

In spring 2019, the North Carolina Institute of Medicine, in partnership with agencies and organizations that provide care and advocacy around issues of palliative care, hospice care, aging, and long-term supports and services, convened the Task Force on Serious Illness Care.

This task force included over 60 experts across many areas relevant to serious illness care, including health care providers (physicians, nurses, pharmacists), other members of serious illness care teams (including social workers and spiritual leaders), community advocates, veterans advocates, private and public payers, legal and financial planning experts, family and community caregiver representatives, health educators, and researchers. The NCIOM and partner agencies made diversity of expertise, experience, and geographic region of the state a key priority for membership. The NCIOM task force model allowed for wide, multi-disciplinary stakeholder engagement, enabled robust discussion, and led to a comprehensive and cohesive plan to address and improve serious illness care in North Carolina.

NOTE FROM THE NORTH CAROLINA INSTITUTE OF MEDICINE

April 2020

The recommendations contained in this report from the Task Force on Serious Illness Care reflect the task force process and deliberations completed in January 2020. In the weeks between January and the time of this report's publication in April 2020, the COVID-19 pandemic developed across the world, including in North Carolina. The task force and the North Carolina Institute of Medicine acknowledge the many ways that the task force recommendations are impacted by and emphasized by the COVID-19 pandemic. In particular, we have seen how recommendations concerning access to care (especially through telehealth), improving insurance coverage, supporting caregivers (including through employer-based policies), improving advance care planning, and supporting the health care workforce, are of dire importance in this pandemic. In addition, we also acknowledge that the current and forthcoming economic situation of the state and nation may impact the prioritization and implementation of recommendations that seek expanded funding for serious illness services. Fortunately, the North Carolina Serious Illness Coalition, a key recommendation from the Task Force, has already started to meet to address how to implement task force recommendations, and has begun to identify new and changing priorities. This Coalition will play a key role in identifying new issues for consideration as we meet the challenges COVID-19 presents now and in the future.

A steering committee contributed to developing the goals and scope of the task force work, selecting the meeting agendas and speakers, and developing dissemination and communications strategies. Jonathan Fischer, MD, Assistant Professor, Duke University Department of Community Health and Family Medicine; Joyce Massey-Smith, Director, Division of Aging and Adult Services, North Carolina Department of Health and Human Services; and Paulette Dillard, PhD, President, Shaw University chaired the task force.

The task force met 10 times in 2019 and 2020 to develop consensus-based, evidence-based, and actionable recommendations to improve serious illness care in North Carolina. The report of the task force provides policymakers, health providers and systems, and other stakeholders with a common vision and action steps to address the impacts of serious illness on North Carolinians.

TASK FORCE ON SERIOUS ILLNESS CARE: VISION STATEMENT

Through the course of the task force work, NCIOM staff guided members through the development of a vision statement that captured the scope and breadth of the areas of serious illness care prioritized for improvement.

Our vision for serious illness care in North Carolina is a system and culture that prioritizes quality of living for people with serious illness, their families, and their communities. This system and culture will incorporate the following elements to achieve this priority:

- Health system and social change to address serious illness care
- High-quality person-centered care
- Engagement with patients and families to meet goals of care
- Development of the health and human services workforce and infrastructure to support serious illness care

WHAT IS "SERIOUS ILLNESS"?

Serious illness occurs when chronic or acute health conditions become serious enough to affect a person's general health and functioning, and the illness is potentially life-threatening. For individuals with serious illness, it is possible that the effectiveness of curative treatment will decrease, and the focus of care may shift toward comfort. Throughout the work of the Task Force on Serious Illness Care, the task force used the above definition of "serious illness," as well as the additional context that the task force scope was defined by individuals for whom a health care provider would not be surprised if they were to die in the next year.

SERIOUS ILLNESS IN NORTH CAROLINA: DEMOGRAPHICS

According to U.S. Census Bureau estimates, 16.3% of North Carolinians, or about 1.7 million people, are over the age of 65.¹ The over-65 population of North Carolina is projected to increase 67% between 2016 and 2036, from 1.6 million to 2.6 million people.²

While serious illness is not solely an issue for older adults, rates are higher in this population. The 2018 Behavioral Risk Factor Surveillance Survey (BRFSS) reported that 65.8% of respondents aged 65 and over had two or more chronic health conditions³, and an additional 31.3% of respondents aged 65 and over had one chronic health condition.³

^a Includes heart disease (heart attack/stroke/angina), current asthma, skin cancer, other cancer, COPD, arthritis, depression, kidney disease, and diabetes. Note: Not all of the reported chronic health conditions would necessarily fall into the definition of serious illness used by the task force.

FIGURE 1 Leading Causes of Death in North Carolina, 2017

	DEATHS	RATE	STATE RANK	US RATE
1. Cancer	19,474	157.1	21st	152.5
2. Heart Disease	18,808	156.5	27th	165.0
3. Accidents	5,985	56.3	20th	49.4
4. Chronic Lower Respiratory Diseases	5,540	45.3	23rd (tie)	40.9
5. Stroke	5,098	43.0	10th	37.6
6. Alzheimer's Disease	4,289	37.3	13th	31.0
7. Diabetes	2,903	23.6	17th	21.5
8. Flu/Pneumonia	2,076	17.5	11th (tie)	14.3
9. Kidney Disease	2,040	17.0	9th	13.0
10. Suicide	1,521	14.3	35th	14.0

Source: CDC National Center for Health Statistics; 2017. <https://www.cdc.gov/nchs/pressroom/states/northcarolina/northcarolina.htm>

In North Carolina, the number of individuals with serious illness is expected to rise as the population ages. In 2009, the North Carolina State Center for Health Statistics projected 46,417 new cancer cases for that year (and 18,277 deaths). For 2019, the number of projected new cancer cases was 62,466 (and 21,426 projected cancer deaths).⁴

Rates of heart disease have also been rising. According to the BRFSS, in 2012, 4.5% of adults reported being told by a health professional that they had angina or coronary heart disease. In 2019, 5.7% of adults reported this diagnosis. Among adults over 65, 15.9% reported being diagnosed with heart disease.⁵

While acknowledging that much of the task force's work focused on older adults, the task force also examined particular needs (and cross-cutting needs) of younger adults and children with serious illness. In 2010, the most recent year for which data is available on a survey module for children with special health care needs, 12.9% of respondents to the statewide Child Health Assessment and Monitoring Program survey answered that their child "currently needs or uses more medical care, mental health or educational services than is usual for most children of the same age." In the same survey, 6.1% of respondents said that their child was "limited or prevented in any way in his/her ability to do the things

