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North Carolina Institute of Medicine

## Improving Serious Illness Care in North Carolina



VISIT  
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*In partnership with the Duke Endowment, with additional support from AARP North Carolina, the North Carolina Health Care Facilities Association, the Association for Home & Hospice Care of North Carolina, and the Carolinas Center.*



## North Carolina Institute of Medicine

The North Carolina Institute of Medicine (NCIOM) is a nonpolitical source of analysis and advice on important health issues facing the state. The NCIOM convenes stakeholders and other interested people from across the state to study these complex issues and develop workable solutions to improve health care in North Carolina.

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### North Carolina Institute of Medicine

Keystone Office Park  
630 Davis Drive, Suite 100  
919.445.6500

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Any opinion, finding, conclusion, or recommendations expressed in this publication are those of the Task Force and do not necessarily reflect the views and policies of the funding organizations above.

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2	<b>ACKNOWLEDGEMENTS</b>	69	<b>CONCLUSION</b>
4	<b>TASK FORCE MEMBERS</b>	70	<b>APPENDIX A</b> Matrix of Responsible Organizations
6	<b>EXECUTIVE SUMMARY</b>		
20	<b>CHAPTER 1</b> Introduction and Overview	72	<b>APPENDIX B</b> North Carolina Advance Directives and Portable Medical Orders
26	<b>CHAPTER 2</b> Health System and Culture Change to Address Serious Illness Care		
30	<b>CHAPTER 3</b> Delivery of High-Quality Person- centered Serious Illness Care		
43	<b>CHAPTER 4</b> Engagement with Individuals and Families to Meet Goals of Care		
58	<b>CHAPTER 5</b> Development of the Health and Human Services Workforce and Infrastructure to Improve Serious Illness Care		

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The North Carolina Institute of Medicine’s (NCIOM) Task Force on Serious Illness Care was convened in April 2019. Funding for the Task Force was provided by the Duke Endowment, with additional support from AARP North Carolina, the North Carolina Health Care Facilities Association, the Association for Home & Hospice Care of North Carolina, and the Carolinas Center.

The Task Force was co-chaired by Paulette Dillard, President of Shaw University; Jonathan Fischer, Assistant Professor, Department of Community Health and Family Medicine, Duke University; and Joyce Massey-Smith, Director of the Division of Aging and Adult Services (DAAS), North Carolina Department of Health and Human Services (DHHS). Their leadership and experience were important to the success of the work of the Task Force.

The NCIOM also wants to thank members of the Task Force and steering committee who gave freely of their time and expertise to address this important topic. The steering committee members provided guidance and content, helped develop meeting agendas, and identified speakers. For the complete list of Task Force and steering committee members, please [see Page 4](#) of this report.

Many experts presented to the Task Force on Serious Illness Care. We would like to thank the following people for sharing their expertise and experiences with the Task Force (positions listed are as of the date of the presentation given.)

John Barkley, Chief Medical Officer of Atrium Health; Nadine Barrett, Assistant Professor at the Department of Community and Family Medicine, Duke School of Medicine; Mary Bethel, Executive Director of the North Carolina Coalition on Aging; Kellie Brockman, Director of Business Development at Duke Home Care and Hospice; Karen Bullock, Chair of the Department of Social Work at North Carolina State University; Jan Busby-Whitehead, Director of the Center of Aging and Health at the University of North Carolina School of Medicine; Ken Burgess, Partner at Poyner Spruill; Christie Burris, Executive Director of the North Carolina Health Information Exchange Authority; Lori Byrd, Associate Director of Academic Programs for Health Sciences

at the North Carolina Community College System; Christine Carr, Chief Clinical Officer of Health Sciences South Carolina; David Cook, President and CEO of Carolina Caring; Kenneth Deans, President & CEO of Health Sciences South Carolina; Ann Elmore, Agency Legal Specialist at the North Carolina Office of the Secretary of State; Charlie Hardy, Founding Dean and Professor at the University of North Carolina - Wilmington College of Health and Human Services; Lauren Heeter, Quality Director at Atrium Health; Mitch Heflin, Associate Professor of Medicine at Duke University School of Medicine; Jonathan Fischer, Palliative Care Physician at Duke Hospice and Palliative Care; Debby Futrell, President and CEO of Area L AHEC; Dawn Oakey Gartman, Alzheimer’s Support Specialist / Project C.A.R.E. Director at DAAS, DHHS; Elizabeth Golding, Medical Director of Cone Health Palliative Care Services; Jay Hemphill, Partner at Hemphill Gelder, P.C.; Mark Hensley, Associate State Director of Community Outreach and Advocacy at AARP North Carolina; Donna Lake, Clinical Associate Professor at East Carolina University College of Nursing; Kristen Lakis, Clinical Social Worker at Duke University Hospital; Sabrena Lea, Associate Director of Long Term Supports at North Carolina Medicaid, DHHS; Deborah Love, Senior Director of Bioethics, Spiritual Care, and Humanities at Novant Health; Adrienne Mims, Vice President and Chief Medical Officer at Alliant Health Solutions; Laura Patel, Chief Medical Officer at Transitions LifeCare; Melanie Phelps, Senior Vice President and Deputy General Counsel at North Carolina Medical Society; Janna Pogers, Chair of Duke Children’s Hospital Patient Family Advisory Council; Sarah Rivenbark, Community Paramedic at New Hanover Regional Medical Center Emergency Medical Services; Tim Rogers, President and CEO of Association for Home & Hospice Care of North Carolina; Cathy Sevier, State President of AARP North Carolina; David Sevier, Managing Director of The Generations Study Group; Holly Sienkiewicz, Director of the University of North Carolina-Greensboro Center for New North Carolinians; Tish Singletary, Community Health Worker Program Coordinator at the Office of Rural Health, DHHS; Heather Smith, Director of Clinical Partnerships and Integration at Advance Home Care; John Smith, Lead Medical Director at Blue Cross Blue Shield of North Carolina, Lynn Spragens, Partner and Founder at Spragens & Gualtieri-Reed; Apollo Stevens, Director of Hospice at UNC Health Care; Sally Streams, Professor of Health Policy and Management at the University of North Carolina - Chapel Hill Gillings School of Global Public Health; Pam Strader, Pastor of Congregational Care and Discipleship at West Market Church; Brad Stuart, Co-founder and Chief Executive Officer of ACI Strategies; Debbie Taylor, Director of Outreach at West Market Church; Don Taylor, Professor of Public Policy

at the Duke University Sanford School of Public Policy; Lori Taylor, Senior Strategic Advisor Care Redesign, Blue Cross Blue Shield of North Carolina; Stan Walters, Patient Advisor at the Duke University Hospital Patient Advisory Council; Ellie Ward, Program Coordinator for Outreach and Education at Vidant Health; Brian Wood, Research and Outreach Coordinator of Mind My Health.

In addition to the above individuals, the staff of the North Carolina Institute of Medicine contributed to the Task Force's study and the development of this report. Adam Zolotor, MD, DrPH, President and CEO, guided the work of the Task Force. Michelle Ries, MPH, Project Director, served as the Project Director of the Task Force and was the primary author of the final Task Force report. Erin Bennett, JD, Graduate Student Intern, Emily Hooks, MEd, Research Assistant, and Brienne Lyda-McDonald, MSPH, Project Director, assisted with writing and research for the final Task Force report. Kaitlin Phillips, MS, edited the final Task Force report and provided social media publicity for the Task Force. James Coleman, MPH, Research Specialist, served as a Research Assistant for the Task Force. Key staff support was also provided by Kisha Markham, Administrative Assistant, and Don Gula, Director of Administrative Operations. Former staff member, Berkeley Yorkery, MPP, Associate Director, helped to guide the work of the Task Force.

## TASK FORCE CO-CHAIRS

**Paulette Dillard, PhD**

*President*  
Shaw University

**Jonathan Fischer, MD**

*Assistant Professor*  
Department of Community Health  
and Family Medicine  
Duke University

**Joyce Massey-Smith, MPA**

*Director*  
Division of Aging and Adult Services  
North Carolina Department of Health  
and Human Services

## TASK FORCE MEMBERS

**Tom Akins**

*President and CEO*  
LeadingAge NC

**Mary Bethel, M. Ed**

*Executive Director*  
North Carolina Coalition on Aging

**Nathan Boucher, DrPH**

*Assistant Research Professor*  
Sanford School of Public Policy  
Duke University

**Victoria Boviall, RN**

*Healthcare integration Nurse*  
Medical Management Team  
Alliance Health

**Christine Brown**

*Healthcare Marketing Consultant*  
Brown Healthcare Associates

**Ken Burgess, JD**

*Partner*  
Poyner Spruill LLP

**Christie Burriss**

*Executive Director*  
North Carolina Health Information Exchange Authority  
North Carolina Department of Information Technology

**Sue Collier, MSN**

*VP for Innovation and Clinical Excellence*  
NC Healthcare Association

**David Cook, MBA**

*President and CEO*  
Carolina Caring

**Representative Carla Cunningham, RN**

District 106 (Mecklenburg)  
North Carolina House of Representatives

**Wendee Cutler**

*Executive Director*  
BJH Foundation for Senior Services

**Linda Darden, MHA, CPA**

*President and CEO*  
Trellis Supportive Care

**M. Bradley Drummond, MD, MHS**

*Associate Professor of Medicine*  
Division of Pulmonary & Critical Care Medicine  
UNC-Chapel Hill School of Medicine

**Bridget Earle, MD**

*Director, Hospice Line Services*  
Atrium Health

**Stacey Ellis-Antisdell**

*Partnership Coordinator*  
NC Partnership for Compassionate Care  
Trellis Supportive Care

**Ann Elmore, JD**

*Agency Legal Specialist, Investor Protection Education  
Services Program*  
Securities Division  
North Carolina Department of the Secretary of State

**Glenn Field**

*Community Development Specialist II*  
Office of Rural Health  
North Carolina Department of Health and Human Services

**Debby Futrell, PharmD**

*President and CEO*  
Area L AHEC

**Elizabeth Golding, DO**

*Medical Director of the Palliative Care Services*  
Cone Health

**Charles Hardy, PhD**

*Founding Dean & Professor*  
College of Health and Human Services  
University of North Carolina at Wilmington

**Representative Pricey Harrison**

District 61 (Guilford)  
North Carolina House of Representatives

**Mitchell Heflin, MD, MHS**

*Associate Professor of Medicine*  
Duke University School of Medicine

**Mark Hensley**

*NC Associate State Director of Community Outreach  
and Advocacy*  
AARP NC

**Sheila Helms**

*Membership Co-Chairperson*  
Sisters Network of Greensboro, NC

**Lin Hollowell**

*Director of Health Care*  
The Duke Endowment

**Jay Kennedy**

*Program Officer*  
The Duke Endowment

**Sue Kirkman, MD**

*Professor of Medicine*  
Division of Endocrinology and Metabolism  
University of North Carolina at Chapel Hill School of  
Medicine

**Donna Lake, PhD, RN**

*Clinical Associate Professor*  
College of Nursing  
East Carolina University  
*Executive Committee Co-Leader*  
North Carolina Future of Nursing Action Coalition

**Kristen Lakis, MDiv, MSW, LCSW**

*Clinical Social Worker*  
Duke Pediatric Quality of Life

**Sabrena Lea**

*Associate Director, Long-term Services and Supports*  
Division of Health Benefits  
North Carolina Department of Health and Human Services

**Deborah Love, MA, JD, MBA**

*Sr. Director, Bioethics and Spiritual Care*  
Novant Health

**Laura Marx**

*President and CEO*  
United Way of North Carolina

**Deborah Mayer, PhD, RN, AOCN, FAAN**

*Distinguished Professor*  
School of Nursing  
University of North Carolina at Chapel Hill

**Eleanor McConnell, PhD, RN**

*Associate Professor*  
School of Nursing  
Duke University



**Sarajane Melton***Region A AAA Director*

Southwestern Commission Area Agency on Aging

**Adrienne Mims, MD, MPH, FAAP, AGSF***Former Vice President & Chief Medical Officer*

Alliant Health Solutions

**Julian Montoro-Rodriguez, PhD***Director, Gerontology Program*

University of North Carolina at Charlotte

**Christopher Morrissette, MBA***Chief Operating Officer of Palliative Care*

Four Season and Teleios Collaborative Network

**Debi Nelson, Ma. Ed***Branch Head-NC Cancer Prevention and Control*

Division of Public Health

North Carolina Department of Health and Human

Services

**Susan Nestor, MSN***Sr. Deputy Commissioner, Health Services Group*

North Carolina Department of Insurance

**Carla Obiol***Vice President of Programs*

Foundation for Health Leadership and Innovation

**Michael Parmer, DO***System Medical Director for Post-Acute Care*

CarePartners

**Laura Patel, MD***Chief Medical Officer*

Transitions LifeCare

**John Perry, MD, MS***Executive Director*

Wake AHEC

WakeMed

**Melanie Phelps, JD***Senior Vice President & Deputy General Counsel*

North Carolina Medical Society

**Janna Pogers, PT, MPT, NCS, CSRS***Chair*

Duke Children's Hospital Patient Family Advisory

Council

**Ursula Robinson, MHA, LCSW***Executive Director*

Triad Pace

**Larry Rocamora, JD***Attorney*

McPherson, Rocamora, Nicholson, Wilson &amp; Hinkle, PLLC

**Timothy Rogers***President and CEO*

Association for Home and Hospice Care of North

Carolina

**Cherie Rosemond, PhD***Director*

Partnership in Aging Program

University of North Carolina at Chapel Hill

**David Sevier, MS***Managing Director*

The Generations Study Group

**John Smith, MD***Lead Medical Director*

BlueCross BlueShield of North Carolina

**Lynn Spragens, MBA***Founder and Partner*

Spragens &amp; Gualtieri-Reed

**Apollo Stevens, DNP, RN, CHPCA***Director*

UNC Hospice

**Keith Stirewalt, MBA, MDiv***Program Director, FaithHealth Clinical Medicine*

Wake Forest Baptist Health

**Pam Strader***Pastor of Congregational Care & Discipleship Ministry*

West Market Church

**Charlotte Sweeney, MD, M. Ed***Volunteer*

Patient/Veteran and Caregiver Engagement

Duke Hospital and Durham VA Medical Center

**Lynn Templeton***Executive Director (retired)*

The Center for Volunteer Caregiving

**Betsy Vetter***Field Grassroots Director*

American Heart Association

**Stan Walters***Patient Advisor*

Duke Patient and Family Advisory Council

**Ellie Ward, RN***Program Coordinator, Community Education and Outreach*

Vidant Health

**Christine Weason, JD***North Carolina Government Relations Director*

American Cancer Society Cancer Action Network

**Polly Welsh, MPH, RN***Executive Vice President*

North Carolina Health Care Facilities Association

**Representative Donna White, RN**

District 26 (Johnston)

North Carolina House of Representatives

**Senator Mike Woodard**

District 22 (Durham, Granville, Person)

North Carolina Senate

**STEERING COMMITTEE MEMBERS****Steve Freedman, MPA***Chief, Service Operations*

Division of Aging and Adult Services

NC Department of Health and Human Services

**Cindy Morgan, RN, MSN, CHC, CHPN***Former Vice President for Hospice, Palliative**Care & Clinical Innovations*

Association for Home &amp; Hospice Care NC

**Catherine Sevier, DrPH, RN***State President*

AARP-NC

*\*Titles at time of Task Force convening*

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.<sup>1</sup> 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.<sup>2</sup>

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 conditions<sup>3</sup>, and an additional 31.3% of respondents aged 65 and over had one chronic health condition.<sup>3</sup>

<sup>a</sup> 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).<sup>4</sup>

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.<sup>5</sup>

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 <sup>b</sup> persons 65+	180,000 (2020)	210,000 (2025)
Cancer <sup>c</sup>	I: 52,752 (2017) IR: 423.9 per 100K (NC Registry) <sup>d</sup> I: 55,394 (2016) IR: 458.4 per 100k people (age adjusted) <sup>e</sup> (CDC)	Projected incidence: 62,466 <sup>f</sup> (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. <sup>g</sup>
Diabetes	P: 12.5% <sup>h</sup> (crude) 2019 P: 11%		Projected to be rising nationwide, especially among adults aged 65 and older. <sup>i</sup>
Heart Disease	Heart attack: 5.4% <sup>k</sup> Angina or CHD: 5.7% <sup>l</sup>		
Kidney Disease	P: 3.2% <sup>m</sup> (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. <sup>n</sup>
Respiratory Illness	P: 8.1% <sup>o</sup>		
Stroke	P: 3.8% <sup>p</sup>		

<sup>b</sup> Alzheimer's Association, 2018. <https://www.alz.org/media/documents/northcarolina-alzheimers-facts-figures-2018.pdf>  
<sup>c</sup> 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/>  
<sup>d</sup> North Carolina State Center for Health Statistics [https://schs.dph.ncdhhs.gov/schs/CCR/incidence/2017/racegender\\_v2.pdf](https://schs.dph.ncdhhs.gov/schs/CCR/incidence/2017/racegender_v2.pdf)  
<sup>e</sup> Centers for Disease Control and Prevention. United States Cancer Statistics <https://gis.cdc.gov/cancer/USCS/DataViz.html>  
<sup>f</sup> North Carolina State Center for Health Statistics <https://schs.dph.ncdhhs.gov/schs/CCR/proj19co.pdf>  
<sup>g</sup> NC Department of Health and Human Services. North Carolina Cancer Prevention and Control Branch. <https://publichealth.nc.gov/chronicdiseaseandinjury/cancerpreventionandcontrol/docs/ReducingtheBurdenofCancerResourceGuide.pdf>  
<sup>h</sup> Centers for Disease Control and Prevention. BRFSS Prevalence and Trends Data, 2018.  
<sup>i</sup> County Health Rankings 2019  
<sup>j</sup> 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>  
<sup>k</sup> North Carolina State Center for Health Statistics <https://schs.dph.ncdhhs.gov/data/brfss/2018/nc/risk/CVDINFR4.html>  
<sup>l</sup> North Carolina State Center for Health Statistics <https://schs.dph.ncdhhs.gov/data/brfss/2018/nc/risk/CVDCRHD4.html>  
<sup>m</sup> Centers for Disease Control and Prevention. BRFSS Prevalence and Trends Data. Kidney Disease, 2018.  
<sup>n</sup> 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.  
<sup>o</sup> North Carolina State Center for Health Statistics. 2018. <https://schs.dph.ncdhhs.gov/data/brfss/2018/nc/risk/CHCCOPD1.html>  
<sup>p</sup> North Carolina State Center for Health Statistics. 2018. <https://schs.dph.ncdhhs.gov/data/brfss/2018/nc/risk/CVDSTRK3.html>

most children of the same age do.”<sup>6</sup> 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.<sup>7</sup>

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

<b>Cancer (all types)</b>	161.0-171.4 per 1,000,000 (2018-2019 age-adjusted cancer incidence rates)
<b>Cystic Fibrosis</b>	25 cases per 100,000 (2017 Newborn Screening)
<b>HIV/AIDS</b>	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)
<b>Congenital Heart Disease</b>	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](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.”<sup>8</sup> 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.<sup>9</sup> 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.<sup>10</sup> For pediatric patients, the inclusion criteria is different: patients do not have to stop curative treatment while receiving hospice care.<sup>11</sup>

**FIGURE 4** Distinctions Between Hospice and Palliative Care

	PALLIATIVE CARE	HOSPICE
<b>Model of care</b>	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
<b>Eligibility</b>	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
<b>Place</b>	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
<b>Payment</b>	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,<sup>9</sup> 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.<sup>12</sup> 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.<sup>13</sup> 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."<sup>14</sup> 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.<sup>15</sup>

**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.<sup>16</sup> 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**

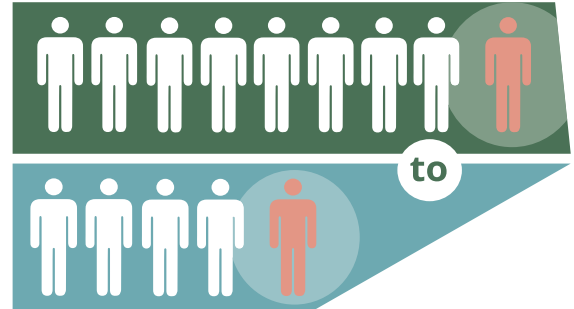
Individuals with serious illness often require increasingly intensive care as their disease progresses. Adult children and spouses are often the primary caregivers for adults with serious illness, with parents and grandparents usually the primary caregivers for children with serious illness. According 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.<sup>17</sup> 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.<sup>18</sup>

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.<sup>19</sup> 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.<sup>20</sup> 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.<sup>21</sup> 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

**REFERENCES**

1. U.S. Census Bureau QuickFacts: North Carolina. U.S. Census Bureau. <https://www.census.gov/quickfacts/NC>. Accessed January 2, 2020.
2. Reddy, S. North Carolina Is Aging! North Carolina Department of Health and Human Services. <https://files.nc.gov/ncdhhs/documents/files/NC%20State%20Aging%20Profile%202016.pdf>. Accessed January 2, 2020.
3. BRFSS 2018 - North Carolina: Summary Index of Chronic Health Conditions. Behavioral Risk Factor Surveillance System. <https://schs.dph.ncdhhs.gov/data/brfss/2018/nc/all/countind.html>. Accessed January 2, 2020.
4. NC State Center for Health Statistics. Statistics and Reports: Cancer: Projections. North Carolina Department of Health and Human Services. <https://schs.dph.ncdhhs.gov/data/cancer/projections.htm>. Accessed January 3, 2020.
5. Explore Heart Disease in North Carolina. 2019 Annual Report. America's Health Rankings. <https://www.americashealthrankings.org/explore/annual/measure/CHD/state/NC>. Accessed January 3, 2020.
6. NC State Center for Health Statistics. Statistics and Reports: CHAMP: 2010 Survey Results. North Carolina Department of Health and Human Services. <https://schs.dph.ncdhhs.gov/data/champ/2010/topics.htm#cshcn>. Accessed January 16, 2020.
7. Siegel DA, Li J, Henley SJ, et al. Geographic Variation in Pediatric Cancer Incidence — United States, 2003–2014. *MMWR Morb Mortal Wkly Rep*. 2018;67(25):707-713. doi:10.15585/mmwr.mm6725a2
8. Cultural Competence. National Prevention Information Network. <https://npin.cdc.gov/pages/cultural-competence>. Accessed January 16, 2020.
9. Palliative Care Definition: What is Palliative Care? Center to Advance Palliative Care. <https://www.capc.org/about/palliative-care/>. Accessed October 18, 2019.
10. National Institute on Aging. What Are Palliative Care and Hospice Care? U.S. Department of Health and Human Services. <https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care>. Accessed January 3, 2020.
11. Bishop L, Flick T, Wildman V. Palliative Care Resource Series Best Practices for Using Telehealth in Palliative Care. National Hospice and Palliative Care Association. 2015. [https://www.nhpco.org/wp-content/uploads/2019/04/PALLIATIVECARE\\_Telehealth.pdf](https://www.nhpco.org/wp-content/uploads/2019/04/PALLIATIVECARE_Telehealth.pdf). Accessed February 19, 2020.
12. Olsen LA, Saunders RS, McGinnis JM. Patients Charting the Course: Citizen Engagement in the Learning Health System. National Academies Press; 2011. doi:10.17226/12848
13. Hibbard JH, Mahoney E. Toward a theory of patient and consumer activation. *Patient Educ Couns*. 2010;78(3):377-381. doi:10.1016/j.pec.2009.12.015
14. Envisioning the National Health Care Quality Report. National Academies Press; 2001. doi:10.17226/10073
15. Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health Aff*. 2013;32(2):223-231. doi:10.1377/hlthaff.2012.1133
16. Centers for Disease Control and Prevention. Advance Care Planning: Ensuring Your Wishes Are Known and Honored If You Are Unable to Speak for Yourself. <https://www.cdc.gov/aging/pdf/advanced-care-planning-critical-issue-brief.pdf> Accessed January 30, 2020.
17. AARP. North Carolina Family Caregiving Guide. <https://www.aarp.org/content/dam/aarp/home-and-family/caregiving/2016/2016-08/nc-caregivers-resource-guide-aarp.pdf>. Accessed November 15, 2018.
18. Schulz R, Beach SR. Caregiving as a risk factor for mortality: The caregiver health effects study. *J Am Med Assoc*. 1999;282(23):2215-2219. doi:10.1001/jama.282.23.2215
19. Spetz J, Dudley N. Consensus-Based Recommendations for an Adequate Workforce to Care for People with Serious Illness. *J Am Geriatr Soc*. 2019;67(S2):S392-S399. doi:10.1111/jgs.15938
20. Van Houtven CH, Hastings SN, Colón-Emeric C. A path to high-quality team-based care for people with serious illness. *Health Aff*. 2019;38(6):934-940. doi:10.1377/hlthaff.2018.05486
21. Interprofessional Education Collaborative. Vision & Mission. <https://www.ipecollaborative.org/vision--mission.html>. Accessed March 16, 2020.

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, physician assistants), 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.

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.

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
- Engaging with patients and families to meet goals of care
- Development of the health and human services workforce and infrastructure to support serious illness care

## ORGANIZATION OF THIS REPORT

This report is structured to address each of the priorities listed above and to provide context and background to support the recommendations of the task force. The recommendations enhance current work being done in the state and aim to build upon this work to meet the vision of the task force. The task force has identified appropriate stakeholder organizations to implement each recommendation.

**The report contains an Executive Summary followed by the following chapters:**

**Chapter One:** Introduction and Overview of Serious Illness Care

**Chapter Two:** Health System and Social Change to Address Serious Illness Care

**Chapter Three:** High-Quality Person-Centered Care

**Chapter Four:** Engagement with Patients and Families to Meet Goals of Care

**Chapter Five:** Development of the Health and Human Services Workforce and Infrastructure

**Chapter Six:** Conclusion

**Appendices**

## 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.<sup>1</sup> 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.<sup>2</sup>

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 conditions<sup>a</sup>, and an additional 31.3% of respondents aged 65 and over had one chronic health condition.<sup>3</sup>

<sup>a</sup> 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 1.1** 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).<sup>4</sup>

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.<sup>5</sup>

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 1.2** Projected Rates of Serious Illness, By Condition

	ACTUAL RATE (2018)	2019-2020 PROJECTED	2030 PROJECTED
Alzheimer's Disease	P: 170,000 <sup>b</sup> persons 65+	180,000 (2020)	210,000 (2025)
Cancer <sup>c</sup>	I: 52,752 (2017) IR: 423.9 per 100K (NC Registry) <sup>d</sup> I: 55,394 (2016) IR: 458.4 per 100k people (age adjusted) <sup>e</sup> (CDC)	Projected incidence: 62,466 <sup>f</sup> (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. <sup>g</sup>
Diabetes	P: 12.5% <sup>h</sup> (crude) 2019 P: 11%		Projected to be rising nationwide, especially among adults aged 65 and older. <sup>i</sup>
Heart Disease	Heart attack: 5.4% <sup>k</sup> Angina or CHD: 5.7% <sup>l</sup>		
Kidney Disease	P: 3.2% <sup>m</sup> (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. <sup>n</sup>
Respiratory Illness	P: 8.1% <sup>o</sup>		
Stroke	P: 3.8% <sup>p</sup>		

<sup>b</sup> Alzheimer's Association, 2018. <https://www.alz.org/media/documents/northcarolina-alzheimers-facts-figures-2018.pdf>

<sup>c</sup> 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/>

<sup>d</sup> North Carolina State Center for Health Statistics [https://schs.dph.ncdhhs.gov/schs/CCR/incidence/2017/racegender\\_v2.pdf](https://schs.dph.ncdhhs.gov/schs/CCR/incidence/2017/racegender_v2.pdf)

<sup>e</sup> Centers for Disease Control and Prevention. United States Cancer Statistics <https://gis.cdc.gov/cancer/USCS/DataViz.html>

<sup>f</sup> North Carolina State Center for Health Statistics <https://schs.dph.ncdhhs.gov/schs/CCR/proj19co.pdf>

<sup>g</sup> NC Department of Health and Human Services. North Carolina Cancer Prevention and Control Branch. <https://publichealth.nc.gov/chronicdiseaseandinjury/cancerpreventionandcontrol/docs/ReducingtheBurdenofCancerResourceGuide.pdf>

<sup>h</sup> Centers for Disease Control and Prevention. BRFSS Prevalence and Trends Data, 2018.

