

**Creating Direction:**  
**A Guide for Improving Long-Term Care in South Carolina**

**EMBARGOED DRAFT**  
**PLEASE DO NOT CIRCULATE**

*A report of the Long-Term Care Taskforce*  
*convened by the South Carolina Institute of Medicine & Public Health*

**SPECIAL NOTE:**

All data points and material referenced in this report will be  
formally cited in the final version.

(INSIDE COVER)

About the South Carolina Institute of Medicine and Public Health (IMPH)'s  
Long-Term Care Taskforce:

The **vision** of the Long-Term Care Taskforce is an integrated and fiscally sustainable system of high quality, affordable and accessible long-term services and supports for South Carolinians who need them, including older adults, people with disabilities and caregivers. Such a system would be person-centered and enable sufficient options for individuals and their caregivers to choose the most appropriate care in the least restrictive setting.

The taskforce **mission** is to create lasting improvements in our state's system of long-term services and supports by developing and recommending cost-effective, actionable solutions to current and future challenges.

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*The South Carolina Institute of Medicine and Public Health (IMPH) is an independent entity serving as a neutral convener around the important health issues in our state. IMPH also serves as a resource for evidence-based information to inform health policy decisions.*

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# CREATING DIRECTION

## A Guide for Improving Long-Term Care in South Carolina

### *Preface*

We all wish we had a roadmap for life...a guide to what's around the corner. Unfortunately, life doesn't come with such a guide, and circumstances change—often with little warning. Whether it is the child born with complex medical needs, the young adult whose independence is lost as a result of an accident or life-changing illness, or the older adult in need of increasing support with daily living, people at all ages in many different circumstances face the need for long-term care. Whether you are an individual needing such care or you know someone who does, all of us have thought of what that circumstance would be like. Where would we turn for help? What help would be available? How would we pay for it? And, ultimately, how would we find our way? That last question is important not only for individuals and families across our state that face these challenging circumstances every day, but it is a vital question for South Carolina.

### *What is the best direction for our state when it comes to improving long-term care?*

To answer this question, the SC Institute of Medicine and Public Health convened a Long-Term Care Taskforce in 2014, to bring together providers, researchers and advocates to develop actionable recommendations that provide solutions to current and future challenges. The collective *vision* of the 65 individuals who took part in this year-long effort is an integrated and fiscally sustainable system of high quality, affordable and accessible long-term services and supports for South Carolinians who need them, including older adults, people with disabilities and their caregivers. The following report outlines the recommendations of the taskforce, offering a rationale and action steps for each. In their entirety, this package of recommendations provides a guide for improving long-term care in South Carolina.

This page held for a message from the taskforce chair,

Mr. Joel A. Smith

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## **Executive Summary**

Throughout 2014, the South Carolina Institute of Medicine and Public Health (IMPH) convened a taskforce of providers, researchers and advocates to explore the complex long-term care needs of older adults and people living with disabilities and how those needs are addressed through the system of long-term services and supports. The Long-Term Care Taskforce engaged experts from across our state in exploring critical issues and identifying solutions to current and future challenges. The result of this process was the development of 30 actionable recommendations that create direction for improving long-term care in South Carolina over the next 5 years. This report highlights different components of the long-term care system and describes the recommendations of the taskforce along with potential action steps for achieving them. It is the goal of the Long-Term Care Taskforce that improvements to South Carolina's system of long-term services and supports occur as a result of these recommendations.

## **List of Recommendations**

*Note: The recommendations have been numbered for ease of reference, not to establish priority. They are also presented within topical areas based on the sections of this report.*

### **Strengthening the Long-Term Care Continuum**

*Recommendation 1:* Increase funding for Medicaid-sponsored long-term services and supports over the next five years to strengthen and expand home and community-based services while sustaining institutional care options.

*Recommendation 2:* Expand access to home and community-based options to meet the needs of specific target populations who do not qualify for current service options.

*Recommendation 3:* Enhance the mission of the Lieutenant Governor's Office on Aging and determine its optimal organizational placement to accomplish that mission.

*Recommendation 4:* Ensure access to a highly qualified and trained workforce of individuals who coordinate and manage care.

### Promoting Efficiencies in the System

*Recommendation 5:* Require agencies providing long-term services and supports to collaborate in the development of their programs/services and in budgetary planning.

*Recommendation 6:* Coordinate state agency consumer assessment processes to improve consumer experience and state-level data collection and analysis.

*Recommendation 7:* Continue efforts to move the state closer to coordinated and integrated care for individuals in need of Medicaid-sponsored long-term services and supports.

### Ensuring an Adequate and Trained Workforce

*Recommendation 8:* Establish a Long-Term Care Workforce Development Consortium to ensure the development of a sufficient workforce of health care professionals and unlicensed workers with competencies in long-term services and supports.

*Recommendation 9:* Seek ways to increase compensation for direct care workers in home and community-based settings and enhance reimbursement rates for home and community-based service providers who employ direct care workers.

*Recommendation 10:* Establish the infrastructure for a comprehensive statewide training program for direct care workers in home and community-based settings that will improve outcomes for consumers.

*Recommendation 11:* Develop a comprehensive Direct Care Worker Registry to be used as a resource for consumers, family caregivers and potential employers.

*Recommendation 12:* Increase the presence and capacity of nurses in the LTC workforce.

*Recommendation 13:* Enable registered nurses to delegate specific nursing tasks to unlicensed direct care workers with sufficient training and demonstrated competencies, subject to consumer protections.

### Protecting Vulnerable Adults

*Recommendation 14:* Develop an Adult Abuse Registry.

*Recommendation 15:* Ensure vulnerable adults are protected through an adequate Adult Protective Services Program and have access to preventive services that keep them safely in their homes and from requiring more expensive services.

*Recommendation 16:* Improve quality and consistency of care in community residential care facilities (CRCFs) through enhancements to and oversight of CRCF licensing regulations and the Optional State Supplementation and Optional Supplemental Care for Assisted Living Participants Programs.

## Supporting Family Caregivers

*Recommendation 17:* Improve access and funding for flexible respite services.

*Recommendation 18:* Increase access to training opportunities and sources of ongoing support for family caregivers to sustain them in their caregiving roles.

*Recommendation 19:* Enhance the capacity of the Aging Network to ensure that family caregivers receive critical services, including thorough assessment, education, training & support.

*Recommendation 20:* Validate the role of family caregivers as a critical member of the care team and encourage family engagement.

*Recommendation 21:* Develop and strengthen financial and employment supports for family caregivers.

## Promoting Choice and Independence through Education

*Recommendation 22:* Enhance and coordinate statewide fall prevention efforts, as well as other preventive programs/services.

*Recommendation 23:* Develop and market a comprehensive, user-friendly online information and referral resource for long-term services and supports, which will include resources for caregivers.

*Recommendation 24:* Institute an ongoing informational campaign to educate consumers about the need to save and plan for long-term care expenses.

*Recommendation 25:* Strengthen the state's infrastructure to provide greater supports to consumers and families regarding options to maintain independence.

*Recommendation 26:* Support and enhance awareness about statewide public education efforts regarding advance care planning based on the needs and values of individuals.

## Future Directions

*Recommendation 27:* Develop a formal strategic plan for providing and sustaining long-term services and supports for older adults and people with disabilities in our state.

*Recommendation 28:* Form a statewide taskforce on transportation that will engage experts, consumers and leaders from across South Carolina in efforts to enhance public transportation services—particularly for older adults and persons with disabilities.

*Recommendation 29:* Develop formal “incubator” processes to pilot new approaches and evaluate results.

*Recommendation 30:* Establish a formal and structured implementation process that would bring collective focus, leadership and accountability to each of these recommendations.



## *Overview of Taskforce Process*

The Long-Term Care Taskforce was convened by the SC Institute of Medicine and Public Health (IMPH) in 2014 with the mission of creating lasting improvements in our state's system of long-term services and supports by developing and recommending cost-effective, actionable solutions to current and future challenges. This extensive, year-long effort was driven by the goal that the long-term care system in our state should be person-centered and enable sufficient options for individuals and their caregivers to choose the most appropriate care in the least restrictive setting.

The work of the taskforce was endorsed by the Board of Directors of IMPH and was guided by a 16-member steering committee chaired by Mr. Joel Smith, a former dean of the University of South Carolina's Moore School of Business and a former president of Bank of America. The full taskforce included 65 providers, researchers and advocates from across the state who conducted their work through four committees focused respectively on the broad issues of **access to care, financing and affordability, providers and workforce**, and **service delivery**. These topics were identified through a deliberative process conducted by the initial members of the Steering Committee in an effort to ensure that a comprehensive array of issues affecting long-term care in our state would be addressed. Respecting that every issue identified could not be examined in detail, the committees were asked to focus more so on issues that could be effectively addressed in the context of a 5-year horizon for change.

The initial eight Steering Committee members selected co-chairs for each of the four committees and included those individuals as members of the full Steering Committee. The co-chairs of each committee, with support from IMPH staff, populated the committees through key contacts and a networking process enacted to ensure an effective array of perspectives, experience and expertise among participants. The individuals committees were then charged with developing actionable recommendations to advance improvements in the long-term care system. Each committee formed sub-committees to examine the details of critical issues, hear from outside experts and craft recommendations for review by the full committees. Once each committee refined and approved its recommendations, the entire package was reviewed and approved by the members of the Steering Committee for presentation to the IMPH Board.

## Long-Term Care Taskforce Members

**Mr. Joel A. Smith, Chair**  
*Former Dean, USC Moore School of Business*  
*Retired President,*  
Bank of America (East Region Banking Group)

## Steering Committee Members

*\* Denotes individuals who served as committee co-chairs*

**Ms. Cindy Alewine**  
*President and CEO*  
Alzheimer's Association, SC Chapter

**Ms. Teresa Arnold**  
*State Director*  
AARP South Carolina

**Ms. Coretta Bedsole\***  
*Associate State Director for Advocacy*  
AARP South Carolina

**Ms. Stephanie Blunt\***  
*Executive Director*  
Trident Area Agency on Aging

**Mr. Bruce Bondo\***  
*Member*  
Silver Haired Legislature

**Dr. Tom Brown\***  
*President and CEO (retired)*  
Lutheran Homes of South Carolina

**Ms. Pam Dukes\***  
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*Dean and Professor*  
USC College of Social Work

**Mr. Sam Waldrep\***  
*Chair (past)*  
Adult Protection Coordinating Council

## *Acknowledgements*

Any effort of this scope and duration would not be possible without the committed involvement of many people. Appreciation goes first and foremost to the numerous individuals who gave their time, talents and insights in support the work of this taskforce. The providers, researchers and advocates involved in this year-long process were truly dedicated and offered critical perspectives on the comprehensive array of issues addressed. They gave generously of themselves and their organizations, and they were purposeful in their work—never forgetting that their efforts were on behalf of a countless number of care recipients and caregivers across our state needing effective solutions to the real challenges they face each day.

The individuals who served on the Steering Committee for this taskforce guided every aspect of this work with careful consideration and focused determination. The combined expertise and experience of this group reflects the very best of the long-term care system in our state. As a group of leaders, they applied their collective wisdom while rising above individual and organizational interests. Together with the members of the full taskforce, they created actionable recommendations that offer an opportunity to improve the system of long-term care in our state for years to come. All of these individuals deserve high praise for their work.

Special recognition goes to the taskforce chair, Mr. Joel Smith. As a distinguished business leader and a member of the SC Business Hall of Fame, Mr. Smith brought respected and unbiased leadership to this entire process. His insightful yet neutral perspective shaped the work without influencing the outcomes. He provided objectivity with a full measure of credibility—requesting as his only compensation a fair and purposeful process leading to effective solutions to current and future challenges.