FIGURE 2 Projected Rates of Serious Illness, By Condition

	ACTUAL RATE (2018)	2019-2020 PROJECTED	2030 PROJECTED
Alzheimer's Disease	P: 170,000 ^b persons 65+	180,000 (2020)	210,000 (2025)
Cancer ^c	I: 52,752 (2017) IR: 423.9 per 100K (NC Registry) ^d I: 55,394 (2016) IR: 458.4 per 100k people (age adjusted) ^e (CDC)	Projected incidence: 62,466 ^f (NC Registry)	In 2017, the North Carolina Prevention and Control Branch: NC Comprehensive Cancer Control Program stated that the incidence rate was on the decline—decreasing 9.4% from 2009 to 2014. ^g
Diabetes	P: 12.5% ^h (crude) 2019 P: 11%		Projected to be rising nationwide, especially among adults aged 65 and older. ⁱ
Heart Disease	Heart attack: 5.4% ^k Angina or CHD: 5.7% ^l		
Kidney Disease	P: 3.2% ^m (crude)		Between 2015 and 2030, prevalence of end stage renal disease (ESRD) is projected to rise 19-39% for adults 45-64 years old, 23-75% for those aged 65-74, and 4-51% for adults over 75. ⁿ
Respiratory Illness	P: 8.1% ^o		
Stroke	P: 3.8% ^p		

^b Alzheimer's Association, 2018. <https://www.alz.org/media/documents/northcarolina-alzheimers-facts-figures-2018.pdf>
^c This data excludes cervical carcinoma and basal and squamous cell carcinomas of the skin. North Carolina State Center for Health Statistics. <https://schs.dph.ncdhhs.gov/units/ccr/>
^d North Carolina State Center for Health Statistics https://schs.dph.ncdhhs.gov/schs/CCR/incidence/2017/racegender_v2.pdf
^e Centers for Disease Control and Prevention. United States Cancer Statistics <https://gis.cdc.gov/cancer/USCS/DataViz.html>
^f North Carolina State Center for Health Statistics <https://schs.dph.ncdhhs.gov/schs/CCR/proj19co.pdf>
^g NC Department of Health and Human Services. North Carolina Cancer Prevention and Control Branch. <https://publichealth.nc.gov/chronicdiseaseandinjury/cancerpreventionandcontrol/docs/ReducingtheBurdenofCancerResourceGuide.pdf>
^h Centers for Disease Control and Prevention. BRFSS Prevalence and Trends Data, 2018.
ⁱ County Health Rankings 2019
^j Lin J, Thompson TJ, Cheng YJ, Zhuo X, Zhang P, Gregg E, Rolka DB. (2018) Projection of the future diabetes burden in the United States through 2060. *Population Health Metrics*, 16(9). <https://pophealthmetrics.biomedcentral.com/articles/10.1186/s12963-018-0166-4>
^k North Carolina State Center for Health Statistics <https://schs.dph.ncdhhs.gov/data/brfss/2018/nc/risk/CVDINFR4.html>
^l North Carolina State Center for Health Statistics <https://schs.dph.ncdhhs.gov/data/brfss/2018/nc/risk/CVDCRHD4.html>
^m Centers for Disease Control and Prevention. BRFSS Prevalence and Trends Data. Kidney Disease, 2018.
ⁿ McCullough KP, Morgenstern H, Saran R, Herman WH, Robinson BM. (2019). Projecting ESRD Incidence and Prevalence in the United States through 2030. *J Am Soc Nephrol* 30: 1-9. <https://jasn.asnjournals.org/content/jnephrol/early/2018/12/13/ASN.2018050531.full.pdf>. The prevalence of those under 45 years of age is projected to move in both directions, decreasing as much as 2% and increasing as much as 7% from its 2015 values.
^o North Carolina State Center for Health Statistics. 2018. <https://schs.dph.ncdhhs.gov/data/brfss/2018/nc/risk/CHCCOPD1.html>
^p North Carolina State Center for Health Statistics. 2018. <https://schs.dph.ncdhhs.gov/data/brfss/2018/nc/risk/CVDSTRK3.html>

IMPROVING SERIOUS ILLNESS CARE IN NORTH CAROLINA

most children of the same age do.”⁶ In addition, in North Carolina, there were 4,834 cases of pediatric cancer between 2003 and 2014, at a rate of 162 cases per 1 million population, one of the higher rates in the country. Overall, pediatric cancer rates are highest among children aged 0-4 and teens aged 15-19, as compared to children aged 5-14.⁷

FIGURE 3 Serious Illness Rates by Disease for Children and Young Adults (0-19 years of age), U.S

Cancer (all types)	161.0-171.4 per 1,000,000 (2018-2019 age-adjusted cancer incidence rates)
Cystic Fibrosis	25 cases per 100,000 (2017 Newborn Screening)
HIV/AIDS	0-13 years old: 4.9 per 100,000 (2018) 13-14 years old: 9.5 per 100,000 (2018) 15-19 years old: 24 per 100,000 (2018)
Congenital Heart Disease	131 cases per 100,000 (2017 Newborn Screening)

Sources: Cancer: <https://www.cdc.gov/cancer/dpcp/research/articles/rates-children-teens-state-region.htm>
Cystic Fibrosis: <http://www.ncmedicaljournal.com/content/80/1/45/T1/graphic-1.large.jpg>
HIV/AIDS: https://epi.dph.ncdhhs.gov/cd/stds/figures/hiv18rpt_02042020.pdf
Congenital Heart Disease: <http://www.ncmedicaljournal.com/content/80/1/45/T1/graphic-1.large.jpg>

HEALTH SYSTEM AND CULTURE CHANGE TO SUPPORT SERIOUS ILLNESS CARE

The Task Force on Serious Illness Care recognized that, with rising rates of many serious and chronic conditions in our state, it is crucially important to develop a system and culture that aims to improve the quality of living for individuals with serious illness, their families, and their communities. The Task Force on Serious Illness Care built recommendations using the previous and ongoing work of many experts throughout the state and nationally. In addition, the task force recognized the need for ongoing collaboration and governance to ensure implementation of the task force recommendations.

In addition, the task force examined the need for broader cultural and systemic changes needed to address the challenges faced by individuals with serious illness. Throughout the development of the recommendations, the task force was guided by principles of health equity, with a special consideration for the disparate impacts of serious illness among vulnerable populations, both in rates of specific conditions as well as in access to services and experience of receiving care. As the health system, and communities more broadly, address disparities in care, they must also keep cultural competency in mind. Cultural competence, in the health care context, is defined as “behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations.”⁸ The task force examined the ways that cultural factors such as customs, values, and institutions of racial, ethnic, religious, or social groups may impact the delivery of serious illness care, advance care planning, and engaging with patients and families, and worked to ensure that the recommendations reflect these considerations.

HEALTH EQUITY is the absence of avoidable or remediable differences, allowing for the attainment of optimal health for all people. Health equity is achieved when everyone has the opportunity to attain their full health potential and no one is disadvantaged because of socially determined circumstances. Achieving it requires focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities.

Source: *Racial and Ethnic Health Disparities in North Carolina: North Carolina Health Equity Report, 2019.*
NC Department of Health and Human Services.