<sup>i</sup> County Health Rankings 2019

<sup>j</sup> 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>

<sup>k</sup> North Carolina State Center for Health Statistics <https://schs.dph.ncdhhs.gov/data/brfss/2018/nc/risk/CVDINFR4.html>

<sup>l</sup> North Carolina State Center for Health Statistics <https://schs.dph.ncdhhs.gov/data/brfss/2018/nc/risk/CVDCRHD4.html>

<sup>m</sup> Centers for Disease Control and Prevention. BRFSS Prevalence and Trends Data. Kidney Disease, 2018.

<sup>n</sup> 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.

<sup>o</sup> North Carolina State Center for Health Statistics. 2018. <https://schs.dph.ncdhhs.gov/data/brfss/2018/nc/risk/CHCCOPD1.html>

<sup>p</sup> North Carolina State Center for Health Statistics. 2018. <https://schs.dph.ncdhhs.gov/data/brfss/2018/nc/risk/CVDSTRK3.html>

most children of the same age do.”<sup>6</sup> 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.<sup>7</sup>

**FIGURE 1.3** Serious Illness Rates by Disease for Children and Young Adults (0-19 years of age), U.S

<b>Cancer (all types)</b>	161.0-171.4 per 1,000,000 (2018-2019 age-adjusted cancer incidence rates)
<b>Cystic Fibrosis</b>	25 cases per 100,000 (2017 Newborn Screening)
<b>HIV/AIDS</b>	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)
<b>Congenital Heart Disease</b>	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](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.”<sup>8</sup> 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.

## 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.<sup>9</sup> 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.<sup>10</sup> For pediatric patients, the inclusion criteria is different: patients do not have to stop curative treatment while receiving hospice care.<sup>11</sup>

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.

**FIGURE 1.4** Distinctions Between Hospice and Palliative Care

	PALLIATIVE CARE	HOSPICE
<b>Model of care</b>	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
<b>Eligibility</b>	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
<b>Place</b>	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
<b>Payment</b>	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>;

## 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,<sup>9</sup> 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.<sup>12</sup> 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.<sup>13</sup> 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."<sup>14</sup> 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.<sup>15</sup>

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

**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*

*q* 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.

**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.<sup>16</sup> 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.<sup>17</sup> 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.<sup>18</sup>

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**



to



**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

Carrie is a live-in caregiver for her 83-year-old great-aunt Mary. Mary is a retired postal worker who was independent well into her 70s, but started needing some extra help around the house after a fall a few years ago. After Carrie moved in, she and Mary would run errands together every week, and would often take flowers from Mary’s garden to neighbors and other friends of Mary’s. In the last few months, Carrie has noticed that her aunt has not wanted to go out as often and has stopped working in her garden. Mary has also lost a fair amount of weight and has not been eating much. Carrie has contacted Mary’s doctor, but Mary has been resistant to going to appointments, and has also refused to drink the nutritional supplements that the doctor has recommended. Carrie worries that Mary may be depressed or in pain, and is at a loss of what to do. She knows that she could force Mary to go to appointments, but really does not want to make her do anything she does not wish to do.

**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.<sup>19</sup> 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.<sup>20</sup> 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.<sup>21</sup> 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. 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.

## REFERENCES

1. U.S. Census Bureau QuickFacts: North Carolina. U.S. Census Bureau. <https://www.census.gov/quickfacts/NC>. Accessed January 2, 2020.
2. Reddy, S. North Carolina Is Aging! North Carolina Department of Health and Human Services. <https://files.nc.gov/ncdhhs/documents/files/NC%20State%20Aging%20Profile%202016.pdf>. Accessed January 2, 2020.
3. BRFSS 2018 - North Carolina: Summary Index of Chronic Health Conditions. Behavioral Risk Factor Surveillance System. <https://schs.dph.ncdhhs.gov/data/brfss/2018/nc/all/countind.html>. Accessed January 2, 2020.
4. NC State Center for Health Statistics. Statistics and Reports: Cancer: Projections. North Carolina Department of Health and Human Services. <https://schs.dph.ncdhhs.gov/data/cancer/projections.htm>. Accessed January 3, 2020.
5. Explore Heart Disease in North Carolina. 2019 Annual Report. America's Health Rankings. <https://www.americashealthrankings.org/explore/annual/measure/CHD/state/NC>. Accessed January 3, 2020.
6. NC State Center for Health Statistics. Statistics and Reports: CHAMP: 2010 Survey Results. North Carolina Department of Health and Human Services. <https://schs.dph.ncdhhs.gov/data/champ/2010/topics.htm#cshcn>. Accessed January 16, 2020.
7. Siegel DA, Li J, Henley SJ, et al. Geographic Variation in Pediatric Cancer Incidence — United States, 2003–2014. *MMWR Morb Mortal Wkly Rep*. 2018;67(25):707-713. doi:10.15585/mmwr.mm6725a2
8. Cultural Competence. National Prevention Information Network. <https://npi.cdc.gov/pages/cultural-competence>. Accessed January 16, 2020.
9. Palliative Care Definition: What is Palliative Care? Center to Advance Palliative Care. <https://www.capc.org/about/palliative-care/>. Accessed October 18, 2019.
10. National Institute on Aging. What Are Palliative Care and Hospice Care? U.S. Department of Health and Human Services. <https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care>. Accessed January 3, 2020.
11. Bishop L, Flick T, Wildman V. Palliative Care Resource Series Best Practices for Using Telehealth in Palliative Care. National Hospice and Palliative Care Association. 2015. [https://www.nhpc.org/wp-content/uploads/2019/04/PALLIATIVECARE\\_Telehealth.pdf](https://www.nhpc.org/wp-content/uploads/2019/04/PALLIATIVECARE_Telehealth.pdf). Accessed February 19, 2020.
12. Olsen LA, Saunders RS, McGinnis JM. Patients Charting the Course: Citizen Engagement in the Learning Health System. National Academies Press; 2011. doi:10.17226/12848
13. Hibbard JH, Mahoney E. Toward a theory of patient and consumer activation. *Patient Educ Couns*. 2010;78(3):377-381. doi:10.1016/j.pec.2009.12.015
14. Envisioning the National Health Care Quality Report. National Academies Press; 2001. doi:10.17226/10073
15. Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health Aff*. 2013;32(2):223-231. doi:10.1377/hlthaff.2012.1133
16. Centers for Disease Control and Prevention. Advance Care Planning: Ensuring Your Wishes Are Known and Honored If You Are Unable to Speak for Yourself. <https://www.cdc.gov/aging/pdf/advanced-care-planning-critical-issue-brief.pdf> Accessed January 30, 2020.
17. AARP. North Carolina Family Caregiving Guide. <https://www.aarp.org/content/dam/aarp/home-and-family/caregiving/2016/2016-08/nc-caregivers-resource-guide-aarp.pdf>. Accessed November 15, 2018.
18. Schulz R, Beach SR. Caregiving as a risk factor for mortality: The caregiver health effects study. *J Am Med Assoc*. 1999;282(23):2215-2219. doi:10.1001/jama.282.23.2215
19. Spetz J, Dudley N. Consensus-Based Recommendations for an Adequate Workforce to Care for People with Serious Illness. *J Am Geriatr Soc*. 2019;67(5):S392-S399. doi:10.1111/jgs.15938
20. Van Houtven CH, Hastings SN, Colón-Emeric C. A path to high-quality team-based care for people with serious illness. *Health Aff*. 2019;38(6):934-940. doi:10.1377/hlthaff.2018.05486
21. Interprofessional Education Collaborative. Vision & Mission. <https://www.ipecollaborative.org/vision--mission.html>. Accessed March 16, 2020.

The Task Force on Serious Illness Care assessed serious illness across the life course and the system and culture changes required to reduce stigma. Community collaboration, culture change, cultural competency, and attention to health equity are requisite for addressing the challenges of serious illness care across the spectrum of care for the person with serious illness and her family and community.

## COMMUNITY COLLABORATION TO TAKE US TO A HIGH-QUALITY SYSTEM OF SERIOUS ILLNESS CARE

There is no singular group or governing body that currently exists in North Carolina to serve as a general coordinator to oversee the implementation of the task force's recommendations. Such entities exist in a few states, for example, the Massachusetts Coalition for Serious Illness Care and the Oregon Coalition for Living Well with Serious Illness. The Massachusetts coalition has over 100 member organizations and has a mission to "ensure that health care for everyone in Massachusetts is in accordance with their goals, values, and preferences at all stages of life and in all steps of their care."<sup>1</sup> The coalition fields surveys of state residents about views on serious illness and advance care planning, publishes monthly newsletters, hosts a yearly summit, and has created a toolkit for promoting advance care planning. Inspired directly by the Massachusetts coalition, the Oregon coalition includes 40 individuals and organizations and seeks to "educate, communicate, and connect in order to help people with serious illness and their caregivers live well."<sup>2,3</sup> Membership in both groups includes health care professionals, hospices, hospital and health systems, policymakers, caregivers, and consumers, among others.

In North Carolina, several groups have been working on some of the issues related to the recommendations of this report. The North Carolina Coalition on Aging, for example, "works collaboratively to give voice to issues that affect older North Carolinians" by providing education and hosting events to support issues of interest to member organizations. With several overlapping member organizations, the Partnership for Compassionate Care formed separately to help educate health care providers about end-of-life issues, focusing primarily on educating health care providers about Physician Orders for Life-Sustaining Treatment (POLST) and Physician Orders for Scope of Treatment (POST), and other resources to increase conversations about goals of care.

### NORTH CAROLINA SERIOUS ILLNESS COALITION

Over the course of the task force's work, members established a coalition to coordinate and oversee the implementation of the task force recommendations, organize work groups as identified in the recommendations, and serve as a repository for information, resources, and expertise in many aspects. This effort should also build upon the existing work of the many state stakeholders currently working to promote messages around serious illness care and ensure that North Carolinians have the information needed to face the challenges of serious illness.

Therefore, the task force recommends:

### 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, 4.15.**

## PROMOTING HEALTH EQUITY WHEN ADDRESSING SERIOUS ILLNESS CARE DISPARITIES IN RATES OF DISEASE

Serious illness affects all populations, yet some groups experience higher rates than others due to a range of issues, such as socioeconomic conditions and access to health care. Across the range of conditions contributing to serious illness that were detailed in Chapter One, populations of color often experience greater disease burden and rates of mortality than their white counterparts. [See Table 2.1](#) on the next page for detailed information across diseases.

**TABLE 2.1** Rates of Serious Illness by Race/Ethnicity

	WHITE	BLACK/AFRICAN AMERICAN	ASIAN/PACIFIC ISLANDER	AMERICAN INDIAN	HISPANIC
Alzheimer's Disease <sup>A</sup>	10%	14%	‡	‡	12%
Cancer (incidence/mortality), per 100,000 <sup>B</sup>	437.7 / 156.7 <sup>C</sup>	430.1 / 178.2 <sup>C</sup>	288.0 / 96.7	302.4 / 141.4 <sup>C</sup>	336.3 / 110.5
Diabetes <sup>D</sup>	10.7%	14.9%	‡	‡	11.3%
Heart Disease <sup>D</sup>	5.0%	3.8%	‡	‡	‡
Chronic Kidney Disease <sup>E</sup>	14.2%	19.3%	14.5%	14.6%	13.6%
Stroke <sup>D</sup>	3.5%	4.8%	‡	‡	‡

‡ Data not available

A Percentage of adults aged 65 and older with Alzheimer's disease; <https://www.cdc.gov/aging/data/pdf/american-alzheimers-racial-ethnic-disparities-infographic-508-h.pdf>

B All cancer sites combined; National Cancer Institute. Surveillance, Epidemiology, and End Results Program. SEER\*Explorer. <https://seer.cancer.gov/explorer/index.html>

C Includes Hispanic ethnicity

D Centers for Disease Control, Behavioral Risk Factor Surveillance System

E Percentage of Medicare patients age 65+ [https://www.usrds.org/2019/view/USRDS\\_2019\\_ES\\_final.pdf](https://www.usrds.org/2019/view/USRDS_2019_ES_final.pdf)

### DISPARITIES IN EXPERIENCE OF CARE

Disparities in rates of serious illness across populations are due in part to differing experiences accessing health care services. This is an issue across racial/ethnic groups, and across factors such as geographic location (rural versus urban), health insurance status, and immigrant documentation status. North Carolina has a relatively high population living in rural areas (34%).<sup>4</sup> Forty counties in the state have fewer primary care clinicians (physicians, physician assistants, and nurse practitioners) than recommended for the population.<sup>5</sup> This creates challenges for rural populations seeking access to primary care for chronic health issues like diabetes.

Another basic challenge to accessing health care is lack of health insurance. Nearly 13% of North Carolina residents under the age of 65 are uninsured.<sup>6</sup> Access to comprehensive, quality health care services is critical to achieve and maintain health, prevent and manage disease, and achieve health equity. Health insurance is the most common means used to obtain affordable health care services.<sup>7</sup> For those without health insurance, care may be inaccessible and unaffordable, resulting in poor health outcomes. In North Carolina, rural residents, non-citizens (54%), Hispanic populations (31%), men (14%), and people who earn less than 200% of the Federal Poverty Level (21%) are more likely than their counterparts to be uninsured.<sup>8,5</sup>

Social needs such as transportation, quality housing, and nutritious food are highly influential factors in an individual's experience of serious illness and the care they receive. Individuals who do not have adequate transportation may not be able to access clinical services that they need to monitor, treat, or alleviate pain or other side effects of their condition. Living conditions and nutrition can exacerbate the severity of an illness and prevent individuals from adhering to treatments recommended by the health care professionals caring for them.

### DISPARITIES IN END-OF-LIFE CARE

The use of hospice care services varies by population. White populations use hospice services at the highest rates, with 34% of whites who died while on Medicare using hospice services, compared to 28% of Hispanics, 27% of African Americans, and 26% of Asians and American Indians. This disparity has been changing, and non-white groups had larger percentage increases in hospice use between 2014 and 2017 than whites.<sup>9</sup> Also, women (58%) use hospice services more than men (42%).

North Carolina has long been a hub for immigrants and refugees from around the world. As of 2017, 7.8% of North Carolina's population was foreign-born, according to the U.S. Census Bureau. The state ranks 10th in the nation for number of refugees settled; in 2015, more than 3,000 refugees settled here, with 2,200 more following in 2016. Providers and systems strive to meet the medical needs of all our residents, but unique challenges and barriers to care remain. Interpretation services can be difficult to obtain, even where legally required. Farmworkers, in particular, are at higher risk of developing chronic conditions such as high blood pressure, as well as higher rates of related serious illnesses such as heart disease. For immigrants and refugees with serious illness in need of additional clinical care, human services, or financial assistance, these barriers may be exacerbated.

Sources: <http://nciom.org/caring-for-north-carolinas-immigrant-and-refugee-populations/>  
<https://www.migrantclinician.org/files/4%20Frank%20et%20al%20Health%20care%20access.pdf>

Preference for use of aggressive treatments up to the end of life and a lack of trust in the health care system based on historical inequities may account for the differing use of services across populations by race/ethnicity. Additionally, differences in advance care planning may account for some of the disparity. African Americans are less likely to have completed advance directive documentation, which has been the focus of efforts to encourage people to plan for end-of-life care.<sup>10</sup> The predominant

reason why fewer African Americans have completed advance directives is distrust of the health care system. Other racial and ethnic groups may have differing beliefs about death that make them less likely to have advance directives.<sup>11</sup> African Americans who have advance directives may be less likely to have outcomes impacted by stated preferences. One study found that African Americans who had a documented preference for less aggressive end-of-life treatment received the same amount of aggressive treatment as African Americans who did not have preferences documented. This was not the case for whites, who received less aggressive treatments if those wishes were documented.<sup>12</sup>

The treatment that people receive for a serious illness can also be variable. Research has shown that people of color are more likely to have pain underestimated by health care providers, less likely to have pain scores documented in medical records, and less likely to have their pain treated than white patients.<sup>13</sup> Studies of non-white individuals who received palliative care have shown that they are less satisfied with their care, their communication with providers, and their pain management than their white counterparts.<sup>14</sup>

The competency of hospice and palliative care staff to work with culturally diverse individuals at the end of their lives is a challenge to providing equitable opportunities for people of all backgrounds to feel comfortable using these services. A survey of hospice and palliative care organizations in one southeastern state found that staff, who are predominately white, lacked awareness of issues around cultural diversity, were not providing information in a culturally appropriate manner, and lacked access to and contact with diverse communities.<sup>15</sup> While limited, research into the barriers non-white individuals face in receiving palliative and end-of-life care has shown that low levels of race-concordant staff, lack of language interpreters, and limited outreach to diverse communities may contribute to inequitable access to these services.<sup>14</sup>

Throughout the task force process, and in this report, “caregiver” is used to address family members, friends, or other social supports that provide unpaid care for an individual with serious illness. The task force also emphasized that “family” should also be inclusive of family of choice. For example, many LGBTQ individuals form strong “families of choice” in response to familial rejection over sexual orientation or identity. These families of choice provide important emotional and social support. The task force recommendations are inclusive of families of choice when referencing family and caregivers.

Source: <https://www.caregiver.org/special-concerns-lgbt-caregivers>

## HEALTH EQUITY

Health equity is the opportunity for all people to attain the highest level of personal health regardless of demographic characteristics.<sup>16</sup> The task force has placed a high priority on the achievement of equity in the availability and quality of serious illness care. As the research into reasons for disparities suggests, growth in cultural competency and understanding of implicit bias by health care professionals is needed to achieve the goal of equity. Cultural competency in health care is the “ability of systems to provide care

to patients with diverse values, beliefs, and behaviors, including tailoring delivery to meet patients’ social, cultural, and linguistic needs.”<sup>17</sup> Cultural competency in serious illness care could be improved through strategies like hiring more diverse staff, training staff to increase cultural awareness, knowledge, and skills, incorporating culture-specific attitudes and values in printed materials, and including family and community members in the health care decision-making process.<sup>18</sup> Health care providers require training to understand their implicit biases. Implicit bias is a “set of assumptions about a social group that affects judgment and decision-making without conscious awareness of that influence.”<sup>19</sup> Implicit bias harms patient-provider communications and trust.

Recommendations through this report reflect the task force’s value of developing an equitable system of serious illness care for patients and their caregivers. The reports embed health equity in recommendations about training for health care providers (**Recommendation 2.2**), development of culturally competent workforce models and standards for advance care planning conversations (**Recommendation 4.4**), and studying the disparities in availability of and access to caregiver services (**Recommendation 4.12**).

The greater burden of serious illness that populations of color often face and the growing number of people with serious illness make cultural competency and health equity priorities for providing the best care possible. Therefore, the task force recommends:

### 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)

The following recommendations are directly related to impacts on underserved populations, and have been included in chapters reflecting the broader principles of health equity and reduction of disparities:

**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

**Recommendation 3.1:** Deliver goal-concordant, coordinated, team-based care for individuals with serious illness

**Recommendation 4.1:** Support patient and family engagement through health care organization policies and processes

**Recommendation 4.2:** Develop statewide initiative for improved awareness of, and support for, completion of advance care planning

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

**Recommendation 4.11:** Expand Home- and Community-based Services to better serve individuals with serious illness and their caregivers

**Recommendation 5.5:** Expand programs for community paramedicine

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

**REFERENCES**

1. Massachusetts Coalition For Serious Illness Care. About Us. 2019. <http://maseriouscare.org/about>. Accessed March 2, 2020.
2. Cambia Health Foundation. Oregon Coalition for Living Well with Serious Illness Launches with Commitment to a Person-Centered Ecosystem of Care. April 8, 2019. <https://www.cambiahealthfoundation.org/posts/news/2019-04-08/oregon-coalition-for-living-well-with-serious-illness-l.html>. Accessed March 2, 2020.
3. Oregon Coalition for Living Well with Serious Illness. Welcome. 2019. <https://na.eventscloud.com/ehome/409961/864382?eb=645277>. Accessed March 2, 2020.
4. North Carolina Department of Commerce. North Carolina Annual Economic Report: Population Change. 2019. [https://www.nccommerce.com/blog/2019/10/31/nc-annual-economic-report-population-change#\\_ftn2](https://www.nccommerce.com/blog/2019/10/31/nc-annual-economic-report-population-change#_ftn2). Accessed March 2, 2020.
5. North Carolina Institute of Medicine. Healthy North Carolina 2030: A Path Toward Health. 2020. <http://nciom.org/wp-content/uploads/2020/01/HNC-REPORT-FINAL-Spread2.pdf>. Accessed March 2, 2020.
6. United States Census Bureau. Small Area Health Insurance Estimates (SAHIE). 2020. [https://www.census.gov/data-tools/demo/sahie/#/?s\\_statefips=37](https://www.census.gov/data-tools/demo/sahie/#/?s_statefips=37). Accessed March 2, 2020.
7. Institute of Medicine. Coverage Matters: Insurance and Health Care. 2001. [http://www.nationalacademies.org/hmd/~media/Files/Report Files/2003/Coverage-Matters-Insurance-and-Health-Care/Uninsurance8pagerFinal.pdf](http://www.nationalacademies.org/hmd/~media/Files/Report%20Files/2003/Coverage-Matters-Insurance-and-Health-Care/Uninsurance8pagerFinal.pdf). Accessed March 2, 2020.
8. Randolph R, Holmes M. Running the Numbers: Health Insurance Coverage in North Carolina: The Rural-Urban Uninsured Gap. *N C Med J*. 2018;79(6):397-401. doi:10.18043/ncm.79.6.397
9. National Hospice and Palliative Care Organization. 2020. <https://www.nhpco.org/>. Accessed February 3, 2020.
10. Johnson KS, Kuchibhatla M, Tulsy JA, Author C, Corresponding Author A. What explains racial differences in the use of advance directives and attitudes toward hospice care? *J Am Geriatr Soc*. 2008;56(10):1953-1958. doi:10.1111/j.1532-5415.2008.01919.x
11. Kwak J, Haley WE. Current Research Findings on End-of-Life Decision Making Among Racially or Ethnically Diverse Groups. *The Gerontologist*. 2005; 45(5):634-64. <https://doi.org/10.1093/geront/45.5.634>.
12. Mack JW, Paulk E, Viswanath K, Holly D, Prigerson G. Black-White Disparities in the Effects of Communication on Medical Care Received Near Death. *JAMA Internal Medicine*. September 27, 2010. doi:10.1001/archinternmed.2010.322
13. Cintron A, Sean Morrison R. Pain and Ethnicity in the United States: A Systematic Review. Vol 9.; 2006. [www.liebertpub.com](http://www.liebertpub.com). Accessed March 2, 2020.
14. Johnson KS. Racial and ethnic disparities in palliative care. *J Palliat Med*. 2013;16(11):1329-1334. doi:10.1089/jpm.2013.9468
15. Reese, DJ, Melton, E, Ciaravino, K. Programmatic barriers to providing culturally competent end-of-life care. *American Journal of Hospice & Palliative Medicine*. 2004;21(5):357-364.
16. National Center for Chronic Disease Prevention and Health Promotion. Health Equity. <https://www.cdc.gov/chronicdisease/healthequity/index.htm>. Accessed March 2, 2020.
17. Betancourt, JR, Green, AR, Carrillo, JE. 2002. Cultural competence in health care: Emerging frameworks and practical approaches. New York: The Commonwealth Fund. [https://www.commonwealthfund.org/sites/default/files/documents/\\_\\_\\_media\\_files\\_publications\\_fund\\_report\\_2002\\_oct\\_cultural\\_competence\\_in\\_health\\_care\\_\\_emerging\\_frameworks\\_and\\_practical\\_approaches\\_betancourt\\_culturalcompetence\\_576\\_pdf.pdf](https://www.commonwealthfund.org/sites/default/files/documents/___media_files_publications_fund_report_2002_oct_cultural_competence_in_health_care__emerging_frameworks_and_practical_approaches_betancourt_culturalcompetence_576_pdf.pdf) Accessed March 2, 2020.
18. Health Policy Institute. McCourt School of Public Policy, Georgetown University. Cultural Competence in Health Care: Is it important for people with chronic conditions? <https://hpi.georgetown.edu/cultural/>. Accessed March 2, 2020.
19. National Institute on Aging. Implicit Bias Resources. <https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources/implicit-bias-resources>. Accessed March 2, 2020.



The Task Force on Serious Illness Care examined how serious illness care is operationalized—including where it is provided, who is part of the care team, and the impact of other factors on care delivery and the experience of care, including payment/financing, access to insurance coverage, and drivers of health. The task force made recommendations for improving the delivery of high-quality, person-centered serious illness care.

## 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 care or services. 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 that provide varying levels of medical 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 long-term care facility. Due to the range of types and locations of long-term services and supports, there are also a range of payment systems for these different types of care.

### HOME AND COMMUNITY-BASED SUPPORTS

Home-based long-term supports and services from unpaid caregivers constitutes the vast majority of long-term care. Additional care needs, such as home health care following surgery or illness; physical, occupational, or speech therapy; or other temporary health needs, are usually provided by paid home health providers. Other paid home-based long-term care may include personal care and assistance with activities of daily living, tasks such as laundry and cooking, instrumental activities of daily living, and companion services.<sup>1,2</sup>

#### ACTIVITIES OF DAILY LIVING

Activities of daily living (ADLs) are every day personal tasks such as bathing, dressing, eating, toileting, and moving around within the home. Other activities, called instrumental activities of daily living, include housework, financial management, medication management, meal preparation, shopping, and responding to emergency alerts.

In North Carolina (2019), there are 1,665 licensed home care agencies, including licensed home care, private duty, companion/sitter, home health, and hospice agencies. Of these, there are 208 Medicare-certified home health agencies (including corporate and branch offices). In FY 2016-17, these agencies served a total of 227,778 home health patients. Over 90% of home health users covered by Medicare had three or more chronic conditions.<sup>3</sup> Recent trends in home health include the approval by the Centers for Medicare and Medicaid Services of home care support through Medicare Advantage plans and the development of specialized home care programs to care for individuals with specific conditions, such as heart failure, chronic obstructive pulmonary disorder, and dementia.<sup>3</sup>

Community-based long-term supports and services consist of services intended to delay or prevent placement in out-of-home care (such as a skilled nursing facility) and help people remain at home as long as possible. These services often include adult day care services, home-delivered meal services, transportation assistance services, in-home aide services, and respite care for unpaid caregivers. These services vary by community and are provided by government agencies such as social services or health and human services or private organizations.<sup>1</sup> Many of these services have long wait lists and are unable to meet service needs of everyone who may need them.

