (2016). *2016 AARP Texas Caregiving Survey: Overwhelming Support for Lifespan Respite Care*. AARP Texas. https://www.hhs.texas.gov/sites/default/files/documents/about-hhs/community-engagement/atw/atw-issue-brief-respite.pdf

[116] Fredman, L., Cauley, J.A., Hochberg, M., Ensrud, K.E., & Doros, G. (2010). Mortality Associated with Caregiving, General Stress, and Caregiving-Related Stress in Elderly Women: Results of Caregiver-Study of Osteoporotic Fractures. *Journal of the American Geriatrics Society, 58*(5), 937-943. https://doi.org/10.1111/j.1532-5415.2010.02808.x

[117] Health and Human Services Commission. (2020). *Texas Palliative Care Interdisciplinary Advisory Council Recommendations to the 87th Texas Legislature.* https://www.hhs.texas.gov/sites/default/files/documents/laws-regulations/reports-presentations/2020/txpciac-recs-86th-leg-oct-2020.pdf

[118] The term "family member" is defined from the following source: U.S. Office of Personal Management. (n.d.). *Definitions Related to Family Member and Immediate Relative for Certain Leave Purposes.* https://www.opm.gov/policy-data-oversight/pay-leave/leave-administration/fact-sheets/definitions-related-to-family-member-and-immediate-relative-for-purposes-of-sick-leave/

unable to perform the functions of their daily living and/or employment, beginning September 1, 2025. Whether taken intermittently or continuously, the weekly benefit shall be 80 percent of the covered individual's average weekly wages for up to twelve weeks within a twelve-month period. To establish a minimum paid leave standard for all workers in Texas, employers should be mandated to participate but employees may choose to opt in or out to the family and medical leave benefit.

Discussion

In states that offer paid family and medical leave laws, most cover the majority of private sector and state and local government employees.[119] Currently, all states with paid family and medical leave laws provide benefits to workers for:[120]

- **Medical leave** to address their own serious health condition.
- **Caregiving leave** to care for a loved one with a serious health condition.
- **Parental leave** to bond with a new child, for both foster and adoptive parents and for parents of any gender.

Most state paid family and medical leave laws provide deployment-related leave, which are benefits to address the impact of a loved one's military deployment. Some states also provide safe leave or benefits to address workers' additional needs when they or their loved ones are victims of sexual or domestic violence.[121]

Paid leave program financing is often accomplished through payroll contributions (i.e., deductions).[122] They operate in a similar manner to social insurance models.[123] Employers and employees share the financing costs, with contribution percentages varying across states. Total payroll deductions do not exceed 1.4% in

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[119] National Partnership for Women & Families. (2023, October). State Paid Family & Medical Leave Insurance Laws [Chart]. https://nationalpartnership.org/wp-content/uploads/2023/02/state-paid-family-leave-laws.pdf
[120] Williamson, M.W. (2024, January 17). *The State of Paid Family and Medical Leave in the U.S. in 2024.* Center for American Progress. https://www.americanprogress.org/article/the-state-of-paid-family-and-medical-leave-in-the-u-s-in-2024/
[121] Ibid.
[122] Shabo, V. (2024, May 3). *Explainer: Paid Leave Benefits and Funding in the United States*. New America. https://www.newamerica.org/better-life-lab/briefs/explainer-paid-leave-benefits-and-funding-in-the-united-states/#:~:text=As%20of%20January%202024%2C%2013,leave%20benefits%20available%20to%20workers.
[123] Williamson, M.W. (2017). Structuring Paid family and Medial Leave: Lessons from Temporary Disability Insurance. *Connecticut Public Interest Law Journal, 17*(1), 7. https://cpilj.law.uconn.edu/wp-content/uploads/sites/2515/2019/06/Structuring-Paid-Family-and-Medical-Leave-Lessons-from-Temporary-Disability-Insurance-by-Molly-Weston-Williamson.pdf

any state.[124] These deductions are then pooled into a state fund through which benefits are distributed. Some states offer a private option as an alternative to the state fund.

Table 1 below provides additional detail on the thirteen states that have passed either mandatory or voluntary paid family and medical leave laws, including the length of leave allotted and weekly benefit offered.