*Ultimately, this report is dedicated to the care recipients and caregivers,  
both formal and informal, who are at the center of the long-term care system.*

## CREATING DIRECTION

### A Guide for Improving Long-Term Care in South Carolina

#### *Introduction*

The phrase “long-term care” evokes images in each of our minds—images that typically reflect other people in circumstances or places we wouldn’t want to be. For those who have personal experience with long-term care, either directly or through a friend or family member, a much clearer image emerges. That image is one of a complex system with high costs, fragmented services and, in far too many instances, unmet need. Unfortunately, that image provides a rather realistic picture of the current system of long-term care in South Carolina. Those in need of long-term services and supports in our state currently rely on a disjointed system of care that can limit individual choice and often fails to adequately foster or extend independence. In addition, issues of quality and safety of care as well as dignity of care receive far too little attention. These concerns—combined with a price tag that is often beyond the reach of individuals and families and increasingly beyond the reach of government—require solutions.

*What is needed are practical solutions that build on what works in the long-term care system and create fixes to identified problems. This report of the Long-Term Care Taskforce provides just such solutions—ones that are urgently needed by individuals and families across South Carolina. Through actionable recommendations addressing specific elements of the system, this report advances solutions to current and future challenges relating to long-term care.*

#### The Urgency of the Problem

**The dramatically shifting demographics of our aging population create a serious problem.**

**It is not someone else’s problem—it is everybody’s problem.**

**The time to address it is NOW.**

Individuals of all ages can find themselves in need of long-term care due to limitations caused by physical, cognitive or chronic health conditions. Older adults, though, are more likely than most to need such services due to the limiting effects of aging. In fact, an estimated 70% of

those over 65 will need long-term care in their lifetime, creating a significant demand for services among a rapidly expanding segment of the population. In 2014, an estimated 734,537 South Carolinians were age 65 and older, a number that is set to grow dramatically with the rise of the “Baby Boom” generation (those born between 1946 and 1964). From 2000 to 2010, South Carolina’s older adult population grew by 32.1%, putting the state in the top 10 fastest growing older adult populations. By 2029, when the youngest Baby Boomers reach age 65, it is expected that our state’s population of older adults will exceed 1.1 million, resulting in 1 in 5 South Carolinians being over the age of 65. Most notably, those 85 and over are among the fastest growing segments of the overall population, and South Carolina is ahead of the national average in that category as well. Over the next two decades, the number of South Carolinians 85 and over is expected to exceed 100,000—an important statistic given the dramatic increase in risk for Alzheimer’s disease and related disorders among this population. As such high-risk, high-need groups expand, demographic trends also show the number of those available to serve as caregivers will actually decline. It is this demographic imperative that drives the urgency of the situation in long-term care. As former Lieutenant Governor Glenn McConnell stated in his “State of Aging” address to the SC General Assembly in March of 2014, “The issue of aging is the central public health challenge of our lifetime.”

The dramatic increase in the older adult population—not just in South Carolina but nationally—will be felt across all aspects of society, impacting far more than the demand for long-term care. However, it is important to realize that long-term care is not an issue just for the aged, as 43% of all those needing such care are under the age of 65. Many younger individuals require long-term services and supports as a result of disability, injury, illness or other complex medical conditions, and their need for such services is often very different from those of older adults and may be of significantly longer duration. While it is important to recognize that the sheer number of those needing services will grow dramatically, the precise and varied needs of the individuals utilizing the long-term care system must be understood as well.

Generally, a person needing long-term services and supports requires assistance with activities of daily living (ADLs, such as eating, bathing and dressing) or instrumental activities of daily living (IADLs, such as transportation, meal preparation or medication management). The need for support may be intermittent for specific activities, or it may be on-going. In more

complex cases, the circumstances may include the need for highly specialized services. This diverse and compelling range of needs can be met by a variety of providers in a variety of places. The long-term care system, as it currently exists, represents a spectrum of services and supports including personal care, adult day services, assisted living, skilled nursing care, caregiver supports and other services. The specific place in which care is delivered and received is influenced by the type, duration and array of services needed, the availability of providers and, more fundamentally, the preferences of the individual. The presence or absence of caregivers—friends or family members offering informal, functional support to a person needing long-term care—is also a major factor influencing the type and degree of services warranted and the point at which they are accessed. Ultimately, the need for long-term care and the setting in which it is delivered are driven by many complex issues and lead to critical questions relating to what is feasible, affordable, preferable and in the best interest of all involved.

Respecting that considerable costs for long-term care are paid for by individuals and families, efforts to promote affordable options are essential in every aspect of the system. Currently, the more traditional service options are often beyond the financial reach of many people in South Carolina. Such traditional forms of long-term care, such as nursing facilities and assisted living, offer comprehensive services, but the total cost is often well beyond the means of individuals and families. For example, the 2014 median annual cost for nursing facility care in South Carolina was \$67,525 (based on a semi-private room). The 2014 median annual cost of assisted living in our state was \$34,485, a cost most often paid directly by the care recipient and/or their families—since assisted living is not traditionally covered by Medicaid or Medicare and less than 3% of South Carolinians have long-term care insurance. Such high out-of-home costs are helping to drive demand for home and community-based services (HCBS) which also align with the overwhelming preference of individuals to live independently and, when possible, to age in place in their own homes. Although HCBS includes a number of lower cost alternatives, these options may be less well known, require considerable coordination, and are still beyond the reach of many in our state.

Due to the high costs of long-term care, publicly funded programs often serve as a safety net not just for the poor but for middle class seniors who have exhausted their resources. As a result, the state covers much of the tab for long-term care through the Medicaid program. Medicaid

actually pays for two-thirds of all long-term care, with the majority of that spent on care in nursing facilities. In 2014, the Medicaid program in South Carolina spent over \$487 million on nursing costs, a figure that has grown at a rate of 2% over the past five years (even though the number of Medicaid residents in nursing facilities has declined during the same time frame). As the Baby Boom Generation moves into their older years, the potential cost of skilled nursing care for a much larger population of South Carolina seniors will be staggering and could severely impact other critical needs and budgetary considerations.

Even for those with effective means of payment and clearly defined needs, accessing and navigating the long-term care system can be challenging. This is especially true given that those who enter the system are most often in the midst of crisis. Making critical, life-changing and sometimes life-sustaining decisions with little opportunity for considering options or comparing providers seems contrary to logic, but it is done countless times every day by individuals and families across South Carolina who are forced by circumstances to confront the reality that they, a friend or a family member need long-term care. To complicate matters more, information is often limited or inconsistent and reliable guidance can seem very hard to find. Simply finding answers to critical questions can take more energy than is available and even good information, once found, does not alleviate all of the problems at hand. Navigating the current system successfully requires obtaining and sharing information in a manner that promotes good, quality care with optimal outcomes, and that is difficult to do without a trusted, experienced guide and a fair amount of determination.

In order to address these critical issues, the SC Institute of Medicine and Public Health convened a taskforce in 2014 to develop actionable recommendations for improving long-term care in our state. The following report reflects their recommendations and offers *A Guide for Improving Long-Term Care in South Carolina*. Ultimately, the success of these recommendations rests on all of us... **as this is everybody's problem.**

## An Overview of the Current System

South Carolina's current long-term care system has been shaped by decades of policy and funding approaches—both state and federal—that have produced a myriad of programs, initiatives and structures created in response to years of changing needs and demographics. The system is layered and complex, involving multiple agencies and organizations that administer and provide services which are both publicly and privately funded. Notably, no one state agency is charged with overseeing and coordinating all of these services. The six primary agencies involved in long-term care are:

- **SC Department of Health and Human Services (SCDHHS)**

SCDHHS administers the state's Medicaid program, which is the largest single payer for LTC needs in the state. Medicaid is required by federal law to provide nursing facility services. In addition, South Carolina operates nine home and community-based waivers that provide services for specific, defined target populations who meet skilled level of care. Other LTC-related services covered by Medicaid include home health and hospice.

- **Lieutenant Governor's Office on Aging (LGOA)**

Individuals who need assistance but do not meet Medicaid's financial or medical eligibility often rely on programs and services administered through the LGOA, which serves as the State Unit on Aging and thereby oversees the distribution of federal Older Americans Act (OAA) funds throughout the state. The OAA does not restrict eligibility for most services based on income level, though services are targeted to those with the greatest social and economic need. The LGOA leads the state's Aging Network. This network includes ten multi-county Area Agencies on Aging/Aging and Disability Resource Centers that are designated to provide planning and administrative oversight of OAA programs and county-level Councils on Aging that carry out activities, programs and services.

- **SC Department of Disabilities and Special Needs (DDSN)**

DDSN operates Medicaid programs for persons with intellectual (or related) disabilities, Pervasive Developmental Disorders, and head and/or spinal cord (or similar) disabilities. These services include home and community-based waivers along with institutions known as Intermediate Care Facilities for Individuals with Intellectual Disabilities.



- **SC Department of Mental Health (DMH)**

DMH operates three veterans' nursing facilities and one community nursing facility. It also provides community-based and in-patient behavioral health services to all individuals across the state, many of whom need long-term services and supports due to mental illness.

- **SC Department of Social Services (DSS)**

DSS administers the Adult Protective Services Program for vulnerable adults who are at risk of or victims of abuse, neglect or exploitation.

Alongside these publicly-funded agencies, private providers, nonprofits, faith-based organizations and their volunteers provide information, support and services for individuals in need of long-term services and supports across our state. Private providers may operate on a statewide basis or may focus on serving a regional or local market. Such providers may be commercial entities or not-for-profit organizations offering services that are fee-based or even charitable. Of course, the lines of private-sector and public services are often interwoven, as the current system of long-term services and supports in our state is interdependent in many ways. Importantly, the entire system is sustained by thousands of individuals who provide essential care every day to friends, neighbors or family members. Over 770,000 South Carolinians serve as informal, unpaid caregivers on an on-going basis. Such individual are vital in preserving the quality of life of their care recipients, just as they are in sustaining the overall system of long-term services and supports in our state.

## Creating Direction: Improving Long-Term Care

The members of the Long-Term Care Taskforce examined our state's current system of long-term services and supports from every angle—respecting that there are many valuable and well-functioning components to the current structure. Throughout 2014, the members of the taskforce met across four committees (Access to Care, Financing and Affordability, Providers and Workforce, and Service Delivery) and numerous subcommittees to review data and information, discuss challenges and opportunities and hear from subject-matter experts. All of that brought rich, substantive debate aimed at creating actionable recommendations for improving long-term care in South Carolina. Those recommendations, which are outlined in this report, specifically address a number of themes that emerged throughout the taskforce process:

- The need for enhanced prevention efforts that support healthy aging;
- The need to promote independent living with choice and dignity;
- The need for improved quality of care and quality of life for care recipients;
- The need for increased supports for caregivers;
- The need for better coordination, structure and efficiency across the system;
- The need for on-going data collection and analysis to inform policy and improve programs and services;
- The need to promote awareness and preparation among the general public for their own long-term care needs; and
- The need for adequate and targeted funding to support a fully functional long-term care system that meets a growing and diverse need.

The actionable recommendations developed by the LTC Taskforce reflect these themes and provide practical solutions to the problems faced by individuals and families across South Carolina who are in need of adequate, reliable long-term services and supports that provide the most appropriate care in the least restrictive setting. The recommendations of the taskforce are presented in this report across six topical areas. A rationale and action steps are presented along with possible responsible entities in support of each of the recommendations. In their entirety, the recommendations and action steps provide a much-needed guide for improving long-term care in South Carolina.