### LONG-TERM CARE FACILITIES

Long-term supports and services are provided within residential facilities. There are a variety of levels of care provided in long-term care facilities, including assisted living facilities and skilled nursing facilities. Adult care homes provide minimal assistance with activities of daily living, but not as much care as is provided in a skilled nursing facility. Additional supplemental services may include meals, housekeeping, and social activities. A skilled nursing facility, also referred to as a nursing home, provides more intensive personal and health care, often including 24/7 nursing care, supervision, and rehabilitation services. Skilled nursing residents are those who need short-term care following an injury or illness, as well as those who require care for a longer period.<sup>4</sup>

### CONTINUING CARE RETIREMENT COMMUNITIES

Continuing care retirement communities also provide long-term supports and services. The range of services needed by residents of these communities includes assisted living care, skilled nursing care, and other health care, along with social engagement, recreation, and often independent living arrangements within the same location. These types of living arrangements are private pay only, not supported by Medicaid or Medicare, and often have long waiting lists and/or substantial entry fees.<sup>4</sup>

## PALLIATIVE CARE AND HOSPICE CARE

Throughout the work of the Task Force on Serious Illness Care, the task force 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.

### LONG-TERM SERVICES AND SUPPORTS

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.

*a As an alternative to enrolling in Original Medicare, individuals have the option of enrolling in Part C, called the Medicare Advantage program (following the enactment of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003). Individuals who choose to have Medicare Advantage enroll in private plans, approved by Medicare, which provide coverage for all services covered by Original Medicare. Medicare Advantage plans also can include coverage for additional services (such as vision and hearing) and often include prescription drug coverage. [http://nciom.org/wp-content/uploads/2018/06/NC\\_Medicare\\_Primer\\_FINAL-copy-1.pdf](http://nciom.org/wp-content/uploads/2018/06/NC_Medicare_Primer_FINAL-copy-1.pdf)*



**WHAT IS PALLIATIVE CARE?**

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.<sup>5</sup>

Many of the components of palliative care can and should be provided by primary care providers and palliative care specialists focused on more complex needs. In practice, however, most health care providers have not received adequate training in palliative care.<sup>7</sup>

Palliative care is most commonly provided in acute care hospitals. Between 2005 and 2015, hospital palliative care programs increased by more than 150%.<sup>7</sup> As of 2019, 94% of hospitals with more than 300 beds and 72% of hospitals with more than 50 beds had palliative care programs nationally.<sup>8</sup> In North Carolina, 94.1% of hospitals with more than 300 beds and two-thirds (67.6%) of hospitals with more than 50 beds have palliative care programs.<sup>8</sup>

Within a hospital setting, palliative care is generally provided by an interdisciplinary consultation team. Some large hospitals may also have dedicated inpatient palliative care units.

Palliative care can also be provided in home and community settings. Historically, community-based palliative care was provided only through hospice programs, limiting the number and type of patients to whom it was available (typically patients with a prognosis of under six months' survival who had chosen not to receive additional curative treatment).<sup>7</sup> While hospice providers continue to provide the majority of home-based palliative care, new community-based palliative care models have emerged to provide palliative care to non-hospice-eligible individuals.<sup>b</sup> Community-based models include many of the same interdisciplinary providers and focus on symptom management, communication on goals of care, as well as care coordination and caregiver support in the home setting.<sup>7</sup>

Palliative care is also increasingly provided within long-term care facilities such as skilled nursing facilities. Palliative care models in long-term care facilities include: provision through external/contracted hospice services; palliative care consultation, in which an external palliative care provider recommends care to facility clinicians; or internal palliative care teams, often for residents with dementia.<sup>7</sup>

**FIGURE 3.1** Components of Palliative Care

1. **Appropriate at any stage in a serious illness; beneficial when provided concurrently with curative treatment**
2. **Provided over time based on patients' needs, rather than prognosis**
3. **Offered in all care settings and by various organizations, including physician practices, health systems, cancer centers, dialysis units, home health agencies, hospices, and long-term care facilities**
4. **Focused on patient and family goals of care and care preferences**
5. **Interdisciplinary**

Source: Adapted from: National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care*, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. <https://www.nationalcoalitionhpc.org/ncp>.

In recent years, the use of palliative care for people with serious illness has been rapidly growing and clinical trial research has shown its benefits, including increased patient and provider satisfaction, improved symptom management, fewer hospital admissions in the last month of life, and lower anxiety and depression. Palliative care has also been shown to lessen caregiver distress and to improve if and how individuals' goals and values for their care and end of life are honored. In addition, palliative care has shown to lower costs of care.<sup>6</sup>

**HOW IS PALLIATIVE CARE DELIVERED?**

Palliative care is interdisciplinary and provided across care settings by a broad variety of health care providers. These providers may include physicians, nurses, physician assistants, nurse practitioners, social workers, chaplains, front line staff, home health workers, and others.

**FIGURE 3.2** Palliative Care Programs in Hospitals: Regional and National Comparisons to North Carolina

GEOGRAPHIC AREA	TOTAL PROGRAMS/ HOSPITALS, 2015 (%)	TOTAL PROGRAMS/ HOSPITALS, 2019 (%)	>300 BEDS, 2019 (%)	<50 BEDS, 2019 (%)
North Carolina	47/72 (65.3)	50/74 (67.6)	16/17 (94.1)	11/22 (50.0)
South Atlantic Region	270/420 (64.3)	313/344 (70.5)	124/133 (93.2)	44/128 (34.3)
United States	1,591/2,393 (66.5)	1723/2409 (71.5)	671/716 (93.7)	557/1535 (36.3)

Sources: Center to Advance Palliative Care (CAPC). *State by State Report Card on Access to Palliative Care in our Nation's Hospitals. Table 1: Prevalence and Distribution of Palliative Care Programs in U.S. Hospitals by State and U.S. Census Region. (2019 and 2015)* <https://reportcard.capc.org/>; Center to Advance Palliative Care (CAPC). *America's Care of Serious Illness. Table 1: Prevalence and Distribution of Palliative Care Programs in U.S. Hospitals by State and U.S. Census Region. (2015)* <https://reportcard.capc.org/tables-charts/>

<sup>b</sup> Please see page 32 for more on hospice eligibility

**FIGURE 3.3** Barriers to Palliative Care

1. Lack of palliative care resources
2. Not knowing that resources exist
3. Not understanding what palliative care is for
4. Reluctance (by providers) to refer individuals to palliative care services
5. Reluctance by individuals to receive referrals to palliative care services
6. Restrictive specialist palliative care eligibility criteria

Source: Hawley P. Barriers to Access to Palliative Care. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5398324/>

### HOW IS PALLIATIVE CARE FINANCED?

Private and public insurers (including Medicare and Medicaid) pay for all or part of palliative care services, in much the same way that they pay for other medical services.<sup>9</sup> However, traditional fee-for-service payment models can prove inadequate for palliative care, as palliative care consists of time-intensive tasks such as care coordination, medical management, and counseling that do not align with the ways fee-for-service payment incentivizes volume.

Since the passage of the Patient Protection and Affordable Care Act (ACA) in 2010, payers have applied new payment models in ways that better align with the goals and logistics of palliative care. Alternative payment models for palliative care may include per-member-per-month payments, shared savings, and bundled payments for episodes of care, often combined with care management services to improve communication with patients and families, improve transitions of care, and reduce spending.<sup>9,10</sup>

### BARRIERS TO PALLIATIVE CARE

Despite an increasing understanding of the value of palliative care through all stages of serious illness, many individuals face barriers to receiving it. Access to palliative care services remains challenging; while there was nearly a three-fold increase between 2000 and 2012 in the number of 50+ bed US hospitals providing palliative care services,<sup>11</sup> nearly one-third of these hospitals still do not provide palliative care services.<sup>12</sup>

Community palliative care settings serve to alleviate some of the barriers regarding access/availability of services. A recent study by the Center to Advance Palliative Care attempted to map available community palliative care services. Researchers found that two-thirds of community palliative care programs are operated by hospitals or hospice care facilities, with the remainder operated by home health agencies, long-term care facilities, and office practices or clinics; nearly two-thirds of community palliative care programs provide care in patients' homes, about half provide care in an office or clinic setting, and nearly one-third provide care in long-term care settings.<sup>13</sup> One noticeable barrier to access to community palliative care is for children: only 6% of programs serve children only, and less than one-quarter (24%) treat children in addition to adults.<sup>13</sup>

Other barriers to palliative care services may include lack of knowledge about available services or a misunderstanding of what palliative care is and when or in what care setting palliative care is appropriate. Research has shown that both patients and providers often think of palliative care as equivalent to end-

of-life care; this misperception can be a major barrier in integrating palliative care into care throughout the course of disease.<sup>11</sup> Health care providers may also worry about their patients' understanding of palliative care; in a survey of 155 physicians caring for people with lung cancer, nearly half of respondents referred fewer than 25% of their patients for palliative care consultations, many citing concern that this type of referral would alarm patients and families. Other provider-cited barriers to palliative care include patients' and families' misunderstandings of disease prognosis and the perception that palliative care means stopping all other treatment.<sup>11</sup>

Additional barriers to palliative care include those related to workforce. Recent national estimates put current hospice and palliative medicine specialists at 4,400 nationally, the equivalent of 1 for every 20,000 older adults with serious illness. To meet the growing need for specialty palliative care, an additional 6,000-10,000 specialty palliative care physicians and an equal number of advanced practice nurses would be needed.<sup>14</sup> In addition, only 25% of hospital-based palliative care programs meet national staffing recommendations (include at least one physician, one advanced practice or other registered nurse, one social worker, and one chaplain). In community palliative care services, training, demand, and turnover were cited as workforce-related barriers to access.<sup>14</sup>

### WHAT IS HOSPICE CARE?

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.<sup>15</sup>

### HOW IS HOSPICE CARE DELIVERED?

"Hospice" does not refer to a specific place or location; hospice can be offered at home, or in a facility such as a hospital, skilled nursing facility, or a separate hospice care facility.<sup>15</sup> Hospice care is provided by specially trained teams, including physicians, nurses, social workers, chaplains or spiritual advisors, and volunteers.<sup>15</sup>

### WHO IS ELIGIBLE AND HOW IS HOSPICE CARE FINANCED?

For individuals covered by Medicare Part A (hospital insurance), hospice care is paid for by Medicare under the following conditions:<sup>16</sup>

- Health care provider certifies that the individual has a life expectancy of six months or less.
- Individual accepts palliative care for comfort, instead of curative care.
- Individual signs a statement choosing hospice care instead of other Medicare benefits to treat illness and related conditions. Individuals can still receive covered services for conditions not related to the illness and related conditions.

**FIGURE 3.4** Elements of Hospice Care:

- Hospice helps improve comfort for people with serious or terminal illness.
- Hospice focuses on comfort, not on curing an illness.
- Hospice care is provided by a specially trained team of professionals and caregivers and emphasizes care for the “whole person,” including physical, emotional, social, and spiritual care.
- Services may include physical care, counseling, spiritual care, prescription drugs, equipment, and supplies.
- Care is provided in the home, in a hospital, or in another health care facility (such as a nursing home)
- Family caregivers can get support.

Source: Adapted from: <https://www.medicare.gov/pubs/pdf/11361-Medicare-Hospice-Getting-Started.pdf>

Under Medicare Part A, individuals can receive hospice care for two 90-day benefit periods, followed by an unlimited number of 60-day benefit periods. The conditions outlined above must be met (and forms signed/completed) before hospice care can continue.<sup>16</sup> Under these requirements, individuals may stop hospice care at any time for any reason, and may return to hospice care at any time, if eligible.

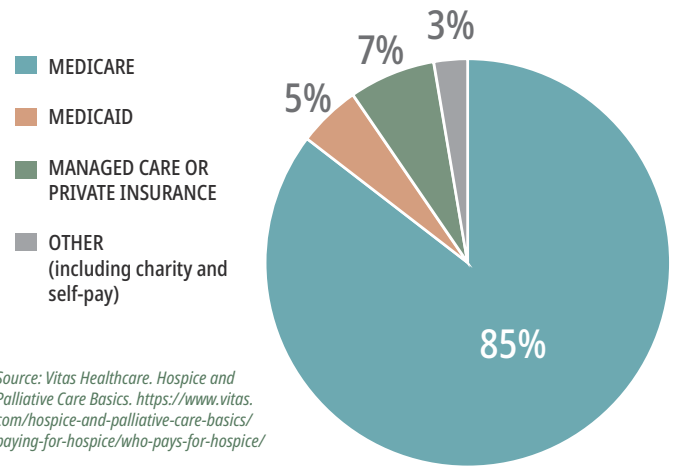
Medicare pays the hospice provider directly, with no deductible for individuals. There are applicable copays for outpatient prescription drugs, and individuals also pay 5% of the Medicare-approved amount for inpatient respite care.<sup>16</sup>

In 2017, Medicare paid hospice providers a total of \$18.99 billion, an increase of 6.3% from 2016. Average spending per patient was \$12,722. Nearly all of the Medicare spending on hospice care (98.2%) was for the last seven days of hospice care.<sup>17</sup>

In North Carolina, Medicaid and NC Health Choice beneficiaries are also eligible for covered hospice services. Services are identified and coordinated by a hospice interdisciplinary group (IDG), which aims to develop and manage comprehensive hospice care plans for eligible beneficiaries. Under NC Division of Health Services Regulation requirements, only Medicare-certified and North Carolina-licensed hospice agencies are eligible to provide hospice services to Medicaid beneficiaries. Each site providing hospice services must be separately licensed, and hospice providers must have contracts with a skilled nursing facility or hospital if hospice services are provided in those facilities (most services are provided at home).<sup>18</sup>

The Veterans Health Administration (VA) also provides hospice care. Hospice services provided by the VA are very similar to those provided under Medicare. Many commercial/private insurers also provide coverage of some hospice services.<sup>19</sup>

**FIGURE 3.6** Who Pays for Hospice Care?



**FIGURE 3.5** What is Covered Under Medicare and NC Medicaid Hospice Benefits?

**MEDICARE HOSPICE BENEFIT:**

- Physician services
- Nursing services
- Social services
- Counseling services (grief/loss, dietary, spiritual)
- Medical equipment (like wheelchairs or walkers)
- Medical supplies (like bandages and catheters)
- Short-term inpatient care (for pain and symptom management)
- Hospice aide and homemaker services
- Physical therapy, occupational therapy, speech-language pathology services

**OTHER:**

- Prescription drugs
- Short-term respite care
- Other Medicare-covered services needed to manage pain and other symptoms

**MEDICAID HOSPICE BENEFIT:**

- Physician services
- Nursing services
- Social services
- Counseling services (bereavement, dietary, spiritual)
- Medical equipment (like wheelchairs or walkers)
- Medical supplies (like bandages or catheters)
- Short-term inpatient care (for pain and symptom management)
- Hospice aide and homemaker services
- Physical therapy, occupational therapy, speech-language pathology services

**OTHER:**

- Interdisciplinary group, care planning, coordination of services
- Volunteer services
- Any other service that is specified in the beneficiary’s plan of care as reasonable and necessary for the palliation and management of the patient’s terminal illness and related conditions and for which payment may otherwise be made under Medicaid
- Ambulance transport services (when related to management of terminal illness)

Source: Centers for Medicare and Medicaid Services. 2020 <https://www.medicare.gov/pubs/pdf/11361-Medicare-Hospice-Getting-Started.pdf>

Source: North Carolina Department of Health and Human Services, Division of Medical Assistance. [https://files.nc.gov/ncdema/documents/files/3D\\_5.pdf](https://files.nc.gov/ncdema/documents/files/3D_5.pdf)

**IMPROVING SERIOUS ILLNESS CARE IN NORTH CAROLINA**

**WHO RECEIVES HOSPICE CARE?**

In 2017, among Medicare hospice patients nationally, nearly half (47.5%) were aged 85 or older. Another 16.7% were aged 80-84. Nearly one-third (31.1%) of Medicare hospice patients had cancer as their primary diagnosis, followed by circulatory/heart disease (17.6%) and dementia (15.4%).<sup>17</sup>

There are large racial/ethnic disparities in the receipt of hospice care. A large majority of Medicare hospice patients ( 82.5%) were white, 8.2% were African American, and 6.4% were Hispanic/Latino.<sup>17</sup> (Please see Chapter 2 for additional discussion of disparities)

While most individuals who receive hospice care in the course of a serious illness are older adults, hospice is also provided to younger adults and children who are eligible. However, reliable statistics for children who receive hospice care are difficult to identify. There are different prognostic criteria for children, and different levels of accessibility to services. In addition, epidemiological data generally focuses on numbers of children who die, have complex chronic conditions, or have special health care needs, while palliative and hospice care programs use definitions such as life-limiting conditions or life-threatening conditions, so the data is not consistent across categories. Pediatric populations are also defined differently by different sources in terms of the age groups included.<sup>20</sup>

**BARRIERS TO RECEIVING HOSPICE CARE**

Many of the barriers to receipt of hospice care have to do with misunderstandings of what hospice care is or the conditions/timing for when it is appropriate. One common misunderstanding is that hospice care is only appropriate when an individual is in the final stages of illness and very close to dying. However, hospice can be most beneficial at the time an individual’s goals of care change from curative care, and when the

individual in hospice care and their caregivers can develop a relationship with the hospice care team and focus on improving quality of living. Earlier discussion and referral to hospice services may prevent costly care delivered for patients often against their wishes at the end of life.

**TEAM-BASED CARE FOR SERIOUS ILLNESS**

The Task Force on Serious Illness Care examined the importance of a team-based model of care in providing high-quality serious illness care. 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. Of particular importance in team-based care for individuals with serious illness is the recognition of the individual and their family as integral members of the care team. Teams focus on understanding the relationships between the individual with serious illness, their family, their medical providers, and their community.<sup>21</sup> Teams also focus on caring for other members of the care team and emphasize the different skills and disciplines that work to provide the best care possible.

The interprofessional collaborative practice model maintains focus on communication and understanding between individuals, families, and providers to maintain the highest quality of care.<sup>4</sup> This model is often seen as the gold standard for providing serious illness care, with shared decision-making, common goals, and blending skills and knowledge to improve care.<sup>22</sup>

**FIGURE 3.7** Distinctions Between Hospice and Palliative Care

	<b>PALLIATIVE CARE</b>	<b>HOSPICE</b>
<b>MODEL OF CARE</b>	Interdisciplinary team, including physicians, nurses, social workers, chaplains, care managers; primary goal is improved quality of life	Interdisciplinary team, including physicians, nurses, social workers, chaplains, care managers, and volunteers; primary goal is improved quality of life and relief of suffering
<b>ELIGIBILITY</b>	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
<b>PLACE</b>	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
<b>PAYMENT</b>	Physician, physician assistant, 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>



In North Carolina, Four Seasons Compassion for Life, a state leader in serious illness care, uses an interprofessional collaborative practice model to develop competency in care teams across four domains: team member roles and responsibilities, communication, collaboration, and values and ethics. Primary elements of the model include continuous assessment of team performance and learning, training on team-based care, and relationship building across team members.<sup>21</sup>

**FIGURE 3.8** Principles of Team-based Health Care

**SHARED GOALS:** The team—including the patient and, where appropriate, family members or other support persons—works to establish shared goals that reflect patient and family priorities, and can be clearly articulated, understood, and supported by all team members.

**CLEAR ROLES:** There are clear expectations for each team member’s functions, responsibilities, and accountabilities, which optimize the team’s efficiency and often make it possible for the team to take advantage of division of labor, thereby accomplishing more than the sum of its parts.

**MUTUAL TRUST:** Team members earn each other’s trust, creating strong norms of reciprocity and greater opportunities for shared achievement.

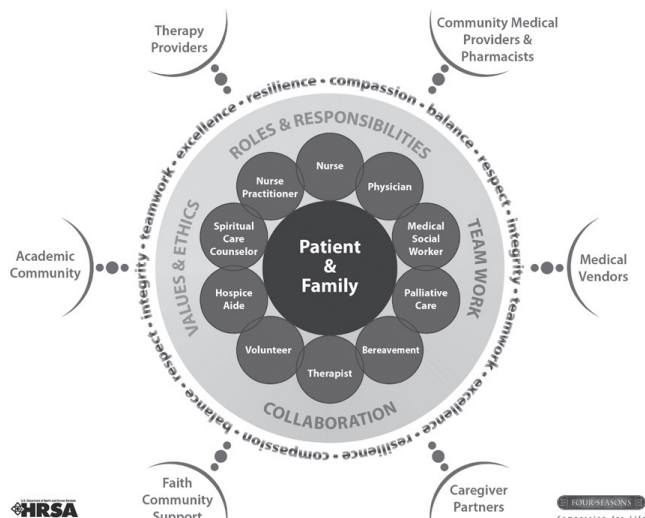
**EFFECTIVE COMMUNICATION:** The team prioritizes and continuously refines its communication skills. It has consistent channels for candid and complete communication, which are accessed and used by all team members across all settings.

**MEASURABLE PROCESSES AND OUTCOMES:** The team agrees on and implements reliable and timely feedback on successes and failures in both the functioning of the team and achievement of the team’s goals. These are used to track and improve performance immediately and over time.

Source: <https://nam.edu/wp-content/uploads/2015/06/VSRT-Team-Based-Care-Principles-Values.pdf>

**FIGURE 3.9** Interprofessional Collaborative Practice Model

The Four Seasons Interprofessional Collaborative Practice (IPCP) model in end-of-life care guides the development of IPCP competency in 4 domains: roles and responsibilities of each team member; communication, collaboration, and values and ethics.



Source: HRSA and Four Seasons. Reprinted from NCMJ 79:4. Available online at: <https://www.ncmedicaljournal.com/content/ncmj/79/4/256.full.pdf>

The Task Force on Serious Illness Care recognized the strengths of this model and recommended that health providers and systems identify and implement similar team-based models of care that will improve quality of living and care delivery for 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)

As included in Recommendation 3.1, the task force also emphasized the importance of providing “goal-concordant care” for individuals with serious illness. Goal-concordant care is care that “promotes (a) patient’s goals, regarding such matters as aggressiveness of curative treatment, hoped-for functional outcomes, and ability to participate in future events.” Goals of care are hard to assess, may not be documented, change over time, and goal concordance is hard to assess retrospectively.<sup>23</sup>

The task force also identified the challenges that providers and health systems have in identifying which individual patients will have higher clinical needs, and how to appropriately anticipate and treat these needs in a goal-concordant way. Cone Health System in Greensboro has utilized predictive analytics to apply a one-year mortality risk score. Individuals above a designated threshold are triaged for clinical needs, scheduled for a visit to discuss advance care planning, and during acute care or emergency department patients receive a consultation with the inpatient palliative care team.<sup>24</sup>



While acknowledging potential benefits of such predictive analytics approaches, the task force also cautions about unintended consequences. Research has shown that some algorithms may underestimate health needs of black patients in particular, running the risk of worsening racial disparities in care and outcomes. Longstanding cultural biases that influence access and utilization of care impact algorithm inputs and results: one studied showed that since black patients generally use less health care, an algorithm was less likely to predict their use of more care in the future, despite many health conditions that might indicate otherwise.<sup>25</sup>

In addition to health system/provider tools for identifying goals of care and clinical needs, providers and systems can also encourage the use of consumer-driven assessment tools. These tools, also known as patient experience measurement tools, are key in the health care framework known as the Triple Aim, used to measure patients' satisfaction and engagement with their care, inform payment and reimbursement models, and improve quality of care. When used with individuals with serious illness, however, they often have shortcomings: they are not always designed to address the unique care needs of people with serious illness and they may be administered too late in the disease trajectory to provide meaningful information to the care team. In addition, many of these tools do not include assessment of goals of care (medical or non-medical), relationships with members of the care team, or whether the patient felt their providers aimed to understand the whole person beyond certain clinical needs.<sup>26</sup> Systems and providers should aim to utilize consumer-driven assessment tools that include measurement of relationships/communication and understanding of goals of care, and these tools should be used earlier and more frequently across the illness trajectory.

In order to improve the delivery of timely, goal-concordant care, and assure that care plans are reassessed and revised as appropriate, the task force recommends:

### 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:

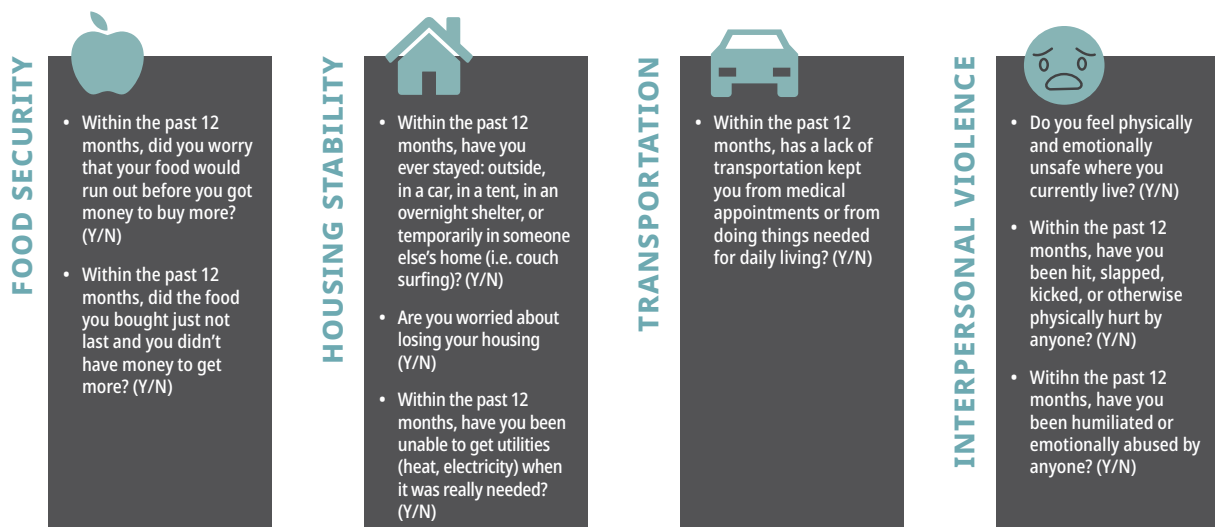
1. Utilize best practices in clinical assessment to identify individuals' clinical health needs and goals of care
2. Explore feasibility of incorporating best practices in predictive analytics and ways to connect results with improving care
3. Connect patients and caregivers with consumer-driven assessment 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

## ADDRESSING OTHER FACTORS THAT IMPACT DELIVERY OF SERIOUS ILLNESS CARE

### DRIVERS OF HEALTH

Increasingly, health care providers and policymakers recognize the ways that factors outside of the medical system influence health status and health outcomes. These factors, known as drivers of health, have been shown to determine up to 80% of an individual's overall health. Social and environmental factors such as education, income, geographic location, food insecurity, housing instability, transportation, and violence can significantly impact overall health. The task force examined the way these factors impact the experience of receiving care.<sup>27</sup>

**FIGURE 3.10** Screening for Unmet Social Needs



Source: NC DHHS. Updated Standardized Screening Questions for Health-Related Resource Needs. Accessed January 30, 2020. <https://www.ncdhhs.gov/about/departments/initiatives/healthy-opportunities/screening-questions>

Alex is a 69-year-old man with end stage kidney disease. At the time of his diagnosis, he was working as a plumber, but is no longer able to work. Alex lives in a small town, and must travel 45 minutes to visit his doctor and receive dialysis. Since he is no longer able to drive, his wife Susan must take off work to take him to his appointments. Although Alex and Susan own their home, they have struggled financially since losing Alex's income and often have difficulty paying bills on time. Alex worries that as his illness progresses, Susan may not be able to afford to keep their house.