RECOMMENDATION 2.1:

Establish coordinated statewide leadership to facilitate implementation of recommendations and ongoing work to achieve quality of living for individuals with serious illness (PRIORITY)

The North Carolina Serious Illness Coalition should provide statewide coordinated leadership to oversee and coordinate the implementation of the recommendations from the Task Force on Serious Illness Care. Under the direction of an executive committee, the Coalition should:

1. Identify and appoint appropriate stakeholders for membership in the Coalition
2. Determine statewide standards for what defines “serious illness” and how it is applied across recommendations
3. Identify and support work groups charged with additional development and implementation of specific recommendations and to serve in an advisory capacity to additional partners
Workgroups may include: awareness/communication, quality metrics/measurement, advance care planning, workforce (including wages), and policy/regulation
4. Develop work plan for prioritization and implementation of recommendations
5. Report progress on implementation on an annual basis to relevant stakeholders
6. Provide support and leadership for the North Carolina Partnership on Compassionate Care
7. Pursue sustainable funding from philanthropic organizations for ongoing work of the Coalition

The following recommendations involve the Coalition: 3.5, 4.2, 4.8, 4.9.

RECOMMENDATION 2.2:

Increase research on cultural competency and health equity as it relates to serious illness care

Industry and professional associations, private funders, and other stakeholders should promote policies and processes that support and encourage improved health equity and understanding of cultural competency in serious illness care, to include:

1. Increased funding for research into disparities in the utilization of serious illness care and advance care planning
2. Health policy researchers, health services researchers, schools of medicine, schools of nursing, continuing education providers, and others, should increase research focused on the structural causes of health disparities and cultural understanding that may affect the utilization of serious illness care (including palliative and hospice care) and influence its delivery. Research goals should also include the development of evidence-based methods to reduce disparities in health outcomes and experience of care, as well as to increase cultural competency among providers
3. Incorporation of patient experience data (including disaggregated by race/ethnicity, rural/urban, and other potential areas of disparity) into the development of new models of care, processes, and technologies relevant to serious illness care delivery
4. Promotion of evidence-based training models in health equity and cultural competency for health care providers and members of serious illness care teams

RECOMMENDATION 2.3:

Prioritize health equity and the reduction of disparities as guiding principles throughout implementation of all recommendations of the Task Force on Serious Illness Care (PRIORITY)

HIGH-QUALITY PERSON-CENTERED CARE

Recommendations in Chapter Three address improvements in care for individuals with serious illness, including care delivery and coordination, financing/payment for serious illness care, and addressing non-clinical needs.

LONG-TERM SERVICES AND SUPPORTS

Among all adults aged 65 and over, it is estimated that around half will develop an illness serious enough to need long-term services and supports. About one in seven adults over 65 will need these services for longer than five years. There are a broad range of long-term services and supports, which provide varying levels of medical care and non-medical care, including assistance with activities of daily living. Long-term services and supports can be provided in the home, in a community setting, or in a designated residential care facility. Due to the range of types and locations of long-term services and supports, there is also a range of payment systems for these different types of care.

LONG-TERM SERVICES AND SUPPORTS include a wide range of paid and unpaid medical and personal care assistance that people may need—over many weeks, months, or years—when they have difficulty completing self-care tasks as a result of aging, chronic illness, or disability. These services can be provided at home, in a community setting, or in an institutional setting such as a nursing home or assisted living.

PALLIATIVE CARE AND HOSPICE CARE

Throughout the work of the Task Force on Serious Illness Care, members discussed palliative care, hospice care, and the similarities and differences between the two, as well as misconceptions about when and how palliative and hospice care are delivered.

Palliative care is a type of specialty care provided to individuals living with serious illness. Palliative care focuses on providing relief from symptoms, increasing comfort, and improving quality of life for individuals and their families. Palliative care includes clinical care, such as symptom management, expert communication about disease trajectory and what to expect, and coordination of care across health care providers and settings.⁹ Hospice care, like palliative care, also focuses on providing comfort, relieving symptoms, coordinating care, and improving quality of living for people with serious illness. Unlike with palliative care, however, in hospice care curative treatments are stopped. Hospice care is for individuals nearing the end of life, usually for those expected to live for less than six months, though hospice can be provided for any individual with a life-limiting illness.¹⁰ For pediatric patients, the inclusion criteria is different: patients do not have to stop curative treatment while receiving hospice care.¹¹

FIGURE 4 Distinctions Between Hospice and Palliative Care

	PALLIATIVE CARE	HOSPICE
Model of care	Interprofessional collaborative practice teams, including physicians, nurses, social workers, chaplains, care managers; primary goal is improved quality of life	Interprofessional collaborative practice teams, including physicians, nurses, social workers, chaplains, care managers, and volunteers; primary goal is improved quality of life and relief of suffering
Eligibility	Any age and with any diagnosis or stage of illness; can be delivered concurrently with life-prolonging and disease-directed treatments	All ages with prognosis of less than six months to live, must forgo Medicare coverage for curative and other treatments
Place	Hospitals, clinics, group practices, home settings, skilled nursing facilities	Home, long-term care facilities including nursing homes and assisted living, residential hospice facilities or inpatient hospice units
Payment	Doctor and nurse practitioner fees covered by Medicare part B for inpatient or outpatient care; hospital care covered by Medicare part A or commercial insurance; flexible bundled payments under Medicare Advantage, managed Medicaid, ACOs, other commercial payers	Medicare hospice benefit; commercial insurance usually modeled after Medicare; Medicaid. Medication costs included for drugs related to primary illness.

Source: Kelley AS, Morrison RS. Palliative care for the seriously ill, *N Engl J Med* 2015; 373:747-755. <https://www.nejm.org/doi/full/10.1056/NEJMra1404684>;

Both palliative care and hospice care utilize a team-based model of care, in which medical staff, including physicians, nurses, certified nursing assistants (CNAs), and non-medical staff such as social workers, chaplains/faith leaders, therapists, and volunteers, work to meet individuals' and families' needs. The recognition of the individual and their family as

integral members of the care team is of particular importance in team-based care for individuals with serious illness as well.

The number of innovative models for paying for specific types of care for individuals with serious illness is increasing. As described above, both Medicare and Medicaid have specific payment models to cover hospice care, with similar covered services. Please see Chapter Three for additional discussion of payment structure and recommendations to improve reimbursement for high-value serious illness care.

DRIVERS OF HEALTH

The Task Force on Serious Illness Care recognized the need for individuals with serious illness to receive services beyond clinical care. Clinical factors only account for around 20% of health outcomes. For individuals with serious illness, access to clinical services is crucial, but social, behavioral, and economic factors such as safe communities, housing, transportation, access to healthy food, education, and health behaviors also impact quality of living. These factors are called drivers of health (also known as social determinants of health). While most traditional clinical health care settings and stakeholders are not designed to address the non-clinical drivers of health, the task force examined ways to improve access to non-clinical services and the impact this will have on individuals with serious illness.