## **Strengthening the Long-Term Care Continuum**

### **Background**

The long-term care (LTC) system should provide a full spectrum of services and supports to ensure that needs and preferences of individuals and families can be met with high quality care and in a cost-effective manner. The system should be structured in such a way that people can move along this continuum of services as their conditions improve or deteriorate. Available services should include in-home services, community-based options and institutional care, as well as supportive services such as case management, information and referral, home modification programs and more. South Carolina's LTC system is not adequately funded to ensure access to a robust continuum of long-term services and supports, and the state's programs and infrastructure need targeted investments to ensure it can meet greater demand as the population needing these services expands.

Needs for long-term services and supports vary greatly—from the need for minimal supportive services to much more complex needs, requiring ongoing medical assistance or supervision. The continuum should provide options for all levels of need, including preventive services that can delay more costly, restrictive placements. Historically, South Carolina has built its LTC continuum primarily around the Medicaid program, investing state resources in a manner that maximizes federal matching dollars. Medicaid is required by Federal law to cover nursing facility services. In addition, South Carolina operates home and community-based services (HCBS) through nine waiver programs for specific, defined target populations who meet institutional level of care but wish to remain in the community. Because the state's current LTC system relies heavily on the Medicaid program, which has a defined (and high) level of care for its services, it can be harder to access services for those who have lower level of care needs.

Nationally, Medicaid-sponsored long-term services and supports have increasingly been serving people in home and community-based settings. Since the statewide implementation of the Community Long Term Care program in 1984, South Carolina's Medicaid program has also grown its HCBS options and now serves more individuals through HCBS waivers than in institutions. HCBS are being offered across the country to meet the needs and preferences of individuals and their families to live as independently as possible. Research also indicates that in

some cases these services may be more cost-effective and could prevent or delay moves to a more costly, institutional setting. In addition to providing consumers with options that support choice, states must also ensure that they are providing robust HCBS options to comply with the 1999 US Supreme Court ruling known as the Olmstead decision and the 2013 Centers for Medicare and Medicaid (CMS) Rule on HCBS. (Provide explanatory footnote.) Both of these require states to have adequate HCBS alternatives (to institutional care) to ensure community-integration. As South Carolina continues to develop its continuum, it is imperative that targeted investments be made to ensure the sustainability of HCBS options currently provided, as well as to address future growth.

Older adults who need assistance but do not meet Medicaid's financial or medical eligibility often rely on programs and services administered through the Lieutenant Governor's Office on Aging (LGOA), which oversees the distribution of federal Older American Act (OAA) funds throughout the state. The OAA does not restrict eligibility for most services based on income level, though services are targeted to those with the greatest social and economic need. While the OAA funds are much more limited than those that can be accessed through Medicaid, they are meant to attract other sources of funding and provide greater flexibility in who can receive services. The OAA funds a range of HCBS, including home-delivered and congregate meals, senior centers and other services that are meant to help older adults who want to age in their own homes and communities. Efforts to enhance such services through the LGOA are vital in light of the changing needs and demographics of South Carolina's population.

Most of the same kinds of services provided through the publicly-funded options can be purchased privately as well. Whether accessing these services via public or private resources, individuals and families often face challenges in navigating the system. Alongside ensuring that continuum includes a robust array of services, we must ensure that it includes ways to help people access those services.

### Recommendations

In order to strengthen the LTC continuum, the Taskforce developed the following recommendations:

- Increase funding for Medicaid-sponsored long-term services and supports over the next five years to strengthen and expand home and community-based services while sustaining institutional care options;
- Expand access to home and community-based services to meet the needs of specific target populations who do not qualify for current service options;
- Enhance the mission of the LGOA and determine its optimal organizational placement to accomplish that mission;
- Ensure access to a highly qualified and trained workforce of individuals who coordinate and manage care.

Further detail on the above recommendations is provided in the pages that follow.

**Recommendation 1: Increase funding for Medicaid-sponsored long-term services and supports over the next five years to strengthen and expand home and community-based services while sustaining institutional care options.**

*(Responsible entity – SC Department of Health and Human Services)*

Rationale

Long-term services and supports should be flexible and provide consumers with meaningful choice, so that they get the right service, in the right place, at the right time, and for the right reimbursement. South Carolina's current LTC system is inadequately funded to support a full range of flexible home and community-based services (HCBS) to meet the real demand. Targeted investments are needed to provide meaningful HCBS alternatives that delay or prevent more costly institutional care. These investments should be considered as a top priority for the state. HCBS growth should be coupled with assurances for an adequate nursing home capacity that meets the real demand.

Action steps

- The SC Department of Health and Human Services (SCDHHS), with stakeholder input, should develop a five-year funding request strategy to quantify the following areas of HCBS investment for the waivers operated through the Community Long Term Care (CLTC) program:
  - Growth in census – Annualizing recent waiver slot increases and sustaining continued growth;
  - Service levels – Increasing the amount of waived services authorized based on best practices and evidence-based information;
  - Reimbursement rates – Increasing provider reimbursements based on a targeted plan that addresses the greatest disparities in rates and is based upon Southeastern averages;
  - New services – Adding in-home respite and caregiver education as waiver services;
  - Infrastructure supports – Establishing a means of addressing key infrastructure resources that support waiver programs, including registered nurses for assessments and level of care determinations, state-level case managers, staff conducting financial eligibility determinations and Phoenix/Care Call enhancements.
- SCDHHS, with stakeholder input, should develop a five-year funding request strategy to quantify future investments in nursing facility services:
  - Complex care – Expanding participation and assuring competitive reimbursement;
  - Additional Medicaid Permit days – Determining real demand based upon:
    - 1) More detailed CLTC “awaiting placement” data;
    - 2) Provider capacity (based upon increased SCDHHS enforcement efforts for more accurate and real-time Nursing Facility Bed Locator data).

A global approach to budget planning and management should be employed by SCDHHS as a tool to be strategic, leverage good outcomes and support the elements of this recommendation.

**Recommendation 2: Expand access to home and community-based services to meet the needs of specific target populations who do not qualify for current service options.**

*(Responsible entities – SCDHHS and LGOA)*

Rationale

The state's continuum of home and community-based services (HCBS) is funded primarily through Medicaid and the Older Americans Act (OAA). Medicaid HCBS waivers serve only those individuals who meet both the Medicaid institutional level of care and financial requirements. The new Healthy Connections Prime program provides an additional alternative by offering HCBS to people who may need services following a hospitalization or may have other short-term needs such as temporary absence of a caregiver. OAA services are generally targeted to those consumers who may not meet Medicaid qualifications, becoming a safety net for this population.

While the services outlined above do meet the needs of many across South Carolina, there are target groups that could benefit from the availability of expanded service options within the state's LTC continuum of care including:

- Individuals who do not meet the current medical necessity or nursing facility level of care requirements for Medicaid-sponsored LTSS\*;
- Individuals who do not meet financial eligibility requirements for Medicaid-sponsored LTSS;
- Individuals who were receiving Medicaid-sponsored LTSS but whose conditions have improved such that they no longer meet the nursing facility level of care. (Note: individuals who meet nursing level of care criteria have HCBS options via Medicaid waivers. If their conditions improve such that they do not meet these criteria, they no longer have access to any waiver services, even though they might need some level of continued support to remain as independent, stable and functional as possible.)

Expanding options would ensure that the state's continuum of care includes a full array of services to support the needs of consumers and families that could prevent or delay the need for more costly out-of-home services and provide assistance during the transitions between care settings. These HCBS must be supported by an infrastructure that includes intake, assessment, eligibility, service planning, case management, and monitoring functions.

\*Examples to illustrate the kinds of people who are described here (to include as a footnote): people who need supervision and cueing in the performance of daily tasks (perhaps because of cognitive impairments due to dementia or a brain injury) but do not yet have qualifying functional deficits required to meet Medicaid level of care criteria.

Action steps

- SCDHHS should:
  - Explore options with the Centers for Medicare and Medicaid Services to modify the Medicaid nursing facility level of care to be less restrictive for HCBS than for nursing facility services;
  - Consider expanding the use of 1915i state plan services targeting consumers who may not qualify currently for one of the state's HCBS waivers;

- Conduct a cost-benefit analysis of offering personal care as a state plan option;
  - Conduct a cost-benefit analysis of expanding the Optional State Supplementation program to target persons in need of HCBS options but who want to reside in a less restrictive setting than a CRCF.
- The LGOA should develop plans that complement the SCDHHS actions outlined above.



**Recommendation 3: Enhance the mission of the Lieutenant Governor’s Office on Aging and determine its optimal organizational placement to accomplish that mission.**

*(Responsibilities entities – LGOA with key outside stakeholders\*)*

Rationale

The LGOA is designated as South Carolina’s State Unit on Aging, administering federal Older American Act (OAA) funds and leading the state’s Aging Network. This network includes ten multi-county Area Agencies on Aging/Aging and Disability Resource Centers (AAAs/ADRCs) that are designated to provide planning and administrative oversight of OAA programs and county-level Councils on Aging that carry out activities, programs and services. The LGOA also performs other mandated state functions, such as operating Ombudsman activities, administering the SC Geriatric Loan Forgiveness program and housing the Alzheimer’s Resource Coordination Center. With the expected growth in the older adult population, South Carolina needs to ensure that this agency is effectively positioned to provide strong leadership to meet this growing demand.

*Exploring changes in programs/services*

Facing an unprecedented growth in the aging population, it is important to undertake a review of current program and services—and to explore what is vital to continue and what new offerings need to be developed. The Taskforce identified several priorities that need to be considered for enhancement, including preventive services, consumer education, family caregiver programs and case management activities. While each of these types of services is currently being offered by through the Aging Network, the Taskforce acknowledges that the quantity, quality and depth of these services must be enhanced to meet coming demand.

*Organizational placement*

Over the last 25 years, the Office on Aging has had four different organizational configurations as: a free-standing state agency; a division in the Office of the Governor; a division in the SC Department of Health and Human Services; and a division of the Office of the Lieutenant Governor. Currently, South Carolina is the only state where the State Unit on Aging is part of the Lieutenant Governor’s Office. With the change in the election processes in 2018 requiring the governor and lieutenant governor to run on the same ticket, the political distinctions of the current structure will change. When addressing organizational placement, issues related to infrastructure and communications both within the agency and throughout the network should be considered.

Action steps

In an effort to achieve this recommendation, the following critical issues related to strengthening the LGOA should be addressed:

- Organizational placement that will maximize the agency’s capacity;
- Service enhancements including in the areas of prevention, family caregiver programs, consumer education and case management;
- Structure of the Aging Network and interface among the state, regional and county levels;
- Connectivity with other agencies, particularly with SCDHHS.

In addition, to address the fiscal viability and stability of the LGOA so that it can effectively achieve its mission:

- The Taskforce recommends that the General Assembly:
  - Allocate an adequate and stable source of state general funds;
  - Increase funding options to provide HCBS to target populations not served via Medicaid (see Recommendation # 2).
- The LGOA should:
  - Promote The Elder Care Trust in order to increase revenues that support innovative programs helping older adults remain in their homes and communities;
  - Maximize opportunities to fully utilize Medicaid funding to complement and strengthen the array of services provided through the Aging Network.

\*This recommendation and associated action steps should be approached with respect to the 2015 Legislative Audit Committee activity relating the Lieutenant Governor's Office on Aging.

