

# **Palliative Care Advisory Council**

**ANNUAL LEGISLATIVE REPORT** 

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Minnesota Palliative Care Advisory Council Annual Legislative Report
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# **Background**

The Minnesota Legislature established the Palliative Care Advisory Council (the Council) in 2017 under Minnesota Statutes, Section 144.059. The Council is charged with assessing, analyzing, and making recommendations to the legislature on issues related to palliative care in Minnesota. Palliative care is focused on providing supportive care to those Minnesotans living with serious illnesses.

The Council is tasked with:

- 1. Assessing the availability of palliative care in Minnesota
- 2. Analyzing barriers to greater access to palliative care, and
- 3. Recommending language for legislative action with draft legislation to implement the recommendations.

The Council is made up of a variety of professionals who have palliative care work experience or expertise in palliative care delivery. They come from a variety of inpatient, outpatient, and community settings, such as acute care, long-term care, or hospice. They work with a variety of patients, including pediatric, youth, and adults. In addition, there are four positions on the council that provide patient or caregiver perspective based on their personal experiences. Each Council member's position is appointed for three years, with final selections appointed by the Commissioner of Health.

Current council positions include:

- Care Coordinators (2)
- Health Plan Representative
- Licensed Health Professionals (3)
- Member (at large) (2)
- Patient or Personal Caregiver (4)
- Physician (2)
- Physician Assistant
- Registered Nurse or Advance Practice Nurse (2)
- Licensed Social Worker

The Council is required to report on its progress by February 15 of each year. Prior Council legislative reports are posted on the Minnesota Department of Health website for the Palliative Care Advisory Council.<sup>1</sup>

The following pages present the Council's summary of work efforts during 2023, and outline the recommendations and work planned for 2024. The report is divided into sections based on the Council's three focus areas: Policy and Payment; Diversity, Equity, and Inclusion; and Education, Training, and Awareness. Detailed reports from each area are provided in the pages following this summary.

## **Current Focus Areas**

## **Policy and Payment**

Medicaid patients living with a serious illness or condition remain one of Minnesota's most vulnerable populations. Medicaid patients live at the bottom of the income distribution and often struggle to meet their basic needs on very limited incomes, even with the added assistance of government programs.<sup>2</sup>

Patients and their caregivers – who receive early palliative care support – have significantly improved outcomes, lower stress burden and depression, and higher quality of life.<sup>3</sup> Recent estimates suggest that fewer than 5% of patients who would benefit from palliative care services actually receive them.<sup>4</sup>

The Council initially called for a comparative cost study in the Council's 2022 Annual Legislative Report. While called a comparative cost study, the request is more than that – it is a request to secure Minnesota specific and relevant deidentified claims data specific to Medicaid enrollees considered eligible for palliative care. With the goal of improving value in health care, data would provide critical information for the development of essential structural elements of palliative care<sup>5</sup>, such as:

- Building interdisciplinary team of clinical staff
- Developing staffing ratios determined by the nature and size of population to be served
- Developing staff training, credentialing, and/or certifications in palliative care
- Developing points of access and responsiveness twenty-four hours per day, seven days per week.

Data is also necessary to identify health disparities and barriers to palliative care within the regional, county, and community settings.

The Council recognizes that without payments for services, providers are unable to offer a comprehensive palliative care benefit. As the Council reviewed the payment landscape, it concluded that the state's Medicaid population could benefit from expanded palliative care benefits. Expanding these benefits, along with applying for a state plan amendment, was considered the best way forward to increase accessibility to palliative care within the state.

The Council reviewed data published by the National Academy of State Health Policy (NASHP) which stated that "effective administration of a Medicaid palliative care benefit for the highest service utilizers could produce cost avoidance savings ranging between \$231 and \$1,165 per Medicaid member per month, with potential return on investment ranging between \$0.80 and \$2.60 for every \$1 spent on palliative care."

The state's Medicaid enrollees, adults 65 or older, and people with disabilities make up around 16 to 17% of the people served by public health care programs yet account for about 60% of spending.<sup>7</sup>

NASHP further reports people with serious and life-threatening health conditions experience care needs that drive costs, including hospital admissions, emergency department utilization, and nursing home care. **State**Medicaid programs invest significant resources on care for beneficiaries with serious illness: roughly \$11 billion to treat cancer, \$51 billion on Alzheimer's disease and other dementias, and \$12.2 billion on chronic

obstructive pulmonary disease (COPD) per year. Well-coordinated care that anticipates and manages the symptoms and stressors of serious illness can help people with these and other complex conditions reduce pain and suffering, avoid receiving treatment that does not align with their wishes, and prevent overutilization of care.<sup>8</sup>

NASHP highlights Minnesota as a leader in delivering system transformation stating "Leading states such as Minnesota have long used Medicaid MCO contracts to address the needs of complex populations and those with serious illness." Minnesota provides a menu of quality measures that plans may select to qualify for value-based payments; plans may also develop and propose their own. In addition to a range of metrics related to promoting prevention and reducing utilization related to ambulatory care-sensitive conditions, ICSP measures have included advanced care planning, evidence of physician order for life-sustaining treatment (POLST), effective care transitions, and assessment and management of chronic pain." <sup>9</sup>

The model is based on Minnesota's successful Integrated Health Partnerships model, which includes a shared savings/losses option that has resulted in over \$400 million in savings to the state compared to expected costs between its inception in 2013 and 2019.<sup>10</sup>

During the last legislative session, the Council requested, but did not receive, \$150,000 in state funding to conduct a Medicaid specific comparative cost study, the equivalent of an actuarial study, during 2024. The Council applied for and received a restricted grant from the Minnesota Cancer Alliance to hire a grant writer to support efforts to secure funding from private and public sources.

Additional details are found in the Palliative Care Comparative Cost Study Section of this report.

## **Diversity, Equity, and Inclusion (DEI)**

The specialty of palliative care enhances the quality of life for individuals facing serious illness through learning about each patient's unique clinical condition, hopes, fears, suffering and sources of strength, along with the experiences of their caregivers. Yet, like all aspects of health care, palliative care is not exempt from systemic, pervasive health disparities in access and quality of care. Regardless of the root causes of health disparities, these systemic issues impact patient, familial, and community-wide outcomes.