RECOMMENDATION 3.1:

Deliver goal-concordant, coordinated, team-based care for individuals with serious illness (PRIORITY)

In order to improve access to care and quality of care for individuals with serious illness, health care providers and systems should identify and implement effective team-based models of care that seek to optimize meeting patient goals of care and care coordination for individuals with serious illnesses. These models should aim to improve care delivery by:

1. Identifying and ensuring the incorporation of patient's self-identified goals of care across all care settings
2. Incorporating a broad array of providers into care team, including physicians, nurses, chaplains, social workers, community health workers, community paramedicine providers, patient navigators, care managers, home health workers, patients, family (and support system) caregivers, volunteers, and others, including those with specific palliative and hospice care expertise
3. Increasing use of family advocates and patient/community navigators to help patients and families receive appropriate services, to ease transitions of care, to identify the health care proxy, and discuss goals of care, with specific attention to ensuring that patients who may be unable to advocate for themselves are receiving needed care and services
4. Recognizing the role of unpaid/family caregivers as members of the health care team, including documenting family caregivers, promoting training options for caregivers to learn necessary skills, and identifying support resources
5. Identifying and connecting to resources for non-clinical health needs (also see recommendation 3.3)

RECOMMENDATION 3.2:

Incorporate regular and timely assessment processes to identify and develop effective and goal-concordant plans of care for individuals with higher health needs

In order to more effectively identify patients with serious illness who may be in need of additional/enhanced/targeted clinical services, and connect them earlier to needed services, health care providers and systems should:

1. Utilize best practices in clinical assessment to identify individuals' clinical health needs and goals of care
2. Explore feasibility of incorporating best practices in predictive analytics and ways to connect results with improving care
3. Connect patients and caregivers with consumer-driven assessment tools (including those that are designed for individuals with serious illness) and encourage self-assessment (and/or family assessment) of needs and goals of care at regular intervals

RECOMMENDATION 3.3:

Assess drivers of health and connect individuals with serious illness and caregivers with appropriate non-clinical services

1. Health care providers working with individuals with serious illness and their caregivers should use the North Carolina Standardized Screening Tool (as developed for NC Medicaid) and/or other applicable screening tools, including caregiver burden assessment tools, to identify and address drivers of health and unmet needs. Tools should be used on an ongoing/regular basis
2. The North Carolina Department of Health and Human Services should develop a communication plan to engage with providers of serious illness care to increase awareness of and capacity to implement screening tools listed above
3. NCCARE360 should develop a plan to integrate specific resources for individuals with serious illness and family caregivers (such as referrals to respite care and advance care planning assistance) into resource platforms including No Wrong Door, NC 2-1-1, and NCCARE360, with particular attention to promoting equity of access to services
4. NCCARE360 should enhance capacity to evaluate appropriate connection to and receipt of services on a statewide level
5. The North Carolina General Assembly and/or County Commissioners should increase appropriations to the State-County Special Assistance Program in order to increase capacity to meet non-clinical needs of individuals with serious illness

RECOMMENDATION 3.4:

Develop and apply new payment models to support palliative care delivery (PRIORITY)

Payers, including Medicaid, should apply payment models that support the use of high-quality palliative care for individuals with serious illness, including community-based palliative care. Models may include the "advanced illness management" model proposed by the Coalition to Transform Advanced Care, and/or the "Patient and Caregiver Support for Serious Illness" model developed by the American Academy of Hospice and

Palliative Medicine. Payment models should:

1. Ensure the delivery of palliative care services, to include comprehensive assessment and care planning services delivered by an interdisciplinary team of health care providers (comprised of physicians, nurses, spiritual leaders, social workers, and advanced practice practitioners)
2. Ensure that all payment models allow concurrent palliative care and disease treatment; evaluate benefits of concurrent hospice care
3. Work toward establishing payment tiered by patient complexity, functional status, and intensity of interdisciplinary services
4. Be subject to quality metrics and models of quality improvement, aligned across payers
5. Utilize screening for non-clinical health needs and connection with community services (also see Recommendation 3.3)
6. Apply across the spectrum of institutional and home-based care

RECOMMENDATION 3.5:

Convene a work group tasked with assessing and developing appropriate quality metrics for serious illness care (PRIORITY)

The North Carolina Serious Illness Coalition (as named in **Recommendation 2.1**) should convene a serious illness quality metrics work group. Work group membership should include experts in quality improvement, data collection, and serious illness care. It should also have inclusive representation of patients, family members, or other support system members/caregivers, as well as members of underserved communities.

This group should be tasked with:

1. Reviewing existing palliative, hospice, and serious illness care metrics, including Centers for Medicaid and Medicare Services standard measures, American Academy of Hospice and Palliative Medicine recommended measures, and/or additional evidence-based measures, including those under development
2. Developing a concise list of recommended process and outcome metrics to assess quality serious illness care, compile current performance data (as available) on these metrics, identify best practices for frequency of data collection, and identify recommended performance targets/benchmarks for improvement on the list of metrics
3. Studying data collection, reporting, risk adjustment, disaggregation of data, and implementation of quality improvement strategies to meet performance targets specific to serious illness care; developing educational materials for professional associations on results of study
4. Determining and recommending metrics specific to pediatric care

RECOMMENDATION 3.6:

Expand access to coverage for health care services

In order to ensure access to health care services for individuals with serious illness:

1. The North Carolina General Assembly should support legislation to:
 - a. Close the health insurance coverage gap

- b. Ensure integration of behavioral and physical health services for Medicaid beneficiaries under Medicaid managed care
2. The North Carolina Department of Health and Human Services should revise processes for determining eligibility for services covered by Medicaid, including long-term care and Special Assistance programs (including Special Assistance for Assisted Living and Special Assistance In-Home programs). Processes should ensure timely and efficient eligibility determination.

ENGAGING WITH PATIENTS AND FAMILIES TO MEET GOALS OF CARE

The Task Force on Serious Illness Care identified several important aspects to ensure that individuals are able to identify and achieve their goals for care, including meeting the principles of patient and family engagement, improving the processes and understanding of advance care planning, and creating a system that supports family and communities as they care for those with serious illness.

PATIENT AND FAMILY ENGAGEMENT

The core of patient and family engagement lies in welcoming the patient and family,⁹ as well as non-family support systems, as important partners in care. The Institute of Medicine of the National Academies (IOM) describes patient and family engagement as a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences. The IOM further states that patients should receive the education and support that they need to make decisions and participate in their own care.¹² For patient and family engagement to work, patients must have, or be given, the knowledge, skills, and confidence to manage their health and health care.¹³ In addition, health care at every level needs to be patient- and family- centered. The Institute for Patient- and Family-Centered Care defines patient- and family-centered care as "an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families."¹⁴ The institute describes the foundations for patient and family engagement as dignity, respect, information sharing, participation, and collaboration. For individuals with serious illness, in particular, increased engagement in care can address anxiety about care and disease trajectory and help individuals identify the values most important to them as they consider treatment preferences and goals.¹⁵

WHAT IS ADVANCE CARE PLANNING? "Advance care planning is about planning for the 'what ifs' that may occur across the entire lifespan. Advance care plans can be developed at any time, whether you are sick or well. Once you are sick and disabled with a progressive illness that will last until death, you really need a comprehensive care plan that considers your social supports, your preferences, and your likely course. Advance care planning is an essential part of such a plan." — Joanne Lynn, MD, *Center for Elder Care and Advanced Illness*

ADVANCE CARE PLANNING

In order to address the ways that individuals and families can best identify their goals of care and ensure that values for care and end of life are reflected in these goals, the task force examined processes and systems for advance care planning, including within the health system, the financial/legal system, and professional training.