**Recommendation 4: Ensure access to a highly qualified and trained workforce of individuals who coordinate and manage care.**

*(Responsible entities – SCDHHS, LGOA, SC Hospital Association, Office for the Study of Aging, and BlueCross BlueShield of South Carolina)*

Rationale

Given the complexity of the LTC system, consumers and families often need help navigating the continuum of care. The extent of the help that they need could range from short-term information and referral to more intensive help during care transitions or ongoing assistance. Consumers and families may be confused about what in-home options are available and how those contrast to the type of care offered in assisted living or nursing facilities. They may be overwhelmed when making critical decisions especially during a crisis situation or when time constraints impact living arrangements or caregiver support. Individuals who provide services to help these consumers and families understand the full range of options available and how to access services in the least restrictive settings may include case managers, service coordinators, care coordinators, discharge planners and care managers. Specific functions provided by these professionals vary from setting to setting but generally include some degree of assessment, care plan development, referral and monitoring. Responsibilities could also encompass service authorization, utilization review, facilitation of self-direction and ensuring effective coordination and communication among providers and family caregivers/informal supports.

In South Carolina, access to case management services is largely dictated by funding source. Depending upon their needs, Medicaid consumers can utilize targeted case management services, waiver case management services or care coordination services if enrolled in a managed care program. Limited case management services are also available through the Older Americans Act funds administered by the Office on Aging. Medicare has recently implemented policies increasing access to care coordination services as well, recognizing that poor coordination can lead to poor outcomes and high costs. Many of these efforts have focused heavily on providing services during care transitions to prevent hospital readmissions. Outside of these publicly funded programs/options, individual consumers and families may access case management services by hiring a private geriatric or disability care manager or in some cases via private insurance (e.g., long-term care insurance), but these options are much more limited. Requirements for case management, as well as training and qualifications for individuals providing these services, vary depending on funding source, leading to inconsistencies in services provided.

Action steps

- In order to support a full range of case management/care coordination services to address all levels of consumer need:
  - SCDHHS and LGOA should ensure that Medicaid targeted case management is fully utilized when appropriate;
  - The LTC Workforce Development Consortium (see Recommendation # 8) will convene a workgroup comprised of SCDHHS and other state agencies, the SC Hospital Association, Blue Cross/Blue Shield, the SC Primary Health Care Association, SC Office of Rural Health and other relevant stakeholders to expand ways to bill these services for non-Medicaid populations;

- LGOA should develop a plan to expand case management to non-Medicaid populations and an outreach strategy to reach individuals who could benefit from these services.
- OSA (with input from colleges/universities, SCDHHS and LGOA) should develop comprehensive training modules for case managers and care coordinators. The target audience for these modules would initially be case managers and care coordinators through Medicaid and the Aging Network. The modules should address the following:
  - The full array of options within the LTC continuum in South Carolina and how to guide consumers in navigating these options and in making successful care transitions;
  - Ways to utilize person-centered models in maximizing consumer input and autonomy in planning for and directing service needs.
- SCDHHS should continue and expand its efforts to promote patient-centered medical homes, as they can play a role in care coordination. It will be important that staff at these patient-centered medical homes have access to information and referral resources and/or training. Other key stakeholder groups focused on patient-centered medical homes should be engaged in this effort related to enhancing care coordination.

In addition to the recommendations above, the Taskforce acknowledges that SCDHHS has developed a transition plan to come into compliance with the federal conflict-free case management requirement, under the CMS Final Rule on HCBS. The applicability and value of this requirement (i.e., conflict-free case management) should be considered for other non-Medicaid, publicly-funded case management.

## **Promoting Efficiencies in the System**

### **Background**

South Carolina's long-term care (LTC) system lacks overarching administrative structures to effectively coordinate programs and services across agency lines. No one agency oversees all long-term services and supports. Without such mechanisms to facilitate interagency communication, data sharing and planning, the system lacks efficiency and investments made with state and federal funds are not wisely utilized. Monitoring and evaluating the effectiveness of programs and services, as well as identifying and addressing unmet needs, is likewise challenging without the ability to track system-wide issues and trends.

Another factor that contributes to inefficiencies in the LTC system is that it relies predominantly on fee-for-service models, which may not effectively coordinate and integrate primary care, behavioral health and long-term services and supports as a managed care approach would and lack a person-centered focus. Inefficiencies in the system and poor interagency collaboration adversely impact consumers and families. A more efficient system will help them better navigate and access needed services at the right time, the right place and for the right cost, improving outcomes and ultimately producing higher levels of consumer satisfaction and engagement.

### **Recommendations**

In order to promote efficiencies in the LTC system, the Taskforce developed the following recommendations:

- Require agencies providing long-term services and supports to collaborate in the development of their programs/services and in budgetary planning;
- Coordinate state agency consumer assessment processes to improve consumer experience and state-level data collection and analysis;
- Continue efforts to move the state closer to coordinated and integrated care for people in need of Medicaid-sponsored long-term services and supports.

Further detail on the above recommendations is provided in the pages that follow.

**Recommendation 5: Require agencies providing long-term services and supports to collaborate in the development of their programs/services and in budgetary planning.**  
*(Lead entities – State Budget Office and all other major impacted state agencies: SCDHHS, LGOA, DMH, DSS, DDSN, and DHEC)*

#### Rationale

Various state agencies provide long-term services and supports, and each of these has its own systems for service delivery, planning and data collection and analysis. In the past, several formal interagency committees were established to foster better communication among state agencies and ensure coordination around common areas of interest or for specific target populations. Examples of such interagency committees include the Long Term Care Council and the Human Services Coordinating Council, both of which have been inactive for over twelve years. Currently, there are several groups that exist to encourage collaboration around particular special interest issues, such as the Adult Protection Coordinating Council. However, there is no high level, interagency committee looking broadly at the populations requiring long-term services and supports, their needs and where/how those needs are being addressed. Other areas in human services do have such an interagency committee in place; the structure of the South Carolina Joint Council on Children and Adolescents, including its composition and staffing, provides a good model.

Outside Cabinet agencies, there is no formal process for coordinating budget requests among various state agencies that provide long-term services and supports. In addition, different agencies are assigned to different Committees within the General Assembly, creating additional challenges in coordinating requests. These factors make it difficult for each agency to be informed about other budget requests that could impact its own mission and its purchase and/or delivery of services. Budget collaboration among these agencies could avoid duplication in effort and present opportunities for coordinating budgetary requests across agency lines. For the health and social service agencies that rely on Medicaid funding, a well-coordinated appropriations request could benefit not only the individual agencies and their consumers but also could aid legislators in their decision-making.

#### Action steps

The Taskforce recommends that General Assembly should:

- Enact a proviso requiring that the State Budget Office establish a collaborative budget submission process for the following state agencies providing LTC services: SCDHHS, LGOA, DMH, DSS, DDSN, and DHEC;
- Re-establish the Interagency LTC Council.

**Recommendation 6: Coordinate state agency consumer assessment processes to improve consumer experience and state-level data collection and analysis.**

*(Responsible entities include: Revenue and Fiscal Affairs Office, SCDHHS, DDSN, and LGOA)*

Rationale

State agencies and service providers use assessment instruments to collect consumer demographics and other information (e.g., medical, functional, financial, caregiver/social support, living environment) to determine program eligibility, assess service needs and preferences and monitor quality. Within South Carolina's long-term care system, each agency has developed its own assessment tools, often using data elements mandated by funders. Agencies have invested in automating these tools, which are an integral part of their client management and/or decision support systems. However, these assessment systems are not currently compatible with one another and information cannot be easily shared among agencies. Information sharing in an efficient way is possible without requiring agencies to abandon their existing tools and automated systems. Having a comprehensive system to share consumer assessment information among key agencies has the potential to create a more efficient and seamless experience for consumers and families as well as reduce administrative burden. Furthermore, such a system would enable the state to capture standardized data that would aid in projecting need, program planning, research and evaluation.

Action steps

The SC Revenue and Fiscal Affairs Office should, in conjunction with SCDHHS, DDSN, and LGOA:

- Review existing assessment tools for consumers and family caregivers that have been validated and are considered best practice;
- Determine common elements that are (or should be) collected across agencies to become the core of a shared assessment data set;
- Make recommendations (based on best practices and common elements) about software development and hosting, ongoing user training, and options for periodic updates;
- Address confidentiality and HIPAA related issues about sharing health information.

**Recommendation 7: Continue efforts to move the state closer to coordinated and integrated care for people in need of Medicaid-sponsored long-term services and supports.**

*(Responsible entity – SCDHHS)*

Rationale

SCDHHS estimates that over 85% of individuals receiving long-term services and supports (LTSS) in South Carolina are dually eligible for both Medicare and Medicaid. Each of these two distinct federal programs has its own enrollment policies and package of benefits. Therefore, many people who are dually eligible often “receive fragmented and uncoordinated care.” Faced with this expensive problem, a growing number of states are turning to managed LTSS models to integrate “care and services into a single program or coordinated delivery system” that will improve the quality of care and lower costs for this high-need population. (Note: Individuals who are not dually eligible could also benefit from coordinated options that would integrate LTSS, primary care and behavioral health. These individuals receiving long-term services and supports are generally people under age 65 who are awaiting Medicare eligibility.)

Better coordination and integration of all care for consumers receiving Medicaid-sponsored long-term services and supports through a managed delivery approach has the potential to:

- Create a more seamless, holistic experience for consumers;
- Strengthen the interplay between LTSS, primary care and behavioral health services;
- Provide access to overall care coordination;
- Provide more appropriate utilization of health care options, especially HCBS, and support transitions between care settings;
- Create the potential for cost savings and more innovative forms of reimbursement for providers.

To date, South Carolina has limited experience with managed LTSS models, through the Program for All-Inclusive Care of the Elderly (PACE) and the recent launch of Healthy Connections Prime. A nationally-recognized best practice, the PACE model integrates Medicare and Medicaid funding and uses a multidisciplinary team based in an adult day health center to coordinate care. South Carolina has two PACE programs that serve a total of approximately 500 adults over the age of 55 in Richland, Lexington, Bamberg, Orangeburg and Calhoun counties with expansion in the Upstate planned for 2016. Healthy Connections Prime also blends Medicare and Medicaid funding and contracts with Managed Care Organizations (MCOs), which assume financial risk. It uses a multidisciplinary team approach in its model of care and provides extensive, boots-on-the-ground care coordination. Healthy Connections Prime is open to people statewide over the age of 65 who are dually eligible (for Medicare and Medicaid) and non-institutionalized (though certain other specified populations are ineligible). Both PACE and Healthy Connections Prime seek to fully integrate primary care, long-term care and behavioral health services—and these programs have given SCDHHS and participating providers and MCOs the opportunity to develop capacity in offering LTSS in a managed care environment.

In order to expand South Carolina’s use of managed care models, it will be important to continue to work closely with institutional and HCBS providers across the state because many still have limited experience in providing services in a coordinated and integrated fashion and contracting with MCOs. While many Medicaid MCOs have extensive out-of-state experience with managed



LTSS, it will likewise be important to work closely with them as they bring their experiences to bear in South Carolina. Ensuring adequate oversight, quality assurance processes and consumer protections is also critical to the success of managed LTSS models.

#### Action steps

SCDHHS should:

- Continue to identify high-cost populations and services that are carved out of Medicaid managed care and determine methods to include them in coordinated and integrated models;
- Continue provider education efforts to increase understanding about the tenets and requirements of managed care;
- Conduct a formal review of the Duals Demonstrations in other states that will guide the State in expansion and/or replication to other target populations;
- Propose methods to link reimbursement to quality of care, using best practices for such areas as performance models and provider incentives.