Table 5. States with mandatory and voluntary paid family leave laws[125,126]

State	Mandatory/Voluntary (Effective Date)	Maximum Benefit (weekly)	Leave Length	Paid Family Leave Law
California	Mandatory (2004)	$1,620	Up to 8 weeks (within 12-month period)	California Family Rights Act (CFRA)
Colorado	Mandatory (2024)	$1,100 (0.9x statewide average weekly wage [SAWW] after 2024)	Up to 12 weeks (within 12-month period)	Colorado Family and Medical Leave Insurance (FAMLI)
Connecticut	Mandatory (2022)	$941.40 (60x CT min wage)	Up to 12 weeks (within 12-month period)	Connecticut Paid Leave Act
Delaware	Mandatory (2026)	$900 (indexed to inflation after	Up to 6 weeks (within 24-month period)	Delaware Paid Family and Medical Leave Insurance Act

[124] Shabo, V. (2024, May 3). *Explainer: Paid Leave Benefits and Funding in the United States*. New America. https://www.newamerica.org/better-life-lab/briefs/explainer-paid-leave-benefits-and-funding-in-the-united-states/#:~:text=As%20of%20January%202024%2C%2013,leave%20benefits%20available%20to%20workers.

[125] Holmes, T.E. (2023, September 12). *Paid Family Leave: Find Out If Your State Offers Benefits for Parents and Caregivers*. AARP. https://www.aarp.org/caregiving/financial-legal/info-2019/paid-family-leave-laws.html#:~:text=Though%20the%20federal%20government%20does,leave%20insurance%20programs%20to%20provide.

[126] Bipartisan Policy Center. (2024, January 16). *State Paid Family Leave Laws Across the U.S.* https://bipartisanpolicy.org/explainer/state-paid-family-leave-laws-across-the-u-s/

		2026)		(passed, not yet in effect)
District of Columbia	Mandatory (2020)	$1,118 (indexed to inflation)	Up to 12 weeks (within 52-week period)	DC Paid Family Leave Act
Florida	Voluntary (2023)	N/A	At least two weeks (within 52-week period)[127]	Florida Paid Family Leave Insurance Act[128]
Maine	Mandatory (2026)	$1,104 (SAWW)	Up to 12 weeks (within 52-week period)	Maine Paid Family and Medical Leave Act (passed, not yet in effect)
Maryland	Mandatory (2026)	$1,000 (indexed to inflation after 2025)	Up to 12 weeks (within 12-month period)	Maryland Paid Family and Medical Leave Insurance Act (passed, not yet in effect)
Massachusetts	Mandatory (2021)	$1,444.90 (0.64x SAWW)	Up to 12 weeks (within 52-week period)	Massachusetts Paid Family and Medical Leave Law
Minnesota	Mandatory (2026)	$1,337	Up to 12 weeks (within 52-week period)	Minnesota Paid Family and Medical Leave Insurance Act (passed, not yet in effect)
New Hampshire	Voluntary (2023)	$1,945	Up to 6 weeks (within a year)	New Hampshire Paid Family Leave Insurance

[127] Florida Legislature, House Bill 721, 2023 Regular Session (enrolled). https://www.myfloridahouse.gov/Sections/Documents/loaddoc.aspx?FileName=_h0721er.docx&DocumentType=Bill&BillNumber=0721&Session=2023

[128] The Standard. (2024, April 11). *States With Paid Family Medical Leave: Explore PFML Nationwide*. https://www.standard.com/businesses-organizations/workplace-solutions/paid-family-medical-leave/states-paid-family-medical

				Program
New Jersey	Mandatory (2009)	$1,055 (0.7x SAWW)[129]	Up to 12 weeks (within 12-month period)	New Jersey Family Leave Insurance Act (FLI)
New York	Mandatory (2018)	$1,151,16 (0.67x SAWW)[130]	Up to 12 weeks (within 52-week period)	New York Paid Family Leave Insurance Law
Oregon	Mandatory (2023)	$1,523.63 (1.2x SAWW)[131]	Up to 12 weeks (within 52-week period)	Oregon Family Leave Insurance (OFLI)
Rhode Island	Mandatory (2014)	$1,007	Up to 12 weeks (within 52-week period)	Rhode Island TDI & Second Injury Fund
Vermont	Voluntary (2025)	$1,945	Up to 6 weeks (within a year)	Vermont Paid Family Leave Insurance Program
Virginia	Voluntary (2022)	N/A	Up to 12 weeks (within a year)	Virginia Paid Family Leave (VA PFL)
Washington	Mandatory (2020)	$1,427 (0.9x SAWW)[132]	Up to 12 weeks (within a year)	Washington Paid Family and Medical Leave (PFML)

[129] Ibid.
[130] Ibid.
[131] Ibid.
[132] Ibid.