Broadly defined, advance care planning is a process by which individuals can discuss and document their care preferences, “to ensure that health care treatment (they) may receive is consistent with wishes and preferences should (the individual) be unable to make decisions or speak” for themselves.¹⁶ While the task force focused much of its work on advance care planning as related to people who have already been diagnosed with or are living with a serious illness, its recommendations also recognize the importance of advance care planning as a process across the lifespan, with many relevant stakeholders both within and outside of the health care system.

CAREGIVER: Throughout the task force process and in the text of the report, “caregiver” is used to refer to unpaid individuals, often family or friends but also volunteers, who provide care for an individual with serious illness.

SUPPORTING CAREGIVERS OF INDIVIDUALS WITH SERIOUS ILLNESS

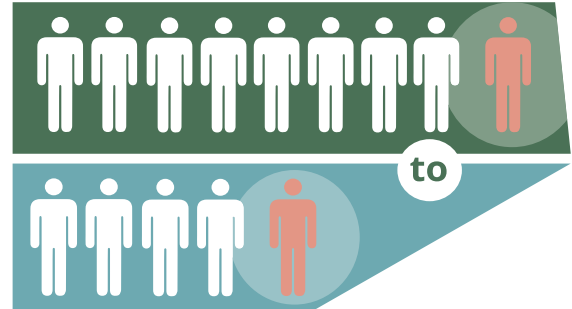
Individuals with serious illness often require increasingly intensive care as their disease progresses. Adult children and spouses are often the primary caregivers for adults with serious illness, with parents and grandparents usually the primary caregivers for children with serious illness. According to the North Carolina Department of Health and Human Services, nearly one-quarter of adults in North Carolina provide regular care or support to an older adult with a long-term illness or disability.¹⁷ Of these caregivers, more than half are also employed full or part time. As the needs associated with serious illness increase, caregivers must often take time off work, hire additional help, and sometimes seek a care setting that offers round-the-clock skilled care. Seventy percent of caregivers have had to adjust work schedules to accommodate the needs of their loved ones. Caregivers experience high incidences of stress, anxiety, and depression and are more likely to incur higher medical costs themselves.¹⁸

Currently in North Carolina, the ratio of potential caregivers—people aged 45-64—to those over the age of 80 is eight to one. By 2030, there will only be four potential caregivers for every older adult in the state. For illnesses that require high levels of care, the declining ratio of potential caregivers to ill individuals may mean that nursing homes and other residential care facilities will play an increasingly large role in caring for those with serious illness.

Chapter Four examines additional aspects of patient and family engagement, advance care planning, and supporting family caregivers to improve care for individuals with serious illness.

The ratio of potential caregivers for each older adult in the state* will sharply decline from

8.0 in 2010



3.9 in 2030

As the caregiver ratio declines, there will be a larger financial, emotional, and logistical burden on individuals and families

*number of potential caregivers are 45-64 for each person 80 or older

RECOMMENDATION 4.1:

Support patient and family engagement through health care organization policies and processes

Industry and professional associations and other stakeholders should promote policies and processes that support and encourage patient and family engagement in all aspects of their health care experience. Stakeholders should:

1. Consider inclusion of patients and caregivers on boards and advisory committees; appointees should reflect the diversity of facility population and community
2. Include family members and caregivers in the development of health promotion materials and caregiver resource guides, and provide training for families on engaging in care
3. Identify consistent and commonly accepted terminology and messaging about person-centered care and patient and family engagement, and provide training for health care providers in these principles
4. Encourage organizational leadership to promote principles of person-centered care and identify strategic benefits to system/facility
5. Include patients and families in processes to identify appropriate metrics for serious illness care (see Recommendation 3.5), in order to ensure inclusion of patient/family needs
6. Recognize facilities and systems that successfully incorporate policies and practices that value and support patient and family engagement

RECOMMENDATION 4.2:**Develop statewide initiative for improved awareness of, and support for, completion of advance care planning (PRIORITY)**

The North Carolina Serious Illness Coalition should serve as a statewide repository for resources related to advance care planning and facilitate public awareness activities to promote it.

1. Repository/resources may include:
 - a. Glossary of common terminology, including clarification of often-confused terminology
 - b. Listing of community education events
 - c. Speakers' bureau
 - d. Best-practices and interdisciplinary training recommendations
 - e. Print/media kits and social media resources
 - f. Personal narratives and videos
 - g. Guide to advance care planning (including those created to meet needs of children, adolescents, and young adults)
 - h. Virtual resource network, including for family and caregiver support services, professional assistance with advance care planning
2. The Coalition should also facilitate additional partnerships with community stakeholders, including the faith community, educational institutions (including secondary and post-secondary), legal professionals, financial/estate planning professionals, etc., to share best practices (including those related to cultural competency and understanding disparities), and coordinate ongoing work

RECOMMENDATION 4.3:**Promote training on advance care planning for legal and financial planning professionals**

In order to increase understanding of serious illness care and advance care planning documents, partners including legal training providers, legal and financial industry and professional associations, legal advocacy organizations, North Carolina Office of the Secretary of State, North Carolina Board of Funeral Service, North Carolina Office of Emergency Medical Services, and others should promote training on advance care planning, to include:

1. Guidelines for aligning legal and financial planning with advance care planning and goals of care discussions in health care settings; guidelines should include standards across professional settings, using consistent language and definitions
2. Legal requirements for different types and formats of advance care planning documents
3. Best practices for conversations with clients on values, goals for end of life, priorities for different stages of life, completing advance care planning, and identifying health care proxy; promote repository (as named in Recommendation 4.2)

4. Understanding of health services, including palliative and hospice care, long-term supports and services, and human services (such as community-based resources for non-medical needs); may include connecting with this sector within the community in order to understand community services and ongoing work
5. Awareness of and training in techniques used by law enforcement to recognize elder abuse and fraud; information on guardianship and Adult Protective Services
6. Consideration of Practical Form for All Adults as sanctioned and preferred advance care planning tool/guide
7. Consideration of alignment with high school and college curricula on financial planning to include planning for end of life

RECOMMENDATION 4.4:**Promote training on advance care planning for health care professionals**

In order to increase understanding of serious illness care and advance care planning documents (including portable medical orders/MOST form) among care team members, regulators, schools of medicine, schools of nursing, community colleges, schools of social work, Geriatric Workforce Enhancement Programs, and North Carolina AHEC should promote training on advance care planning, to include:

1. Guidelines for advance care planning and goals of care discussions in health care settings; guidelines should include standards across professional settings, using consistent and culturally competent language and definitions.
 - a. Also consider metric: % of patients having advance care planning conversations with care team
2. Best practices for conversations with patients and families on values, goals for end of life, priorities for different stages of life, completing advance care planning (including portable medical orders), identifying health care proxy
 - a. Include specialized training for communication with individuals/families with mild cognitive impairment or dementia
3. Understanding of services across health care settings, including palliative and hospice care, long-term supports and services, and human services (such as community-based resources for non-medical needs)
4. Framing of advance care planning discussion as a normal part of financial, legal, and life planning
5. Guidelines for incorporating advance care planning in annual wellness visits and other regular points of service
6. Access to cross-disciplinary workshops and other trainings in advance care planning
7. Awareness of and training in techniques used by law enforcement to recognize elder abuse and fraud; information on guardianship and Adult Protective Services