## Ensuring an Adequate and Trained Workforce

### Background

The long-term care (LTC) workforce is comprised of a range of professions and occupations—including licensed professionals such as doctors, nurses, social workers, case managers and allied health professionals as well as direct care workers (DCWs)—who work in a variety of settings: institutional, community-based and in-home. Current and projected shortages in this workforce are a serious cause for concern both nationally and in South Carolina. As South Carolina faces an unprecedented growth in the population of individuals who need long-term services and supports, the workforce must expand to meet the increasing demand, and problems that plague it must be addressed, including:

- *The need for better training* – As those who require long-term services and supports grow in number and their needs become more medically complex, the skill level and training of the LTC workforce must expand. South Carolina will need more people trained as specialists in LTC and will need to ensure that personnel and professionals across the workforce receive training in both LTC competencies and geriatric content.
- *Problems of recruitment and retention* – Across the range of the professions and occupations that comprise the LTC workforce, recruitment and retention problems seriously compromise the availability and stability of the workforce. Key issues affecting recruitment and retention include financial disincentives, poor work environments and the emotionally draining and often physically demanding nature of the work.

Additionally, in order to meet the needs and preferences of consumers and their families, efforts must be undertaken to increase the appeal of working in the long-term care system, raising the profile of the work through increased salaries, career advancement, recognition and appreciation.

### Recommendations

In order to ensure an adequate and trained workforce, the Taskforce developed the following recommendations:

- Establish a Long-Term Care Workforce Development Consortium to develop a sufficient workforce of health care professionals and unlicensed workers with competencies in long-term services and supports;

- Seek ways to increase compensation for DCWs in home and community-based settings and enhance reimbursement rates for HCBS providers who employ DCWs;
- Establish the infrastructure for a comprehensive statewide training program for DCWs in HCBS that will improve outcomes for consumers;
- Develop a comprehensive Direct Care Worker (DCW) Registry to be used as a resource for consumers, family caregivers and potential employers;
- Increase the presence and capacity of nurses in the long-term care workforce;
- Enable registered nurses to delegate specific nursing tasks to unlicensed DCWs with sufficient training and demonstrated competencies, subject to consumer protections.

Further detail on the above recommendations is provided in the pages that follow.

**Recommendation 8: Establish a Long-Term Care Workforce Development Consortium to develop a sufficient workforce of health care professionals and unlicensed workers with competencies in long-term services and supports.**

*(Responsible entities – TBD prior to report release)*

Rationale

The number of specialists in geriatrics and LTC is extremely limited, and health care professionals trained as generalists often lack experience and training in treating older adults and people with disabilities. As the LTC population across South Carolina increases, these problems will become more pronounced. Therefore, South Carolina needs to undertake deliberate and ongoing workforce planning. Currently, there is no one entity studying or addressing the LTC workforce as a whole. A statewide entity, comprised of key stakeholders, should be established to provide leadership in addressing issues related to the availability and competency of the LTC workforce—both licensed professionals and unlicensed workers. (The LTC Workforce Development Consortium would be valuable in leading efforts related to other recommendations listed this workforce section.)

*Licensed Professionals*

Major goals for the Consortium related to licensed professionals should include: 1) increasing the number of professionals specializing in long-term care, and 2) ensuring that all health care professionals have foundational competencies in long-term care services. The following activities could address these goals:

- Work with colleges and universities to develop specialized LTSS tracks and certifications;
- Work with colleges and universities to infuse foundational LTSS competencies across curricula;
- Develop continuing education opportunities that provide foundational competencies or specialized certificates in LTSS;
- Develop the plans for increasing financial incentives such as loan forgiveness programs and scholarships to encourage students and professionals to pursue specialized tracks in LTSS.

While opportunities such as these do exist at various colleges and universities across the state, a more coordinated, deliberate effort to expand them is needed.

*Unlicensed Workforce*

Another critical goal for the consortium to address should be to ensure a stable, adequately-trained and accessible direct care workforce. The Consortium should work with vocational and technical schools, health care and LTSS providers and other stakeholders throughout the state to address key areas related to this workforce, including improving/standardizing training and competency verification, raising awareness about the importance of these workers and providing technical assistance related to models of care that integrate direct care workers.

*Overarching Areas*

In support of the goals outlined above, the Consortium will need to:

- Survey the field, including the number and distribution of current professionals/unlicensed workers as well as training and educational requirements/offering;
- Conduct an analysis of the workforce, including identification of gaps and unmet needs across the workforce and priority areas that need to be addressed;
- Develop strategies to address identified needs and priorities as well as a plan to track and evaluate the effectiveness of these strategies;
- Disseminate current research on evidence-based practices and identify or create training materials, as needed.

#### Action steps

The USC Arnold School of Public Health's Office for the Study of Aging will convene stakeholders to develop the mission and objectives of the LTC Workforce Development Consortium. The Consortium should have stable, ongoing funding and permanent staff, and membership from key stakeholder agencies, departments, educational institutions and professional associations.

## **Further Background on the Direct Care Workforce**

The Taskforce decided to make the direct care workforce a particular focus because direct care workers (DCWs) play such a primary role in providing LTSS and often have less-than-adequate support and limited training requirements, particularly in home and community-based settings. The following information is meant to provide an introduction to the direct care workforce and is followed by four specific recommendations that were developed to ensure a stable, adequately trained and accessible workforce of DCWs.

### Who are Direct Care Workers and Why are They Important?

Direct Care Workers—also known as unlicensed assistive personnel or paraprofessionals—provide 70 to 80 percent of the hands-on care in the LTC system. The direct care workforce is comprised of a variety of occupations such as nursing assistants, home health aides and personal care aides that serve older adults and people with disabilities in institutional, community and residential settings. These workers help to meet some of the most basic human needs, providing assistance with essential tasks that most take for granted, such as eating, dressing, bathing, toileting and basic housekeeping. They provide companionship and comfort in the face of challenging and potentially isolating circumstances. Their assistance often provides much-needed hours of respite to family caregivers. Working on the front lines of the system, DCWs are critical to ensuring quality care and maintaining the dignity and, to the extent possible, the independence of people who rely on long-term services and supports.

The DCW workforce in South Carolina accounted for approximately 40,000 jobs in 2011, though the actual number is likely considerably higher because private-pay data is difficult to quantify. Many DCWs are employed directly by consumers so are not accounted for in formal surveys.

### Problems of Recruitment, Retention and Turnover

DCWs can find their work highly rewarding, but they also face difficulties that make recruitment and retention a persistent challenge. Despite how critical their assistance and care is to the lives of consumers and their families, this workforce is undervalued, not well compensated, and receives inconsistent, inadequate training. The work they perform is emotionally draining and

difficult, often requiring caring for individuals with deteriorating conditions and/or challenging behaviors. It is also physically demanding. Compared to other occupations, DCWs working in nursing homes, for instance, have one of the highest rates of workplace injury. Within the current system, DCWs often lack opportunities for job advancement and for providing input into care planning. All of these factors contribute to high rates of turnover, which may impact quality of care as well as the financial health of providers because of costs associated with constant recruitment and training. Ultimately, these problems translate into a high cost for the state because public money pays for a significant share of these services.

**Recommendation 9: Seek ways to increase compensation for direct care workers (DCWs) in HCBS settings and enhance reimbursement rates for HCBS providers who employ DCWs.**

*(Responsible entities – DHHS, LGOA, DMH and DDSN)*

Rationale

Poor compensation is a significant obstacle to recruiting and retaining a high-quality direct care workforce. The low wages earned by direct care workers, who are performing physically taxing and emotionally draining work, are often comparable to entry-level positions in retail or food service. This problem of poor pay is particularly pronounced for workers providing services in home and community-based settings; aides working in home care were profiled by *Forbes* magazine as one of the 25 worst-paying jobs in America. The average hourly wage of personal care aides and home health aides in South Carolina 2013 was \$9.36 and \$9.23, respectively. Furthermore, trends in pay are flat, primarily because government reimbursement increases to agencies employing these workers have been limited. Even when increases have occurred, they may have been directed towards rising administrative costs/overhead and not to increased worker compensation. Alongside poor wages, DCWs often are only scheduled to work part-time with limited, unpredictable hours and have little access to employee benefits such as health insurance, retirement benefits, and sick leave; many are dependent upon public assistance. Many of these workers must provide their own transportation or are dependent on public transportation to reach their clients in various settings that are often far apart. Increasing wages for this segment of the workforce is crucial in order to decrease instability and turnover—and to meet the growing demand.

Action steps

- As the major funder of HCBS, the SC Department of Health and Human Services should seek budget requests to increase reimbursement rates over a 5 year period starting no later than FY 16-17. It is crucial that these financial investments are implemented in such a way as to ensure that the money directly benefits the DCWs through such means as hourly wage increases, improved fringe benefits, or enhanced travel reimbursement.
- State agencies (SCDHHS, LGOA, DMH and DDSN) should utilize their contractual requirements with providers to include provisions for financial incentives or shared savings. To accomplish this, standardized means for collecting data on cost-savings and improved outcomes should be developed.
- The LTC Workforce Development Consortium should work with provider associations to enhance education and technical assistance to HCBS providers regarding ways to stabilize their business models and diversify their funding streams, thereby creating greater opportunities for them to pay more competitive wages.



**Recommendation 10: Establish the infrastructure for a comprehensive statewide training program for DCWs in HCBS that will improve outcomes for consumers.**

*(Responsible entity – LTC Workforce Development Consortium)*

Rationale

The work that DCWs are called upon to do is important, challenging and frequently complex, yet the training they receive is often nonexistent or insufficient. Training for DCWs in South Carolina is not standardized and requirements vary across care settings and occupational categories as well as by funding source. Currently, DCWs who are certified as nursing assistants (CNAs) or home health aides have the most rigorous and defined training, due to federal training requirements set by Medicare and Medicaid. There are no such federal training standards for other DCWs working in home and community-based settings and that contributes to a more fragmented system. In its landmark report “Retooling for an Aging America,” the Institute of Medicine recommends that states should “establish minimum training requirements for personal-care aides.” With increasing numbers of individuals being served in home and community-based settings, these workers need adequate training because they may have less supervision in these settings, must work more independently and are increasingly dealing with more complex care needs.

Developing and implementing a statewide, competency-based training program in South Carolina for DCWs in HCBS would help improve the consistency and quality of care. Training has been linked positively to higher job satisfaction, improved retention rates and decreases in costly turnover. All of these, in turn, would lead to better outcomes for consumers. A comprehensive, statewide program would also improve system efficiency by coordinating and standardizing multiple training sources and infrastructures that already exist, streamlining training processes for public and private agencies as well as for DCWs themselves.

Actions steps

The LTC Workforce Development Consortium should lead the effort to establish the training and associated infrastructure, which should:

- Establish core curriculum and training standards;
- Include an accessible, flexible training service delivery system and network of trainers;
- Address testing and skills competency processes;
- Offer continuing education opportunities and a tier of advanced levels of training opportunities that could be posted on a statewide training website;
- Build on existing resources and infrastructure, especially those used for Certified Nursing Assistants (CNAs) training and testing;
- Be implemented as a pilot for Medicaid and LGOA providers;
- Include the appropriate administrative processes necessary to support a statewide system (i.e. review and compliance of training providers, processes to modify and update the curriculum, documentation of training results, enforcement, etc.);
- Address issues related to the costs of funding this infrastructure, including the training, testing, and skills competencies;
- Make recommendations about how to mandate training (i.e., via policy change and/or state agency provider contract changes) and to whom the mandate applies.