Caring for caregivers can also improve the well-being of the care recipient. Individuals with serious illnesses, particularly Alzheimer's disease or related dementias, are more likely to have high emergency department and hospital utilization if their caregivers are under psychological and physical distress.<sup>11</sup> Therefore, caregiver burden assessment tools provide a means by which providers can gain insight into the caregiver-recipient relationship and identify areas where support would be beneficial.

To begin to address the unmet needs related to drivers of health, health systems must identify these unmet needs, generally through a systematic approach to screening.<sup>28</sup> The North Carolina Department of Health and Human Services (NC DHHS) has developed a standardized screening tool. The tool, developed by a group of stakeholders representing public health, health care, and sectors related to health-related social needs, incorporates tested and standardized items from existing screening tools (e.g., PREPARE, Health Leads, and items standardized for use in multiple tools). Through 2018, the draft tool was field tested through the Community Health Grants at 18 clinical sites, as well as through telephonic care management settings through Community Care of North Carolina.<sup>29</sup> The screening tool contains nine questions across four priority domains: food, housing/utilities, transportation, and interpersonal safety. There are also three optional questions about the nature of the needs and whether help is wanted to address those needs. Upon transition to Medicaid managed care, prepaid health plans will be required to screen beneficiaries for unmet needs upon enrollment.

Last year, Kimberly's 9-year-old son Christopher was diagnosed with an aggressive leukemia after breaking his leg in a soccer game. While chemotherapy has been effective in reducing the size of his tumors, Christopher has spent many weeks in the hospital with recurring infections. After Christopher's diagnosis, Kimberly and her husband decided that she would quit her job to be Christopher's primary caregiver. Although her husband and daughter help out when they are able to, Kimberly attends every appointment with her son, and sleeps on a mattress on the floor in his bedroom at home to assist him if he needs help in the night. Kimberly is exhausted, and feels like she doesn't have the energy for fun things that the family can do together on Christopher's good days.

### CAREGIVER BURDEN ASSESSMENT TOOLS

Many long-term supports and services are provided by nonprofessional caregivers—generally a close friend or family member of the care recipient.<sup>30</sup> Family caregivers play a critical role in the treatment and support of persons with serious illnesses, supplementing any medical and paid caregiving that an individual might be receiving. However, many caregivers lack training and support to manage their caregiving responsibilities. Caregivers may also have unmet social, physical, and mental needs that impact their ability to provide care for a loved one or to ensure they are taking care of themselves. Screening can be used to identify strengths that caregivers have and areas in which supports could improve their health and well-being and that of the care recipient. Specific tools<sup>e</sup> are designed to assess aspects of the caregiving situation, such as the caregiver's psychological well-being, financial circumstances, social isolation, employment status, ability to provide necessary care, and the anticipated duration of caregiving.<sup>30,31</sup> Assessment results can then be used to connect caregivers to support groups, therapy programs, financial support programs, and educational opportunities that can help caregivers develop coping mechanisms and alleviate stress.<sup>32</sup> These interventions can be directed at both the caregiver individually and at the care dyad (the caregiver and the care recipient) and can be incorporated into care management plans.<sup>33</sup>

### CONNECTING TO SERVICES

The North Carolina Department of Health and Human Services is currently rolling out NCCARE360, a statewide coordinated care network connecting individuals to local services and resources. NCCARE360 is a partnership between Unite Us, NC 2-1-1, Benefits Data Trust, and Expound. A public-private partnership led by the Foundation for Health Leadership and Innovation oversees and funds development of NCCARE360, which consists of a call center run by NC 2-1-1 and a shared technology platform powered by Unite Us. Through NCCARE360, health and human service providers can send and receive secure electronic referrals, communicate in real time, share client information, and collect outcome and cost data. NCCARE360 integrates the NC DHHS standardized screening tool, a community resource identification and referral system, and referral status tracking. In its first phase, the focus areas for available resources will be the NC DHHS priority domains of food security, housing stability, transportation, interpersonal violence, and employment.<sup>34</sup> Currently, NCCARE360 has the capacity for weekly analysis of number of organizations included in the system, organizations' response to referrals, open/closed referrals, number of users, and number of referrals. There is not currently capacity for state or system-wide analysis of receipt of services.<sup>f</sup>

### STATE-COUNTY SPECIAL ASSISTANCE

Cost of residential or home care can be a barrier for individuals with serious illness. The state has designed a financial assistance program that helps individuals afford the cost of room and board in a residential facility, or alternatively, helps offset some of the costs associated with arranging supportive services to remain at home.<sup>35,36</sup> The core State-County Special

<sup>e</sup> The Zarit Burden Interview is perhaps the most well-known of these tools, although many have been developed to assist providers in assessing their patients' caregivers. ([https://journals.lww.com/jbisirir/fulltext/2007/05101/a\\_comparison\\_of\\_tools\\_used\\_to\\_screen\\_for\\_caregiver.12.aspx](https://journals.lww.com/jbisirir/fulltext/2007/05101/a_comparison_of_tools_used_to_screen_for_caregiver.12.aspx))

<sup>f</sup> Bridges, J. NC Department of Health and Human Services, Division of Aging and Adult Services. Written (email) communication. Feb. 28, 2020.

Assistance program provides low-income individuals with financial support to live in a residential adult care home, family care home, or group home approved by the state. To be eligible for the program, applicants must be over the age of 65,<sup>9</sup> must require residential care services, and must meet income requirements.<sup>36,37</sup> The General Assembly sets an annual maximum rate that residential facilities can charge individuals within the Special Assistance program. If an individual qualifies for the program, he or she will receive the maximum rate, plus a small personal needs allowance, less any individual financial contribution (i.e., social security income or retirement income).<sup>36</sup>

The State-County Special Assistance In Home Program for Adults (SA/IH) provides support to those who are eligible for residential care but can safely remain in their homes with assistance. To qualify for the SA/IH program, an individual must meet the general Special Assistance program eligibility requirements but must also be eligible for Medicaid. Applicants for the program are assessed on their ability to afford safe housing, care and support needs, community and family caregiver resources, and any barriers they may face in accessing the services they need. If a case manager determines that an individual can remain safely in his or her home, a care plan and payment structure is developed to ensure applicant needs are met.<sup>35,38</sup>

The task force recognized the importance of assessing and providing non-clinical services to individuals with serious illness as an integral part of improving care and well-being.

### 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.

## PAYMENT AND FINANCING FOR SERIOUS ILLNESS CARE

The Task Force on Serious Illness Care also examined models of and challenges to paying for specific types of care for individuals with serious illness. As described above, both Medicare and Medicaid have specific payment models to cover hospice care with similar covered services. Researchers and advocates have developed proposed payment models that seek to provide similar comprehensive coverage for palliative care.

One innovative model examined by the task force was the Advanced Illness Management model (AIM) currently under proposal to the Center for Medicare and Medicaid Innovation (CMMI). Sutter Health developed AIM in 2003 as a model of providing home-based palliative care services to individuals with serious illness as they transition from intensive curative services to end-of-life-care. The model aimed to address the confusion many patients and families face during this transition, as well as the challenges faced as they make choices about curative treatments and those focused on providing comfort and improving quality of life.<sup>39</sup> AIM staff emphasize coordinating care and services across providers, starting or continuing advance care planning conversations, pain management, and hospice enrollment when appropriate. Patients can receive concurrent curative treatment (unlike in hospice); however, patients eligible for AIM services must have a high disease burden, meet criteria for hospice services but decline them, have nutritional and/or functional decline, have recurrent and unplanned hospitalizations, or their providers would not be surprised if they were to die within the next 12 months.<sup>40</sup> Patients spend an average of 190 days in the AIM program; about 50% of patients move to hospice, 15% die, and 10% stabilize and can be supported by a Sutter disease management program.<sup>h,39</sup>

At Sutter, a retrospective cohort study showed that participation in the AIM program resulted in a 28% increase in hospice referrals compared to patients receiving usual care within the same branch of the Sutter home health program, including a 60% increase among African American patients.<sup>40</sup> The AIM model has shown financial benefits to Sutter Health: for a cost of between \$2,400 and \$2,500 per patient per year, it has produced annual savings of approximately \$8,000 to \$9,000 per patient, primarily from reduced emergency department visits and hospitalizations at the end of life. Based on these results, the Center to Transform Advanced Care (CTAC) has proposed the use of an AIM delivery and payment model to CMMI.

The Patient and Caregiver Support for Serious Illness model (PACSSI), developed by the American Academy of Hospice and Palliative Medicine, aims to move palliative care services from a fee-for-service to a value-based payment model. Under the PACSSI model, providers would receive tiered monthly payments to support interdisciplinary palliative care teams who provide care for individuals with diagnosis of a serious illness, multiple chronic conditions, functional limitations, and/or high health care utilization.<sup>41</sup> The goal of the PACSSI model is to allow payers (Medicare first, with others as interested) to provide goal-concordant palliative

*g* There is also funding available to individuals between the ages of 18 and 65 who have SSD-qualifying disabilities and children who are legally blind and living in residential centers (Special Assistance Program, 2016).

*h* The remainder of patients leave the program for other reasons, including moving from service area.

care services of higher quality and with reductions in unnecessary and unwanted spending. Providers such as social workers, spiritual advisors, and others not currently reimbursed by Medicare for palliative care services could be reimbursed as part of the care team under this model.

CMMI has also developed a Medicare payment model to encourage primary care practices to manage care for individuals with serious illness in high need of care. CMMI will attribute what it identifies as Seriously Ill Population patients to Primary Care First<sup>i</sup> practices participating in this payment model option. Practices must show relevant capabilities, care coordination experience, and a network of relationships with other care organizations in the community in order to receive payment under the Primary Care First model for caring for these patients.<sup>42</sup> There are several cautions of this model, including that some palliative care providers have reported concerns that payments may be less than what they receive from commercial payers, and that differences between expertise/care delivery of specialty palliative care physicians and primary care providers may not be appropriately accounted for in this model. In addition, small practices may be at a disadvantage, as they must have at least 125 Medicare beneficiaries, have relevant experience with value-based payment models and coding models used to identify higher-risk patients, and use certified electronic health record technology with the capability of connecting to other providers and to a state health information exchange.<sup>42</sup>

Currently, North Carolina is not eligible to participate in the Primary Care First model, or in the model allowing Primary Care First practices to care for the seriously ill population, as the state is a control in the federal Primary Care First pilot experiment.<sup>42</sup>

Some private payers are also implementing payment structures designed to improve care for individuals with serious illness. Blue Cross and Blue Shield of North Carolina has designed Care 360, a comprehensive payment system for palliative care, with the intent of meeting challenges inherent in providing palliative care services under a fee-for-service payment model.<sup>j</sup> Care 360 uses per-member-per-month reimbursement to pay for all palliative care services provided by an interdisciplinary palliative care team. Goals of the payment system include improved quality of living for patients and caregivers, supported family and caregivers, and reduced stress, anxiety, and unwanted care. The model also aims to decrease unplanned care, especially utilization of the emergency department, intensive care, and ambulance transportation, and to decrease preventable hospitalization and readmission rates. Under the Care 360 model, Blue Cross and Blue Shield of North Carolina has provided care for 201 enrolled members as of June 2019. With this new model, Blue Cross and Blue Shield of North Carolina cautions that payment systems may not be enough to incentivize referrals to some palliative care providers, that misperceptions about palliative care must continue to be addressed among both providers and patients, and that access and provider capacity remain a challenge. Blue Cross and Blue Shield of North Carolina is currently evaluating the pilot.

The task force acknowledged the limitations of fee-for-service models to deliver quality palliative care and identified models for consideration for payers.

#### **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

#### **QUALITY MEASUREMENT FOR SERIOUS ILLNESS CARE**

As part of addressing payment for serious illness care, the task force discussed existing metrics that aim to assess quality of serious illness care and cost impacts. The Centers for Medicare and Medicaid Services (CMS) develops quality measures at the federal level for use in quality improvement and related reporting programs for health care providers. Data on these measures is reported through a variety of sources, including claims, patient and provider-reported data, provider chart data (including electronic medical records), and population-level registries.

The Hospice Quality Reporting Program at CMS requires reporting on the Hospice Item Set and the Hospice Consumer Assessment of Healthcare Providers and Systems survey. In addition, hospital-based metrics such as length of stay or mortality rates are often used to assess outcomes of palliative care. Other metrics, such as those addressing clinical care or patient satisfaction, are also used to assess quality of palliative care.<sup>43</sup>

<sup>i</sup> Primary Care First is a CMS-developed payment model that aims to improve quality, improve patient experience of care, and reduce costs. The model aims to increase patient access to primary care, with elements designed to support care for patients with serious illness or complex needs. Participating practices will be incentivized to reduce hospitalization, improve access and continuity, improve care management, increase care coordination, emphasize patient and caregiver engagement, and improve population health.

<sup>j</sup> Fee-for-service has traditionally been the dominant payment structure in American health care. Under a traditional fee-for-service health care payment model, health care providers and health systems receive compensation for each clinical encounter or service provided during discrete episodes of care. While this model has some advantages, namely that it is a familiar model to many patients and health care providers, it also tends to disproportionately reward volume of care rather than quality of care, and also does not reward important elements of high-quality care such as care coordination or care management.



**FIGURE 3.11** Hospice Quality Reporting Program Quality Measures (CMS)

Patients Treated with an Opioid who are Given a Bowel Regimen

Pain Screening

Pain Assessment

Dyspnea Screening

Dyspnea Treatment

Treatment Preferences

Beliefs/Values Addressed (if desired by patient)

Hospice Visits when Death is Imminent

Hospice and Palliative Care Composite Process Measure: Comprehensive Assessment at Admission

Source: Centers for Medicare and Medicaid Services <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Current-Measures> Accessed February 9, 2020.

**FIGURE 3.12** Palliative Care Outcome Metrics

Length of stay

Mortality rate

30-day readmission

Consultation volume

Consultation rate

Symptom measures

Live discharges

Inpatient deaths

Hospice discharges

Source: Grodwohl R, Brant JM. Hospital-Based Palliative Care: Quality Metrics that Matter. *J Adv Pract Oncol* 2015;6:597–610 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5017551/pdf/jadp-06-606.pdf>

Recent collaborative efforts have addressed ways in which CMS or other standardized quality measures may not be specific enough to effectively measure the quality of serious illness care. A team of experts from the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association convened a process called Measuring What Matters that aimed to identify and prioritize measures to benchmark best practices in palliative care.

The Task Force on Serious Illness Care recognized the many ways that quality measures for serious illness care may be revised to more effectively assess the experience of care specific to serious illness and end of life, and recommends additional study to develop a concise list of metrics.

### 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

## ACCESS TO HEALTH INSURANCE COVERAGE FOR SERIOUS ILLNESS CARE

Access to comprehensive, quality health care services is critical to achieve and maintain health, prevent and manage disease, and achieve health equity. For most people, access to affordable health care services is dependent upon whether they have health insurance coverage. For those without health insurance, care may be inaccessible and unaffordable, resulting in poor health outcomes. Lack of health insurance coverage can also lead to financial burdens that further negatively impact one's health. For North Carolinians with serious illness, lack of health insurance can be a significant barrier to receiving needed health care services. While much of the population discussed by the task force is eligible for Medicare coverage, younger adults with serious illness are often vulnerable to being uninsured, particularly once their illness has progressed to impact employment. Although uninsured rates in North Carolina decreased between 2013 and 2016, they have started to rise again. Policy options available to state lawmakers have the potential to greatly reduce the number of people who are uninsured in North Carolina.



**FIGURE 3.13** Measuring What Matters Project Metrics

Comprehensive assessment
Screening for physical symptoms
Pain treatment
Dyspnea screening and management
Discussion of emotional or psychological needs
Discussion of spiritual/religious concerns
Documentation of surrogate for decision-making
Treatment preferences
Care consistency with documented care preferences
Patient and family quality perceptions

Source: Grodwohl R, Brant JM. Hospital-Based Palliative Care: Quality Metrics that Matter. *J Adv Pract Oncol* 2015;6:597–610 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5017551/pdf/jadp-06-606.pdf>

As serious illness progresses, individuals may also be in need of behavioral health services to address the psychological impact of long-term illness or end of life. People with serious illness are at higher risk of depression, for instance. Some risk factors are directly related to the other illness, such as changes in the brain from stroke or Parkinson's disease. For some people, anxiety and stress related to their diagnosis and illness may trigger symptoms of depression.<sup>44</sup> Under North Carolina Medicaid's move to managed care plans, there is opportunity to ensure improved integration of behavioral health services with physical health services.

## REFERENCES

1. National Institute on Aging. What Is Long-Term Care? U.S. Department of Health and Human Services. <https://www.nia.nih.gov/health/what-long-term-care>. Accessed February 6, 2020.
2. Mlinac ME, Feng MC. Assessment of Activities of Daily Living, Self-Care, and Independence. *Arch Clin Neuropsychol*. 2016;31(6):506-516. doi:10.1093/arclin/acw049
3. Rogers T. Presentation to NCIOM Task Force on Serious Illness Care. May 2019. Home Health & Home Care Trends and Serious Illness.
4. National Institute on Aging. Long-Term Care. U.S. Department of Health and Human Services. <https://www.nia.nih.gov/health/caregiving/long-term-care>. Accessed February 6, 2020.
5. Palliative Care Definition: What is Palliative Care. Center to Advance Palliative Care. <https://www.capc.org/about/palliative-care/>. Accessed October 18, 2019.
6. Hughes MT, Smith TJ. The Growth of Palliative Care in the United States. *Annu Rev Public Heal*. 2014;35:459-475. doi:10.1146/annurev-publhealth-032013-182406
7. Kelley AS, Morrison RS. Palliative care for the seriously ill. *N Engl J Med*. 2015;373(8):747-755. doi:10.1056/NEJMr1404684
8. America's Care of Serious Illness. Center to Advance Palliative Care. 2019. <https://reportcard.capc.org/> Accessed February 10, 2020.
9. Palliative Care Report Card : FAQ. Center to Advance Palliative Care. <https://reportcard.capc.org/frequently-asked-questions/>. Accessed October 29, 2019.
10. Siderow S, Silvers A. Alternative Payment Supports Palliative Care Across the Continuum. Center to Advance Palliative Care. [https://media.capc.org/posters/2016/Cen-ter\\_to\\_Advance\\_Palliative\\_Care\\_1\\_Allison\\_Silvers\\_Alternative\\_Payment\\_Supports\\_PC\\_Across\\_the\\_COntinuum.pdf](https://media.capc.org/posters/2016/Cen-ter_to_Advance_Palliative_Care_1_Allison_Silvers_Alternative_Payment_Supports_PC_Across_the_COntinuum.pdf) Accessed February 9, 2020.
11. Aldridge MD, Hasselaar J, Garralda E, et al. Education, implementation, and policy barriers to greater integration of palliative care: A literature review. *Palliat Med*. 2016;30(3):224-239. doi:10.1177/0269216315606645
12. Hawley P. Barriers to Access to Palliative Care. *Palliat Care*. 2017;10. doi:10.1177/1178224216688887
13. Mapping Community Palliative Care: A Snapshot | Center to Advance Palliative Care. [https://www.capc.org/documents/700/?utm\\_source=Mapping+Community+Palliative+Care+report&utm\\_campaign=Mapping+report&utm\\_medium=email](https://www.capc.org/documents/700/?utm_source=Mapping+Community+Palliative+Care+report&utm_campaign=Mapping+report&utm_medium=email). Accessed January 2, 2020.
14. Palliative Care Research. National Palliative Care Registry. <https://registry.capc.org/metrics-resources/research-in-the-field/>. Accessed January 2, 2020.

As discussed throughout this chapter, there are various services for individuals with serious illness that can be covered through Medicaid, including long-term supports and services, hospice benefits, and non-clinical services such as Special Assistance programs. These services have different eligibility requirements, application processes, and administrative homes. The task force acknowledged the need for ensuring that these processes are examined and revised to improve efficiency of eligibility determination and delivery of services.

### 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.

15. National Institute of Aging. What Are Palliative Care and Hospice Care? U.S. Department of Health and Human Services. <https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care>. Accessed January 3, 2020.
16. Centers for Medicare and Medicaid Services. Medicare and Hospice Benefits. U.S. Department of Health and Human Services. February 2019.
17. NHPCO Facts and Figures: 2018 Edition. National Hospice and Palliative Care Organization.
18. NC Medicaid: Hospice Services. North Carolina Department of Health and Human Services. 2019.
19. FAQ: How is Hospice Care Paid For? American Hospice Foundation. <https://americanhospice.org/learning-about-hospice/how-is-hospice-care-paid-for/>. Accessed January 9, 2020.
20. Friebert S, Williams C. 2015 Edition.; 2015. [www.ssa.gov/OP\\_Home/ssact/title18/1861.htm](http://www.ssa.gov/OP_Home/ssact/title18/1861.htm). Accessed March 17, 2020.
21. Albers A, Bonsignore L, Webb M. A team-based approach to providing person-centered care at the end of life. *N C Med J*. 2018;79(4):256-258. <http://www.ncmedicaljournal.com/content/79/4/256.full.pdf>. Accessed February 3, 2020.
22. Bridges DR, Davidson RA, Odegard PS, Maki I V., Tomkowiak J. Interprofessional collaboration: Three best practice models of interprofessional education. *Med Educ Online*. 2011;16(1). doi:10.3402/meo.v16i0.6035
23. Halpern SD. Goal-Concordant Care — Searching for the Holy Grail. *N Engl J Med*. 2019;381(17):1603-1606. doi:10.1056/NEJMp1908153
24. Golding, E. All's Well That Ends Well: A Comprehensive Advance Care Planning Strategy. Presentation to NCIOM Taskforce on Serious Illness; 2019.
25. Johnson CY. Scientists detected racial bias in a product sold by Optum, but the problem likely extends to algorithms used by major health systems and insurers . *The Washington Post*. Oct. 24, 2019. [https://www.washingtonpost.com/health/2019/10/24/racial-bias-medical-algorithm-favors-white-patients-over-sicker-black-patients/?fbclid=IwAR1Ski2dDr\\_zPhVxdLnCjNAbvjwL17Wockzp4t0hb5KAosDM\\_hHDSjL06w](https://www.washingtonpost.com/health/2019/10/24/racial-bias-medical-algorithm-favors-white-patients-over-sicker-black-patients/?fbclid=IwAR1Ski2dDr_zPhVxdLnCjNAbvjwL17Wockzp4t0hb5KAosDM_hHDSjL06w). Accessed February 3, 2020.
26. Fernstrom KM, Shippee ND, Jones AL, Britt HR. Development and validation of a new patient experience tool in patients with serious illness. *BMC Palliat Care*. 2016;15(1):99. doi:10.1186/s12904-016-0172-x
27. North Carolina Department of Health and Human Services. Healthy Opportunities Pilots. <https://www.ncdhhs.gov/about/departments-initiatives/healthy-opportunities/healthy-opportunities-pilots>. Accessed December 16, 2019.
28. How to improve screening for social determinants of health . American Medical Association. <https://www.ama-assn.org/delivering-care/patient-support-advocacy/how-improve-screening-social-determinants-health>. Accessed March 17, 2020.
29. North Carolina Department of Health and Human Services. Field Test Report: Standardized Screening for Health-Related Resource Needs in North Carolina. <https://files.nc.gov/ncdhhs/NC-Screening-Questions-Report-Final-73019.pdf>. Accessed January 30, 2020.
30. Kepic M, Randolph A, Hermann-Turner KM. Care for Caregivers: Understanding the Need for Caregiver Support. *Adultspan J*. 2019;18(1):40-51. doi:10.1002/adsp.12068
31. Darlak, L. Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners 2nd Edition. Margaret Blenkner Research Institute. 2012.
32. Reinhard SC, Given B, Petlick NH, Bemis A. Supporting Family Caregivers in Providing Care. Agency for Healthcare Research and Quality (US); 2008. <http://www.ncbi.nlm.nih.gov/pubmed/21328765>. Accessed February 14, 2020.
33. Slaboda J, Fail R, Norman G, Meier DE. A study of family caregiver burden and the imperative of practice change to address family caregivers' unmet needs. *Health Affairs Blog*. January 11, 2018. <https://www.healthaffairs.org/doi/10.1377/hblog20180105.914873/full/>. Accessed February 14, 2020.
34. NCCARE360. Now Live in 50 North Carolina Counties. <https://nccare360.org/nccare360-now-live-in-50-north-carolina-counties/>. Accessed January 30, 2020.
35. North Carolina Department of Health and Human Services. State-County Special Assistance, In Home. <https://www.ncdhhs.gov/assistance/adult-services/state-county-special-assistance-in-home>. Accessed February 14, 2020.
36. North Carolina Department of Health and Human Services. State-County Special Assistance. <https://www.ncdhhs.gov/assistance/adult-services/state-county-special-assistance>. Accessed February 14, 2020.
37. North Carolina Department of Health and Human Services. How and Where Can I Apply? <http://www.ncdhhs.gov/dss/local/index.htm>. Accessed February 14, 2020.
38. North Carolina Department of Health and Human Services. Am I Eligible?
39. Hostetter M, Klein S, McCarthy D. Sutter Health's AIM Model and Patients at End of Life. *The Commonwealth Fund*. <https://www.commonwealthfund.org/publications/case-study/2018/jan/supporting-patients-through-serious-illness-and-end-life-sutter>. Accessed February 7, 2020.
40. Stuart B, Mahler E, Koomson P. A Large-Scale Advanced Illness Intervention Informs Medicare's New Serious Illness Payment Model. *Health Aff (Millwood)*. 2019;38(6):950-956. doi:10.1377/hlthaff.2018.05517
41. Smith SR. Physician-Focused Payment Model Technical Advisory Committee. U.S. DHHS Asst. Secretary for Planning and Evaluation Office of Health Policy. 2017.
42. Primary Care First Model Options. Center for Medicare & Medicaid Innovation. <https://innovation.cms.gov/initiatives/primary-care-first-model-options/>. Accessed February 9, 2020.
43. Current Measures. CMS. <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Current-Measures>. Accessed February 14, 2020.
44. Chronic Illness & Mental Health. National Institutes for Mental Health. <https://www.nimh.nih.gov/health/publications/chronic-illness-mental-health/index.shtml>. Accessed March 17, 2020

The Task Force on Serious Illness Care identified several important aspects of care to ensure that individuals are able to identify and achieve their goals of care, including addressing 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.