RECOMMENDATION 4.5:**Incentivize advance care planning that prioritizes the assessment and honoring of individual goals of care**

Under existing fee for service models, in order to incentivize advance care planning conversations and document creation, better achieve patients' goals of care, and address inequities in completion of documents, payers who do not currently provide reimbursement for these services should:

1. Apply incentives (including compensation) for health care teams to receive training in having conversations with patients and families about goals of care and/or creation of advance care planning documents
2. Align with Medicare Advance Care Planning codes 99497 and 99498 to pay providers for time spent during annual visits (with no additional copays), and at other times when appropriate, discussing advance care planning. These discussions should ensure that documentation is up to date as patients' conditions and/or preferences change
3. Align reimbursement policies to ensure that nurses, social workers, chaplains, and other team members receive training in and are being reimbursed for advance care planning discussions, using Medicare codes as a guideline

RECOMMENDATION 4.6:**Revise signature and notary requirements for advance directive documents (PRIORITY)**

In order to ease administrative burden, increase participation in completing documents, and improve accuracy of advance directives, the North Carolina General Assembly should revise North Carolina General Statute § 32A-15 and General Statute § 90-320 to change the requirement for two witnesses and notarization for advance directive documents, including living wills and health care powers of attorney. Requirement should be changed to either two witness signatures OR notarization.

RECOMMENDATION 4.7:**Ease administrative burden, increase participation in completing documents, and improve accuracy of advance directives (PRIORITY)**

In order to ease administrative burden, increase participation in completing documents, and improve accuracy of advance directives, the North Carolina General Assembly should:

1. Revise NCGS § 130A-470 to eliminate consumer fees for filing a document in the Secretary of State's Advance Health Care Directive Registry
2. Allocate recurring funding for the ongoing processing of filings and enhanced maintenance of the state's Advance Health Care Directive Registry and to allow new services, including:
 - a. Online filing of advance directives with the registry.
 - b. Reconfiguring the filing and storage of advance directives to provide electronic access by NC HealthConnex to records for which the filers have given consent to access, while continuing to provide personal access to filers who opt out.

- c. Covering the one-time cost of soliciting existing filers to inquire if they would like to make their records electronically accessible to NC HealthConnex and, if so, to obtain any missing data points needed by NC HealthConnex to accurately link advance directives with patients.
3. Revise NCGS § 130a-468 to allow acceptance of electronic versions of advance directives to be entered into registry database
4. Revise NCGS § 130A Article 21 to include statutory language to ensure that distribution to individuals of written advance directives and assistance in completion and execution of such forms by health care providers (or other non-legal professionals) shall not constitute the unauthorized practice of law

RECOMMENDATION 4.8:**Ease administrative burden and increase uptake and accessibility of portable medical orders**

In order to ease administrative burden and increase uptake and accuracy of portable medical orders (including Medical Orders for Scope of Treatment):

1. The North Carolina General Assembly should revise NCGS § 90-21.17 to:
 - a. Include acceptance of electronic versions of portable medical orders (including Medical Orders for Scope of Treatment form and Do Not Resuscitate) in all health care settings
 - b. Permit electronic signatures on portable medical orders as valid
 - c. Require acceptance of portable medical orders (if POLST Paradigm-endorsed) completed in other states and facilities (that meet North Carolina criteria as defined in NCGS § 90-21.17)
 - d. Establish reciprocity for portable medical orders established through US Department of Veterans Affairs health system
2. The North Carolina General Assembly should amend NCGS § 90-21.13 to include an emergency provision for patients to identify a health care decision-maker if they do not have one upon admission to a health care facility
3. North Carolina Serious Illness Coalition should convene a workgroup to assess discrepancies between the Medical Orders for Scope of Treatment Form and Do Not Resuscitate form and make recommendations for appropriate changes, including potential statewide uptake of National POLST form as accepted documentation

RECOMMENDATION 4.9:**Promote electronic completion and adequate integration of advance directives and portable medical orders (PRIORITY)**

In order to increase access to and implementation of advance care planning documents, the North Carolina Serious Illness Coalition should convene a workgroup of industry and professional associations, payers, and health information technology stakeholders to:

1. Identify best practices and promote electronic completion (including electronic notarization) of all documents when possible and adequate integration of advance directives and portable medical orders within electronic health record (EHR) systems

2. Conduct additional research on technological feasibility of integration of these documents in EHR systems. This research might address feasibility of developing/implementing methods of updating/replacing documents; necessary components to transmit to NC HealthConnex (see **Recommendation 4.10**), indicating current and voided documents; “event triggers” for evolving conditions and changes in patients’ care to remind providers to encourage the completion of advance directives and portable medical orders; and other communication prompts and documentation aids appropriate to unique patient characteristics.

RECOMMENDATION 4.10:

Improve access to advance care planning documents through optimization of health information technology

In order to improve access to advance care planning and portable medical order documentation, and improve interoperability between health care providers, technology product vendors, and data repositories,

1. Industry and professional associations should:
 - a. Encourage members to utilize consumer-facing portals where consumers can upload and see most recent versions of advance directives, portable medical orders, and goals of care conversations
 - b. Explore potential for integration of consumer-facing technological solutions to NC HealthConnex and the Secretary of State’s ADP Registry, to increase efficiency and accessibility to advance directives and portable medical orders
2. The North Carolina General Assembly should allocate funding to the North Carolina Department of Health and Human Services (including Office of Emergency Medical Services), Department of Information Technology, and the Secretary of State’s Office to perform a statewide survey of existing databases (registries, portals, or electronic health records) where advance care planning documents are stored; and collaborate on a study of necessary components and resources needed to:
 - a. Perform technical analysis of the Secretary of State’s ADP Registry, including technical architecture of the existing database, technical limitations, and necessary development/enhancements to link ADP Registry data to NC HealthConnex via APIs or other standard
3. Meet existing technical standards (including federal standards) and determine feasibility and level of effort to transmit advance care planning documents from an electronic health record, consumer portal, and/or registry database, to NC HealthConnex using APIs; to include review of broadband accessibility and access disparities across state (see **Recommendation 5.6**)
 - a. Review and provide recommendations on best practices for transmitting advance directives/portable medical orders electronically via NC HealthConnex, in order to be used by appropriate providers of health services

RECOMMENDATION 4.11:

Expand home- and community-based services to better support individuals with serious illness and their caregivers (PRIORITY)

In order to address issues including financial burden and physical and mental well-being of family caregivers and better serve individuals with serious illness across the lifespan, the North Carolina General Assembly should allocate recurring funding to expand home and community-based services and family caregiver support services. The North Carolina General Assembly should also include resources for ongoing collaboration between North Carolina Department of Health and Human Service Division of Aging and Adult Services, Division of Health Benefits, patient and caregiver advocacy organizations, Area Agencies on Aging, and local service providers to enhance and supplement existing home- and community-based services, including identifying innovative payment strategies for these services. Funding should be adequate to:

1. Increase number of Community Alternatives Program for Disabled Adults and Community Alternatives Program for Children slots in order to allow family caregivers to access appropriate services
2. Include recurring funding for the Home and Community Care Block Grant in the amount of \$3.5 million in the first year of the biennium and \$7 million in the second year of the biennium to address the waiting list for services funded by the Block Grant
3. Expand the availability of PACE (Program for All-Inclusive Care for the Elderly) services across the state, as identified by the NC PACE Association as areas of greatest need and/or ability to meet the need. This should also include a review of eligibility determination processes, with the goal of reducing administrative burden and increasing efficiency
4. Provide state funding to expand the Family Caregiver Support Program to include direct services
5. Increase the number of available slots in the NC County Special Assistance In-Home Program
6. Explore the development of a respite benefit for Medicaid recipients, using Medicare hospice respite (supportive services) benefit as a model
7. Promote assessment procedures to identify training needed by family and volunteer caregivers (including basic medical skills, assistance with activities of daily living, etc.)
8. Develop and implement sustainable funding models for addressing food, housing, transportation, and caregiver support (including adult day care and adult day health) needs, using Medicaid procedures and additional provision through Healthy Opportunities pilots as a model. Include resources for dissemination and awareness activities, including provisions for local community work on increasing awareness and navigation of services, including resources for promoting NCCARE360
9. Evaluate impacts of expanded services on caregivers’ intent to place out of home, real delays in placement, and improved patient-centered outcomes (i.e., adherence to patients’ goals of care, access to care, caregiver well-being). Evaluation should also include an analysis of cost savings for NC Medicaid, other payers, and to individuals and families, as a result of expanded caregiver support services

10. Ensure that individuals, family caregivers, and other unpaid caregivers are integral in all aspects of collaboration and partnership

RECOMMENDATION 4.12:

Establish Task Force on Caregiving for Those with Serious Illness and analyze additional legislative solutions and financing options to meet the needs of caregivers (PRIORITY)

In order to address issues, including financial burden and physical and mental well-being of family caregivers, the North Carolina General Assembly should:

1. Establish a Task Force on Caregiving for Those with Serious Illness within the Department of Health and Human Services. Task force scope should include caregivers for those with serious illness across the lifespan (including younger adults and children). Among other work, the Task Force on Caregiving for those with Serious Illness would:
 - a. Examine the availability of supports and services within the state and counties for caregivers of individuals with serious illness
 - b. Study the needs of care recipients and the nature of care provided by family caregivers, availability and sufficiency of caregiver training programs or caregiver training opportunities, and the frequency with which caregivers engage in those programs or opportunities
 - c. Identify costs and burdens associated with caregiving, incorporating input from diverse stakeholders and interest groups that reflect diverse patient and caregiver populations
 - d. Study disparities in availability of and access to caregiver services (geography, income, awareness, socio-cultural caregiving practices)
 - e. Study ways the state, including employers, can be more supportive of employed caregivers
 - f. Study serious illness care and special needs workforce, including pre-service and in-service training, opportunities to develop the workforce pipeline, and methods of supporting wages and addressing provider burnout and compassion fatigue
 - g. Operate with a shared authority across agency divisions and with focus across lifespan in order to ensure broad responsibility and support across stakeholders
 - h. Include study of the feasibility, benefits, and challenges of establishing a state-based benefit for long-term supports and services, and recommendations
 - i. Report study results and additional recommendations to the North Carolina General Assembly, the governor, and other stakeholders
2. Study requirements for health providers to identify and track family caregivers, inform them of status changes of loved ones, and provide in-home training for medical tasks; also identify potential benefits to other health care facilities that adopt these standards ([see Recommendation 4.14](#))

RECOMMENDATION 4.13:

Develop employer resources for supporting working caregivers

In order to encourage employer support for family caregivers, the North Carolina Coalition on Aging should convene stakeholders, to include the North Carolina Chamber of Commerce, Society for Human Resource Management, employer partners, and advocacy organizations, to collaborate on the development and dissemination of:

1. Education for employers on the prevalence and challenges of family caregivers supporting family members with serious illness and the benefits of referral programs, respite services, and other employee assistance services that support family caregivers
2. Model benefit policies that support employee caregivers, including flex time, paid and unpaid family leave, non-discrimination against caregivers in workplace, telecommuting, on-site support groups, expansion of the definition of family for caregiving and leave-related policies
3. Employee assistance programs to support family caregivers and introduce advance care planning and available resources
4. Identification of corporate/employer champions to promote benefits of supportive employer policies to employers' and employees' economic interests, as well as employee caregivers' interests
5. Development of an award model to recognize employers, businesses, and other partners who develop and implement policies that are supportive of family caregivers
6. Development of policy/advocacy strategy focused on exploring the costs and benefits of state legislation for paid family and medical leave, and additional legislation to support the needs of working family caregivers

RECOMMENDATION 4.14:

Promote industry standards to identify, train, and track family caregivers

Industry associations should encourage members to voluntarily implement processes to identify and track family caregivers, inform them of status changes of loved ones, and provide in-home training for medical tasks.

DEVELOPMENT OF THE HEALTH AND HUMAN SERVICES WORKFORCE AND INFRASTRUCTURE TO SUPPORT SERIOUS ILLNESS CARE

The Task Force on Serious Illness Care also focused on enhancing the health and human services infrastructure and workforce that delivers care to individuals with serious illness.

WORKFORCE TRAINING & INNOVATIVE WORKFORCE MODELS

As the number of Americans with serious illness increases as the population ages, an adequately trained health care workforce is critical to ensure that those with serious illness receive high-quality care.¹⁹ With seriously ill patients often receiving care from multiple providers across different settings, team-based interprofessional collaborative practice is essential in providing for care coordination.²⁰ A strong interprofessional collaborative team should not only consist of physicians and nurses, but also include various others such as social workers, members of the faith community, care managers, patient managers, and community managers to ensure not only are the patient's clinical needs met, but their psycho-social needs are as well. Despite the importance of interprofessional collaborative teams in serious illness care, health professionals, community, and faith-based care managers need further interprofessional education training to ensure a team approach to patient-centered care.²¹ To promote the development, training, and sustainability of interdisciplinary teams in serious illness care, the task force developed recommendations on promoting and implementing interdisciplinary trainings models (See Chapter 5). The task force also examined ways to promote training in serious illness care among primary care providers and geriatric and gerontology specialists.

In addition to training the health care workforce, the task force looked at different innovative workforce models in order to increase access to serious illness care in community-based settings. The community-based workforce models the task force examined included community paramedicine and community health worker programs. Both models are focused on providing high-quality care to patients in their communities and often in their homes.

ADDITIONAL INFRASTRUCTURE

In order to improve access to and quality of care for individuals with serious illnesses, the task force developed recommendations for building serious illness care infrastructure through the enhancement of health care provider and system interoperability and the usage of new care delivery technologies such as telehealth services. The task force focused on these areas to improve care coordination and communication capabilities among providers and/or systems, and access to care for the seriously ill in their own homes and communities.