4. Conclusion

The 84th Texas Legislature (2015) established the Palliative Care Interdisciplinary Advisory Council to provide objective evaluation and consensus recommendations to increase the availability of patient and family-focused supportive palliative care in Texas and to assist the HHS system with the establishment and operation of a palliative care information and education program. Since launching this ongoing initiative, the state has made meaningful, relevant, impactful, and necessary modernization and innovation toward advancing Supportive Palliative Care education, awareness of palliative care, and developing capabilities to enhance high quality delivery of specialty services across the state.

This fifth legislative report is the culmination of the expert Council's efforts to continue to provide evidence based and Texas specific recommendations while mindful of appropriate fiscal stewardship. To build on this momentum, the Council convened three times during 2024 in Austin as well as virtually to develop the findings and recommendations published in this 2024 report. The meetings occurred in full public view and in partnership with the many stakeholders committed to improving supportive palliative care services in Texas. The Council's recommendations support the Legislature's original belief that significant advancements in supportive palliative care is needed and is possible in Texas when teams collaborate for the good of the patient and place patients and families first. Expert collaboration of interdisciplinary supportive palliative care specialist are improving the quality of life of seriously ill patients and their families and care teams while also improving fiscal stewardship by placing the patients goals of care first when determining the focus of health care directed therapies.

The Council hopes its fifth report can serve as a renewed catalyst for sustained quality improvement efforts. The Council reaffirms the commitment to further advance SPC in Texas and the nation by providing evidenced based, compassionate, and high-quality specialty supportive palliative care to at risk and vulnerable Texans suffering from a serious and/or life-threatening illness, which is provided at any age and at any stage of serious illness.

List of Acronyms

Acronym	Full Name
ACHPN	Advanced Certified Hospice and Palliative Nurses
ACP	Advance Care Planning
AHA	American Hospital Association
APM	Alternative Payment Model
APRN	Advanced Practice Registered Nurse
BRFSS	Behavioral Risk Factor Surveillance System
CAPC	Center to Advance Palliative Care
CE	Continuing Education
CCLS	Certified Child Life Specialist
CMS	Centers for Medicare & Medicaid Services
CPT	Current Procedural Terminology
DPOA	Durable Power Of Attorney
ED	Emergency Department
EOL	End Of Life
HB	House Bill
HC	Hospice Care
HCPCS	Healthcare Common Procedure Coding System
HEDIS	Healthcare Effectiveness Data and Information Set
HHSC	Health and Human Service Commission
HPCC	Hospice and Palliative Credentialing Center
HPM	Hospice and Palliative Medicine
IDT	Interdisciplinary Team
MCO	Managed Care Organization
MPOA	Medical Power of Attorney
NQF	National Quality Forum
PA	Physician Assistant
PCIAC	Palliative Care Interdisciplinary Advisory Council
PHR	Public Health Region

Acronym	Full Name
SB	Senate Bill
SPC	Supportive Palliative Care

Appendix A. Supplemental Tables

Table A-1: Percentage of Hospitals with Palliative Care Programs or Inpatient Units (≥ 300 Staffed Beds)[133]

Year	Hospitals with ≥ 300 beds that have a palliative care program	Total hospitals with ≥ 300 beds	Percentage of hospitals with a palliative care program
2014	42	59	71%
2015	42	59	71%
2016	46	62	74%
2017	47	63	75%
2018	46	61	75%
2019	50	63	79%
2020	52	64	81%
2021	52	66	79%
2022	52	67	78%

[133] Hospitals types included General and Surgical, Cancer and Heart hospitals, as well as hospitals that indicated 'Other' and would be expected to possibly have a palliative care unit.

Table A-2: Percentage of Hospitals with Palliative Care Programs or Inpatient Units (≥ 50 Staffed Beds)[134]

Year	Hospitals with ≥ 50 beds that have a palliative care program	Total hospitals with ≥ 300 beds	Percentage of hospitals with a palliative care program
2014	87	208	42%
2015	97	209	46%
2016	101	205	49%
2017	102	206	50%
2018	100	204	49%
2019	101	198	51%
2020	102	198	52%
2021	106	200	53%
2022	110	197	56%

[134] Hospital types included General and Surgical, Cancer and Heart hospitals, as well as hospitals that indicated 'Other' and would be expected to possibly have a palliative care unit.