**Recommendation 11: Develop a comprehensive Direct Care Worker (DCW) Registry to be used as a resource for consumers, family caregivers and potential employers.**

*(Responsible entity – SC Department of Labor, Licensing and Regulation)*

Rationale

Individual consumers and their families as well as HCBS providers experience difficulties finding qualified workers to meet their needs and preferences. People who want to hire direct care workers need a reliable mechanism by which to verify basic requirements for potential employees (e.g., criminal background check, up-to-date on screenings, geographic availability). Ideally, they could also access information about such things as trainings completed, previous employment experience, other qualifications and references. The creation of the DCW Registry would address these needs by providing a portal through which to connect to direct care workers. In addition, the registry has another potential value for HCBS providers as well: it could help decrease overhead and administrative costs associated with vetting potential employees. An additional benefit of establishing a formal registry of information about direct care workers is that the registry could help South Carolina gather data needed to track and plan for the workforce, including data regarding its size and characteristics.

Action steps

SC Department of Labor, Licensing and Regulation should establish a stakeholder advisory committee to assist in the development of enabling legislation and the creation of a registry that will:

- Be self-sustaining and funded through established fee structures;
- Could potentially draw from existing workforce databases such as those maintained by SCDHHS or its contractors and the LGOA;
- Provide information on the DCWs listed, including such as elements as required screenings, criminal background check information, and training/certifications achieved;
- Offer an online, searchable registry system to both consumers and potential employers seeking to find or employ DCWs;
- Be established incrementally, starting with basic information on workers, but laying the groundwork for a more comprehensive registry that could include more detailed information (e.g., previous job performance, references, and links to training systems).

**Recommendation 12: Increase the presence and capacity of nurses in the LTC workforce.**  
*(Responsible entities – LTC Workforce Development Consortium, SC Nurses Association, State Board of Nursing, South Carolina colleges and universities with nursing programs)*

Rationale

Nurses fill many critical roles in the long-term care system in a variety of settings and agencies, providing hands-on care and care coordination/assessment, educating consumers and family caregivers, serving as supervisors for other direct care staff and functioning as policy makers and advisors. While the need for nurses in LTSS will continue to increase due in large part to the unprecedented growth in the size of our older adult population and the fact that people are living longer with more complex medical needs, the LTSS nursing workforce suffers from poor retention rates and high turnover. The obstacles in recruitment and retention of LTSS nurses are related to pervasive negative perceptions of the field, inadequate staffing levels and poorer pay than that which can be secured by working in hospitals or other clinical settings. The shortage of LTSS nurses and high turnover rates are particularly problematic given that research has shown improved outcomes for consumers when nurses are involved in long-term care.

Better integration of LTSS issues into academic coursework and clinical training opportunities is one crucial strategy to strengthen the nursing presence in LTSS. Partnerships between schools of nursing and long-term care agencies and providers must be built and strengthened “to foster adequate preparation of graduates for practice in LTSS and to foster accelerated implementation of new knowledge into LTC.” Furthermore, efforts must be undertaken to enhance education and training in issues particularly relevant to LTSS work—e.g., supervisory skills, increasingly complex medical needs in LTC settings, geriatric care, issues related to working with people with disabilities. In “Retooling for an Aging America,” the IOM reported that, nationally, less than 1% of RNs and only 3% of APRNs are certified in geriatrics. Furthermore, only one-third of the nation’s baccalaureate nursing programs required a course focused on geriatrics. Even nurses who are not directly pursuing employment in LTSS need adequate preparation in and exposure to the complexities of geriatric care because older adults are high volume users of health care services and their numbers are growing.

Action steps

Multiple stakeholders, including the SC Nurses Association and State Board of Nursing, South Carolina colleges/universities with nursing programs and the LTC Workforce Development Consortium should spearhead efforts to:

- Require state colleges/universities with nursing programs to have at least one certified gerontological nursing faculty with long-term care experience to lead geriatric courses and serve as a role model for students;
- Require state colleges/universities with nursing programs to incorporate long-term care settings in clinical experiences beyond the basic foundations course (i.e. senior community health practicums, chronic illness/gerontology course, leadership, population-based care, and care coordination/case management);
- Refine curriculum, preceptor education/development and ways to welcome and recruit students to the team;

- Seek funds to conduct and evaluate pilot projects that will foster partnerships between long-term care agencies/providers and state colleges/universities to encourage reciprocal dialogue and learning and increase student recruitment and employment.

**Recommendation 13: Enable registered nurses to delegate specific nursing tasks to unlicensed direct care workers (DCWs) with sufficient training and demonstrated competencies, subject to consumer protections.**

*(Responsible entities – SC Board of Nursing and the SC Nurses Association)*

Rationale

Delegation is the process by which a nurse can “direct another person to perform nursing tasks and activities” that s/he would not normally be allowed to do, while “the nurse retains accountability” for the delegation. Nurse practice acts in each state establish which tasks can be delegated to paid DCWs. Of the 16 tasks that are tracked nationwide, South Carolina currently allows only one task (administering an enema) to be delegated while 23 states allow delegation of more than 11 of these tasks. Examples of tasks that are widely approved for delegation in other states are: administering a glucometer test (41 states allow that) and performing ostomy care (40 states). The Federal Commission on Long-Term Care considered the issue of nurse delegation in 2013 and recommended that states permit delegation of tasks to DCWs with “sufficient training and demonstrated competency to perform them, particularly in home and community-based settings that do not have regularly scheduled registered nurses.”

Expanding nurse delegation in South Carolina—via a comprehensive approach involving multiple stakeholders and addressing statutory and regulatory provisions, necessary training resources and quality assurance systems— could have numerous positive impacts. It could help expand the capacity of the LTC workforce and alleviate the already stretched nursing workforce, “allowing care to be provided more efficiently” and giving professionals “more time to perform tasks for which only they are qualified.” Delegating certain tasks, when safe and appropriate, to less costly personnel could also reduce costs to public funding sources such as Medicaid. Other key reasons for authorizing nurse delegation include empowering consumers and supporting family caregivers, who are increasingly providing complex care for their care recipients at home. In acute care or rehabilitation settings, nurses often train family caregivers to perform nursing tasks as a part of discharge planning, but many of these same tasks cannot be delegated to DCWs. Therefore, if family caregivers are employed or need respite, they must rely on costly private duty nurses or institutional options. Expanding nurse delegation could ease the difficulty of obtaining and affording assistance and respite.

Action steps

The SC Board of Nursing and the SC Nurses Association should develop an advisory group of stakeholders to operationalize this recommendation. This group should:

- Review what tasks can be delegated under the SC Nurse Practice Act and the current status of delegation in South Carolina;
- Review the history of past attempts to increase nurse delegation in South Carolina and determine barriers and challenges, especially those related to liabilities and risks;
- Review other states’ actions related to nurse delegation, especially Good Samaritan provisions to protect nurse delegators and reimbursement issues;
- Provide specific guidance on targeted areas where it is believed that delegation is needed and appropriate.

## **Protecting Vulnerable Adults**

### **Background**

Many consumers receiving long-term care services and supports are among our state's most vulnerable individuals, due to physical, cognitive or chronic health conditions. A strong adult protection system is an integral safeguard for those individuals who are at risk of abuse, neglect (including self-neglect) and exploitation. Such a system includes legal and regulatory safeguards, investigative and preventive efforts as well as services for victims.

Protections for vulnerable adults must cover consumers across the LTC continuum, from those who live at home to those in residential or institutional settings. The adult protection system in South Carolina consists of a network of programs and services provided by many different agencies with different roles and jurisdictions. SC Department of Health and Environmental Control (DHEC), SC Law Enforcement Division and the Attorney General's Office all have defined investigative roles. The Long Term Care Ombudsman Program in the Lieutenant Governor's Office on Aging (LGOA) is charged with investigating complaints and advocating for residents of facilities across the state, including nursing facilities, community residential care facilities, and programs and facilities operated by the SC Department of Disabilities and Special Needs and SC Department of Mental Health. The Adult Protective Services (APS) Program in the SC Department of Social Services plays a parallel role for people in their homes. Especially as efforts continue to develop home and community-based options and expand policies that promote consumer choice and self-direction of care, South Carolina needs to ensure that there are the resources necessary to guarantee protection, regardless of setting.

South Carolina was one of the first states to enact a comprehensive law to protect vulnerable adults with the passage of the Omnibus Adult Protection Act (OAPA) in 1993. OAPA also established the Adult Protection Coordinating Council (APCC). The APCC brings together health and social services agencies, law enforcement agencies, regulators, enforcers, advocates and consumer representatives to assure that the state is adequately coordinating its system of protections. While South Carolina has a strong state law and adequate oversight and coordination through the APCC, staffing and funding resources for the state agencies charged

with the enforcement of OAPA and performance of statutory duties have been inadequate to effectively serve a growing and increasingly complex LTC system.

### Recommendations

In order to protect vulnerable adults, the Taskforce developed the following recommendations:

- Develop an Adult Abuse Registry;
- Ensure vulnerable adults are protected through an adequate Adult Protective Services Program and have access to preventive services that keep them safely in their homes and from requiring more expensive services;
- Improve quality and consistency of care in community residential care facilities (CRCFs) through enhancements to and oversight of CRCF licensing regulations and the Optional State Supplementation (OSS) and Optional Supplemental Care for Assisted Living Participants (OSCAP) Programs.

Further detail on the above recommendations is provided in the pages that follow.

#### **Recommendation 14: Develop an Adult Abuse Registry.**

*(Responsible entities – Adult Protection Coordinating Council, Department of Labor, Licensing and Regulation and Protection and Advocacy for People with Disabilities)*

##### Rationale

The current system of long-term services and supports does not provide the necessary safeguards for protecting consumers from direct care workers and other caregivers who may have a proven history of adult abuse, neglect or exploitation. It is possible for unlicensed personnel with a history of abuse, neglect or exploitation to move from employer to employer without a record of these actions. An Adult Abuse Registry would provide needed information to consumers and families, providers, regulators and enforcement agencies. To be effective and unbiased, such a registry should be independent of the service delivery system.

At least twenty other states have some form of an abuse registry. The Adult Protection Coordinating Council (APCC) first researched the need for such a registry in South Carolina in a report released in 2000. Model statutes from other states were reviewed. At that time, the most significant challenges identified to developing an Adult Abuse Registry in South Carolina were funding issues, establishing an appropriate host agency for the registry and defining the criteria/process for placement on the registry. The Legislative Audit Council also called for the establishment of an Adult Abuse Registry in both its 2008 and 2014 audits of the Department of Disabilities and Special Needs.

There are existing sources of information that could be linked to a registry. Two such sources are the current abuse registry required under federal law and maintained by DHEC for certified nursing assistants who work in nursing facilities and LLR's professional and occupational boards for social workers, nurses, physical therapists, long term care health care administrators, etc. An important administrative consideration will be the technical interface between the Direct Care Worker Registry (Recommendation # 11) and the Adult Abuse Registry.

##### Action steps

APCC, Department of Labor, Licensing and Regulation (LLR) and Protection and Advocacy for People with Disabilities (P&A) should:

- Review existing reports and recommendations and propose legislation, including identifying a host agency and addressing due process and employment prohibitions, to establish the registry;
- Prepare an accompanying budget request to provide the necessary funding.



**Recommendation 15: Ensure vulnerable adults are protected through an adequate Adult Protective Services Program and have access to preventive services that keep them safely in their homes and from requiring more expensive services.**

*(Responsible entities – TBD)*

Rationale

An essential component of South Carolina's adult protective efforts is the Adult Protective Services (APS) Program, administered by SC Department of Social Services (DSS). APS is charged with investigating reports of abuse, neglect and exploitation of non-institutionalized vulnerable adults and providing social services (e.g., making living arrangements or securing financial, medical or legal services) to actual or potential victims.