A driving factor for quality of life, and one of the foundational measures for social determinants of health (SDOH), is "the conditions in the environments where people are born, live, learn, work, play, worship and age that affect a wide range of health, functioning and quality-of-life outcomes and risks." <sup>11</sup>

The Healthy People 2030 report identifies that SDOH can be grouped into five domains: 12

- Health care access and quality
- Economic stability
- Social and community context
- Neighborhood and built environment
- Education access and quality

Access to culturally relevant care is a fundamental pillar of equitable and effective health care. In a health care setting, racial and ethnic biases can affect health care delivery and ultimately, lead to health disparities.<sup>13</sup>

Palliative care is uniquely positioned to provide a culturally safe space for people to recognize and honor the rich tapestry of cultural backgrounds, beliefs, and values that patients and health care providers bring. Culturally relevant care must extend beyond language proficiency, and needs to include an understanding of cultural nuances, traditions, and preferences for individuals, rather than broad community and cultural generalizations.

Trust created through cultural sensitivity is particularly important for palliative care providers during patient conversations, particularly regarding pain and symptom management, advanced care directives, and wishes at end-of-life.<sup>14</sup>

Inequities and disparities exist in communities across the country and Minnesota. A recent review of 150 of the United States' largest metropolitan areas found that inequities and disparities existed in some form in all the communities investigated. Even in affluent communities, inequities exist. Researchers have demonstrated that lasting inequities pose a threat to overall community prosperity.

To address health disparities, health care systems, community leaders and residents need credible data to advance social equity. Using recent, good quality quantitative and qualitative data will advance health equity and identify the unique needs of historically excluded populations. With deeper understanding, communities are better equipped to identify and evaluate strategies, policies, and programs to address disparities.

In the coming year, the Council looks forward to additional discussion and action to improve cultural competency among all providers, so that they are prepared to care for a diverse patient population.<sup>15</sup>

Additional information is found in the Diversity, Equity, and Inclusion section of this report.

# **Education, Training, and Awareness**

At the federal level, the Council is closely monitoring the **Palliative Care and Hospice Education and Training Act** (PCHETA). Reintroduced in the 118<sup>th</sup> Congress with bipartisan support, PCHETA will make a difference in the lives of millions of patients living with a serious illness, and their families. If passed, PCHETA will create and promote education programs to expand the palliative care profession workforce, support research on palliative care interventions and delivery, and implement a public awareness campaign to educate the public on palliative care and its benefits. <sup>16</sup>

The bill would also provide funding to establish Palliative Care and Hospice Education Centers to improve the training of interdisciplinary health professionals in palliative care; develop and disseminate curricula relating to palliative care; support the training and retraining of faculty; support continuing education; provide students with clinical training in appropriate sites of care; and provide traineeships for advanced education nursing degrees, social work degrees, or advanced degrees in physician assistant studies, with a focus in interprofessional team-based palliative care.<sup>17</sup>

Additional information on PCHETA is found in the Education, Training, and Awareness section of this report.

# Status Updates: Recommended Actions from the 2023 Annual Legislative Report

- 1. **Recommended Action #1:** Submit the Palliative Care Advisory Council's proposed definition of Palliative Care to state legislators during the 2022 legislative session for action.
  - a. **COMPLETED.** Definition approved and signed into law effective Aug. 1, 2022.
- 2. Recommended Action #2: Draft a recommended core set of palliative care services for Minnesota.
  - a. COMPLETED. The recommended palliative care core services are outlined in detail in the Council's 2023 Annual Legislative Report
     (https://www.health.state.mn.us/people/palliative/docs/pcaclegreport2023.pdf).<sup>18</sup>
  - b. **IN PROGRESS.** The core services identified in the prior annual report will be reviewed continuously throughout 2024 with key stakeholder groups including providers, payers, and patients and their caregivers.
- 3. **Recommended Action #3:** Collaborate with stakeholders, such as the Department of Human Services (DHS), to identify and align palliative care payment models to a recommended set of core palliative care services.
  - a. **IN PROGRESS.** Members of the Council discussed the Council's recommendations and progress to date with Minnesota Department of Health's Dr. Cunningham and Department of Health Service's Medicaid Medical Director Dr. Chomilo. Additional conversations will be held in 2024 with MDH, DHS, and key stakeholder groups.
- 4. **Recommended Action #4:** Request the appropriate state agenc(ies) conduct a comparative cost study (both quantitative and qualitative measures) based on recommended palliative care payment models.
  - a. IN PROGRESS. The Council requested, but did not receive, public funding for the cost study during the 2023 legislative session. In October, the Council received a \$5,000 grant in October from the Minnesota Cancer Alliance to hire a grant writer to accelerate efforts in securing public and private funding for the actuarial cost study, provider capacity analysis, pricing and analytics, and policy development supporting efforts for development of a Medicaid State Plan Amendment (SPA). This recommendation is discussed in detail in the following section.
- 5. **Recommendation Action #5:** Extend the Council's sunset date from 2025 to 2035 allowing the Council to continue the policy, education, training, awareness, and diversity efforts to be developed, implemented, and stabilized for Minnesotans.
  - a. COMPLETED. The 2023 legislative session removed the sunset for the Council enabling the Council to continue the work of assessing the availability of palliative care in Minnesota, analyzing barriers to greater access to palliative care, and recommending language for legislative action with draft legislation to implement the recommendations.

## **Policy and Payment: Palliative Care Cost Study Update**

**Recommended Action #4 (from 2023 annual legislative report):** Request the appropriate state agenc(ies) conduct a comparative cost study (both quantitative and qualitative measures) based on recommended palliative care payment models.

**UPDATE:** In progress. A thorough determination of the availability of, and barriers to, greater access to palliative care requires funding to obtain current Minnesota specific data for analysis.

Since 2022, the Council has recommended funding a comparative cost study (actuarial study) for Minnesota's Medicaid population. This recommendation is based on results reported by the National Academy of State Health Policy (NASHP). A key finding from the NASHP study states:

"Effective administration of a Medicaid palliative care benefit for the highest service utilizers could produce cost avoidance savings ranging between \$231 and \$1,165 per Medicaid member per month, with potential return on investment ranging between \$0.80 and \$2.60 for every \$1 spent on palliative care. 19

At the beginning of 2023, six states were selected to participate in NASHP's State Policy Institutes to Improve Care for People with Serious Illness. The Institute will engage the six state teams for two years. Selected teams will receive technical support from NASHP and subject matter experts on serious illness and palliative care policy.<sup>20</sup> Requirements of the teams included participation from two state employees.

The Council applied to the institute, however, failed to meet the team composition requirement of two state employees. States qualifying and accepted include Colorado, Maine, Maryland, Ohio, Texas, and Washington.<sup>21</sup>

Unable to receive the technical and subject matter expertise support at no cost through the Institute, the Council requested \$150,000 for a comparative cost study be included in the state's budget during the 2023 legislative session. While included in early House and Senate budgets, the cost study was not included in the final budget.