## PATIENT AND FAMILY ENGAGEMENT

The core of patient and family engagement lies in welcoming the patient and family, as well as non-family support systems, as important partners in care. Patients who are actively involved in their health and health care tend to have better outcomes and care experiences, and, in some cases, lower costs.<sup>1, 23</sup> Implementing patient and family engagement strategies has led to fewer hospital-acquired infections, reduced medical errors, reduced serious safety events, and increased patient satisfaction scores.<sup>24</sup>

Patient- and family-centered care is 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.

The National Academy of Medicine 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 they need to make decisions and participate in their own care.<sup>6</sup> 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.<sup>7</sup> 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."<sup>8</sup> The Institute describes the foundations for patient and family engagement as dignity, respect, information sharing, participation, and collaboration.

For individuals with serious illness, the focus of patient and family engagement is not primarily on improved health outcomes, as it may be with other populations, but with ensuring that care is person centered and that an individual's goals, preferences, and values drive their serious illness care. The task force discussed several primary components of patient and family engagement and the ways that incorporating these components can reinforce and support the provision of goal-concordant care.

A key strategy for increasing patient and family engagement is for an organization to measure care improvement, facilitate changes in processes, and assess the relationships among engagement, experiences, and outcomes.<sup>9</sup> The tactics include developing measures of patient-level

experiences, goals, and outcomes as well as measures that assess the process of patient and family engagement—how and to what extent engagement occurs. For individuals with serious illness, measures can be used to assess alignment with goals of care, provide feedback to clinicians and organizations, and drive organizational change.

In addition, organizations can be designed or redesigned with patients and families included in governance structure. The perspective of patients and families should be included when developing policies and procedures related to health and health care, as well as when designing informational materials and training curricula. This redesign includes preparing clinicians, staff, and health care leaders to partner with patients and families at the organization and system level. Tactics to achieve organizational partnership involve creating roles for patients and families such as advisory councils, representation on boards, and training for leaders on person-centered care and principles of patient and family engagement.

The task force recommends:

### 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

## 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 are reflected in these goals, the task force examined processes and systems for advance care planning, including within the health and financial/legal systems and within professional training.

In order to align care with individuals' goals, providers must know what those goals are, how they might change, and how an individual's values and experience impact them. While the process of advance care planning serves to identify goals and values, there are many barriers to advance care planning. 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, the 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.

**FIGURE 4.1** Types of Advance Directives in North Carolina

**Health Care Power of Attorney:** A document that allows an individual to name a "health care agent" to speak for them if they are unable, and identifies wanted and not-wanted treatments

**Living Will (declaration of a desire for a natural death):** A legal document that describes an individual's preferences for medical treatment, life support, and end-of-life care

**Advance Instructions for Mental Health Treatment:** A legal document that describes which mental health treatments an individual would want or not want if unable to speak for themselves. It can be combined with or separate from a health care power of attorney.

Sources: Phelps, M. "It's Not About the Forms." Presentation to NCIOM Task Force on Serious Illness Care, May 2019.

### WHAT IS ADVANCE CARE PLANNING?

Broadly defined, advance care planning is a process by which individuals 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.<sup>10</sup> The process of advance care planning includes communication about diagnoses, care trajectory, what to expect from an illness, and discussion about goals of care and end of life. In addition, advance care planning includes the documentation of goals, preferences, and representatives, through the completion of legal, financial, and medical forms.

### ADVANCE DIRECTIVES

An advance directive is a legal document that goes into effect when an individual is incapacitated and can no longer make or communicate decisions.<sup>11</sup> It allows individuals to express preferences for care, including end-of-life care, and may be adjusted as circumstances or diagnoses changes.<sup>12</sup> Decisions documented in advance directives may include those about which emergency treatments (cardiopulmonary resuscitation, ventilator use, artificial nutrition or hydration) an individual would want, or what kind of comfort care they prefer.<sup>12</sup> In North Carolina, advance directives include health care power of attorney and living will, and are defined in general statutes (see Figure 4.1).<sup>a,b</sup> The advance instructions for mental health treatment form is another advance directive that addresses mental health treatment.<sup>11,13,14</sup>

### COMPLETING AN ADVANCE DIRECTIVE

In North Carolina, there are several requirements for completing an advance directive. Health care powers of attorney, living wills, and advance instructions for mental health treatment must be **1)** written; **2)** signed while the individual can still make and communicate health care decisions; **3)** witnessed and signed by two qualified adults; and **4)** notarized.<sup>15</sup> Qualified witnesses must be competent adults who witness the signing of the advance directive, and cannot be relatives or beneficiaries to the individual completing the advance directive. Witnesses also cannot be physicians, nurses, or any licensed or paid employee of the individual's health care providers or of a health care facility where the individual lives or is being treated.<sup>15</sup> Individuals can register their advance directives with the North Carolina Advance Health Care Directive Registry (see page 58 for additional information on the Advance Health Care Directive Registry).

Living wills can be cancelled at any time by communicating to family members and health care providers about the intent to cancel. Health care powers of attorney and advance instructions for mental health treatment can be cancelled or changed while the individual still has the ability to make and communicate these changes.<sup>15</sup>

### PORTABLE MEDICAL ORDERS

Portable medical orders direct care according to an individual's preferences and are actionable by health care providers. They may be informed by the completion of advance directives. In North Carolina, portable medical orders include the Do Not Resuscitate (DNR) order and the Medical Orders for Scope of Treatment (MOST) form (see Appendix B for full forms).

In emergency or end-of-life situations, the default of care may be to do everything possible, though the care may be costly, futile, and/or contrary to an individual's wishes. The completion of DNR and MOST forms allows these wishes to be documented and put into effect at the time care is needed.<sup>15</sup>

<sup>a</sup> NC Gen Stat 90-321.NC Statutory "Declaration of a Desire for a Natural Death" or "Living Will" form

<sup>b</sup> NC Gen Stat 32A-25.1 NC Statutory Health Care Power of Attorney form

### BARRIERS TO ADVANCE CARE PLANNING

Though the completion of advance directives may seem relatively straightforward, individuals and families face many barriers when making and documenting advance care planning decisions. The task force discussed many of these barriers, including language/communication, provider training, legal, logistical, and financial barriers.

The task force explicitly addressed the fact that advance care planning is not a process that has completion of advance directive documentation as its main goal. Rather, advance care planning is a process for families to begin discussions about care, goals for end of life, and the values that drive what individuals perceive as quality of living while facing serious illness and death.

#### FIGURE 4.2 Portable Medical Orders

**PORTABLE DO NOT RESUSCITATE (DNR) ORDER:** A medical order that can be followed by health care providers, including emergency responders, that tells them not to do cardiopulmonary resuscitation if breathing and heart stop. A DNR form goes into effect after being completed and signed by a physician, nurse practitioner, or physician assistant.

**MEDICAL ORDER FOR SCOPE OF TREATMENT (MOST) FORM:** Medical order that can be followed across settings (including hospital, skilled nursing facility, home, etc.). A MOST form may include instructions on CPR, nutrition/hydration, or other end-of-life treatments. Must be signed by a physician, nurse practitioner, or physician assistant, as well as by the individual or their proxy.

Source: NC Medical Society. *Medical Care Decisions and Advance Directives: What you Should Know*. Accessed February 24, 2020. <https://www.ncmedsoc.org/wp-content/uploads/2014/02/Medical-Care-Decisions-and-Advance-Directives-full.pdf>

Many families, however, may be reluctant to have advance care planning discussions. They may fear talking about the trajectory of a serious illness and the possibility of death, or they may believe that advance care decisions cannot be changed once they are documented. Patients and families may also misunderstand the types of care available, including a belief that starting to talk about palliative care or hospice care means that death is imminent. Figuring out the different advance directive documents, which are most appropriate, and how to complete and register them, can also be challenging for many individuals and families. The task force addressed the need for awareness of advance care planning, clarification among patients and families about its goals and definitions of care options, and increased understanding of the types of default care provided if other preferences are not known.

There are also wide disparities in advance care planning across populations, as measured by the uptake of advance directives. Advance care planning, and the accompanied increase in quality of care toward end of life, occurs at much lower rates among ethnic and racial minorities. For example, among African Americans, research has shown

that cultural factors such as religious beliefs, distrust of the health care system, discomfort talking about illness and death, and increased desire for aggressive end-of-life care may lead to families being less likely to participate in an advance care planning process, or to choose palliative or hospice care services.<sup>16</sup> The task force recognized the importance of understanding disparate ways that communities and individuals may perceive advance care planning when addressing communication and awareness of the process.

#### 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

### TRAINING ON ADVANCE CARE PLANNING

Advance care planning is a process that may be undertaken across professional disciplines, as well as in a more informal way by individuals and families. The task force identified examples of current work in advance care planning across sectors and made recommendations for the improvement and promotion of training.

The North Carolina Bar Foundation administers "A Gift to Your Family," a statewide, collaborative initiative that aims to promote advance care planning through legal services.<sup>17</sup> In addition, the North Carolina State Employee Credit Union provides counseling on advance care planning and related financial planning services at low cost to SECU members across



the state.<sup>18</sup> As legal and financial professionals provide these services, it is important that their communication of advance care planning concepts aligns with that of the health system, with a common understanding of terminology, sensitivities about conversations, and familiarity with cultural factors that may impact advance care planning. Such alignment may also help to promote advance care planning across the life trajectory, not just when families face illness and end of life.

When discussing the need for aligned training processes and terminology, the task force also discussed the Practical Form for All Adults, deciding it should be considered across sectors as the standard advance directive form for North Carolina, and acknowledging it may require changes to conform with statute. The Practical Form for All Adults includes health care power of attorney and living will in one document, and also includes instructions and simple explanations for each directive<sup>19</sup> (see [Appendix B](#) for the Practical Form for All Adults).

### **PROTECTING INDIVIDUALS WITH SERIOUS ILLNESS FROM FINANCIAL FRAUD**

The task force discussed the particular ways that individuals with serious illness, especially older adults, may be susceptible to financial exploitation or abuse. Financial exploitation is defined in NC G.S. § 108A Articles 6 and 6A as the illegal or improper use of a disabled adult's resources for another's profit or advantage, including such things as taking money or property by coercion, undue influence, or false pretenses; forging an adult's signature to legal documents such as deeds or wills; or misuse of a power of attorney. Perpetrators of elder financial abuse can be family members, trusted professionals, fiduciaries, caretakers, predatory individuals, or dishonest businesspeople.<sup>20</sup>

Older adults are commonly targeted for financial fraud because they often have significant assets and are often more likely to be vulnerable. In 2014, such frauds contributed to losses of over \$10 million, with the vast majority of elder financial fraud going unreported.<sup>21</sup> If the perpetrator is someone who has been granted power of attorney by the defrauded adult, criminal prosecution is very difficult. The task force acknowledged these concerns and identified training on financial fraud as an integral part of training on advance care planning (for more information and additional recommendations concerning elder abuse and fraud, please see *Dementia-Capable North Carolina*, a report of the NCIOM 2016 Task Force on Alzheimer's Disease and Related Dementias).

The task force recommends:

#### **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

While the task force acknowledged the need for training in advance care planning among legal and financial professionals, it also addressed the need for improved training for health care providers and other workers in the health care system on common terminology and different types of care, having difficult conversations, framing these discussions as a normal part of life planning, and understanding of risks for fraud.

The task force recommends:

#### **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

As discussed above, advance care planning is a process, rather than a goal, and as such, it can take time over a series of conversations, appointments, or consultations. Within health care, in order to ensure that advance care planning receives the dedicated time and thoughtful approach that it needs, providers and systems must ensure that there are payment models in place to reimburse staff for time spent on and training in advance care planning.

Currently under Medicare fee-for-service, CPT codes 99497 and 99498 reimburse providers for “advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate” (CPT code 99497), and then an additional 30 minutes on the same (CPT code 99498).<sup>22</sup> These Medicare codes do not have limits on the number of times a beneficiary can receive these services; however, Medicare expects a documented change in either health status or wishes for end-of-life care when the service is billed multiple times for a given person. The codes can be used in all care settings, including inpatient, outpatient, and skilled nursing. One important restriction on these codes, however, is that billed services must be provided by physicians or nonphysician practitioners under the order and medical management of the treating physician. Because of this restriction, there may be payers who do not provide reimbursement for time spent by other members of a care team discussing options for care, goals for end of life, or other advance care planning conversations.

Providing payment for such conversations may also reduce health care costs for intensive and/or end-of-life treatments. In North Carolina in 2016, Medicare was billed for advance care planning conversations for approximately 1% of beneficiaries—19,056 conversations across a total of 1.8 million beneficiaries.<sup>23,24</sup> Studies have shown cost savings to intensive

care and other treatments following the use of advance care planning; a University of Washington study found that national use of advance care planning consultation would save \$1.9 billion in intensive care treatment for 2 million individuals with serious illness.<sup>23</sup>

In order to ensure that all members of a serious illness care team are able to spend sufficient time with families discussing plans for care, the task force recommends:

#### 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

#### ADDRESSING LEGAL AND TECHNOLOGICAL BARRIERS TO ADVANCE CARE PLANNING

In North Carolina an advanced directive must be witnessed by two qualified adults and notarized.<sup>c,d</sup> Qualified witnesses must be competent adults who witness the signing of the advance directive and cannot be relatives of or beneficiaries to the individual completing the advance directive. Witnesses also cannot be physicians, nurses, or any licensed or paid employee of the individual’s health care providers or of a health care facility where the individual lives or is being treated.

Many health care providers, including several of those on the task force, have acknowledged that the current North Carolina signatory requirements constitute a logistical barrier for many individuals and families as they seek to complete advance directives. For families who may be currently facing a serious illness, perhaps to the point of a family member being hospitalized, there may be a sense of urgency to complete the advance directive before the affected individual is unable to express their wishes for care. In such a circumstance, or for families without means to receive appropriate legal, financial, or medical guidance, the requirement of both two qualified witnesses and a notary signature may be particularly burdensome. Signatory restrictions may

c North Carolina General Statute § 32A-15

d North Carolina General Statute § 90-320

also disproportionately impact individuals who are socially isolated, do not have relationships with qualified witnesses, or who are homeless, institutionalized, or migratory.<sup>25</sup>

North Carolina is currently one of three states that require both the two qualified witness signatures and a notary signature for completion of advance directives. Most other states require either one or the other.<sup>26</sup> In task force discussion, members expressed concern about protecting individuals from financial abuse; however, there is a lack of evidence that states with less restrictive signature requirements have greater incidence of fraud, or that changing from more restrictive to less restrictive requirements increases abuse. In addition, the task force acknowledged the ways that the definitions of qualified witness serve to protect against fraudulent activity.

Due primarily to concerns about ensuring adequate protection against fraud, the task force had broad but not unanimous support for the following recommendation from its members. The task force also acknowledged the need for additional stakeholder engagement with organizations concerned about protecting residents from potential fraud, prior to enactment of a statute change.

In order to ease burden for families seeking to complete advance directives and outline their goals for care, the task force recommends:

#### **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.

The North Carolina Advance Health Care Directive Registry allows individuals to register their advance directive documents with the state. This registry was established in 2001 by state law and is administered by the Office of the Secretary of State. The intention of the registry is to assure that documents are secure and available. The Advance Health Care Directive Registry is voluntary and documents do not need to be submitted to the registry to be valid. Registered documents are accessible using a document file number and dedicated password.<sup>27</sup> They are not subject to public records disclosure. Users are charged a one-time \$10 fee to submit their advance directives. Hard copies of advance directives and payment by check must be mailed to the Advance Health Care Directive Registry for submission.<sup>28</sup> In 2017, there were 7,785 advance directives filed with the registry. There is no means to submit documents or payments electronically.

The task force acknowledged that some specific components of the registry, as currently administered, may create burdens on individuals or families who may wish to register their documents. While it is a low fee, the \$10 filing fee and payment accepted only by check might make filing difficult for some individuals. In addition, lack of technological capability to accept electronic documents and payments may be burdensome. Ideally, the documents should be electronic, interoperable with the Health Information Exchange, NC HealthConnex, and electronic health records, and accessible at the point of care by health care providers and emergency medical personnel. However, abuse protection and data privacy for users is critical and people should be required to opt in to provide access to documents through NC HealthConnex. In addition, users should feel comfortable with procedures to change electronic documents when needed.

The task force also discussed the need to protect health care providers who may be initiating conversations or assisting families with the completion of advance directives. Virginia's statute addressing the issue reads "The distribution to patients of written advance directives...and assistance to patients in the completion and execution of such forms by health care providers shall not constitute the unauthorized practice of law."<sup>29</sup> The task force identified the revision of NCGS § 130A Article 21 to include similar protections as an important step to increasing participation in completion of advance directives.

The task force recommends:

#### **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

Members of the task force had similar concerns about access to portable medical Orders. Portable medical orders instruct other health care providers about the level of care to provide and must be filled out by a health care provider in consultation with the patient or the patient's representative. Currently, the Medical Orders for Scope of Treatment (MOST) form may be submitted into a patient's medical record in either paper or electronic form.<sup>29</sup> In addition, current statute requires that, if it is not practical for a patient's representative to sign an original MOST form, the representative must sign a copy of the completed form and return it to the signing provider, at which point the signature is placed on file.<sup>f</sup>

Once a MOST form is completed, there are many logistical barriers to accessing it. In North Carolina, electronic versions are valid, but these are scanned PDF copies of original documents, not versions that were completed via an online/electronic system. Health care providers must either receive a hard copy of the MOST form, or be able to access a patient's electronic health record to view the scanned copies. In practice, access to electronic medical records is difficult or impossible for many health care providers, especially in emergency situations, in a person's home, or elsewhere outside a health care facility. As many individuals with serious illness have multiple care providers across multiple care settings, it is imperative to improve access to portable medical orders via electronic versions and acceptance of electronic signatures.

Gabriel is a 58-year-old man with early-onset dementia. Since his diagnosis, he has moved in with his brother Jack and his sister-in-law Sarah. While Gabriel is still able to take care of himself and run simple errands, he often becomes confused about where he is and becomes upset. Last week, during a doctor's appointment, Jack noticed that Gabriel seemed to be having trouble following what the doctor was discussing, and Jack repeatedly had to interject to ensure that necessary questions were asked. Afterwards, Jack realized that he does not really know how Gabriel feels about his illness and treatment. Jack remembers that before their mother passed away, she insisted upon sitting the family down to talk about her DNR and other end-of-life decisions. Although he does not like thinking about Gabriel's worsening condition, Jack wonders if he should start to ask Gabriel about his wishes for the future.

In addition, the task force examined the barriers created when health care facilities are not able to accept portable medical orders completed by providers at other facilities or in other states. Current law allows facilities to develop processes to accept these orders, but some health systems chose not to execute portable orders based on advice from legal counsel.

The task force recommended a change to the statute to require reciprocity across facilities and state lines, given that the portable medical orders meet criteria outlined in NCGS § 90-21.17. This recommendation also applies to orders established through the US Department of Veterans Affairs health system and facilities.

The National POLST (Physician Orders for Life-Sustaining Treatment) Paradigm is a national organization that provides guidance and support to states as they implement or revise medical orders—in North Carolina, this includes the MOST form. The National POLST Paradigm has created a standard national POLST form that aims to meet legal standards across states and make it easier to honor patient wishes across states.<sup>30</sup> Potential revision of North Carolina statute to include the national POLST form may improve access to portable medical orders and improve adherence to individuals' wishes for end-of-life care across the state.

The task force recommends:

#### 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

As described above, there is great opportunity to improve access to advance directives and portable medical orders through the development and acceptance of electronic versions of these forms. If Recommendations 4.7 and 4.8 are accomplished, with described statutory changes, a next challenge will be how to improve electronic completion and integration into electronic health records.

<sup>f</sup> North Carolina General Statute § 90-21.17 [https://www.ncleg.net/EnactedLegislation/Statutes/PDF/BySection/Chapter\\_90/GS\\_90-21.17.pdf](https://www.ncleg.net/EnactedLegislation/Statutes/PDF/BySection/Chapter_90/GS_90-21.17.pdf)



An electronic health record (EHR) is a digital version of a patient's paper chart. An EHR can be created and managed by health care providers and patients, and is intended to be shared with other providers, within and between health systems, and with patients.<sup>31</sup> EHRs are intended to create efficiencies in practices and health systems, as well as improved care coordination, improved communication, and reductions in costs.<sup>32</sup> Integration of advance directives and portable medical orders into existing electronic health record systems may improve access to the documents across providers and systems and lead to improved goal-concordant care for individuals with serious illness.

In addition, capacity to include electronic versions of advance directives and portable medical orders into EHRs can also facilitate connection with NC HealthConnex, North Carolina's health information exchange. The North Carolina General Assembly established the NC Health Information Exchange Authority (NC HIEA) in 2015. NC HealthConnex is the secure, standardized electronic system that allows health care providers to share patient health information. Health care providers who receive state funds are required to connect their patient health information to NC HealthConnex.<sup>33</sup> Integrating advance directives and portable medical orders into EHRs could also allow this information to be shared by providers through NC HealthConnex.

However, there are many questions regarding best practices and technological feasibility of integrating advance directives and portable medical orders into EHRs, as well as connecting them to NC HealthConnex. Federal requirements for integrating and sharing data between existing technologies must be met, and technology must be sufficient to implement methods of updating documents as care goals or health status changes. The task force recognized the need for additional study and stakeholder engagement to gain a full understanding of technological feasibility of integrating advance directives and portable medical orders into electronic medical records.

Therefore, the task force recommends:

#### **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

Existing health information technology provides additional opportunities to improve access to documented goals of care. Several consumer-facing portals designed to address advance care planning allow users to store and access their documents and improve access for individuals, their families, and their health care providers. An example of such a product is Mind My Health, a free online tool that allows users to store advance care planning documents in a secure, cloud-based registry and to access the documents from a computer or mobile device at any time. Documents can also be downloaded from the registry to share with family members and health care providers. Developed by health experts and supported through initial funding from the Duke Endowment and additional funding from patient advocacy groups and health systems, Mind My Health provides an example of a resource that can be promoted to individuals and families as they develop advance care plans and goals of care.<sup>34</sup> As services like Mind My Health gain traction among consumers, there may also be opportunity to provide an option through these services to connect documents to the Secretary of State's Advance Directives Registry and NC HealthConnex.

However, the task force acknowledged the need for an improved understanding of the existing state of advance directives and portable medical order registration and capacity for sharing across systems. Building on Recommendation 4.9, above, state stakeholders, including the North Carolina Department of Health and Human Services, Department of Information Technology, and the Office of the Secretary of State, should collaborate to analyze the Secretary of State's Advance Directives Registry, including current use data, technical architecture and limitations, and what infrastructure updates would be necessary to connect registered documents to NC HealthConnex. In addition, this analysis should address ways in which health systems, providers, and users may have disparate access to advance planning documents due to lack of broadband service, electronic health records systems (for providers), or other technologies. The goals of this study are to identify specific necessary improvements and resources to increase access to advance care planning documents through technological solutions.

The task force recommends:

#### **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
  - b. 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 5.7)
  - c. 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

## SUPPORTING CAREGIVERS OF THOSE WITH SERIOUS ILLNESS

Caring for a person with serious illness is often very intensive and can require much of a caregiver's time, financial resources, and emotional and physical commitment. Families also often find themselves unprepared for the many adjustments, decisions, and preparations they have to make when faced with serious illness. In coming years, the burden on caregivers will greatly increase. According to AARP, census data shows that the ratio of individual caregivers (number of potential caregivers aged 45-64 for each person aged 80 or older) will change from 7.2 in 2010 to 4 in 2030, and fall further to 3 by 2050.<sup>35</sup> As the caregiver ratio declines, there will be a larger financial, emotional, and logistical burden on individuals and families. The task force examined the needs of family and other unpaid caregivers and developed actionable recommendations with the goal of providing needed resources and assistance.

Throughout the work of the task force, members defined "caregiver" primarily as a family member or other support person (friend, neighbor, volunteer) who provides unpaid care for an individual with serious illness.

Currently in North Carolina, there is a broad system of resources and supports for people providing unpaid care to their family members with serious illness. Services such as adult day care, home-delivered meal services, transportation, caregiver support groups, and respite care can provide much-needed assistance to caregivers. Studies show that respite care, when coupled with education and ongoing support, reduces caregiver stress and burnout.<sup>36</sup> Unfortunately, caregivers often experience difficulty in learning about available resources, accessing these resources, and/or identifying the resources for which they may be eligible. In addition, the availability of resources varies by location, and services remain unaffordable for many North Carolinians.

### HOME AND COMMUNITY-BASED SERVICES TO SUPPORT INDIVIDUALS WITH SERIOUS ILLNESS AND FAMILIES

For the purposes of this report, home and community-based services refers to services funded through state and federal dollars administered at the county level. These services are generally designed to supplement and improve care provided in the home of older adults, to assist unpaid caregivers caring for loved ones in the home, and to delay placement in a long-term care facility outside of the home. These programs may include services such as in-home care, nutrition programs such as home-delivered meals, respite programs, adult day care, and transportation services. Funding streams for these programs vary, as do eligibility criteria. Many of these services, if provided, could prevent or delay placement out of the home. An AARP analysis of home and community-based services provided in 25 states between 2005 and 2012 showed overwhelming evidence that investment in expanded home and community-based services contains costs and slows cost growth, largely due to savings from delayed or prevented out-of-home placement.<sup>37</sup> Research has shown that an increase of \$100 toward respite care produced approximately a one-week delay in out-of-home placement.<sup>38</sup>

For home-based services, such as homemaker services or home health aides, median annual prices in North Carolina range from \$38,000 to \$40,000. Community-based services, such as adult day services or respite care, are less expensive, but adult day care, for instance, still has a median annual price of around \$14,000.<sup>39</sup>

### HOME AND COMMUNITY-BASED SERVICES WAIVERS AND COMMUNITY ALTERNATIVES PROGRAMS

Established in 1981, under section 1915(c) of the Social Security Act, Medicaid Home and Community-based Service (HCBS) waivers—including North Carolina's CAP/DA and CAP/C waivers—have become increasingly popular as states look to reduce Medicaid spending on long-term services and supports delivered in institutional settings.

