

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.^{1, 23} 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.²⁴

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.⁶ 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.⁷ 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."⁸ 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.⁹ 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.¹⁰ 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.¹¹ It allows individuals to express preferences for care, including end-of-life care, and may be adjusted as circumstances or diagnoses changes.¹² 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.¹² In North Carolina, advance directives include health care power of attorney and living will, and are defined in general statutes (see Figure 4.1).^{a,b} The advance instructions for mental health treatment form is another advance directive that addresses mental health treatment.^{11,13,14}

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.¹⁵ 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.¹⁵ 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.¹⁵

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.¹⁵

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

^b 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.¹⁶ 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.¹⁷ 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.¹⁸ 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 directive¹⁹ (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.²⁰

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.²¹ 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).²² 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.^{23,24} 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.²³

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.^{c,d} 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.²⁵

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.²⁶ 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.²⁷ 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.²⁸ 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."²⁹ 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.²⁹ 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.^f

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.³⁰ 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.

^f North Carolina General Statute § 90-21.17 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.³¹ EHRs are intended to create efficiencies in practices and health systems, as well as improved care coordination, improved communication, and reductions in costs.³² 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.³³ 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.³⁴ 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 2050.³⁵ 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.³⁶ 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.³⁷ Research has shown that an increase of \$100 toward respite care produced approximately a one-week delay in out-of-home placement.³⁸

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 \$14,000.³⁹

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.^{40,41} These waivers are administered through the Long-Term Supports and Services Unit of NC Medicaid.⁴² 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.⁴²

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.⁹ 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.⁴⁰

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.⁴¹ 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.⁴¹

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 60.⁴³ 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.^h

Currently in North Carolina, there are 11,114 people on the wait-list for services provided through the Home and Community Care Block Grant.⁴³ 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.⁴⁴

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.⁴⁵ 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.⁴²

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.⁴⁶ 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.⁴⁷ 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.⁴⁷

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.⁴⁸ 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.⁴⁹ 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.⁵⁰ 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 2005.⁵¹ 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.⁵² Individuals on the wait-lists for services through CAP/DA may be referred to PACE programs if they are locally available.⁵³

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.⁵⁴

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

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.⁵⁵ 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.⁵⁵ Income and benefit losses for family caregivers aged 50 and older are estimated at \$303,880 over the caregiver's lifetime.⁵⁶

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 \$2,110.⁵⁷ 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.⁵⁷ 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.^j

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.⁵⁸ 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.⁵⁵ 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.

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

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