In the absence of funding, the Council evaluated Minnesota's public-facing websites that included downloadable data. The following MDH and DHS websites have been reviewed to determine if those websites contained data that could be used in the absence of a fully funded cost study.

- Minnesota Department of Health Data Access County Data (https://data.web.health.state.mn.us/web/mndata/download-county-data)
- Minnesota Department of Human Services (https://mn.gov/dhs/medicaid-matters/who-medicaid-and-minnesotacare-serves/)
- Minnesota Department of Health Cancer Statistics and Reports (https://www.health.state.mn.us/data/mcrs/data/index.html)
- Minnesota All Payer Claims Database (https://www.health.state.mn.us/data/apcd/index.html)

A minimum dataset would support quantification of the Medicaid population including but not limited to:

- A count of deidentified patients eligible for palliative care
- Their geographic data (e.g., where they live, where they receive care)
- Their demographic data (e.g., age, gender, race, ethnicity, disability)

- Types and costs of health care services received, (e.g., office visits, emergency room, hospital admissions)
- Additional data facilitating identification of health disparities

In the absence of public funding for the cost study, the Council is working with community partners for potential funding opportunities. The Council received a \$5,000 restricted grant from the Minnesota Cancer Alliance for the purpose of hiring a professional grant writer to assist with the procurement of private funding.

# Diversity, Equity, and Inclusion (DEI) Update

The specialty of palliative care enhances the quality of life for individuals facing serious illness through learning about each patient's unique clinical condition, hopes, fears, suffering and sources of strength, along with the experiences of their caregivers. Yet, like all aspects of health care, palliative care is not exempt from systemic, pervasive health disparities in access and quality of care. Regardless of the root causes of health disparities, these systemic issues impact patient, familial, and community-wide outcomes.

The DEI working group was also guided by the reflections of Nathan Chomilo, M.D., FAAP, Director of Minnesota Medicaid & MinnesotaCare, in his recent Ascend at the Aspen Institute Fellow Spotlight interview <sup>22</sup> on the known "Minnesota paradox":

Dr. Samuel Myers coined the term "Minnesota paradox" to describe how Minnesota has one of the highest qualities of life for White Minnesotans, while "African Americans are worse off in Minnesota than they are in virtually every other state in the nation." This appalling disparity speaks to the role structural racism and inequity play in our health care system and in our broader society.

A summary of projects and resources, many of which are local, that advance understanding of tools that help to improve access and reduce barriers for those with serious illness facing health disparities in Minnesota are included in Appendix B. It is imperative that action is taken now to identify efficient and effective options for change. Action is needed to rectify the dire nature faced by Minnesotans today.

Using the Minnesota Department of Human Services report "Building Racial Equity into the Walls of Minnesota Medicaid: A Focus on U.S.-born Black Minnesotans" <sup>23</sup> and the resources available within the Center to Advance Palliative Care (CAPC) Project Equity: Improving Health Equity for People with Serious Illness <sup>24</sup> as source material, the Diversity, Equity, and Inclusion Working Group has identified areas of need and opportunity specific to palliative care. Palliative care requires a transformation in clinical training and practice, research, policy, and leadership.

# 1. Collect and monitor data by race and ethnicity, in addition to religion and spirituality, for quality improvement efforts.

Inequities and disparities exist in communities across the country and Minnesota. A recent review of 150 of the United States' largest metropolitan areas found that inequities and disparities existed in some form in all the communities investigated. Even in affluent communities, inequities exist. Researchers have demonstrated that lasting inequities pose a threat to overall community prosperity. Moreover, equity is not a "zero-sum" process, and good outcomes can exist for all communities. Further, data that is collected from different sources (e.g., health care systems/electronic medical record; private and state health care insurers; state departments) is

often disparate, incongruent, or incomplete. Gathering and comparing datasets can be somewhat like assembling puzzle pieces without an image to guide the process. Balboni, et al. describes and outlines the importance of supporting patient experience in serious illness is often not possible due to the fact this information is rarely requested. Yet, health and outcomes in serious illness have implications when spirituality is not fully understood within the point of care, and certainly beyond the "walls of the clinic." <sup>26</sup>

It is widely accepted that access to preventive and basic health care improves quality of life. In addition, specialty services, like Palliative Care, are most beneficial when patients are diagnosed, rather than in the final stages of illness. Not only can Palliative Care alleviate and mitigate the symptoms of life-limiting illness, and overall improve quality of life, it has long demonstrated that among the benefits is a longer life expectancy for those who have access early.<sup>27</sup>

These results are also documented in the United States, between 2019 and 2021, for American Indians and Alaska Natives (AIAN), Hispanic, and Black people, who experienced larger declines in life expectancy than white people.<sup>28</sup>

Health care systems, community leaders and residents need credible data to advance social equity. Using recent, good quality quantitative and qualitative data will advance health equity and identify the unique needs of historically excluded populations. With deeper understanding, communities are better equipped to identify and evaluate strategies, policies, and programs to address disparities.

One Minnesota example is a Wilder Research report that reinterprets and aggregates several datasets from St. Cloud and its surrounding rural areas.<sup>29</sup> The report identified significant disparities for Black and African American residents, as well as for foreign-born residents. Along with analyzing data, Wilder Research conducted a series of qualitative listening sessions to deepen their understanding of the quantitative data. The final product is a comprehensive dashboard that includes this data. The project provides a template for other communities to interrogate their own datasets, inform the community and policymakers as a whole about issues that exist within each community, and focus resources and support.

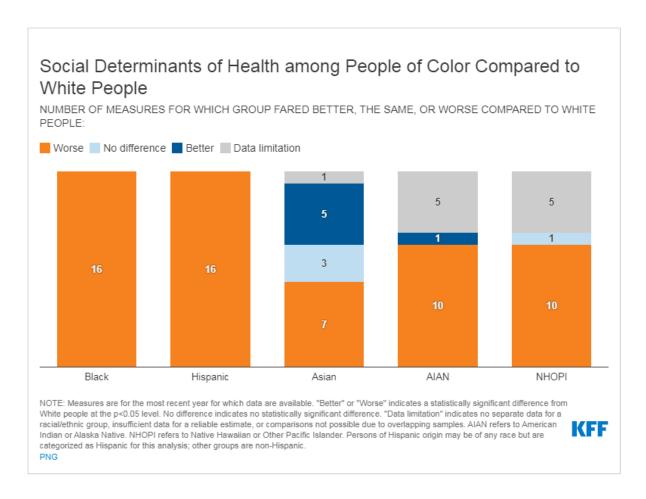
A driving factor for quality of life, and one of the foundational measures for social determinants of health (SDOH), is "the conditions in the environments where people are born, live, learn, work, play, worship and age that affect a wide range of health, functioning and quality-of-life outcomes and risks." <sup>30</sup>

Further, the Healthy People 2030 report identifies that SDOH can be grouped into five domains:<sup>31</sup>

- Health care access and quality
- Economic stability
- Social and community context
- Neighborhood and built environment
- Education access and quality

Arguably, the first four of these five domains have a direct impact on how a person with a serious illness experiences life and can function in their community. Palliative care, as the definition expresses, is core to quality of life and social functioning at all stages of life, not just in the context of serious or life-limiting illness. Within Minnesota, the burden of living with the impacts of SDOH experienced by BIPOC (Black, Indigenous, and

People of Color) communities is profound. This burden decreases patients' access to care, confidence in their ability to receive care, and leads them to forego care altogether due to cost or insurance-related issues.