The Community Alternatives Program for Disabled Adults (CAP/DA) waiver covers services including in-home care, personal care, adult day care, and caregiver respite services.<sup>40,41</sup> These waivers are administered through the Long-Term Supports and Services Unit of NC Medicaid.<sup>42</sup> The waiver was renewed in October 2018, and additional services now include equipment/technology to address safe transport, flexibility in use of respite care, and goods and services to address gaps in transportation.<sup>42</sup>

As of December 2019, North Carolina had 11,534 approved CAP/DA slots across the state, with a wait list of over 2,100 individuals.<sup>9</sup> CAP/DA lead agencies are required to utilize at least 95% of their available CAP/DA slots and this utilization rate is reviewed quarterly. Many counties or service providers may, technically, have “open” slots for individuals seeking services through waivers, but the slots cannot be filled due to lack of local funding. The current average waiting list for CAP/DA services is two years. CAP/DA is only available for low-income individuals who qualify for Medicaid coverage. Currently families of two must have a monthly income at or below \$1,328; households of one must have a monthly income at or below \$981 to be eligible for Medicaid.<sup>40</sup>

The Community Alternatives Program for Children (CAP/C) is a similarly structured program for child beneficiaries of Medicaid. Available to children from birth to age 20 who meet Medicaid eligibility and CAP/C criteria, CAP/C services also include a case manager to help families identify needs and develop a plan of care.<sup>41</sup> Additional services include home and vehicle modifications, palliative care, caregiver training and education, and reusable diapers. Children receiving CAP/C services also have access to regular Medicaid services, including physical/occupational/speech therapy and durable medical equipment.<sup>41</sup>

### HOME AND COMMUNITY CARE BLOCK GRANT

The North Carolina General Assembly established the Home and Community Care Block Grant in 1992 to provide home and community-based services to older adults in North Carolina (NCGS § 143B-181.1(a) (11)). These services target non-Medicaid eligible older adults in the state, and is the primary non-Medicaid funding source for services for those over age 60.<sup>43</sup> The North Carolina Division of Aging and Adult Services administers the block grant and the Area Agencies on Aging disburse funds to counties. Funding is derived from several sources including the federal Older Americans Act (Title III-B funding for supportive services, Title III-C-1 funds for congregate meals, Title-III-C-2 funding for home delivered meals, Title III-D funds for frail elderly services), state appropriations for older adult services, and local matching funds.<sup>h</sup>

Currently in North Carolina, there are 11,114 people on the wait-list for services provided through the Home and Community Care Block Grant.<sup>43</sup> In the 2019 North Carolina General Assembly legislative session, the General Assembly budget (which had not received approval as of this writing) included Home and Community Care Block Grant funding 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. With funding of this amount, an estimated additional 1,500 individuals can be served in the first year of the biennium and an estimated 2,735 served in the second year.<sup>44</sup>

### PROGRAMS OF ALL-INCLUSIVE CARE FOR THE ELDERLY (PACE)

Programs of All-Inclusive Care for the Elderly (PACE) is a federal- and state-funded model that provides services to older adults in need of extensive care, with the goal of allowing people to remain in their homes and communities for longer. Services include adult day care, nutritional assistance (meals and counseling), social work, medical care, home health care, medications, social services, and respite care. Services are coordinated by an interdisciplinary team and are paid by either Medicare or Medicaid through a capitated payment system.<sup>45</sup> In North Carolina, there are disparities to accessing to PACE services, with the Eastern and far Western parts of the state not as well covered as central areas.<sup>42</sup>

### FAMILY CAREGIVER SUPPORT PROGRAM

The National Family Caregiver Support Program provides grant funding for many caregiver support services. These services include information for caregivers, assistance in accessing services, counseling and support groups, training for caregivers on health and nutrition, training on financial literacy, respite care, and some additional supplemental services. Eligible caregivers are those of any age providing care for an adult over age 60 or with Alzheimer’s disease or other dementia, or a non-parent caregiver over age 55 raising a related child or disabled adult. Available services vary by county and work in conjunction with other state and community-based services.<sup>46</sup> While funding for the Family Caregiver Support Program is solely federal, there is opportunity to expand services by providing state funding to support the program.

### STATE-COUNTY SPECIAL ASSISTANCE PROGRAM

As described in Chapter Three, the core State-County Special Assistance program provides low-income individuals with financial support to live in a residential adult care home, family care home, or group home approved by the state. To be eligible for the program, applicants must be over the age of 65 or disabled, must require residential care services, and must meet income and asset requirements.<sup>47</sup> The General Assembly sets an annual maximum rate that residential facilities can charge individuals within the Special Assistance program. If an individual qualifies for the program, he or she will receive the maximum rate, plus a small personal needs allowance, less any individual financial contribution (i.e., social security income or retirement income) (Special Assistance Program, 2016). Individuals eligible for this program are also automatically eligible for Medicaid.

The State-County Special Assistance, In Home (SA/IH) program provides support to those who are eligible for residential care but can safely remain in their homes with assistance. To qualify for the SA/IH program, an individual must meet the general Special Assistance program eligibility requirements but must also be eligible for Medicaid. Applicants for the program are assessed on their ability to afford safe housing, care and support needs, community and family caregiver resources, and any barriers they may face in accessing the services they need. If a case manager determines that an individual can remain safely in his or her home, they develop a care plan and payment structure to ensure applicant needs are met.<sup>47</sup>

*g* This wait-list is reduced from 8000 in 2013, following implementation of Recommendation 5.6 in the NCIOM report *Dementia-Capable North Carolina*. In the 2016 legislative session, funding was provided for an additional 320 CAP/DA slots for individuals with Alzheimer’s or related dementia.

*h* Bethel, M. NC Coalition on Aging (retired) Written (email) communication. March 13, 2020.

### NEW MODELS OF PAYMENT FOR SERVICES

In order to expand home and community-based services, including caregiver support services, the task force examined potential opportunities for new models of payment.

Currently, Medicare has a provision to pay for caregiver respite under Medicare Part A. Medicare will cover respite care when it is part of an eligible beneficiary's hospice care (please see Chapter Three for information on Medicare hospice eligibility). Under this benefit, Medicare only pays for respite care that takes place in a Medicare-approved inpatient facility. The benefit covers up to five days at a time, with an unlimited number of stays. Beneficiaries may be responsible for 5% of the cost of inpatient respite care. Medicare does not cover respite care provided at home.<sup>48</sup> As it moves to managed care, North Carolina Medicaid should consider creating a similar respite benefit for beneficiaries and their caregivers, and evaluate potential cost savings and improved caregiver well-being. The task force cautions, however, that in considering this benefit, NC Medicaid must also review eligibility processes to ensure efficiency and accuracy.

North Carolina Medicaid is also currently developing an innovative pilot model to pay for additional services, seeking to increase value and beneficiaries' health outcomes through payment for services to address non-clinical health needs. Through a series of programs throughout the state, Medicaid's "Healthy Opportunities" program will contract with human services providers in the pilot regions to pay for services in four areas: food, housing, transportation, and interpersonal violence. In paying for services that can significantly impact individuals' health status, many of which are less expensive than clinical health care, Medicaid hopes to save overall Medicaid costs while also improving population health in the state. If the Healthy Opportunities model is shown to be effective in improving health and reducing costs of care, NC Medicaid plans to integrate services throughout Medicaid managed care.<sup>49</sup> This model may be an innovative way to integrate additional services into the Medicaid payment structure. NC Medicaid and communities should explore integrating caregiver support and other home and community-based services for families facing serious illness. In addition, communities and service providers should work to ensure inclusion of these services in the NCCARE360 resource platform (see Chapter Three for additional information).

### SAVINGS FROM HOME- AND COMMUNITY-BASED SERVICES

Recent studies have shown that home and community-based services are likely to be cost-effective over time. On the individual level, a home and community-based services waiver costs Medicaid far less than institutional care—a difference of about \$57,338 per waiver participant.<sup>50</sup> Evidence shows that while states are in the process of expanding HCBS programs, Medicaid spending on long-term care will increase more rapidly than in states with small HCBS services. However, once large HCBS programs are established, Medicaid long-term care spending increases at a slower rate than in states with small HCBS programs. States with large HCBS programs

experienced an inflation-adjusted net reduction in Medicaid expenditures on nursing homes of about 15% between 1995 and 2005.<sup>51</sup> HCBS program expansion can help save Medicaid money over time by slowing the growth of long-term care expenditures.

States have begun to look beyond HCBS at different models for delivering community-based services, including consumer-directed care and capitated payment models. The evidence on Medicaid costs for these models is mixed. On the whole, these alternative programs have elevated patient and caregiver satisfaction above institutional care satisfaction. Some have demonstrated improved health outcomes—most notably the Program for All-Inclusive Care for the Elderly (PACE), which uses capitated Medicaid and Medicare payments to provide community-based integrated care. Some studies have found that Medicaid costs increased as a result of these programs, while others have found cost reductions.<sup>52</sup> Individuals on the wait-lists for services through CAP/DA may be referred to PACE programs if they are locally available.<sup>53</sup>

Overall, the evidence is mixed on the cost-effectiveness of HCBS and other community-based care models. Some populations are unequivocally more cost-effective to serve in the home or community. For example, state HCBS funding significantly decreases the likelihood of out-of-home placement for childless seniors.<sup>54</sup>

The task force recommends:

#### 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

*i* See NCIOM report, *Dementia-Capable North Carolina for more state data on impact of delays in out of home placement through expanded Home and Community-based Services*. Available at [www.nciom.org](http://www.nciom.org)

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

While the recommendation above addresses expansion of existing services and evaluation to analyze the impacts of expansion, there are also opportunities to improve quality of living for caregivers of those with serious illness through new models of family caregiver support. Many caregivers for people with serious illness face logistical and financial difficulties in caring for their family members, especially with regard to employment. Family caregivers often find themselves having to be absent from work or leave the workforce completely to attend to their family members' needs. According to the North Carolina Coalition on Aging, the number one question received by the NC Division of Aging and Adult Services is whether there are programs through which caregivers can be paid to stay home with their ill or disabled loved one.

In the United States, more than 60% of family caregivers (for all conditions) are employed, and in North Carolina, more than 75% of family caregivers have had to adjust work schedules to care for family members.<sup>55</sup> Fifteen percent of family caregivers have to give up employment entirely in order to care for a family member. These changes often result in lowered earnings, reduced Social Security benefits, and loss of other employment-related benefits such as health insurance and retirement savings.<sup>55</sup> Income and benefit losses for family caregivers aged 50 and older are estimated at \$303,880 over the caregiver's lifetime.<sup>56</sup>

Nationally, employers report a productivity loss of nearly \$33.6 billion related to family caregiving, with an average cost per full-time employee caregiver at \$2,110.<sup>57</sup> Employers can contribute to relieving stress on their caregiver employees and also recoup productivity losses through supportive benefits such as enhanced resource referral programs and flexible and accommodating leave policies. Research has shown that flexible workplace policies enhance productivity, lower costs, reduce absenteeism, and improve profits.<sup>57</sup> Additional employer-based policies that can provide support for family caregivers include remote work arrangements, on-site support groups, and backup home care for emergencies.

Numerous bills have been introduced in the state legislature over the last decade to establish paid or unpaid family and medical leave that would support family caregivers. Some would provide paid sick days that could be used for caregiving for family members, and also allow employees to take leave for family members' illness, injury, or medical needs.

In addition, there is also opportunity to look at experiences in other states with such models as state-based long-term care benefits or paying caregivers through a model similar to that of foster care payments.

In order to determine the ways in which these new models of care may be appropriate in North Carolina, assess needed services and disparities in access, and identify additional methods of supporting caregivers for those with serious illness, the task force recommends:

#### **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 below and Recommendation 4.14)

In addition to the study recommended in Recommendation 4.13, the Task Force also identified an additional recommendation focused more specifically on promoting employer-based policies to address the needs of working caregivers. There is recognition that dialogue and collaboration is needed between employers, employee groups, and advocates for caregivers and those with serious illness to identify ways to better support caregivers in the workforce. Information has been provided previously in this chapter about the financial implications of caregiving on family members who are employed as well as the cost to businesses in lost productivity from working caregivers. Supporting employed caregivers results in benefits to businesses including enhanced employee productivity, lower absenteeism, and reduced cost such as the recruitment and hiring cost for replacement workers.<sup>j</sup>

Various stakeholders work across North Carolina to develop and disseminate information and best practices for accommodating family caregivers. There are additional models across sectors that provide lessons for how to support working caregivers. Family Forward NC is an initiative of the North Carolina Early Childhood Foundation focused on working directly with employers to teach them about the benefits of family-friendly policies for both the employer and employees. Much of this work is focused on promoting benefits to families with young children (such as improved child and maternal health, financial security for families with children, etc.). However, policies included in the Family Forward NC such as flexible work schedules, paid sick time, and employee resource networks, align directly with the needs of people caring with family members with serious illness.<sup>58</sup> In addition, many individuals may face a situation of caring for both children and ill family members. Family Forward NC is also developing a recognition award for business and employers who meet family friendly criteria for their

employees. A similar award model for employers who implement policies to support family caregivers would provide an opportunity for employers to emphasize their commitment to these policies to their workforce.

#### 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

Over the past five years, 43 states and territories have passed the Caregiver Advise, Record, Enable (CARE) Act, with several additional states initiating the legislative process. While the specific provisions vary by state, generally the CARE Act requires hospitals to advise individuals of their opportunity to identify a family caregiver, record that caregiver's name in their health record, and provide that caregiver with information about hospital discharge timing and discharge planning. In addition, caregivers would be trained on aspects of their role in discharge and in caring for their family member at home.<sup>55</sup> While it is unclear whether similar legislation would be appropriate in North Carolina, and some North Carolina stakeholders may not be amenable to the requirements, the task force identified the need for improved processes for identification, tracking, and training of 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.



**REFERENCES**

1. Smith M, Saunders R, Stuckhardt L, McGinnis M. Best Care at Lower Cost. National Academies Press; 2013. doi:10.17226/13444
2. Conway J, Johnson B, Edgman-Levitan S, et al. Partnering with patients and families to design a patient- and family-centered health care system: A roadmap for the future. *A Work in Progress In Collaboration with Institute for Healthcare Improvement*. 2006.
3. Coulter A. Patient engagement-what works? *J Ambul Care Manage*. 2012;35(2):80-89. doi:10.1097/JAC.0b013e318249e0fd
4. The Problem. Centers for Disease Control and Prevention. [www.cdc.gov/nchs/](http://www.cdc.gov/nchs/). Accessed February 19, 2020.
5. North Carolina Institute of Medicine. Patient and Family Engagement: A Partnership for Culture Change. A Report of the NCIOM Task Force on Patient and Family Engagement. Morrisville, NC: North Carolina Institute of Medicine; 2015.
6. Olsen LA, Saunders RS, McGinnis JM. Patients Charting the Course: Citizen Engagement in the Learning Health System. National Academies Press; 2011. doi:10.17226/12848
7. Hibbard JH, Mahoney E. Toward a theory of patient and consumer activation. *Patient Educ Couns*. 2010;78(3):377-381. doi:10.1016/j.pec.2009.12.015
8. Committee on the National Quality Report on Health Care Delivery Institute of Medicine. Envisioning the National Health care Quality Report. 2001. <http://www.ncbi.nlm.nih.gov/pubmed/25057551>. Accessed January 16, 2020.
9. American Research Institute. A Roadmap for Patient + Family Engagement in Healthcare. <https://www.air.org/project/roadmap-guides-patient-and-family-engagement-health-care> Accessed February 20, 2020.
10. Centers for Disease Control and Prevention. Advance Care Planning: Ensuring Your Wishes Are Known and Honored If You Are Unable to Speak for Yourself. <https://www.cdc.gov/aging/pdf/advanced-care-planning-critical-issue-brief.pdf> Accessed February 20, 2020
11. Phelps M. It's Not About the Forms. Presentation to NCIOM Task Force on Serious Illness Care. May 2019.
12. Advance Care Planning: Healthcare Directives. <https://www.nia.nih.gov/health/advance-care-planning-healthcare-directives>. National Institute of Aging. Accessed February 19, 2020.
13. Field Test Report: Standardized Screening for Health-Related Resource Needs in North Carolina. North Carolina Department of Health and Human Services. <https://files.nc.gov/ncdhs/NC-Screening-Questions-Report-Final-73019.pdf>. Accessed January 30, 2020.
14. Medical Care Decisions and Advance Directives: What you Should Know. NC Department of Health and Human Services Division of Medical Assistance. <https://files.nc.gov/ncdma/documents/files/advanceddirectcondensed.pdf>. Accessed February 19, 2020.
15. Medical Care Decisions and Advance Directives: What you Should Know. NC Department of Health and Human Services Division of Medical Assistance. <https://files.nc.gov/ncdma/documents/files/advanceddirectcondensed.pdf>. Accessed February 19, 2020.
16. Johnson, KS. Creating Communities to Address Health Disparities. Duke School of Medicine. <https://medschool.duke.edu/about-us/news-and-communications/som-magnify/kimberly-s-johnson-creating-communities-address-health-disparities>. Accessed February 21, 2020.
17. NCBA Health Law Section. North Carolina Bar Association. <https://www.ncbar.org/members/sections/health-law/>. Accessed February 21, 2020.
18. Advance Health Care Directive State Employees' Credit Union. <https://www.ncsecu.org/EstatePlanning/HealthCareDirective.html>. Accessed February 21, 2020.
19. North Carolina Medical Society. An Advance Directive For North Carolina A Practical Form for All Adults. <https://www.ncmedsoc.org/wp-content/uploads/2014/06/Editable-simplified-AD.pdf>. Accessed February 20, 2020.
20. Financial Abuse Costs Elders More than \$2.6 billion Annually, According to MetLife Mature Market Institute Study. MetLife. <https://www.metlife.com/about-us/newsroom/2009/march/financial-abuse-costs-elders-more-than-2-6-billion-annually-ac/>. Accessed March 20, 2020.
21. Kirkman D. Presentation to NCIOM Task Force on Alzheimer's Disease and Related Dementias. August 2015. <http://nciom.org/wp-content/uploads/2017/07/Kirkman-8-21-15.pdf>. Accessed March 20, 2020.
22. Frequently Asked Questions about Billing the Physician Fee Schedule for Advance Care Planning Services. Centers for Medicare and Medicaid Services. 2016. <https://www.cms.gov/Outreach-> Accessed February 24, 2020.
23. Goldsmith T. Choices for End-of-life Require Conversation, Paperwork. North Carolina Health News. <https://www.northcarolinahealthnews.org/2018/03/12/choices-for-end-of-life-advance-directives/>. Accessed February 24, 2020.
24. Total Number of Medicare Beneficiaries. Henry J. Kaiser Family Foundation. <https://www.kff.org/medicare/state-indicator/total-medicare-beneficiaries/?currentTimeframe=2&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>. Accessed March 20, 2020.
25. Castillo LS, Williams BA, Hooper SM, Sabatino CP, Weithorn LA, Sudore RL. Lost in Translation: The Unintended Consequences of Advance Directive Law on Clinical Care. *Ann Intern Med*. 2011;154(2):121. doi:10.1059/0003-4819-154-2-201101180-00012
26. Finalization Requirements for Health Care Directives. Nolo. <https://www.nolo.com/legal-encyclopedia/finalization-requirements-health-care-directives.html>. Accessed February 24, 2020.
27. Elmore, A. Presentation to NCIOM Task Force on Serious Illness Care. May 2019. [http://nciom.org/wp-content/uploads/2019/02/Elmore\\_AHCDR-PPT-Master.pdf](http://nciom.org/wp-content/uploads/2019/02/Elmore_AHCDR-PPT-Master.pdf). Accessed February 20, 2020.
28. North Carolina Secretary of State Frequently Asked Questions. North Carolina Office of Secretary of State. [https://www.sosnc.gov/frequently\\_asked\\_questions/by\\_title/\\_advance\\_healthcare\\_directives](https://www.sosnc.gov/frequently_asked_questions/by_title/_advance_healthcare_directives). Accessed February 20, 2020.
29. Fretwell MD. MOST: A New Portable Medical Order for North Carolina. [www.polst.org](http://www.polst.org). Accessed February 25, 2020.
30. National POLST Form: Portable Medical Order. The POLST Paradigm. <https://polst.org/national-form/?pro=1>. Accessed February 25, 2020.
31. Office of Health Information Technology. What is an electronic health record (EHR)? U.S. Department of Health and Human Services. <https://www.healthit.gov/faq/what-electronic-health-record-ehr>. Accessed February 25, 2020.

32. Office of Health Information Technology. Medical Practice Efficiencies & Cost Savings | U.S. Department of Health and Human Services. <https://www.healthit.gov/topic/health-it-and-health-information-exchange-basics/medical-practice-efficiencies-cost-savings>. Accessed February 25, 2020.
33. NC Health Information Exchange Authority. About the NC HIEA. North Carolina Department of Information Technology. <https://hiea.nc.gov/about-us/about-nc-hiea>. Accessed February 25, 2020.
34. How It Works. Mind My Health. <https://www.mindmyhealth.org/how-it-works>. Accessed February 25, 2020.
35. North Carolina family caregivers provide \$13.4 billion in unpaid care according to AARP study. AARP NC. <https://states.aarp.org/north-carolina/north-carolina-family-caregivers-provide-13-4-billion-in-unpaid-care-according-to-aarp-study>. Accessed March 20, 2020.
36. Respite care. Arch Respite. <https://archrespite.org/productspublications/products-and-publications>. Accessed February 27, 2020.
37. Fox-Grage W, Walls J, Associates HM. Spotlight State Studies Find Home and Community-Based Services to Be Cost-Effective.; 2013. [www.aarp.org/ppi](http://www.aarp.org/ppi). Accessed February 27, 2020.
38. Kosloski K, Montgomery RJV. Impact of Respite Use on Nursing Home Placement. *The Gerontologist*. 1995; 35(1): 67-74. <https://academic.oup.com/gerontologist/article/35/1/67/572128>. Accessed February 27, 2020.
39. Frequently Asked Questions. North Carolina Adult Day Services Association. <https://www.ncadsa.org/faqs.php>. Accessed March 20, 2020.
40. NC Medicaid: Community Alternatives Program for Disabled Adults. North Carolina Department of Health and Human Services. <https://medicaid.ncdhhs.gov/medicaid/get-started/find-programs-and-services/community-alternatives-program-for-disabled-adults>. Accessed February 27, 2020.
41. NC Medicaid: Community Alternatives Program for Children. North Carolina Department of Health and Human Services. <https://medicaid.ncdhhs.gov/medicaid/get-started/find-programs-and-services/community-alternatives-program-for-children>. Accessed February 24, 2020.
42. Lea S. Presentation to NCIOM Task Force on Serious Illness Care: LTSS Landscape | NC Medicaid Long-Term Service and Supports Overview. June 2019.
43. Bethel, M. NC Coalition on Aging. 2020 Legislative Priorities for NC Coalition on Aging. 2020.
44. Conference Report: House and Senate Budget. North Carolina Medical Society. <https://www.ncmedsoc.org/conference-report-house-and-senate-budget/>. Accessed March 20, 2020.
45. Quick Facts about Programs of All-Inclusive Care for the Elderly (PACE). Centers for Medicare and Medicaid Services. <https://www.npaonline.org/sites/default/files/PDFs/PACE-Quick-Facts.pdf> Accessed February 25, 2020.
46. Family Caregiver Support. North Carolina Department of Health and Human Services <https://www.ncdhhs.gov/assistance/adult-services/family-caregiver-support>. Accessed February 26, 2020.
47. State-County Special Assistance. North Carolina Department of Health and Human Services <https://www.ncdhhs.gov/assistance/adult-services/state-county-special-assistance>. Accessed February 14, 2020.
48. Does Medicare Cover Respite Care? Medicare & Medicare Advantage Info, Help and Enrollment. Medicare.org <https://www.medicare.org/articles/does-medicare-cover-respite-care/>. Accessed February 26, 2020.
49. Healthy Opportunities Pilots. North Carolina Department of Health and Human Services. <https://www.ncdhhs.gov/about/department-initiatives/healthy-opportunities/healthy-opportunities-pilots>. Accessed February 26, 2020.
50. Harrington C, Ng T, Kitchener M. Do Medicaid Home and Community Based Service Waivers Save Money? *Home Health Care Serv Q*. 2011;30(4):198-213. doi:10.1080/01621424.2011.622249
51. Kaye HS, LaPlante MP, Harrington C. Do noninstitutional long-term care services reduce medicaid spending? *Health Aff*. 2009;28(1):262-272. doi:10.1377/hlthaff.28.1.262
52. Grabowski DC. The cost-effectiveness of noninstitutional long-term care services: Review and synthesis of the most recent evidence. *Med Care Res Rev*. 2006;63(1):3-28. doi:10.1177/1077558705283120
53. Bratts-Brown W, Operations Manager W. CAP/DA-Priority Planning for Individuals with Alzheimer's Disease and Related Disorders. 2017. [https://files.nc.gov/ncdma/documents/Providers/Programs\\_Services/CAPDA/CAP-DA\\_Alzheimers\\_Disease\\_Webinar\\_2017\\_08.pdf](https://files.nc.gov/ncdma/documents/Providers/Programs_Services/CAPDA/CAP-DA_Alzheimers_Disease_Webinar_2017_08.pdf) Accessed February 27, 2020.
54. Muramatsu N, Yin H, Campbell RT, Hoyem RL, Jacob MA, Ross CO. Risk of nursing home admission among older americans: does states' spending on home- and community-based services matter? *J Gerontol B Psychol Sci Soc Sci*. 2007;62(3):S169-78. doi:10.1093/geronb/62.3.s169
55. The Goal of the CARE Act: Drive Family Caregiver Guidance for Complex Care. AARP Public Policy Institute. 2019. [www.aarp.org/nolongeralone](http://www.aarp.org/nolongeralone). Accessed February 26, 2020.
56. Feinberg LF. Breaking New Ground: Supporting Employed Family Caregivers with Workplace Leave Policies - AARP Insight on the Issues. AARP Public Policy Institute. 2018. <https://www.aarp.org/content/dam/aarp/ppi/2018/08/breaking-new-ground-supporting-employed-family-caregivers-with-workplace-leave-policies.pdf>
57. Feinberg L, Choula R. Understanding the Impact of Family Caregiving on Work Most Family Caregivers Juggle Caring for an Aging Relative or Friend with Employment. AARP Public Policy Institute. 2012. [https://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/ltc/2012/understanding-impact-family-caregiving-work-AARP-ppi-ltc.pdf](https://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/understanding-impact-family-caregiving-work-AARP-ppi-ltc.pdf). Accessed February 27, 2020.
58. Family Forward NC. Guide to Family Forward Workplaces. North Carolina Early Childhood Foundation. 2019. <https://familyforwardnc.com/guide/>. Accessed February 27, 2020.

## IMPROVING SERIOUS ILLNESS CARE IN NORTH CAROLINA

Providing high-quality, person-centered care to individuals who are experiencing a serious illness requires providers who are adequately trained and an infrastructure that supports and encourages coordinated care. The Task Force on Serious Illness Care examined components of the serious illness workforce including capacity, specialization, training, and workforce models, and components of the health system infrastructure to support delivery of care.