Despite the fact that the abuse, neglect and exploitation of vulnerable adults is recognized as a widespread and increasing problem across the country, South Carolina's APS Program has taken on fewer cases each year over the past fifteen years. In FY2001, there were over 7,600 clients receiving services, while in 2013 there were 4,200. Additionally, while 35 of 50 states provide some level of state funding for their APS programs, South Carolina relies on Federal funds. Notably, the total funds for APS have been reduced by more than half since 2001:

- In 2001, total funds allocated to DSS for APS were \$7.5 million, including \$1.9 million in state funds;
- In 2014, total funds allocated to DSS were \$3.2 million, including \$0 state funds.

During this time, there has been a corresponding decrease in total FTEs for APS, from 133 to 88. Currently, not every county in South Carolina has a dedicated APS worker. Complicating these internal staffing and funding issues, APS faces external challenges when serving consumers. These challenges include difficulties in finding emergency placements due to limited resources.

A comprehensive review of APS has been lacking and could bring needed attention and support to the program. Focused study and data in South Carolina are also needed to analyze trends related to those vulnerable adults who receive protective services. Further research could investigate whether targeted improvements, active intervention and new preventive services could impact subsequent outcomes and thereby reduce public services costs.

Action step

The Taskforce recommends that the General Assembly initiate an independent review of APS, through such means as an ad hoc oversight committee similar to the Senate Department of Social Services Oversight Sub-Committee, the Legislative Audit Council process or other review process. This review should determine whether cases referred to APS are being properly accepted, if response time is adequate and if abuse, neglect and exploitation are being properly identified and addressed.

**Recommendation 16: Improve quality and consistency of care in Community Residential Care Facilities (CRCFs) through enhancements to and oversight of CRCF licensing regulations and the Optional State Supplementation (OSS) and Optional Supplemental Care for Assisted Living Participants (OSCAP) Programs.**

*(Responsible entities – DHEC, SCDHHS, P&A and APCC)*

Rationale

In South Carolina, there are 473 community residential care facilities (CRCFs), commonly known as assisted living facilities, which are licensed by DHEC. They provide room and board, supervision and personal supportive services (i.e., personal care, hygiene assistance, medication administration and socialization) in a residential setting for people who lack resources or support to live independently and may not qualify for skilled nursing level of care. Residents of these facilities include older adults, people with physical disabilities and people with cognitive impairments or behavioral health issues. Importantly, there is a high degree of variability across these facilities. They range in size from 2 beds to over 100 beds. They differ by ownership as well, from nationally operated, corporate owned facilities to locally operated, independently owned facilities. There are examples of quality providers at both ends of the spectrum, reinforcing that size and ownership do not define quality. However, the focus of the Taskforce was on those facilities with the most concerning quality. Although care in these facilities is largely private pay, OSS and OSCAP are state-funded, means-test programs administered by SCDHHS that provide public assistance for eligible people to reside in a CRCF. In 2014, there were over 3,400 participants in OSS/OSCAP.

The quality and consistency of care provided in CRCFs varies dramatically and greater oversight capacity is needed. In July 2009, Protection and Advocacy for People with Disabilities (P&A) issued an investigative report, *No Place to Call Home: How South Carolina Has Failed Residents of Community Residential Care Facilities*, documenting a number of key areas related to quality of care and oversight. A follow-up report was released in April 2013, *Still No Place to Call Home: How South Carolina Continues to Fail Residents of Community Residential Care Facilities*. A key finding was that little progress had been made in the overall improvement of living conditions in CRCFs documented in 2009 and that none of the five recommendations made in the earlier report had been implemented. In 2013-14, the APCC convened an ad hoc committee of its members to review recommendations from both reports; this follow-up study cited the status of each proposed recommendation and suggested action steps to address them.

Action steps

- APCC, P&A, DHEC and SCDHHS should work together to implement the follow-up steps outlined by the APCC on the recommendations in the SC Protection and Advocacy reports of 2009 and 2013.
- The Taskforce recommends that the General Assembly allocate funds to increase DHEC's enforcement capacity through additional funded staff positions.
- SCDHHS should link future reimbursement increases in OSS/OSCAP to performance and quality of care.
- DHEC, with input from stakeholders, should explore modifications of the CRCF licensing regulations to differentiate facilities that have the capacity to support residents who have higher levels of mental and functional disabilities.

## **Supporting Family Caregivers**

### **Background**

In South Carolina, over 770,000 individuals serve as unpaid family caregivers (footnote this term), including those caring for a parent, child, friend or other loved one. The range of responsibilities these family caregivers assume varies greatly depending on the needs, preferences and resources of the care recipient. Family caregivers may provide assistance with daily tasks (e.g., eating, bathing, toileting), arrange appointments with multiple providers, coordinate services, act as an advocate and offer social support and encouragement. They are also increasingly performing complex medical tasks such as administering medications or operating medical equipment. Often the incredible efforts of family caregivers enable their care recipients to live in less restrictive settings than otherwise might be possible. Many family caregivers find meaning and fulfillment in their caregiving roles. At the same time, they often have to make significant sacrifices to do what they do. The strains and stresses of caregiving can be significant, impacting physical and mental wellbeing as well as financial security.

Family caregiving can be a complex juggling act, requiring the need to balance caregiving responsibilities with ongoing demands such as employment and family responsibilities. Caregiving demands also require the development of new skills and drawing on reserves of energy and perseverance. The skills required to perform caregiving duties are not always instinctive or simple. Caregivers sometimes have to learn new ways of interacting with those they care for—that requires planning, self-awareness, patience and sometimes formal training. Finally, caregivers must learn not only how to care for others, but also how to care for themselves to sustain themselves throughout their caregiving responsibilities. Support for these unpaid caregivers is essential in sustaining the overall system of long-term services and supports.

### **Recommendations**

In order to provide support for family caregivers, the Taskforce developed the following recommendations:

- Improve access and funding for flexible respite services;
- Increase access to training opportunities and sources of ongoing support for family caregivers to sustain them in their caregiving roles;

- Enhance the capacity of the Aging Network to ensure that family caregivers receive critical services, including thorough assessment, education, training and support;
- Validate the role of family caregivers as a critical member of the care team and encourage family engagement;
- Develop and strengthen financial and employment supports for family caregivers.

Further detail on the above recommendations is provided in the pages that follow.

## **Recommendation 17: Improve access and funding for flexible respite services.**

*(Responsible entities – SCDHHS, LGOA, and SC Respite Coalition)*

### Rationale

The physical, emotional and financial strains of caregiving are significant and can mount, especially without regular, planned breaks. Respite—temporary relief from the responsibilities associated with taking care of a person of any age who has a disability, special need or chronic illness—can sustain the health of caregivers, enabling them to continue to function in their caregiving roles. Respite care can be provided at home, in the community or in institutional settings “by paid providers, volunteers, family members or friends, all of whom should have appropriate training and supervision.” Despite the critical relief that can come from respite, caregivers often do not know what it is or how to access it. Many also need education on the importance of respite (and self-care, more broadly) to their own wellbeing and on how to use it appropriately as one essential strategy in addressing caregiving responsibilities.

The demands on caregivers are complicated and dynamic, and the need for respite varies based on the care recipient’s status, needs and preferences as well as on the caregiver’s situation. Respite options must be flexible to meet these varying needs. Respite is considered to be a critical support by many stakeholders for enabling families to care for care recipients at home. At the same time, it alone is not sufficient to meet caregiver needs. It must be addressed “in the context of other forms of assistance provided by states including information/assistance, education, and training and other caregivers support services.” Only such a comprehensive strategy can sustain caregivers and enable them to care effectively for their care recipients long-term.

In South Carolina, eligible caregivers can receive financial support for respite care from multiple funding sources, including Title III-E of the Older Americans Act, state funds, federal Lifespan Respite grant funds and Medicaid waivers. These are authorized through multiple agencies (e.g., LGOA, SCDHHS, DDSN, SC Respite Coalition). However, according to South Carolina’s 2013 State Respite Plan, due to the size of the need, “these resources are critically inadequate to meet the needs of most families. Some population groups are served better than others; but, in general, respite is in short supply, inaccessible or unaffordable.” In order to ensure access to respite services, the Taskforce feels current sources of public funding should be stabilized and increased, and the infrastructure supporting both the provision of these funds and education about respite should be strengthened.

### Action steps

- The Taskforce recommends that the General Assembly provide and increase stable state funding for respite for family caregivers.
- With input from the AAAs/ADRCs, local providers and consumers/families, the LGOA should identify current practices that could be improved to ensure that an adequate infrastructure and administrative capacity exist to efficiently distribute respite funds and provide meaningful respite services through the Aging Network (See Recommendation #19).

- SCDHHS, through its proscribed stakeholder input policy, should develop an amendment to the CLTC Community Choice Waiver to add in-home respite as a CLTC service with established eligibility criteria and benefit caps during the initial phase.
- The Respite Coalition and the LGOA should develop a formal action plan to partner with faith communities to expand respite programs and identify seed funding from such sources as the Elder Care Trust Fund in developing, implementing, and replicating these services.

In addition to the recommendations above, the Taskforce acknowledges the critical importance of the recommendations outlined in the 2013 State Respite Plan. That plan provides detailed background information on the need for and barriers to obtaining respite care in South Carolina. It also provides a comprehensive overview of the state's respite infrastructure, funding and service delivery and presents recommendation in the following key areas: Gaps & Obstacles, Education and Outreach, Legal and Policy Issues and Provider Network Development.

**Recommendation 18: Increase access to training opportunities and sources of ongoing support for family caregivers to sustain them in their caregiving roles.**

*(Responsible entities – LGOA, OSA, SCDHHS and PART initiative)*

Rationale

Caregivers need training and sources of ongoing support “to prepare them for their roles in order to provide better care while maintaining their own health and wellbeing.” Family caregiving roles have long included providing assistance with everyday tasks like bathing, dressing, preparing meals, shopping and managing finances. Increasingly, family caregivers are also being called upon to perform “medical/nursing tasks of the kind and complexity once provided only in hospitals and nursing homes and by home care professionals. This change has occurred because of the prevalence of chronic conditions in an aging population, economic pressures to reduce hospital stays, and the growth of in-home technology.” Family caregivers often develop their skills and knowledge through trial and error and practical experiences, especially if thrust into their roles unexpectedly. They often need more training and support to help them fulfill the varied responsibilities required of them. Formal training interventions and sources of ongoing support can develop skills and empower caregivers, thereby ensuring the safety of the care recipient and sustaining the caregiver in his or her role.

Many family caregivers learn specific health-related caregiving tasks from home health, acute care or rehab staff. Training and other kinds of assistance are also available through publicly-funded programs (e.g., Family Caregiver Support Program) as well through peer-to-peer mentoring that occurs in support groups and other programs. However, more formalized training opportunities and additional sources of ongoing support are needed. Drawing on a combination of local and national best practices, effective training resources should be further developed, including on-line training modules, courses that are available at easily-accessible local venues such as technical colleges and caregiver coaching services that provide one-on-one support. Importantly, current funding sources, such as the Family Caregiver Support Program funds and Lifespan Respite grant funds, can be used to support caregiver training, in addition to providing respite care.