Source: Key Data on Health and Health Care by Race and Ethnicity. Published: Mar. 15, 2023. KFF Health News. Hill, Latoya; Ndugga, Nambi; and Artiga Samantha.<sup>32</sup>

Returning to the St. Cloud example, researchers interrogated the impact of poverty on members of the community. The poverty rate in the greater St. Cloud area is similar to statewide rates of 9.3%. Information on poverty rates from 2019 in Minnesota can be found through a data set housed by the Minnesota Department of Health. <sup>33</sup>

A 10% poverty rate for St. Cloud and 11% for the greater St. Cloud region does not help to identify the impact of poverty in communities of color in St. Cloud and the surrounding community area. According to the Wilder Research dashboard:<sup>34</sup>

Residents of color have poverty rates that are two to five times higher than the regional rate. The difference is pronounced for American Indian and Black communities in particular, with poverty rates of 61% and 47%, respectively.

The poverty rate among Greater St. Cloud's foreign-born residents is 38%, more than three times higher than the regional rate and more than four times higher than the rate among native-born residents.

Factors other than economic stability led to health disparities generally, and access to palliative care services specifically, but the impact of poverty is pervasive. Communities also encounter barriers such as limited health care resources, inadequate insurance coverage, and insufficient access to trained palliative care providers or palliative services at diagnosis and/or throughout the course of their disease journey. All barriers lead to patients not receiving the comprehensive care they require, leading to avoidable suffering. Measuring social determinants of health to examine how each community is impacted will help increase understanding, as well as identification of areas like palliative care needing specific strategies and resources.

Many tools are available to assess SDOH and the impact on individual patients. Our recommendation is to identify tools that can be utilized in discussion with patients, as opposed to tools that are self-administered. "The EveryONE Project™"<sup>35</sup> has developed a short eleven-question form<sup>36</sup> that can be administered by any member of the care team—further increasing efficiency as it doesn't need to be administered by a provider. The National Association of Community Health Centers' Protocol for Responding to and Assessing Patients' Asset, Risks and Experiences tool<sup>37</sup> includes 15 core questions and five supplemental questions, translated into 25 different languages, in addition to culturally sensitive version developed for particular SDOH impacted by AIAN community members.<sup>38</sup> The data can be directly uploaded into many electronic health records and can be administered by clinical or nonclinical staff at the time of the visit, with a paper version to be given to the patient to self-administer.

It is critical that care team members document patient responses in electronic health records to benefit from understanding the current and future needs of patients. Additionally, this information, when deidentified, can help health care systems and insurers better understand patient needs and assets. Given where data and how these data are collected, we recommend the point of care is the most reasonable starting point to begin gathering this data. We encourage continued efforts around this area, to further support deeper and more specific data collection within communities, beyond the point of care, to further understand the needs of each community.

In 2023, The Minnesota Department of Health will release data for the updated statewide state health assessment. Many changes have occurred in our community since the release of the last health assessment (2017). Another state investment through the Minnesota Department of Health is the newly established Equitable Health Care Task Force. <sup>39</sup> The task force will examine inequities in how patient groups and communities experience health care based on race, religion, culture, sexual orientation, gender identity, age, and disability. It will identify strategies for ensuring that all Minnesotans can receive care and coverage that is respectful and ensures equitable health outcomes. In addition to the Equitable Health Care Task Force, the Minnesota Department of Health is in the process of establishing an African American Health State Advisory Council (AAHSA), and its key role will be to shape the African American Health Special Emphasis Grant Program and, similar to PCAC will make recommendations to review any statutes, rules, or administrative policies or practices specifically impacting African American health disparities.

#### 2. Increase Access to Culturally Relevant Care

Access to culturally relevant care is a fundamental pillar of equitable and effective health care. We must do better, especially when people are facing serious and life-limiting illness. Palliative care is uniquely positioned to provide a culturally safe space for people to recognize and honor the rich tapestry of cultural backgrounds, beliefs, and values that patients and health care providers bring. Culturally relevant care must extend beyond

language proficiency, and needs to include an understanding of cultural nuances, traditions, and preferences for individuals, rather than broad community and cultural generalizations. In this context, providing access to culturally relevant care is not just a matter of sensitivity; it is a matter of paramount importance for promoting health equity, improving patient outcomes, and fostering trust in health care systems.

Recruitment and retention of health care providers from BIPOC and AIAN communities to practice in health care and specialties, such as palliative care, continues to be an ongoing priority. Another priority is education of all health care providers to identify new ways to offer supportive and culturally relevant care. Increasing emphasis and engagement in these areas will help to shift how health care is currently offered. Evidence suggests that care in the current structure does not provide adequate or safe support for diverse communities. Also, underrepresentation in health care education can perpetuate stereotypes and biases among future health care professionals. A diverse health care workforce reflects the communities it serves, leading to improved patient-care team relationships through providing culturally relevant care.

Expanding support for community care beyond the traditional clinic "walls" requires bridging support within the larger service and non-traditional service community to benefit all residents. M Health Fairview's (MHFV) Community Advancement Program is an example of such an effort. It employs cultural brokers, through partnerships with nonprofit community organizations, to improve access to health care and other resources that support wellbeing. The Cultural Broker Prevention Program supports the role of each cultural broker as a liaison to assist people in navigating complex health systems and reducing barriers. <sup>40</sup> Yet, despite being crucial to reducing health disparities, these programs can be difficult to sustain. The Council supports the growth of programs such as these within health care systems and throughout Minnesota, additionally ensuring staff receive access to palliative education that supports the needs of community members.

Cultural Broker programs provide culturally relevant, community-based, accessible, preventive health care that is crucial to reducing health disparities and decreasing costs. However, legal frameworks and reimbursement models often fail to capture the essence of community-oriented preventive models of care. 41

The release of the national Center to Advance Palliative Care (CAPC)'s Project Equity provides a freely accessible web portal for all health care leaders, community members and policymakers.<sup>42</sup> The initial focus for publications, tools and recommendations will focus on supporting the shift in care to improve how care is offered and accessed by U.S.-born Black people.

