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Improving Serious Illness Care in North Carolina

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.

The NCIOM task force model allowed for wide, multidisciplinary stakeholder engagement, enabled robust discussion, and led to a comprehensive and cohesive plan to address and improve serious illness care in North Carolina

The task force met 10 times in 2019 and 2020 to develop consensus-based, evidence-based, and actionable recommendations for improving 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.

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 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 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, the creation of which is a key recommendation from the task force, has already started to meet to address how to implement task force recommendations, and will play an instrumental role in identifying new and changing priorities as we meet the challenges that COVID-19 presents now and in the future.

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.

VISION STATEMENT: 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," and limited the scope of the task force work to 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 US 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. In North Carolina, the number of individuals with serious illness is expected to rise as the population ages.

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.

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.

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)

Throughout the development of the recommendations, the task force was guided by principles of health equity and cultural competency, 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.

RECOMMENDATION 2.2:

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

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

The Task Force on Serious Illness Care made recommendations for improvements in care for individuals with serious illness, including care delivery and coordination, financing/payment for serious illness care, and addressing non-clinical needs. Types of care addressed included acute care, long-term services and supports, palliative care, and hospice care. Palliative care is a type of specialty care provided to individuals living with serious illness, focused on providing relief from symptoms, increasing comfort, and improving quality of life for individuals and their families.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.¹⁰ For pediatric patients, the inclusion criteria is different: patients do not have to stop curative treatment while receiving hospice care.¹¹

The task force also 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. Most traditional clinical health care settings are not designed to address non-clinical drivers of health. The task force examined ways to improve access to non-clinical services for individuals with serious illness.

RECOMMENDATION 3.1:

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

RECOMMENDATION 3.2:

Incorporate regular and timely assessment processes for identifying and developing effective and goal-concordant plans of care for individuals with higher health needs

RECOMMENDATION 3.3:

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

RECOMMENDATION 3.4:

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

RECOMMENDATION 3.5:

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

RECOMMENDATION 3.6:

Expand access to coverage for health care services

ENGAGING WITH PATIENTS AND FAMILIES TO MEET GOALS OF CARE

The Task Force on Serious Illness Care identified several important aspects of ensuring 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 families and communities as they care for those with serious illness.

The core of patient and family engagement lies in welcoming the patient and family^a, as well as non-family support systems, as important partners in care. 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

RECOMMENDATION 4.1:

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

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

^a In general, when "family" is referred to throughout this report, this includes non-relative members of an individual's personal support system, and the task force agrees that "family" should be defined by the individual.

RECOMMENDATION 4.2:

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

RECOMMENDATION 4.3:

Promote training on advance care planning for legal and financial planning professionals

RECOMMENDATION 4.4:

Promote training on advance care planning for health care professionals

RECOMMENDATION 4.5:

Incentivize advance care planning that prioritizes the assessment and honoring of individual goals of care

RECOMMENDATION 4.6:

Revise signature and notary requirements for advance directive documents (PRIORITY)

RECOMMENDATION 4.7:

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

RECOMMENDATION 4.8:

Ease administrative burden and increase uptake and accessibility of portable medical orders

RECOMMENDATION 4.9:

Promote electronic completion and adequate integration of advance directives and portable medical orders (PRIORITY)

RECOMMENDATION 4.10:

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

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

RECOMMENDATION 4.11:

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

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)

RECOMMENDATION 4.13:

Develop employer resources for supporting working caregivers

RECOMMENDATION 4.14:

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

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. As the number of Americans with serious illness increases as the population ages, an adequately trained health care workforce is critical to ensuring 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 The task force also examined ways to promote training in serious illness care among primary care providers and geriatric and gerontology specialists.

RECOMMENDATION 5.1:

Develop a supported and engaged serious illness care workforce

RECOMMENDATION 5.2:

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

RECOMMENDATION 5.3:

Incentivize training in serious illness care, including palliative care

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 (See Chapter Five). Both models are focused on providing high-quality care to patients in their communities and often in their homes.

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)

RECOMMENDATION 5.5:

Expand programs for community paramedicine

RECOMMENDATION 5.6:

Expand community health worker programs

In order to improve access to and quality of care for individuals with serious illness, 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 5.7:

Enhance health information technology infrastructure to improve care coordination and quality of care

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A copy of the full Task Force report, including background information, references, and full recommendations, can be found online at www.nciom.org

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