### SERIOUS ILLNESS CARE WORKFORCE DEVELOPMENT

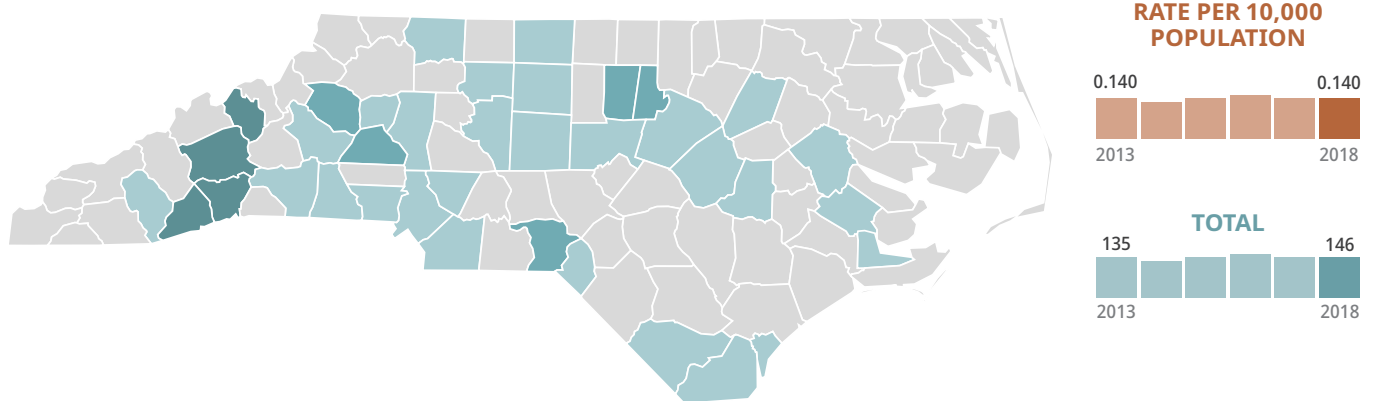
Currently in North Carolina, there are shortages throughout the workforce trained to meet the needs of those who are seriously ill.<sup>1</sup> These shortages limit access to care and are expected to increase over the coming decades due to provider burnout, an aging workforce, low wages, and an inadequate workforce pipeline.<sup>1,2</sup> In many facets of the serious illness workforce, there are barriers to a sustained and adequate workforce. In addition to these shortages, the demographic characteristics of the current workforce, as a whole, are not representative of North Carolina.<sup>3,4</sup> The task force recognized the need to understand the ways in which an unrepresentative workforce could impact the presence of implicit bias within palliative care resulting in lower-quality care for seriously ill individuals who are members of a marginalized community, and the need for policies and processes that increase cultural competency within the workforce.<sup>5</sup>

### PALLIATIVE CARE WORKFORCE

Palliative care as a medical subspecialty was formally recognized in 2008, and as of 2018, there were 221 active, licensed physicians in practice in North Carolina who were board certified in Hospice and Palliative Medicine.<sup>9</sup> Palliative care has grown significantly over the past two decades—less than 25% of hospitals had a palliative care program in 2000,<sup>6</sup> and 93.7% of hospitals with more than 300 beds had a palliative care team in 2019.<sup>1</sup> Despite the growth of the field, access to palliative care varies widely and many communities lack access, particularly in rural areas where health care access remains challenging across types of care. Although North Carolina received a “B” grade for the prevalence and distribution of palliative care programs from the Center to Advance Palliative Care (CAPC) and the National Palliative Care Research Center (NPCRC),<sup>1</sup> in 2018 there were 64 counties in North Carolina without a physician that specialized in palliative medicine.<sup>7</sup>

The current palliative care workforce shortage is projected to grow even greater over the next several decades due to burnout and an aging workforce.<sup>2,4,8</sup> One analysis estimated there is one palliative care physician for every 808 eligible patients, which results in an unsustainable workload, especially considering the emotional impact of working with seriously ill patients.<sup>4</sup> Nearly one-quarter of hospice and palliative care physicians consider leaving the field within their first five years of practice; palliative care clinicians experience one of the highest rates of burnout of specialty physicians, at a rate of 62%.<sup>9,10</sup> The current palliative care workforce

**FIGURE 5.1** Physicians with a Primary Area of Practice of Hospice Palliative Medicine per 10,000 Population by County, North Carolina, 2018



Physicians with a primary area of practice of Hospice Palliative Medicine include the following: Hospice & Palliative Care (OB/GYN), Hospice & Palliative Medicine (Anesthesiology), Hospice & Palliative Medicine (Emergency Medicine), Hospice & Palliative Medicine (Family Medicine), Hospice & Palliative Medicine (Physical Medicine & Rehabilitation), Hospice & Palliative Medicine (Psychiatry & Neurology), Hospice & Palliative Medicine (Radiology), Hospice & Palliative Medicine (Surgery), Hospice and Palliative Medicine, Hospice and Palliative Medicine (Internal Medicine), Palliative Medicine.

Notes: Data include active, licensed physicians in practice in North Carolina as of October 31 of each year who are not residents-in-training and are not employed by the Federal government. Physician data are derived from the North Carolina Medical Board. County estimates are based on primary practice location. Population census data and estimates are downloaded from the North Carolina Office of State Budget and Management via NC LINC and are based on US Census data.

Source: The Cecil G. Sheps Center for Health Services Research, North Carolina Health Professional Supply Data. Accessed February 20, 2020. <https://nchealthworkforce.unc.edu/supply/>

is also largely comprised of older (aged more than 50 years) clinicians with approximately 40% of palliative care physicians being eligible for retirement in the next decade.<sup>4,11</sup> Projections suggest this aging workforce will not be replaced at a sustainable rate. Over the next two decades, the patients eligible for palliative care will grow by 20%, but there is only a 1% expected growth in the physician workforce.<sup>12</sup>

Nurses are critical providers in palliative care and interact with those who are seriously ill and their families more than any other sector of the workforce.<sup>13</sup> Although there is not an overall shortage of nurses in North Carolina, there is disparate distribution of nurses within the state.<sup>3</sup> In 2014, metropolitan (urban) counties had 112.6 registered nurses per 10,000 people, while non-metropolitan (rural) counties had 80.7 registered nurses per 10,000 population.<sup>3</sup> This maldistribution may lead those in rural counties to experience decreased access to care or decreased quality of care.

**FRONTLINE WORKFORCE**

The task force also reviewed the important role of frontline staff such as certified nursing assistants, home health aides, and others. The bulk of day-to-day care that is not provided by family caregivers is provided by this frontline staff. Frontline staff who work with seriously ill patients often work long, non-traditional hours with low wages and perform physically and emotionally demanding tasks. Home care workers make up the largest portion of the workforce that cares for the seriously ill and enables patients to stay within their homes by tending to their health needs as well as assisting with bathing, dressing, and eating.<sup>14</sup> The physical nature of the tasks results in high rates of occupational injury,<sup>14</sup> and most home care workers are not offered health insurance through their employment.<sup>15</sup> The median pay for home health aides in 2018 was \$11.57 per hour, or \$24,060 per year,<sup>16</sup> which is not competitive with fast food or retail positions that offer more traditional work hours. Many home care workers feel they are poorly trained to handle the illness-specific needs of their patients, and there is currently no federal training standard for personal care aides.<sup>14</sup> In 2019, there was an 82% turnover rate among home care workers.<sup>17</sup>

**ADDITIONAL MEMBERS OF THE SERIOUS ILLNESS CARE WORKFORCE**

Social workers’ involvement in serious illness care provides those who are experiencing serious illness and their caregivers with much needed psychological, emotional, spiritual, and cultural aspects of care.<sup>18</sup> Social workers often provide invaluable connections to community resources and education for those who are seriously ill.<sup>18</sup> A review of the field found social workers provide behavioral health support, care management, and referrals to other providers.<sup>19</sup> This multifaceted approach to care may increase access for marginalized communities.<sup>19</sup> The impact of social workers is largely dependent on the amount of time they are able to spend with seriously ill individuals and their families, and decreased social worker caseloads increased satisfaction amongst family members of those in palliative care.<sup>20</sup>

In addition, workers including chaplains and spiritual advisers are also integral components of the serious illness workforce, providing important spiritual care to those facing illness and end of life. Generally, spiritual care “encompasses religious rituals and practices, as well as activities that comfort and support the person who is seriously ill as they search for meaning and for connection” as they navigate care and end-of-life decisions.<sup>21</sup> Qualitative research has shown that spiritual care that improves spiritual and religious coping is associated with stronger social support, less psychological distress, and improved quality of life for people with serious illness.<sup>21</sup> The Center for the Advancement of Palliative Care has issued guidelines and toolkits for health providers and health systems to effectively integrate spiritual care into their palliative, hospice, and serious illness care processes.

In order to create a more sustainable workforce, the task force recommends:

**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 (patient-reported outcomes), 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

### TRAINING THE SERIOUS ILLNESS WORKFORCE

There is a great need for the future and current health care workforce to receive training in order to increase awareness of serious illness care and improve access to quality care.<sup>1</sup> The National Academy of Medicine defined three existing barriers within current training of those who provide care for the seriously ill: lack of palliative care content within the curriculum, lack of focus on communication skills, and the siloed approach to education, which causes a lack of interprofessional collaboration.<sup>22</sup> Despite gains in the recognition of types of serious illness care and the growth of palliative care programs, there is a deficit of palliative care curriculum within undergraduate and graduate medical education.<sup>22</sup> There are also currently no federal training requirements for in-home health workers.<sup>23</sup>

Improved training can also help to increase retention of the serious illness care workforce. An Iowa private home health company that implemented a training program on communication, mentoring, and building relationships with supervisors reduced staff turnover by 20% in one year.<sup>24</sup> Investing in training can better prepare the workforce for the occupational, physical, and emotional demands of their positions.

Training can also serve to redirect traditional, siloed professions toward an interprofessional approach to care and education for those who provide it.<sup>25</sup> Interprofessional education “occurs when two or more professions learn about, from and with each other to enable effective collaboration and improve health outcomes.”<sup>26</sup> This approach to education is crucial for a workforce that works closely with a variety of professionals and often involves referring patients to specialists or additional services. Interprofessional education puts the focus of curricula on specific population needs and promotes collaboration that is needed to provide coordinated serious illness care.<sup>25</sup>

#### PRE-SERVICE TRAINING

Given the current shortage in the serious illness care workforce, it is unlikely that the number of specialty clinicians will be adequate to serve the growing population. Therefore, it is imperative that all clinicians be trained in serious illness care.<sup>27</sup> Primary care providers are often the first step for diagnoses and treatment of serious illness, and patients with a serious illness typically maintain a relationship with their primary care provider over the course of their illness. Primary care clinicians can utilize the ongoing relationship with their patients and help them navigate complex care systems and facilitate end-of-life conversations.<sup>28</sup> In order to ensure that individuals receive access to quality care, the pre-service training curricula of all health care professionals should incorporate components of serious illness care, including palliative care skills such as symptom management and communication skills about disease trajectory and goals for end-of-life care.

Many undergraduate and graduate students’ curricula do not incorporate opportunities to practice communication skills or reinforce empathetic approaches to comforting patients and their family members.<sup>29,30</sup> Feeling unprepared for communicating with patients can lead to emotional distress and subsequent burnout.<sup>31</sup> Learning how to effectively communicate with patients and their families requires ongoing pre-service training and the opportunity for feedback. The most effective communication training requires multiple opportunities throughout pre-service and in-service training and involves role-play scenarios and observations.<sup>30</sup>

#### TRAINING IN CULTURAL COMPETENCY AND IMPLICIT BIAS

**E – Engage in empathetic perspective taking**

**P – Practice the right message**

**I – Individuate, recognizing the individual person’s needs**

**C – Challenge stereotypes**

*Source: American College of Physicians. Accessed February 21, 2020 <http://aahpm.org/quarterly/summer-16-feature>*

In order to effectively provide care for and communicate with seriously ill patients and their families, providers benefit from training in cultural competency and implicit bias. People with a serious illness who also speak a different language, come from marginalized communities, or have differing abilities encounter increased barriers to accessing quality care.<sup>32</sup> Cultural and religious beliefs can add complexity to end-of-life care. Culture can influence a variety of factors in palliative care, including preferences for pain management, communication styles, involvement of family, views on death, and emotional expression.<sup>33</sup> Lack of understanding can lead to dissatisfaction with care and dishonoring pain management or end-of-life wishes.<sup>32</sup> Serious illness workforce training should give providers an opportunity to recognize and confront their own implicit biases and learn strategies to develop empathetic approaches to facilitating conversations that focus on individual needs and wishes.<sup>34</sup>

#### CONTINUING EDUCATION

Although the Accreditation Council for Graduate Medical Education requires curricula for physicians to address communication with patients and families and provide the experience of working at least 100 hours with older patients, the standards do not specify how to facilitate these learning objectives, or address components of palliative care.<sup>28</sup> The current standards also do not recognize the age diversity of people who experience serious illnesses and they create varying levels of competency for providers. For nearly 20 years, there has been a consensus that palliative care training should be incorporated into the education of new- to mid-career physicians,<sup>26</sup> yet if any training is provided on palliative care, it likely takes place during preclinical years.<sup>29</sup> Continuing education provides the current workforce with the opportunity to feel more connected to their work and increase their knowledge which, in turn, decreases turnover.<sup>38</sup>



Continuing education is vital to filling gaps in training the current workforce and addressing the shortage of the palliative care workforce in particular. Currently, North Carolina has a Geriatrics Workforce Enhancement Programs (GWEP) at the University of North Carolina at Chapel Hill. The core common elements of the Geriatric Workforce Education Program include interprofessional education, quality improvement, development of interprofessional teams in primary care, and enhancement of geriatric skill in primary care. The Geriatrics Workforce Enhancement Program partners with academic, primary care, and community-based partners to increase access to education for medical professionals and caregivers in order to deliver continuing education and provide better care for patients in rural, underserved, and diversely populated areas.<sup>22</sup> It also builds workforce capacity by providing distance learning opportunities, conferences, and e-consults. The varied curriculum has enabled the program to train professionals and caregivers in all 100 counties.<sup>23</sup> The Geriatrics Workforce Enhancement Program builds a greater awareness of geriatric screening and conditions through two-year interprofessional fellowship programs in nursing, geriatric medicine, pharmacy, and dentistry.<sup>22</sup> The program also works with family caregivers and communities to enhance skills and preparation, and with partners with state Area Health Education Centers to enhance the availability of interprofessional education.<sup>39-41</sup>

The North Carolina Area Health Education Centers (NC AHEC) operates nine centers that link the state's universities, community hospitals, and health agencies, and provides continuing education opportunities for health care professionals across disciplines. Many of NC AHEC's programs are multidisciplinary and/or interprofessional. The Greensboro AHEC offers a course titled, "What Do I Say? A Course in Talking about Death and Dying," designed for members of the serious illness care workforce.<sup>38</sup> In this interprofessional program, participants are made aware of their own personal beliefs and attitudes about death in order to build cultural competency. The course provides participants with the basic skills needed to empathetically respond to people who are dying and their families, as well as the opportunity to practice those skills.<sup>38</sup> This and other AHEC courses provide an opportunity for the serious illness workforce in North Carolina to build on existing knowledge and learn from colleagues across the workforce to build community and best practices.

The task force recognized the strength of existing interprofessional training programs in serious illness care and recommends the promotion and development of these programs.

**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

**INCENTIVIZE TRAINING IN SERIOUS ILLNESS CARE**

By 2030, the estimated number of physicians specializing in palliative care will not be adequate to care for individuals with serious illness.<sup>42</sup> The workforce needs incentives to encourage and promote specialization in palliative care. Providing palliative care necessitates specialized training, yet many of the professionals on palliative care teams have not received training for their roles.<sup>43</sup> Several states have passed laws requiring continuing education in competencies specific to serious illness care, including pain management, safe opioid prescribing, and palliative care.<sup>44</sup> There may also be opportunity through the expansion of value-based

### IMPROVING SERIOUS ILLNESS CARE IN NORTH CAROLINA

payment models to incentivize additional training in serious illness care, including palliative care, hospice care, and specific core competencies. Models such as the Patient and Caregiver Support for Serious Illness model, the Primary Care First model, and private payment models like Blue Cross and Blue Shield of North Carolina's Care 360 provide a structure through which specific training in serious illness care competencies could be promoted as part of an overall strategy of improving quality and rewarding high-value care. [Please see Chapter Three](#) for additional information on these payment models.

#### 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.

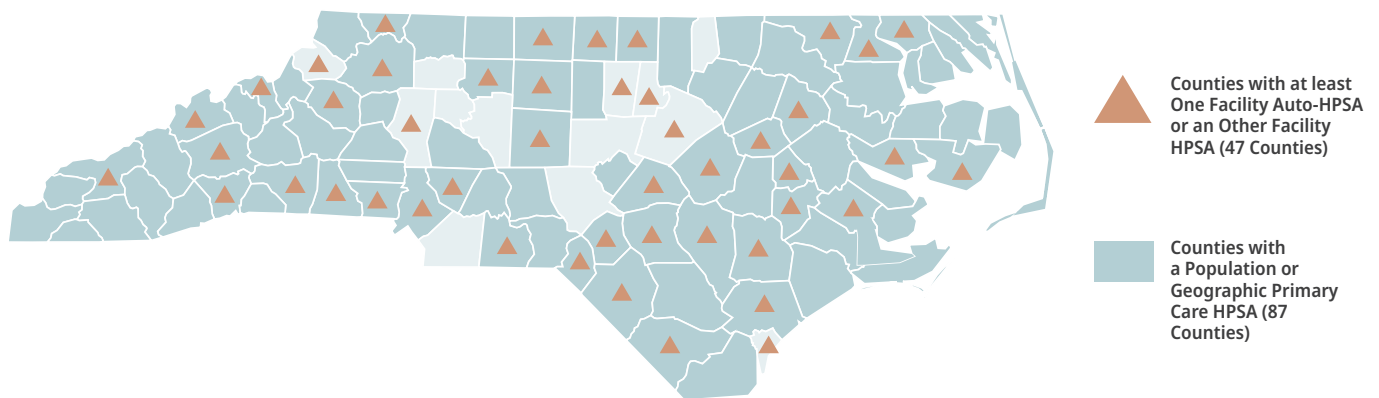
### IMPROVING ACCESS THROUGH HOME- AND COMMUNITY-BASED MODELS OF CARE

In North Carolina there are 83 whole or partial counties with a Health Professional Shortage Area (HPSA) designation for primary care.<sup>45</sup> In order for seriously ill patients to receive non-emergent care in those counties, they must either drive long distances or receive care in emergency rooms or urgent care facilities, which increases cost for the patient and the system. Community-based care provides expanded access to care, particularly for individuals who live in rural communities. Geography, lack of public transportation, and fewer hospitals make it difficult for those who live in rural communities to access care.<sup>46</sup> Rural areas tend to have older residents with lower incomes, which increases the likelihood that those residents will experience a serious illness.<sup>23</sup> Although inpatient care at a hospital may be required for specialized medical services, community-based care can provide patients with safe, reliable, and timely care. This type of care can also alleviate stress for caregivers and provide them with much needed support.

#### TELEHEALTH AND REMOTE CARE

Telehealth services hold promise for improving access to care and reducing costs for the patient and provider. Telehealth is a method for expanding access to care in areas where there is a shortage of primary care providers. Although telehealth services do not allow in-person connection with individuals and providers, they can serve as an important component to serious illness care, particularly in rural areas. Telehealth increases the opportunity for contact with providers, including the opportunity to screen for unmet social needs. These needs can be addressed through NCCARE360, which enables providers to send and receive electronic referrals in order to create a coordinated care network ([see Chapter Three](#)).<sup>47</sup>

**FIGURE 2** North Carolina Office of Rural Health Primary Care - Health Professional Shortage Areas (HPSA)



#### DISCLAIMERS:

- Primary site only, does not include, Correctional Facilities or Federally Qualified Health Center (FQHC) satellite site
- Shortage area may be whole county, or population group or geographical area within county
- Counties that are in white represent urban or rural counties without an official HPSA designation
- The map is not reflective of counties that, if reviewed, would qualify for a primary care HPSA

The National Hospice and Palliative Care Organization has identified three types of telehealth that can be deployed for serious illness care—web-based applications, remote patient monitoring, and store and forward.<sup>48</sup> In web-based applications, patients access portals through the internet and can self-report health indicators such as glucose levels. Remote patient monitoring requires mobile devices or applications but allows real-time information sharing with providers. Both remote services enable providers to receive data to make more informed decisions and can alert providers to the need for care early. Store and forward capabilities enable video and or photos to be shared between a patient and provider.<sup>48</sup> The use of real-time telemedicine in palliative care is relatively new but can expand access to rural areas. In 2016, Four Seasons Compassion for Life in Western North Carolina piloted a program that utilized video conferencing and remote patient monitoring in homes with wireless internet or 3G/4G cellular reception. After participation in the pilot program, patients and caregivers reported a high level of satisfaction with the remote care and appreciated the ongoing and timely communication they were able to have with providers.<sup>49</sup>

**COMMUNITY- AND HOME-BASED CARE DELIVERY**

Community- and home-based care delivery provides those who are seriously ill with an opportunity to receive care in their own homes and communities instead of an institutionalized setting, a wish that has grown increasingly important to most Americans.<sup>50</sup> This type of care delivery also addresses the triple aim of reducing costs, improving patient experience, and improving population health.<sup>50</sup> Costs may be reduced through follow-up visits that enable providers and caregivers to address concerns and intervene in a timely manner, therefore decreasing the risk for hospitalization.<sup>51</sup> The experience of those who are seriously ill can be improved by receiving care from providers who live in their community and are more apt to being culturally attuned to their needs and beliefs. The overall health of the seriously ill population is improved through this care delivery because it enables providers to increase access to care, address social and physical needs, and provide education for positive health behaviors.<sup>52</sup> Therefore, the task force recommends:

**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 (see Chapter Three). 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

**COMMUNITY PARAMEDICINE**

Community paramedicine relies on state-licensed emergency medical services (EMS) professionals and agencies to reduce non-urgent transports to emergency rooms and increase access to primary care through home visits.<sup>48</sup> States are increasingly utilizing community paramedicine to provide care to rural areas, and pilot programs have shown decreased emergency room visits and 9-1-1 calls, improved patient satisfaction, and increased screening of geriatric residents.<sup>53,54</sup> EMS professionals visiting the homes of patients also present an opportunity to provide assistance to family caregivers and assess their well-being.<sup>55</sup> The Centers for Medicare and Medicaid (CMS) payment model of Emergency Triage, Treat, and Transport (ET3) could expand community paramedicine programs. ET3 would pay participating EMS providers to transport a patient to a hospital, primary care, or clinic, or provide treatment through a qualified health professional or telehealth.<sup>56</sup>

There are 24 existing community paramedicine programs in North Carolina.<sup>57</sup> McDowell County saved \$102,833 in six months through its community paramedicine program.<sup>58</sup> In New Hanover County, the New Hanover Regional Medical Center (NHRMC) utilizes community paramedicine for patients who have been referred by a health care provider and live within 30 miles of the hospital’s main campus.<sup>57</sup> The NHRMC piloted the program after more than 700 calls to 9-1-1 came from only 10 people with non-emergency complaints.<sup>58,59</sup> In the pilot program, 20 high-utilization patients were encouraged to call their assigned paramedic instead of 9-1-1 and were visited throughout a 12-month period. After these interventions, there was a 40.4% reduction in emergency department visits; a 27.9% reduction in EMS transports; and a 21.7% reduction in charges.<sup>58</sup> The NHRMC aims to see a referred patient within the first five days of being discharged from the hospital.<sup>58</sup> During these visits, an EMT reviews the patient’s medical history and discharge

### IMPROVING SERIOUS ILLNESS CARE IN NORTH CAROLINA

instructions, refers the patient to community resources, inspects safety of the home environment, conducts a physical exam, and provides education for the patient and their caregivers.<sup>57</sup> This type of care is critical for patients who are seriously ill and wish to stay at home.

Community paramedicine provides a community-based model for increasing access to care for individuals with serious illness, therefore the task force recommends:

#### 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

#### COMMUNITY HEALTH WORKERS

A community health worker is “a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served. This trusting relationship enables the worker to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery.”<sup>60</sup> Community health workers are members of the communities in which seriously ill patients live, making them critical to the provision of timely and culturally competent care for these patients. The North Carolina Department of Health and Human Services has defined four roles for community health workers: cultural liaison, health navigator, health and wellness promoter, and advocate.<sup>61</sup> These roles and the relationships that community health workers form with members of the community are critical to ensuring quality coordinated care for seriously ill patients, particularly those from underserved communities.

Community health workers serve as a bridge between medical providers, social service organizations, and individuals with serious illness. This is particularly important in communities that have traditionally been treated unethically or intentionally underserved by the medical community.

One study that focused on patients from impoverished areas found that community health workers can reduce hospitalization by 65% and improve satisfaction with primary care.<sup>62</sup> Community health workers also aim to reduce hospitalization by addressing social determinants of health and providing culturally sensitive education for patients and caregivers.<sup>63</sup>

Community health workers are part of a sustainable and effective approach to providing non-critical care to those who are seriously ill.<sup>64</sup> NCDHHS has developed core competencies and curricula for community health workers that include communication skills, capacity-building skills, service coordination skills, interpersonal skills, advocacy skills, knowledge base, outreach skills, personal skills and development, and education and facilitation skills. These core competencies and subsequent curricula could be taught at community colleges, AHECs, or other relevant agencies.<sup>61</sup> Community health workers may be a sustainable and effective solution to the serious illness workforce shortage and are liaisons who provide culturally relevant and timely care to seriously ill patients, and the task force recommends:

#### 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. 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
3. Partnership with North Carolina AHEC, community colleges, and other training organizations

#### INFRASTRUCTURE TO SUPPORT SERIOUS ILLNESS CARE

The task force identified several current initiatives in place to address infrastructure needs, particularly in rural North Carolina, and the potential ways that addressing these needs can improve serious illness care in these areas. Those who are seriously ill receive care from hospitals, doctors’ offices, at home, and in assisted living or skilled nursing facilities, necessitating care coordination between the various settings.<sup>65</sup> In order to provide well-coordinated and high-quality care, there must be technological infrastructure to support care coordination and transitions between the various settings where seriously ill patients receive care. In 16 counties in North Carolina, at least 35% of households have



no internet connection. In three North Carolina counties, nearly half of households are without internet.<sup>66</sup> Access to high-speed internet is increasingly required both for recruiting workers and to support individuals' employment (i.e., finding/applying to jobs, communicating with colleagues, or telecommuting). Enhancing the broadband infrastructure is crucial for rural North Carolinians. Many North Carolina broadband projects target the "middle mile," the portion of the telecommunications network that connects the network operator's core to the local network plant, generally located with the local telecommunications provider.<sup>67</sup> Other projects target the "last mile," the portion of the telecommunications network that reaches individual consumers. Because it is often not cost-effective for telecommunications companies to install appropriate technologies in areas that serve few consumers, rural areas are often underserved by these technologies, particularly for the "last mile."<sup>67</sup>

Improved internet capacity through an enhanced broadband infrastructure can improve access to and coordination of care, increase access to personal medical information through online patient portals, and is instrumental in helping practices reach "meaningful use" standards for health information technology. With the expansion of new models of providing care, including telehealth as well as the community health worker and community paramedicine models described above, access to adequate broadband becomes more imperative. The North Carolina Telehealth Network, run by Cabarrus Health Alliance and subsidized by the Federal Communications Commission's Healthcare Connect Fund, provides a telecommunications network and high-speed broadband services with large discounts to eligible public and nonprofit health care providers. The North Carolina Telehealth Network provides this network for health institutions throughout the state and supports telehealth needs, exchange of health information, and disaster monitoring and response support.<sup>68</sup> In addition, the North Carolina Department of Information Technology's Broadband Infrastructure Office provides grants to broadband service providers to facilitate the expansion of broadband infrastructure in underserved areas. The Growing Rural Economies with Access to Technology program funds broadband expansion projects in economically distressed counties.<sup>68</sup>

**OFFICE OF RURAL HEALTH NC ELECTRONIC HEALTH RECORD FUNDING PROGRAM**

NC HealthConnex is a health information exchange that "compiles patients' health information from disparate sources to build a comprehensive view of a patient's electronic health record."<sup>69</sup> This provides an overview of a patient's health, promotes conversations between authorized providers, and reduces duplicative testing, therefore reducing costs for patients and providers.<sup>69</sup> In 2018 the Office of Rural Health offered the Electronic Health Record Funding Program to behavioral health and intellectual or developmental disabilities providers to improve access to care and health outcomes.<sup>70,71</sup> This grant allowed these providers to be reimbursed for electronic health record technology that would enable them to participate in NC HealthConnex.<sup>72</sup> If expanded, this program could offer

an opportunity for providers to improve care coordination and access to care through connecting to NC HealthConnex, especially home health or long-term care providers that may benefit from assistance in developing or enhancing their technological capacity.