Black people living with serious illness suffer disproportionately compared to their white counterparts. Literature shows that Black patients experience worse pain and symptom management, less effective communication from providers, and an outsized burden on family caregivers.

What goes wrong for Black patients with serious illness, and their families? What interventions have successfully addressed disparities, and how can they be replicated?

Recommendations from CAPC include a comprehensive literature review and identification of successful equity-focused models. Along with web-based learning, there are practical insights to be gleaned that can inform policies to reduce racial disparities and improve health outcomes.

#### 3. Engaging with and creating opportunities for community and culturally specific conversations

Engaging with communities disproportionately impacted by access to care begins through connection and conversation. The Minnesota Department of Health's newly created Equitable Health Care Task Force will "examine inequities in how people experience health care based on race, religion, culture, sexual orientation, gender identity, age, and disability, and identify strategies for ensuring that all Minnesotans can receive care and coverage that is respectful and ensures optimal health outcomes." (MN Session Laws 2023, Chapter 70, Section 105). The Minnesota Department of Health is investing in the development of the African American Health State Advisory Council (MN Laws 2023 Chapter 70, Article 4, Section 18) which will work to address the upstream social factors impacting US-born African American Minnesotans, thereby positively contributing to health outcomes for Black Minnesotans. The Palliative Care Advisory Council applauds the development of these two bodies and will work to connect with both the taskforce and council in the future. Mutual education and support will benefit the work of the separate entities – ultimately positively impacting all Minnesotans.

As already discussed, much of what is proposed for changes in health care and health policy also needs to involve greater investment, contribution, and feedback from communities most impacted by the change and by current inequities. Bringing more voices to the table, early in these processes and throughout integration, can offer a feedback loop that tailors these approaches to better meet the needs of all Minnesotans.

In conclusion, the imperative for diversity, equity, and inclusion (DEI) in health care and state policy is paramount. In health care, specifically palliative care, DEI is essential to ensure that all individuals, regardless of their background, receive equitable access to quality care. Disparities in health care outcomes can be rectified through proactive measures. In state policy, this lens is vital for creating legislation and regulations that address the unique needs of diverse populations and dismantle systemic barriers. By prioritizing DEI in both health care and state policy, society can work towards achieving equitable and inclusive health outcomes for all.

Note: Additional DEI resources, including recommended readings and Minnesota initiatives, can be found in Appendix A.

# **Education, Training and Awareness Update**

People living with serious illness account disproportionately for health care utilization and costs. <sup>43</sup> It is estimated that fewer than 5% of patients who would benefit from palliative care services actually receive them. <sup>44</sup> This gap highlights the need for consumer awareness as well as more training for clinicians in palliative care skills.

The Education and Training, and Awareness Work Group recognizes that creating a robust palliative care workforce is crucial to meeting the needs of patients with serious illness, therefore we recommend required palliative care education early in the training of all health care professionals.

This workgroup has researched and examined options and approaches to implementing required training. The best approach is to embed the appropriate education into the new learner's curriculum and create opportunities for ongoing learning for the current workforce. In-person and on-line training opportunities are available from a variety of organizations, and there is a need to consolidate this and make it easier to access. Funding for this work is essential and will pay multifold dividends in improved health and lower costs. The Palliative Care and Hospice Education and Training Act (PCHETA) is important new legislation, not yet passed by Congress, that will promote this work. This bipartisan federal funding bill will "ensure an adequate,

appropriately trained workforce is available to provide the pain and symptom management, intensive communication, and level of care coordination that addresses the episodic and long-term nature of serious and complex chronic illness."<sup>45</sup>

Without additional funding, the palliative care and hospice provider workforce is estimated to grow just over one percent in the next 20 years while the number of patients eligible for palliative care will increase by more than 20%. 46

The American Academy of Hospice and Palliative Medicine summarized the bill's key funding endeavors<sup>5</sup> as the following:

#### **Palliative Care and Hospice Education Centers**

Establishes Palliative Care and Hospice Education Centers to improve the training of interdisciplinary health professionals in palliative care; develop and disseminate curricula relating to palliative care; support the training and retraining of faculty; support continuing education; provide students with clinical training in appropriate sites of care; and provide traineeships for advanced education nursing degrees, social work degrees, or advanced degrees in physician assistant studies, with a focus in interprofessional team-based palliative care.

#### **Physician Training**

Authorizes grants or contracts to schools of medicine, teaching hospitals and graduate medical education programs to train physicians (including residents, trainees, and fellows) who plan to teach palliative medicine. Such programs will provide training in palliative medicine through a variety of service rotations, such as consultation services, acute care services, extended care facilities, ambulatory care and comprehensive evaluation units, hospice, home health, and community care programs. Programs will be required to develop specific performance-based measures to evaluate the competency of trainees.

#### **Academic Career Awards**

Establishes a program to promote the career development of physicians who are board certified or board eligible in Hospice and Palliative Medicine and have a junior (non-tenured) faculty appointment at an accredited school of medicine. Eligible individuals must provide assurance of a full-time faculty appointment in a health professions institution and commit to spend a majority of their funded time teaching and developing skills in interdisciplinary education in palliative care.

#### **Workforce Development**

Establishes fellowship programs within the new Palliative Care and Hospice Education Centers to provide short-term intensive courses focused on palliative care. Supporting the team approach to palliative care, the fellowships will provide supplemental training for faculty members in medical schools and other health professions schools with programs in psychology, pharmacy, nursing, social work, physician assistant education, chaplaincy, or other allied health disciplines approved by the HHS Secretary so that providers who do not have formal training in palliative care can upgrade their knowledge and skills for the care of individuals with serious or life-threatening illness as well as enhance their interdisciplinary teaching skills.

#### **Career Incentive Awards**

Provides grants or contracts for eligible health professionals who agree to teach or practice in the field of palliative care for at least five years. Eligible individuals include advanced practice nurses, social workers, physician assistants, pharmacists, or students of psychology who are pursuing a doctorate, master's or other advanced degree with a focus in palliative care or related fields in an accredited health professions school.

#### **Nurse Training**

Creates special preferences in existing nurse education law for hospice and palliative nursing, in education, practice and quality grants, workforce development, and nurse retention projects.

#### **Palliative Care Education and Awareness**

Provides for the establishment of a national campaign to inform patients, families, and health professionals about the benefits of palliative care and the services that are available to support patients with serious or lifethreatening illness. Directs the dissemination of information, resources, and materials about palliative care services to health professionals and the public in a variety of formats, in consultation with professional and patient stakeholders.