RECOMMENDATION 5.1:

Develop a supported and engaged serious illness care workforce

In order to support the serious illness care workforce (including physicians, nurses, home health aides, direct care workers, the skilled nursing workforce, and others), the North Carolina General Assembly should require the North Carolina Department of Health and Human Services to convene a study of necessary components and resources for a supported workforce. Partners should include: North Carolina Community College System, University of North Carolina system, Area Health Education Centers. Study/analysis should review:

1. Current demographics, including number of agencies providing hospice, palliative care, home health services, long-term care, including number of individuals receiving services and geographic distribution of the workforce
2. Cost of care, its impact on other health care metrics (such as hospitalization, readmission) that impact overall cost, and potential cost savings from delaying institutional care
3. Performance on additional metrics, including those regarding patient and family satisfaction with care, and review of metrics under development, such as those regarding days at home, social isolation, and loneliness; also, performance on provider satisfaction (including turnover)
4. The effect of wages and other compensation across industries on the serious illness workforce; develop competitive compensation models to sustain a qualified and engaged workforce
5. Pipeline training, curricula and existing educational resources and programs within the state

RECOMMENDATION 5.2:

Promote models of interprofessional training for best practices in serious illness care, including palliative care (PRIORITY)

In order to increase awareness of serious illness care options and improve access to quality serious illness care, schools of medicine, schools of nursing, schools of dentistry, schools of pharmacy, allied health training programs, divinity schools, community colleges, schools of social work, Geriatric Workforce Enhancement Programs, and North Carolina AHEC should develop and implement interprofessional training modules on serious illness progression and end-of-life care. Training should:

1. Incorporate providers/students including physicians, nurses, care managers, chaplains, social workers, community health workers, community paramedicine providers, patient and community navigators, care managers, home health workers, frontline staff (including high school training programs), advance practice providers, and others. Training should align with needs of providers who care for individuals across the age spectrum (i.e., appropriate for pediatric providers through geriatric providers), as well as for providers working with vulnerable or underserved populations such as immigrant/refugee populations, homeless populations, and rural communities

2. Consist of a varied curriculum at both pre-service and in-service levels, delivered through in-person classes/conferences, podcasts, interactive video, e-learning modules, and individualized guidance, as applicable
3. Include information on services provided through hospice and palliative care, with an emphasis on goals of person-centered care, meeting care goals of patients and families, and aligning understanding and expectations of serious illness trajectory and options for care between providers and families
4. Focus on new roles and functions serving individuals with serious illness, including retraining and upgrading skills. Also focus on workforce resiliency and prevention of compassion fatigue
5. Include communication skills around conveying difficult prognosis, fear, and vulnerability; early and frequent conversations about goals of care, end-of-life preferences, what to expect following a family member's death; and identifying grief/bereavement supports for families
6. Emphasize "purposeful exposure" to team-based care, palliative care, and hospice, and include rotations in community-based care settings and home health
7. Emphasize importance of cultural competency, disparities in illness and access to care, roles of drivers of health in serious illness care, ways that different providers can influence these drivers, needs of vulnerable populations, and innovations in connecting individuals with resources for non-clinical health needs, such as NCCARE360
8. Include strategies to reduce stigma and misunderstandings about end-of-life care, including hospice and palliative care
9. Include communication as a key component and should address the ways communication skills are crucial in addressing psychological, spiritual, cultural, and ethical aspects of care

RECOMMENDATION 5.3:

Incentivize training in serious illness care, including palliative care

In order to incentivize entry into relevant specialties, including geriatric and gerontology specialization, and additional training in palliative care for the primary care and specialty workforce, private and public payers should identify incentive methods for health professionals' specialization and training in these areas. Methods may include higher rates of reimbursement for individual practitioners, support by value-based payment models for training to ensure quality and value; and/or reimbursement based on performance on quality metrics (including those identified in work group named in Recommendation 3.5). Incentives should be tailored for broad application to health and human services professional designations.

RECOMMENDATION 5.4:

Increase access to serious illness care through expanded implementation of innovative models of care delivery (including telehealth and community- and home-based care) (PRIORITY)

In order to improve access to and quality of care for individuals with serious illness, Medicaid and private payers, medical and behavioral health providers, and the North Carolina Department of Health and Human Services (including but not limited to Medicaid and the Office of Rural Health) should prioritize expansion of new models of care delivery, including opportunities through managed care implementation and value-based payment reforms. Models may include:

1. Telehealth services (see Recommendation 5.7), including:
 - a. Remote diagnostic capacity and ongoing consultation, medication management, and behavioral management when appropriate
 - b. Home monitoring of activities of daily living, with local capacity for follow-up
 - c. Integration of behavioral health and substance use disorder services to address issues related to serious illness (including but not limited to social isolation, hopelessness, and pain management)
 - d. Remote screening for unmet social needs and connection to non-clinical health-related services using state screening tool and resource networks such as NCCARE360 as model
 - e. Capacity for consultations between palliative care clinicians and community-based service providers and means of increasing skills and competencies
2. Community- and home-based health services, home-based primary care, home-based palliative care, and other home-based services

RECOMMENDATION 5.5:

Expand programs for community paramedicine

In order to improve access to high-quality serious illness care, the North Carolina Healthcare Association and community partners should promote/expand the development and implementation of innovative workforce approaches to serious illness care, including community paramedicine programs. These programs should:

1. Enable collaborations between emergency medical technicians, hospitals, primary care medical homes, social/human services, and other providers
2. Emphasize recruitment from within the service community, in order to ensure understanding of patient/caregiver/community characteristics and needs
3. Incorporate measurement of:
 - a. Improved outcomes on metrics such as preventable hospitalizations, 30-day readmission rates, medication management, care management, and patient satisfaction with care
 - b. Process metrics, such as number of programs, trained providers, etc.
 - c. Outcomes in metrics under development, including measures of social isolation, loneliness, or others

RECOMMENDATION 5.6:**Expand community health worker programs**

In order to improve access to high-quality serious illness care, the North Carolina Department of Health and Human Services should expand the current community health worker program. Expansion should ensure:

1. Recruitment from within the service community, in order to ensure understanding of patient/caregiver/community characteristics and needs
2. Incorporation of measurement of:
 - a. Improved outcomes on metrics such as preventable hospitalizations, 30-day readmission rates, medication management, care management, and patient satisfaction with care
 - b. Process metrics, such as number of programs, trained providers, etc
 - c. Outcomes in metrics under development, including measures of social isolation, loneliness, or others
3. Partnership with North Carolina AHEC, community colleges, and other training organizations

RECOMMENDATION 5.7:**Enhance health information technology infrastructure to improve care coordination and quality of care**

In order to improve care coordination, communication capabilities, and the ability to share documents and patient information between health care providers, health care systems, technology product vendors, and data repositories, the North Carolina Department of Information Technology should:

1. Provide continued funding and support to municipalities and community organizations in rural North Carolina and other areas where access to broadband is limited, to enhance broadband access and to maintain broadband infrastructure
2. Consider renewal of funding to the NC DHHS Office of Rural Health NC Electronic Health Record Funding Program, with a new strategic focus on determining the feasibility of providing funding for small health care providers (including home health agencies and long-term care/skilled nursing facilities) to purchase and implement electronic medical record technologies in order to meet connection requirements/deadlines for NC HealthConnex

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