In order to improve the technological infrastructure and provide improved and better coordinated serious illness care, the task force recommends:

**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



### REFERENCES

1. Center to Advance Palliative Care, National Palliative Care Research Center. America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals. 2019. [https://reportcard.capc.org/wp-content/uploads/2019/09/CAPC\\_ReportCard19-Digital\\_9\\_19.pdf](https://reportcard.capc.org/wp-content/uploads/2019/09/CAPC_ReportCard19-Digital_9_19.pdf). Accessed January 30, 2020.
2. Kamal MBA MHS AH, Bull MBA JH, Swetz MA KM, Wolf MS SP, Shanafelt TD, Myers MPH ER. Future of the Palliative Care Workforce: Preview to an Impending Crisis. 2017. doi:10.1016/j.amjmed.2016.08.046
3. Fraher E. The Nursing Workforce, Trends and Challenges: Presentation to NCGA Joint Legislative Workforce Development System Reform Oversight Committee. 2016. [https://www.shepscenter.unc.edu/wp-content/uploads/2016/09/Fraher\\_NCGenAssembly\\_Mar2016.pdf](https://www.shepscenter.unc.edu/wp-content/uploads/2016/09/Fraher_NCGenAssembly_Mar2016.pdf). Accessed February 25, 2020.
4. Kamal AH, Wolf SP, Troy J, et al. Policy Changes Key To Promoting Sustainability And Growth Of The Specialty Palliative Care Workforce. *Health Aff.* 2019;38(6):910-918. doi:10.1377/hlthaff.2019.00018
5. Hostetter M, Klein S. In Focus: Reducing Racial Disparities in Health Care by Confronting Racism. The Commonwealth Fund. 2018. <https://www.commonwealthfund.org/publications/newsletter-article/2018/sep/focus-reducing-racial-disparities-health-care-confronting>. Accessed February 25, 2020.
6. Palliative Care Growth Trend Continues, According to Latest Center to Advance Palliative Care Analysis. Center to Advance Palliative Care. <https://www.capc.org/about/press-media/press-releases/2014-9-2/palliative-care-growth-trend-continues-according-to-latest-center-advance-palliative-care-analysis/>. Published 2014. Accessed January 30, 2020.
7. Cecil G. Sheps Center for Health Services Research. North Carolina Health Professional Supply Data: Hospice palliative medicine 2018. <https://nhealthworkforce.unc.edu/supply/>. Published 2020. Accessed February 5, 2020.
8. Lupu D, Quigley L, Mehfood N, Salsberg ES. The Growing Demand for Hospice and Palliative Medicine Physicians: Will the Supply Keep Up? *J Pain Symptom Manage.* 2018;55(4):1216-1223. doi:10.1016/j.jpainsymman.2018.01.011
9. Kamal AH, Bull JH, Wolf SP, et al. Prevalence and Predictors of Burnout Among Hospice and Palliative Care Clinicians in the U.S. 2016. doi:10.1016/j.jpainsymman.2015.10.020
10. Harrison KL, Dzeng E, Ritchie CS, et al. Addressing Palliative Care Clinician Burnout in Organizations: A Workforce Necessity, an Ethical Imperative. *J Pain Symptom Manage.* 2017;53(6):1091-1096. doi:10.1016/j.jpainsymman.2017.01.007
11. Kamal AH, Bull J, Wolf S, et al. Characterizing the Hospice and Palliative Care Workforce in the U.S.: Clinician Demographics and Professional Responsibilities. *J Pain Symptom Manage.* 2016;51(3):597-603. doi:10.1016/j.jpainsymman.2015.10.016
12. Lupu D, Quigley L, Mehfood N, Salsberg ES. The Growing Demand for Hospice and Palliative Medicine Physicians: Will the Supply Keep Up? Vol 168. National Academies Press; 2008. [www.aahpm.org/7Cwww.PalliativeDoctors.org](http://www.aahpm.org/7Cwww.PalliativeDoctors.org). Accessed February 7, 2020.
13. Schroeder K, Lorenz K. Nursing and the future of palliative care. *Asia-Pacific J Oncol Nurs.* 2018;5(1):4-8. doi:10.4103/apjon.apjon\_43\_17
14. Primary Care First Model Options. Center for Medicare & Medicaid Innovation. <https://innovation.cms.gov/initiatives/primary-care-first-model-options/>. Accessed February 9, 2020.
15. Chou CF, Johnson PJ, Ward A, Blewett LA. Health care coverage and the health care industry. *Am J Public Health.* 2009;99(12):2282-2288. doi:10.2105/AJPH.2008.152413
16. U.S. Bureau of Labor Statistics. Occupational Outlook Handbook: Home Health Aides and Personal Care Aides. <https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm#tab-1>. Published 2019. Accessed February 5, 2020.
17. Marcum A. The 2019 Home Care Benchmarking Study. <https://www.homecarepulse.com/articles/letter-from-aaron-marcum-2019-home-care-benchmarking-study/>. Published 2019. Accessed February 6, 2020.
18. Otis-Green S. Passion, Purpose, and Preparation: The Power of Palliative Social Work. <https://csupalliativecare.org/social-workers-2019/>. Published 2019. Accessed February 25, 2020.
19. Fraser M, Lombardi B, Wu S, et al. Social Work in Integrated Primary Care: A Systematic Review . 2016. doi:10.1093/hsw/hlt002
20. McCormick AJ, Curtis JR, Stowell-Weiss P, Toms C, Engelberg R. Improving social work in intensive care unit palliative care: Results of a quality improvement intervention. *J Palliat Med.* 2010;13(3):297-304. doi:10.1089/jpm.2009.0204
21. Hanson LC, Dobbs D, Usher BM, et al. Providers and Types of Spiritual Care during Serious Illness. *J Palliat Med.* 2008;11(6). doi:10.1089/jpm.2008.0008
22. National Academy of Medicine. Professional Education and Development.; 2014. <https://www.ncbi.nlm.nih.gov/books/NBK285682/>. Accessed February 7, 2020.
23. CDC. Rural Health. <https://www.cdc.gov/chronicdisease/resources/publications/factsheets/rural-health.htm>. Published 2019. Accessed February 10, 2020.
24. Bylander J. Community-Focused Health Care For The Seriously Ill. *Health Aff.* 2019;38(3):344-346. doi:10.1377/hlthaff.2019.00111
25. Fraher E, Brandt B. Toward a system where workforce planning and interprofessional practice and education are designed around patients and populations not professions. *J Interprof Care.* 2019;33(4):389-397. doi:10.1080/13561820.2018.1564252
26. World Health Organization. Framework for Action on Interprofessional Education & Collaborative Practice. 2010. [https://apps.who.int/iris/bitstream/handle/10665/70185/WHO\\_HRH\\_HPN\\_10.3\\_eng.pdf;jsessionid=E4DA586C929614AB9F8FE16E85BCCA1E?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/70185/WHO_HRH_HPN_10.3_eng.pdf;jsessionid=E4DA586C929614AB9F8FE16E85BCCA1E?sequence=1). Accessed February 6, 2020.
27. Meier DE, Back AL, Berman A, Block SD, Corrigan JM, Morrison RS. A National Strategy For Palliative Care. *Health Aff.* 2017;36(7):1265-1273. doi:10.1377/hlthaff.2017.0164
28. Fischer J. Serious Illness Care in Primary Care: Presentation to the NCIOM Serious Illness Care Task Force.; 2019. [http://nciom.org/wp-content/uploads/2019/09/Fischer-Presentation\\_NCIOM-SIC-TF\\_Meeting-6.pdf](http://nciom.org/wp-content/uploads/2019/09/Fischer-Presentation_NCIOM-SIC-TF_Meeting-6.pdf). Accessed February 13, 2020.
29. von Gunten C, Ferrell B. Palliative Care: A New Direction For Education And Training. doi:10.1377/HBLOG20140528.039119;ISSUE:ISSUE:10.5555

30. Back AL, Fromme EK, Meier DE. Training Clinicians with Communication Skills Needed to Match Medical Treatments to Patient Values. *J Am Geriatr Soc*. 2019;67(5):S435-S441. doi:10.1111/jgs.15709
31. Wolf AT, White KR, Epstein EG, Enfield KB. Palliative Care and Moral Distress: An Institutional Survey of Critical Care Nurses. *Crit Care Nurse*. 2019;39(5):38-49. doi:10.4037/ccn2019645
32. American Psychological Associations. Culturally Diverse Communities and Palliative and End-of-Life Care. 2019. <https://www.apa.org/pi/aging/programs/eol/end-of-life-diversity.pdf>. Accessed February 26, 2020.
33. Givler A, Maani-Fogelman PA. The Importance Of Cultural Competence in Pain and Palliative Care. StatPearls Publishing. 2019. <http://www.ncbi.nlm.nih.gov/pubmed/29630206>. Accessed February 26, 2020.
34. Beresford L. Unconscious Bias Requires Concentration, Consistent Effort from Providers. <http://aahpm.org/quarterly/summer-16-feature>. Accessed February 26, 2020.
35. Bodenheimer T, Sinsky C. From triple to Quadruple Aim: Care of the patient requires care of the provider. *Ann Fam Med*. 2014;12(6):573-576. doi:10.1370/afm.1713
36. Sanchez-Reilly S, Morrison LJ, Carey E, et al. Caring for oneself to care for others: Physicians and their self-care. *J Support Oncol*. 2013;11(2):75-81. doi:10.12788/j.suponc.0003
37. Buss MK, Lessen DS, Sullivan AM, Von Roenn J, Arnold RM, Block SD. Hematology/oncology fellows' training in palliative care: Results of a national survey. *Cancer*. 2011;117(18):4304-4311. doi:10.1002/cncr.25952
38. Brum S. What Impact Does Training Have on Employee Commitment and Employee Turnover?; 2007. [https://digitalcommons.uri.edu/cgi/viewcontent.cgi?article=1022&context=lrc\\_paper\\_series](https://digitalcommons.uri.edu/cgi/viewcontent.cgi?article=1022&context=lrc_paper_series). Accessed February 20, 2020.
39. Willy E. ECU awarded \$2.5 million to enhance geriatric health care. <http://www.ecu.edu/cs-admin/news/geriatricgrant.cfm>. Published 2015. Accessed February 17, 2020.
40. Duke University School of Medicine. Duke awarded \$2.5 million grant for geriatric workforce enhancement. <https://medicine.duke.edu/medicineneeds/duke-award-ed-25-million-grant-geriatric-workforce-enhancement>. Published 2015. Accessed February 20, 2020.
41. UNC Health Care. Center for Aging and Health receives federal grant. <http://news.unchealthcare.org/som-vital-signs/2015/aug-6/center-for-aging-and-health-receives-federal-grant>. Published 2015. Accessed February 20, 2020.
42. Kamal AH, Bowman B, Ritchie CS. Identifying Palliative Care Champions to Promote High-Quality Care to Those with Serious Illness. *J Am Geriatr Soc*. 2019;67(5):S461-S467. doi:10.1111/jgs.15799
43. Chiu N, Cheon P, Lutz S et al. Inadequacy of palliative training in the medical school curriculum. *J Canc Educ*. 2015;30:749-753.
44. Center to Advance Palliative Care. Policy Initiatives to Support Palliative Care. <https://reportcard.capc.org/recommendations/>. Accessed February 19, 2020.
45. North Carolina Department of Health and Human Services. North Carolina Health Professional Shortage Area. 2018. [https://files.nc.gov/ncdhhs/2018 NC DHHS ORH HPSA One Pager\\_0.pdf](https://files.nc.gov/ncdhhs/2018%20NC%20DHHS%20ORH%20HPSA%20One%20Pager_0.pdf). Accessed February 19, 2020.
46. Center to Advance Palliative Care. Providing Hospice and Palliative Care in Rural and Frontier Areas. 2005. <https://www.issueab.org/resources/17305/17305.pdf>. Accessed February 10, 2020.
47. North Carolina Department of Health and Human Services. NCCARE360. <https://www.ncdhhs.gov/about/department-initiatives/healthy-opportunities/nccare360>. Accessed February 19, 2020.
48. Bishop L, Flick T, Wildman V. Palliative Care Resource Series: Best Practices for Using Telehealth in Palliative Care.; 2015. [https://www.nhpco.org/wp-content/uploads/2019/04/PALLIATIVECARE\\_Telehealth.pdf](https://www.nhpco.org/wp-content/uploads/2019/04/PALLIATIVECARE_Telehealth.pdf). Accessed February 19, 2020.
49. Bonsignore L, Bloom NM, Steinhauer K, et al. Evaluating the Feasibility and Acceptability of a Telehealth Program in a Rural Palliative Care Population: TapCloud for Palliative Care. 2018. doi:10.1016/j.jpainsymman.2018.03.013
50. Lee T, Landers S, Madigan E, et al. The Future of Home Health Care: A Strategic Framework for Optimizing Value. *Home Health Care Manag Pract*. 2016;28(4):262-278. doi:10.1177/1084822316666368
51. Cornwell T. Home-Based Primary Care: How The Modern Day "House Call" Improves Outcomes, Reduces Costs, And Provides Care Where It's Most Often Needed | Health Affairs. <https://www.healthaffairs.org/doi/10.1377/hblog20191003.276602/full/>. Accessed February 26, 2020.
52. Harper K. Building the Science of Population Health. Robert Wood Johnson Foundation. <https://www.rwjf.org/en/library/research/2016/12/building-the-science-of-population-health.html>. Accessed February 26, 2020.
53. Graig L, Alper J. Models and Strategies to Integrate Palliative Care Principles into Care for People with Serious Illness: Proceedings of a Workshop. 2018. doi:10.17226/24908
54. Rural Health Information Hub. Rural Project Examples Addressing Community paramedics. <https://www.ruralhealthinfo.org/project-examples/topics/community-paramedics>. Accessed February 19, 2020.
55. Dow DC, Partain D, Traub M, Smith K. Caring for the Caregiver: I'm Not OK, But That's OK - JEMS. *Journal of Emergency Medical Services*. <https://www.jems.com/2019/04/17/caring-for-the-caregiver-i-m-not-ok-but-that-s-ok/>. Published 2019. Accessed February 19, 2020.
56. Abrashkin KA, Poku A, Ramjit A, et al. Community paramedics treat high acuity conditions in the home: A prospective observational study. *BMJ Support Palliat Care*. 2019. doi:10.1136/bmjspcare-2018-001746
57. Rivenbark S. NHRMC Leading Our Community to Outstanding Health: Presentation to the NCIOM task force on Serious Illness Care. <http://nciom.org/wp-content/uploads/2019/04/2019-NC-Institute-of-Medicine-Presentation.pdf>. Published 2019. Accessed February 4, 2020.
58. North Carolina Department of Health and Human Services. Community Paramedicine Pilot Programs Report to the Joint Legislative Oversight Committee on Health and Human Services and Fiscal Research Division. 2017. [https://files.nc.gov/ncosbm/documents/files/DHHS\\_2017-10-19\\_AppendixB.pdf](https://files.nc.gov/ncosbm/documents/files/DHHS_2017-10-19_AppendixB.pdf). Accessed February 4, 2020.

59. Jones CA, Glendenning D. New Hanover, N.C., Finds Promising Results in Community Paramedicine - JEMS. *J Emerg Med Serv.* 2015;40(2). <https://www.jems.com/2015/01/26/new-hanover-n-c-finds-promising-results-in-community-paramedicine/>. Accessed February 19, 2020.
  60. North Carolina Department of Health and Human Services. Community Health Workers. <https://www.ncdhhs.gov/divisions/office-rural-health/community-health-workers>. Accessed February 19, 2020.
  61. North Carolina Department of Health and Human Services. Community Health Workers in North Carolina: Creating an Infrastructure for Sustainability.; 2018. <https://files.nc.gov/ncdhhs/DHHS-CWH-Report-Web-7-18-18.pdf>. Accessed February 19, 2020.
  62. Kangovi S, Mitra N, Norton L, et al. Effect of Community Health Worker Support on Clinical Outcomes of Low-Income Patients Across Primary Care Facilities: A Randomized Clinical Trial. *JAMA Intern Med.* 2018;178(12):1635-1643. doi:10.1001/jamainternmed.2018.4630
  63. Mobula LM, Okoye MT, Ebony Boulware L, Carson KA, Marsteller JA, Cooper LA. Cultural competence and perceptions of community health workers' effectiveness for reducing health care disparities. *J Prim Care Community Heal.* 2015;6(1):10-15. doi:10.1177/2150131914540917
  64. National Rural Health Association. Community Health Workers: Recommendations for Bridging Healthcare Gaps in Rural America. 2017. [https://www.ruralhealthweb.org/NRHA/media/Emerge\\_NRHA/Advocacy/Policy documents/Community-Health-Workers\\_Feb-2017\\_NRHA-Policy-Paper.pdf](https://www.ruralhealthweb.org/NRHA/media/Emerge_NRHA/Advocacy/Policy%20documents/Community-Health-Workers_Feb-2017_NRHA-Policy-Paper.pdf). Accessed February 26, 2020.
  65. Graig L, Alper J. Models and Strategies to Integrate Palliative Care Principles into Care for People with Serious Illness. 2018. doi:10.17226/24908
  66. NCDIT. American Community Survey: Percent of NC households without internet access. <https://nconemap.maps.arcgis.com/apps/webappviewer/index.html?id=8d455dfdf4bb496192c89ad3a4ab8574>. Accessed February 19, 2020.
  67. NC Broadband Infrastructure Office. Connecting North Carolina: State Broadband Plan. 2017. [https://www.ncbroadband.gov/wp-content/uploads/2017/02/NC-Broadband-Plan\\_2017\\_Online\\_FINAL\\_PNGs3www.pdf](https://www.ncbroadband.gov/wp-content/uploads/2017/02/NC-Broadband-Plan_2017_Online_FINAL_PNGs3www.pdf). Accessed February 26, 2020.
  68. North Carolina Telehealth Network. <http://nctn.web.unc.edu/>. Accessed February 19, 2020.
  69. North Carolina Department of Health and Human Services. A Focus on Health Information Exchange. [https://files.nc.gov/ncdhhs/UNC\\_Rural\\_PhysicianPractice\\_FactSheet.pdf](https://files.nc.gov/ncdhhs/UNC_Rural_PhysicianPractice_FactSheet.pdf). Accessed February 26, 2020.
  70. North Carolina Department of Health and Human Services. How to Connect: NC Health Information Exchange Authority. <https://hiea.nc.gov/providers/how-connect>. Accessed February 26, 2020.
  71. North Carolina Department of Health and Human Services. North Carolina EHR Funding Program for Behavioral Health/IDD Providers. <https://www.ncdhhs.gov/divisions/office-rural-health/office-rural-health-programs/rural-health-information-technology-0>. Accessed February 26, 2020.
  72. Moore L, Servia K, McCaskill M. North Carolina EHR Funding Program for BH/IDD Providers.; 2018. [https://files.nc.gov/ncdhhs/Behavioral Health - IDD EHR Incentive Program Welcome Webinar 12.14.18.pdf](https://files.nc.gov/ncdhhs/Behavioral%20Health%20-%20IDD%20EHR%20Incentive%20Program%20Welcome%20Webinar%2012.14.18.pdf). Accessed February 26, 2020.
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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 recommendations developed by the Task Force serve as an actionable and achievable state plan to meet this goal.

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. 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.

The Task Force developed 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. In addition, the Task Force identified recommendations for several important actions 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. Lastly, the Task Force on Serious Illness Care developed recommendations for enhancing the health and human services infrastructure and workforce that delivers care to individuals with serious illness.

The North Carolina Serious Illness Coalition, which first convened in February 2020, will serve to provide organizational and implementation support as the recommendations move forward. As the Coalition and the many state stakeholders implement the recommendations developed by the Task Force on Serious Illness Care, our state will be able to reach the goal of improving quality of living for those with serious illness.

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RECOMMENDATIONS	RESPONSIBLE AGENCY/ORGANIZATION										
	North Carolina Serious Illness Coalition	North Carolina Department of Health and Human Services	North Carolina Medicaid	North Carolina General Assembly	North Carolina Office of the Secretary of State	North Carolina Department of Information Technology	Private Health Insurers	Geriatric Workforce Enhancement Programs	North Carolina AHEC	Professional and Trade Organizations	Other
<b>Recommendation 2.1:</b> Establish coordinated statewide leadership to facilitate implementation of recommendations and ongoing work to achieve quality of living for individuals with serious illness (PRIORITY)	X										
<b>Recommendation 2.2:</b> Increase research on cultural competency and health equity as it relates to serious illness care										Health care professional associations, facility associations, legal and financial professional associations	Philanthropy, health policy researchers, health services researchers, schools of medicine, schools of nursing, continuing education providers, advocacy organizations, health systems
<b>Recommendation 2.3:</b> 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)	X	X	X	X	X	X	X	X	X	X	All stakeholders
<b>Recommendation 3.1:</b> Deliver goal-concordant, coordinated, team-based care for individuals with serious illness (PRIORITY)											Health care providers, health systems
<b>Recommendation 3.2:</b> Incorporate regular and timely assessment processes to identify and develop effective plans of care for individuals with higher health needs											Health care providers, health systems
<b>Recommendation 3.3:</b> Assess drivers of health and connect individuals with serious illness and caregivers with appropriate non-clinical services		X		X							North Carolina United Way/NC 2-1-1, NCCARE360, health care providers, county commissioners
<b>Recommendation 3.4:</b> Develop and apply new payment models to support palliative care delivery (PRIORITY)			X				X				
<b>Recommendation 3.5:</b> Convene a work group tasked with assessing and developing appropriate quality metrics for serious illness care (PRIORITY)	X										
<b>Recommendation 3.6:</b> Expand access to coverage for health care services		X		X							
<b>Recommendation 4.1:</b> Support patient and family engagement through health care organization policies and processes										Health care professional associations, facility associations	Health care providers, health systems
<b>Recommendation 4.2:</b> Develop statewide initiative for improved awareness of, and support for, completion of advance care planning (PRIORITY)	X										
<b>Recommendation 4.3:</b> Promote training on advance care planning for legal and financial planning professionals		North Carolina Office of Emergency Medical Services			X					Legal and financial industry and professional associations	Legal training providers (including schools of law and continuing education), North Carolina Board of Funeral Service, legal advocacy organizations
<b>Recommendation 4.4:</b> Promote training on advance care planning for health care professionals								X	X		Regulators, schools of medicine, schools of nursing, community colleges, schools of social work
<b>Recommendation 4.5:</b> Incentivize advance care planning that prioritizes the assessment and honoring of individual goals of care			X				X				Health systems, schools of medicine, nursing, social work, pharmacy, community colleges
<b>Recommendation 4.6:</b> Revise signature and notary requirements for advance directives documents (PRIORITY)				X							
<b>Recommendation 4.7:</b> Ease administrative burden, increase participation in completing documents, and improve accuracy of Advance Directives (PRIORITY)				X							
<b>Recommendation 4.8:</b> Ease administrative burden and increase uptake and accuracy of Portable Medical Orders	X			X							
<b>Recommendation 4.9:</b> Promote electronic completion and adequate integration of advance directives and portable medical orders (PRIORITY)	X										
<b>Recommendation 4.10:</b> Improve access to advance care planning documents through optimization of health information technology		X		X	X	X				X	
<b>Recommendation 4.11:</b> Expand Home and Community-Based Services to better support individuals with serious illness and their caregivers (PRIORITY)		X		X							Patient and caregiver advocacy organizations, Area Agencies on Aging, local services providers
<b>Recommendation 4.12:</b> Establish Task Force on Caregiving for Individuals with Serious Illness and analyze additional legislative solutions and financing options to meet the needs of caregivers (PRIORITY)		X		X							
<b>Recommendation 4.13:</b> Develop employer resources for supporting working caregivers											NC Chamber of Commerce, Society of Human Resource Management, employer partners, advocacy organizations, NC Coalition on Aging
<b>Recommendation 4.14:</b> Promote industry standards to identify, train, and track family caregivers										X	
<b>Recommendation 5.1:</b> Develop a supported and engaged serious illness care workforce to meet the needs of North Carolinians		X		X					X		NC Community College System, UNC system, other colleges and universities, health systems
<b>Recommendation 5.2:</b> Promote models of interprofessional training for best practices in serious illness care, including palliative care (PRIORITY)								X	X		Schools of medicine, schools of nursing, schools of dentistry, schools of pharmacy, allied health training programs, divinity schools, community colleges, schools of social work
<b>Recommendation 5.3:</b> Incentivize training in serious illness care, including palliative care			X				X				
<b>Recommendation 5.4:</b> Increase access to serious illness care through expanded implementation of innovative models of care delivery (including telehealth and community- and home-based care) (PRIORITY)		X	X				X				Medical and behavioral health providers
<b>Recommendation 5.5:</b> Expand programs for community paramedicine										NCHA	Community Partners
<b>Recommendation 5.6:</b> Expand community health worker programs		X									Medical and behavioral health providers
<b>Recommendation 5.7:</b> Enhance health information technology infrastructure to improve care coordination and quality of care		X				X					

NCHA = North Carolina Healthcare Association

AHEC= Area Health Education Centers

**HEALTH CARE POWER OF ATTORNEY:**

[https://www.sosnc.gov/documents/forms/advance\\_healthcare\\_directives/health\\_care\\_power\\_of\\_attorney.pdf](https://www.sosnc.gov/documents/forms/advance_healthcare_directives/health_care_power_of_attorney.pdf)

**ADVANCE DIRECTIVE FOR A NATURAL DEATH “LIVING WILL”:**

[https://www.sosnc.gov/documents/forms/advance\\_healthcare\\_directives/advance\\_directive\\_for\\_a\\_natural\\_death.pdf](https://www.sosnc.gov/documents/forms/advance_healthcare_directives/advance_directive_for_a_natural_death.pdf)

**AN ADVANCE DIRECTIVE FOR NORTH CAROLINA: A PRACTICAL FORM FOR ALL ADULTS:**

<https://www.ncmedsoc.org/wp-content/uploads/2014/06/Editable-simplified-AD.pdf>

**NORTH CAROLINA SECRETARY OF STATE ADVANCE HEALTH CARE DIRECTIVE REGISTRY:**

[https://www.sosnc.gov/divisions/advance\\_healthcare\\_directives](https://www.sosnc.gov/divisions/advance_healthcare_directives)

**MEDICAL ORDERS FOR SCOPE OF TREATMENT (MOST):**

<https://info.ncdhhs.gov/dhsr/EMS/pdf/ncmostform.pdf>

**DO NOT RESUSCITATE (DNR):**

<https://info.ncdhhs.gov/dhsr/EMS/pdf/DNR.pdf>

For full versions of documents, please visit [www.nciom.org](http://www.nciom.org)

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