#### **Enhanced Research**

Directs the National Institutes of Health (NIH) to use existing authorities and funds to expand palliative care research to advance clinical practice and improve care delivery for patients with serious or life-threatening illness.

Because Minnesota is recognized as a national leader in the palliative care community, the Council believes that Minnesota would be the perfect convener for a federally funded Palliative Care and Hospice Education Center. There is already informal discussion amongst the interested at the University of Minnesota, the Mayo Clinic, Minnesota Hospital Association, Minnesota Medical Association, Minnesota Network of Hospice & Palliative Care, the Serious Illness Action Network, Minnesota Association of Geriatrics Inspired Clinicians and Stratis Health just to name a few. There is also interest from the surrounding states. This collaboration would create an incubator and disseminator of palliative care knowledge in the upper Midwest.

To this end, the Council recommends developing a plan for application for federal funding. This type of planning will require a great deal of coordination, a fiduciary agency, and an investment by the state in support of application for this federal funding.

PCHETA has overwhelming bipartisan support federally and is expected to pass in the near future. The Council encourages Minnesota to be prepared to apply for federal funding and the creation of the Palliative Care and Hospice Education Center. This work needs to start now. Other states have created Palliative Care Advisory Councils or Task Forces. The work these groups have done is important but creating palliative care license plates or palliative care awareness months isn't enough. Now is the time to invest in the future of our health care system, the future of our health care workforce and the health of all Minnesotans regardless of age, race, gender identity, socioeconomic status, or health status. We cannot afford to look away. When PCHETA is passed, Minnesota needs to be ready for it.

Every nurse, physician assistant (PA), physician, nurse practitioner (NP) and social worker can learn the basic principles of palliative care and be able to facilitate access to such care. Primary care physicians, PAs and NPs must have foundational knowledge of palliative care and be able to manage pain and symptoms and have patient-centered goals of care conversations. This is not unlike the fact that most high blood pressure or depression is managed by primary care providers. Specialty level care can then be provided by specialists when conditions are more complex. So, the emphasis on workforce development includes specialty and primary palliative care trained providers.

Other recommendations for workforce development include:

- 1. Require medical schools to include minimum standards for primary palliative care education for all students.
- 2. Require physician residencies to include minimum standards for primary palliative care education for all residents
- 3. Establish or expand reimbursement programs or loan forgiveness for training in specialty palliative care for all core interdisciplinary team members (Physician, Advanced Practice Provider, Registered Nurse, Social Work, Chaplain, Child Life Specialists).
- 4. Require more advanced palliative care education and skills in key physician fellowships including but not limited to oncology, radiation oncology, cardiology, geriatrics, neonatology, critical care/pulmonology, nephrology, and surgical specialties such as neurosurgery, cardiothoracic surgery, and trauma surgery.
- 5. Require nursing schools to include minimum standards for primary palliative care education for all nursing students.

Action items for the Education, Training and Awareness Workgroup in 2023 included: meetings with the leadership of the Minnesota Department of Health (MDH), MNHPC and collaborating organizations, State of Minnesota Department of Human Services (DHS) Medicaid & MinnesotaCare, Palliative Care Network of Wisconsin (PCNOW), University of Minnesota Dept. of Geriatrics and Palliative Care, Honoring Choices Minnesota (under management by Light the Legacy), Ariadne Labs, Massachusetts (authors of the Serious Illness Conversation Guide).

We are grateful to the legislators of the State of Minnesota for providing funding to PCAC to support administrative costs, and for extending the "sunset" of this Council so that we can continue this important work for years to come.

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<sup>&</sup>lt;sup>4</sup> Meier, D.E. (2011). *Increased access to palliative care and hospice services: opportunities to improve value in health care.* The Milbank Quarterly. PMID: 21933272.

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#### **Conclusion**

Minnesota continues to face challenges in health care. Despite a 10% decrease in staffing vacancy since 2022, vacancy rates remain critically high at 17% for report year 2023 – a 253% increase since report year 2019.<sup>1</sup>

Nearly 30% of U.S. rural hospitals are facing closure, according to the Center for Healthcare Quality and Payment Reform, and that could include as many as a half dozen in Minnesota if urgent action is not taken.<sup>2</sup>

Now more than ever, palliative care is needed at the whole state level. Palliative care remains uniquely positioned to lean into the current and predicted health care challenges and provide that extra layer of support for those directly involved with patients of any age living with serious illnesses/conditions and the terminally ill—the patients themselves, their caregivers, and their physicians.

Minnesota can do better for our most vulnerable populations. In addition to being a leader in delivery system transformation, let's make Minnesota a recognized leader in palliative care.

The Council is grateful to the legislators of the State of Minnesota for removing the Council's sunset date and providing funding for administrative support, enabling the Council to continue the work of expanding palliative care in Minnesota.

A complete listing of the Council's key recommendations for 2024 are available in Appendix B. Next Steps

The Council's 2023 annual legislative report identified four recommended actions as the roadmap for setting the policy stage to advance palliative care in Minnesota. The recommended actions were:

- 1. Submit the Palliative Care Advisory Council's proposed definition of Palliative Care to state legislators this session for action.
- 4. Draft a recommended core set of palliative care services (benefit) for Minnesota.
- 5. Collaborate with stakeholders, such as the Department of Human Services (DHS), to identify and align palliative care payment models to a recommended set of core palliative care services.
- 6. Request the appropriate state agenc(ies) to conduct a comparative cost study (both quantitative and qualitative measures) based on recommended palliative care payment models.

As 2023 ends, the Council celebrates the completion of recommended action #1: an updated / corrected definition of Palliative Care made it through the legislative process and was signed into law effective 8/1/2022.

The bulk of the Council's 2023 annual legislative report focused on recommended action #2: define a recommended core set of palliative care services for Minnesota. The Council developed a comprehensive palliative care benefit using both federal<sup>3</sup> and state<sup>4</sup> specific success stories and lessons learned from those states that have advanced palliative within their jurisdiction, predominantly through waivers through their Medicaid programs.

As the Council looks forward toward 2024, our efforts will focus on collaboration, as we seek to validate recommendations with those partners connected to health care.

The Council recognizes the power of data and a comparative cost study – using Minnesota specific health care data – as we seek to identify the impact that palliative care could have through cost savings, cost avoidance and improvements to quality of life.

The Council recognizes that public awareness is critical. As long as a lack of awareness and confusion exists around what palliative care is, and isn't, the effectiveness of palliative care will be less than it could be, leaving patients and caregivers receiving less support than is needed.

The Council is once again grateful for the continued support, collaboration, and partnerships with the Center to Advance Palliative Care, the Serious Illness Action Network, the Minnesota Network of Hospice and Palliative Care (MNHPC), Stratis Health and the Minnesota Alliance for Ethical Healthcare, and the American Cancer Society Cancer Action Network.

The Council looks forward to the next steps on the journey toward providing quality palliative care with access for all Minnesotans.

# Appendix A: Recommended Diversity, Equity, and Inclusion Readings and Minnesota Initiatives

- Advocates for Better Health (ABH) Foundation Awards \$64,000 in Grants
   (https://www.abhmn.org/blog/abh-the-foundation-awards-64000-in-grants)
- <u>BlueCross BlueShield Minnesota, Center for Prevention, "Health Equity Animated"</u> (https://www.centerforpreventionmn.com/health-equity-animated/)
- BlueCross BlueShield Minnesota, Center for Prevention "Racial and Health Equity Toolkits" (https://www.centerforpreventionmn.com/learn/toolkits/)
  - Series of foundational workbooks and toolkits, developed for health care industry
- University of Minnesota Center for Bioethics (https://bioethics.umn.edu/events/ethics-grand-rounds)
  - Event Recordings for "Ethics Grand Rounds" with a specific focus in 2023-2024 in the intersection of health equity and bioethics
- <u>University of Minnesota Medical School Health Equity & Care Delivery</u>
   (https://med.umn.edu/familymedicine/equity-diversity-inclusion/health-equity-care-delivery)
- University of Minnesota Medical School Program in Health Disparities Research (https://med.umn.edu/healthdisparities)
- Institute for Health Care Improvement (IHI) Improving Health Equity: Guidance for Health Care
   Organizations (https://www.ihi.org/resources/Pages/Publications/Improving-Health-Equity-Guidance-for-Health-Care-Organizations.aspx)
- Minnesota Medical Association (MMA) Conversations on Race and Equity (CORE)
   (https://www.mnmed.org/CORE)
  - Sessions for health care providers and systems, offered via Zoom and a trained facilitator
- Stratis Health "Culture Care Connection" (https://culturecareconnection.org/)
  - An online learning and resource center that supports clinical and non-clinical health care professionals to reduce health disparities and promote health equity
- Minnesota Network for Hospice and Palliative Care (MNHPC) "Responding to Racism." April 14, 2023.
  - An exclusive workshop customized specifically for hospice and palliative care providers.
- Morgan Family Foundation Greater St. Cloud Equity Dashboard (https://morganfamilyfdn.org/wp-content/uploads/2021/10/Morgan.-Wilder-.GreaterSaintCloudEquityDashboard\_10-21.pdf). Wilder Research, October 2021.

# **Appendix B: Summary of 2024 Key Recommendations**

#### Policy and Payment (carried forward from 2023 annual legislative report.)

- 1. Continue with actions supporting the four recommendations from the 2023 Annual Legislative Report:
  - a. **COMPLETED** effective 8/1/2022. Submit the Palliative Care Advisory Council's proposed definition of Palliative Care to state legislators this session for action.
  - b. **COMPLETED.** Draft a recommended core set of palliative care services for Minnesota.
  - c. IN PROGRESS / CONTINUE THROUGH 2024: Review with key stakeholders.
  - d. **IN PROGRESS CONTINUE DURING 2024.** Collaborate with stakeholders, such as the Department of Human Services (DHS), to identify and align palliative care payment models to a recommended set of core palliative care services.
  - e. **REQUIRES FUNDING**. Request the appropriate state agenc(ies) conduct a comparative cost study (both quantitative and qualitative measures) based on recommended palliative care payment models.
- 7. COMPLETED Council's sunset date removed. Extend the Council's sunset date from 2025 to 2035 allowing the Council to continue the policy, education, training, awareness, and diversity efforts to be developed, implemented, and stabilized for Minnesotans.

## **Diversity, Equity, and Inclusion**

- 1. Collect and monitor data by race and ethnicity, in addition to religion and spirituality, for quality improvement efforts.
- 8. Increase access to culturally relevant care.
- 9. Engage with and create opportunities for community and culturally specific conversations.

## Education, Training, and Awareness (carried forward from 2023 annual legislative report.)

- Establish or expand reimbursement programs or loan forgiveness for training in specialty palliative care for all core interdisciplinary team members (Physician, Advanced Practice Provider, Registered Nurse, Social Work, Chaplain, Child Life Specialists).
- 10. Require nursing schools to include minimum standards for primary palliative care education for all nursing students.
- 11. Require medical schools to include minimum standards for primary palliative care education for all students.
- 12. Require physician residencies to include minimum standards for primary palliative care education for all residents.
- 13. Require more advanced palliative care education and skills in key physician fellowships including but not limited to oncology, radiation oncology, cardiology, geriatrics, neonatology, critical care/pulmonology, nephrology, and surgical specialties such as neurosurgery, cardiothoracic surgery, and trauma surgery.

# **Appendix C: Summary of 2023 Recommended Actions**

## **Policy and Payment**

- Continue with actions supporting the four recommendations from the 2023 Annual Legislative Report:
  - a. **COMPLETED** effective 8/1/2022. Submit the Palliative Care Advisory Council's proposed definition of Palliative Care to state legislators this session for action.
  - b. **IN PROGRESS** CONTINUE DURING 2023. Draft a recommended core set of palliative care services for Minnesota. Review with key stakeholders.
  - c. **IN PROGRESS** CONTINUE DURING 2023. Collaborate with stakeholders, such as the Department of Human Services (DHS), to identify and align palliative care payment models to a recommended set of core palliative care services.
  - d. **TO BE DEFINED DURING 2023**. Request the appropriate state agenc(ies) conduct a comparative cost study (both quantitative and qualitative measures) based on recommended palliative care payment models.
- 14. Extend the Council's sunset date from 2025 to 2035 allowing the Council to continue the policy, education, training, awareness, and diversity efforts to be developed, implemented, and stabilized for Minnesotans.

# **Diversity, Equity, and Inclusion**

- 1. Reported quality measures that are relevant to the population with serious illness (or better yet, include such measures in value-based payment and financial incentive arrangements)
- 15. Growing the Primary and Specialty Palliative Care Workforce
- 16. Increase Public and Provider Awareness of Palliative Care
- 17. Provide Ancillary Opportunities to Support More Seamless Palliative Care Delivery
  - Preserving and expanding access to telehealth, including all the surrounding considerations (e.g.,
    increase broadband access, provision of devices, supporting interstate practice of medicine as long as
    there are appropriate patient protections) that are being championed outside of specialty palliative care
  - b. Growing investment in direct care and community health workers

# **Education, Training, and Awareness**

- 1. Establish or expand reimbursement programs or loan forgiveness for training in specialty palliative care for all core interdisciplinary team members (Physician, Advanced Practice Provider, Registered Nurse, Social Work, Chaplain, Child Life Specialists).
- 18. Require nursing schools to include minimum standards for primary palliative care education for all nursing students.
- 19. Require medical schools to include minimum standards for primary palliative care education for all students.
- 20. Require physician residencies to include minimum standards for primary palliative care education for all residents.

21. Require more advanced palliative care education and skills in key physician fellowships including but not
limited to oncology, radiation oncology, cardiology, geriatrics, neonatology, critical care/pulmonology, nephrology, and surgical specialties such as neurosurgery, cardiothoracic surgery, and trauma surgery.

# **Appendix D: Summary of 2022 Recommendations**

- 1. Submit the Palliative Care Advisory Council's proposed definition of Palliative Care to state legislators this session for action.
- 2. Draft a recommended core set of palliative care services for Minnesota.
- 3. Collaborate with stakeholders, such as the Department of Human Services (DHS), to identify and align palliative care payment models to a recommended set of core palliative care services.
- 4. Request the appropriate state agenc(ies) conduct a comparative cost study (both quantitative and qualitative measures) based on recommended palliative care payment models.

# **Appendix E: Summary of 2021 Recommendations**

This summary does not include all the identified recommendations but rather identifies the few key recommendations for 2021 as follows:

- 1. Consider revising the language in 144.75A Subdivision 12 to eliminate the exclusive association of palliative care with hospice care.
- 2. Adopt the suggested definition of Palliative Care for Minnesota. (See Definition Section for suggested language.)
- Enable Minnesota's Medical Assistance and MinnesotaCare to pay for high-value services such as palliative
  care and advance care planning to benefit those with serious illnesses or life-limiting conditions using
  existing CPT or HCPCS codes.
- 4. Explicitly incorporate palliative care into existing Medical Assistance and MinnesotaCare waiver programs that focus on high need patients.
- 5. Consider options with the Medical Assistance and MinnesotaCare plans to remove or offset the "loaded miles" benefit restriction that currently exists in benefits authorized by Centers for Medicare & Medicaid Services in order to reduce the financial burden on caregivers providing transportation.
- 6. Consider making palliative care coverage a requirement for all Medical Assistance and MinnesotaCare managed care contracts in the next contracting cycle.
- 7. Consider adding palliative care coverage requirements in all settings to Medical Assistance and MinnesotaCare managed care organization contracts, including special considerations for pediatrics, adolescent, and young adult, and perinatal.
- 8. Rethink how technology can support those with serious illness care.
- 9. Develop a registry for provider orders for life-sustaining treatment (POLST) and advance care planning (ACP) documentation.
- 10. Improve access to and support for the use of technology for patients and caregivers.
- 11. Normalize and proactively support ACP as part of health care delivery.
- 12. Support workforce development and confidence in technology use for remote care delivery.
- 13. Reduce variations in coverage and payment requirements across payers that make it challenging to develop and deliver serious illness care.
- 14. Provide adequate reimbursement and regulatory incentives for increasing utilization of ACP.
- 15. Implement regulatory and reimbursement flexibilities to structure services that better meet the needs of seriously ill patients.
- 16. Improve access to and consumer experience for all needed care service primary, specialty care, and hospital care. (see the Health Equity Section for a list.)
- 17. Consider options with the Medical Assistance and MinnesotaCare plans to remove or offset the "loaded miles" benefit restriction that currently exists in benefits authorized by Centers for Medicare & Medicaid Services in order to reduce the financial burden on caregivers providing transportation.
- 18. Request research on rural transportation challenges affecting access to timely, appropriate health care (including palliative care).

# **Appendix F: Summary of 2020 Recommendations**

During 2019, the Palliative Care Advisory Council identified the following 19 recommendations to improve and strengthen palliative care within Minnesota.

- 1. Establish a clear definition for palliative care in state statute and relevant regulations, independent of hospice regulations.
- 2. Fund a statewide public education campaign around serious illness.
- 3. Fund a statewide public education campaign around end-of-life care.
- 4. Require a minimum number of hours of instruction in primary palliative care and pain management through state health professional licensure and continuing education guidelines for those who have Minnesota state licensure (Physician, Advanced Practice Provider, Registered Nurse).
- 5. Fund efforts to train professionals in primary palliative care.
- 6. Fund efforts to train professionals in specialty palliative care.
- 7. Support innovative certification opportunities for mid-career providers who want to focus in palliative care including tele-education and mentorship programs.
- 8. Establish or expand reimbursement programs for training in specialty palliative care for all core interdisciplinary team members (Physician, Advanced Practice Provider, Registered Nurse, Social Worker, Chaplain, Child Life Specialist).
- 9. Require nursing schools to include minimum standards for primary palliative care education for all nursing students.
- 10. Require medical schools to include minimum standards for primary palliative care education for all medical students.
- 11. Require physician residencies to include minimum standards for primary palliative care education for all residents.
- 12. Require more advanced palliative care education and skills in key physician fellowships including but not limited to oncology, radiation oncology, cardiology, geriatrics, neonatology, critical care/pulmonology, nephrology, and surgical specialties such as neurosurgery, cardiothoracic surgery, and trauma surgery.
- 13. Ensure that palliative care benefits offered by private and public payers are comprehensive and support the full interdisciplinary team.
- 14. Expand access to home-based palliative care.
- 15. Expand access to pediatric palliative care in all settings to reduce the gap in services.
- 16. Establish a state-wide interdisciplinary palliative care research center or hub.
- 17. Require state regulatory agencies to develop measures, collect data, and report on palliative care access and quality. Measures should include disparities in access and utilization of palliative care across populations, care settings, and geography.
- 18. Encourage Minnesota based palliative care programs to participate in currently established national data collection efforts such as the Center to Advance Palliative Care National Palliative Care Registry.
- 19. Establish minimum standards for what constitutes a palliative care program with attention to challenges faced by different types of providers.

<sup>&</sup>lt;sup>1</sup> Ibid.

<sup>&</sup>lt;sup>2</sup> Ibid.

<sup>&</sup>lt;sup>3</sup> Federal resources used in the creation of this report include but are not limited to The National Academy for State Health Policy (NASHP), the Center to Advance Palliative Care (CAPC), the National Hospice and Palliative Care Organization, The Coalition to Transform Advanced Care (C-TAC).

<sup>&</sup>lt;sup>4</sup> States sharing their palliative care journeys include Arizona, California, and Hawaii.