Action steps

- Based upon prior research from the USC Arnold School of Public Health’s Office for the Study of Aging (OSA) and pilot program experiences, SCDHHS should amend the CLTC Community Choices Waiver to add Caregiver Coaching as a service. (Special footnote: a Caregiver Coaching Service pilot was developed, tested and evaluated by the OSA in two CLTC regional offices in 2011.)
- The LGOA should:
  - With the assistance of the OSA and building upon the Caregiver Coaching service modules, establish a suite of training modules for family caregivers to be made available online. These modules should cover a variety of topics including hands-on care provision, self-care/wellness, and grief/loss. (See Recommendation #23.)
  - Partner with the SC Technical College network to provide low cost/no cost education and training opportunities in evidence-based caregiving programs.
  - Develop capacity within the Aging Network to provide more hands-on education, training and coaching opportunities for family caregivers, including exploring

- new funding sources to pay for these services and providing support for staff members to be trained in evidence-based intervention protocols.
- Explore best practices that motivate caregivers to obtain education and training through incentives such as additional respite funding and develop an action plan for incorporating these motivational techniques into program policy.
- The Preventing Avoidable Readmissions Together (PART) initiative should explore and recommend ways for hospitals to provide enhanced training during post-acute care transitions.

Note: Trainings for family caregivers could be developed in conjunction with those for direct care workers because the content in many cases will be similar (see Recommendation # 10).



**Recommendation 19: Enhance the capacity of the Aging Network to ensure that family caregivers receive critical services, including thorough assessment, education, training and support.**

*(Responsible entity – LGOA)*

Rationale

In South Carolina, the Family Caregiver Support Program (FCSP) is administered through the ten Area Agencies on Aging (AAAs)/Aging and Disabilities Resource Centers (ADRCs). The majority of AAAs/ADRCs have only one Family Caregiver Advocate who is responsible for a multi-county region. Family Caregiver Advocates work directly with family caregivers, assessing their needs and providing crucial services, including information, assistance, counseling/support groups, training and respite care vouchers. Considering that South Carolina has over 770,000 family caregivers and that most AAAs/ADRCs have only one Family Caregiver Advocate who is responsible for multiple services in four to six counties, the current structure is not adequate to meet current or future demand.

Importantly, the data from family caregiver assessments, if regularly analyzed, could assist in monitoring services, identifying unmet needs and gaps and evaluating quality and effectiveness of services. While caregiver assessments can provide valuable information, it is important that the process requires ongoing training and should not be too overly burdensome, especially given high caseloads for Family Caregiver Advocates.

While LGOA and AAAs/ADRCs across the state provide an important network of support for family caregivers in South Carolina, there are many other public and private groups working with and on behalf of family caregivers (e.g., state agencies, nonprofits, support groups, faith-based organizations, hospitals). Further coordination among these entities could serve to strengthen the system. For example, in Georgia, each Area Agency on Aging houses a coalition of caregiver support organizations, including representatives from across a broad array of illnesses and disabilities. This organized structure of local coalitions is known as Georgia CARE-NET. These coalitions “provide ongoing assessment of community resources, identify and remedy gaps in services, share information and resources among agencies, develop strategies for complementary professional and family caregiver activities, offer caregiver education” and advocate for family caregivers.

Action steps

- The Taskforce recommends that the General Assembly increase funding for the Family Caregiver Support Program (FCSP) so that each county has an adequate number of Family Caregiver Advocates, as determined by client base.
- The LGOA should:
  - Develop an action plan to augment the capacity of Family Caregiver Advocates through additional support staff and volunteers;
  - Provide support for staff members who work directly with family caregivers to be certified in evidence-based intervention protocols;
  - Ensure that appropriate data are collected through caregiver assessment processes by providing regular, thorough training on assessment skills/instruments;

- Formally review Georgia's CARE-NET (with key stakeholders—e.g., possibly a family caregiver advisory group), and other similar state networks that support family caregivers, to determine if a similar structure could effectively strengthen South Carolina's system. If it is determined appropriate for South Carolina, propose membership, funding and structure of such an effort.

**Recommendation 20: Validate the role of family caregivers as a critical member of the care team and encourage family engagement.**

*(Responsible entity – LGOA with input from a possible family caregiver advisory group)*

Rationale

Family caregivers can offer valuable input in developing care plans for their care recipients and are essential links in the implementation and monitoring of those plans. They often serve as care coordinators and perform a wide range of health-related tasks from preparing special diets and administering medications to performing wound care and more. Due to the frequency and nature of their contact with their care recipients, they can provide essential information about care needs, overall changes in condition and compliance to prescribed regimens. For these reasons, formal inclusion of the family caregiver as a member of the health care team has been increasingly recognized across the country as a critical strategy to ensure good outcomes for consumers. Family caregivers are no longer viewed simply as a “resource” for their recipients, but are increasingly seen as “partners on the care team.” National advisory groups, such as the Institute of Medicine and the Federal Commission on Long-Term Care, acknowledge the benefits of integrating family caregivers with the formal health care team. Including family caregivers on the care team can improve communication between providers and family caregivers who are performing functions that are essential for the health of the care recipient. It can also ensure family caregivers have the capacity and resources they need to fulfill the necessary duties.

Consumer and family participation in care assessment and plan development is a major tenet of person-and family-centered planning. There are different approaches and models to involve family caregivers that have been developed across the country. In South Carolina, such approaches have primarily been implemented through programs serving populations dually eligible for Medicare and Medicaid; Healthy Connections Prime and Program of All-inclusive Care for the Elderly both use a multi-disciplinary team approach that incorporates consumer and family input and participation.

Action steps

The LGOA, with input from key stakeholders and a possible family caregiver advisory group (which should include physicians, nurses, social workers, case managers and actual family caregivers), should:

- Educate health care providers about the value of engaging family caregivers as a part of the care team and including family caregivers in the development of care plans for the consumer;
- Develop an action plan to encourage state agencies, primary care physicians, hospital discharge planners and home health agencies to incorporate a brief caregiver screening (e.g., AMA Caregiver Self-Assessment Questionnaire) as a part of assessment processes (see Recommendation #2);
- Conduct outreach to health care providers to encourage their use of SC Access when making referrals for caregivers and consumers to community resources such as AAA/ADRCs, Alzheimer’s Association, SC Respite Coalition and others (see Recommendation # 23).

## **Recommendation 21: Develop and strengthen financial and employment supports for family caregivers.**

*(Responsible entities – Joint Legislative Committee to Study Services, Programs and Facilities for Aging, SCDHHS, and LGOA)*

### Rationale

While many family caregivers are able to find meaning and fulfillment in their roles, the pervasive and variable nature of their responsibilities can cause significant strain on their finances and negatively affect their employment. Many family caregivers incur direct out-of-pocket costs, spending their own money “to help support a family member or friend with a disability or chronic care needs.” Expenditures related to family caregiving can affect the ability of the caregiver to save for his or her own future. Furthermore, to create a balance between job responsibilities and caregiving responsibilities, family caregivers often have to make workplace accommodations—such as modifying schedules, taking unpaid leave, turning down overtime opportunities or refusing new assignments that require travel or relocation. Some caregivers leave the workforce entirely. The necessities of caregiving, then, can have a long-term impact on financial and employment security. Efforts should be undertaken to support family caregivers through targeted efforts to off-setting essential expenses and provide other supports.

The demands of caregiving not only impact the individual worker who is serving as a family caregiver, but also impacts his or her employer. A 2006 MetLife Study estimated that employers lose more than \$33 billion each year due to costs linked to employees who are full-time caregivers; these costs are associated with replacing employees, absenteeism, supervisory time, unpaid leave and more. As the aging population increases and more individuals assume family caregiving roles, employers must develop policies and workplace supports that address the realities of family caregiving.

### Action steps

- The Joint Legislative Committee to Study Services, Programs and Facilities for Aging should review draft legislation regarding tax credits for family caregiving expenses, which uses the Georgia tax credit for caregiving expenses as a possible model.
- SCDHHS should expand the paid family caregiver option to all personal care-like Medicaid waiver and state plan services, while ensuring adequate oversight. (Special footnote: Very little currently exists in the way of direct financial assistance or benefits for family caregivers. However, consumers receiving HCBS through some Medicaid waivers do have the option to pay eligible family members as their personal attendants, providing personal care services such assistance with eating, bathing and housekeeping. Paid family caregiver programs such as these provide financial supports to over 1,000 family members and have been growing in recent years.)
- The LGOA should convene stakeholders from the business community to develop an action plan that will encourage employers to review their human resource policies and develop caregiver friendly policies (e.g., providing flexible leave policies, access to information/referral and case management, education about dependent care savings accounts). Stakeholder groups to involve could include: SC Business Coalition on Health, State Chamber of Commerce, small business associations, PEBA, Municipal Association, Councils of Government, Association of Counties, South Carolina Association of Nonprofit Organization.

## **Promoting Choice and Independence through Education**

### **Background**

To ensure choice and maximize independence for individuals and family caregiver, the Long-Term Care (LTC) system must enhance educational and preventive opportunities. Currently such efforts often take the back seat in the midst of providing crucial direct services. Programs that provide information, referral, educational components and preventive services have had to compete with these direct services for limited resources—and that has resulted in less emphasis in these areas across the system.

Without deliberate educational efforts, individuals and families could be less able to identify their needs and preferences and plan for their care before an urgent situation arises. Without access to information, individuals and their families are ill-equipped to access the services available to them, and might assume their choices to be more limited than they are. For example, if a family caregiver is unaware of respite services, that lack of knowledge could influence their decision-making and capacity to care for their care recipient at home. By way of another example, if providers do not know of community resources, their referrals and recommendations are limited and might not reflect all options available to meet consumers' preferences.

Likewise, preventive efforts put individuals and families in a better position to maximize their independence and quality of life. Such efforts (e.g., evidence-based exercise programs, preventive screenings and vaccines, fall prevention, medication adherence programs) can keep people active, engaged in their communities, functioning at highest possible levels and living in least restrictive setting. Like education, attention to prevention has often taken a back seat to the provision of services that meet pressing, urgent needs. A system that emphasizes prevention and education has the potential to save public and private dollars and to maximize the safety and independence of consumers.

Efforts to provide education and critical information to individuals, families and providers will become increasingly important as the population needing LTC grows. As more people are choosing to receive services in home and community-based settings, access to planning tools, preventive services and resources and information about service options is important for

consumers and their families. Health care and services providers also must have easy access to information about community resources. To truly be effective, education must be ongoing and aimed at individuals and caregivers not only when they access the system but also earlier in life to increase preparation and planning. Specific messages must be developed to target individuals at various points in the LTC system. To gain the attention necessary, these messages should be carefully coordinated, conveyed through multiple channels and technologies, and reinforced often.

### Recommendations

In order to promote choice and independence through education, the Taskforce developed the following recommendations:

- Enhance and coordinate statewide fall prevention efforts, as well as other preventive programs/services;
- Develop and market a comprehensive, user-friendly online information and referral resource for long-term services and supports, which will include resources for family caregivers;
- Institute an ongoing informational campaign to educate consumers about the need to save and plan for long-term care expenses;
- Strengthen the state's infrastructure to provide greater support to consumers and families regarding options to maintain independence;
- Support and enhance awareness about statewide public education efforts regarding advance care planning based on the needs and values of individuals.

Further detail on the above recommendations is provided in the pages that follow.

**Recommendation 22: Enhance and coordinate statewide fall prevention efforts, as well as other preventive programs/services.**

*(Responsible entity – Statewide coalition of partners)*

Rationale

One third of adults over the age of 65 experience a debilitating fall over their lifetime, with the rate of falls increasing to half for the population 80 and older. Of the adults over 65 who fall, 20 to 30% sustain injuries serious enough to make it difficult or impossible for them to return to independent living and increase the risk of an early death. In 2010, the direct medical costs of fall related injuries totaled \$30 billion nationally, with those annual direct and indirect costs estimated to reach \$67.7 billion in 2020.

A look at South Carolina's statistics from 2012 reveal the significant effect falls have on the quality of life for thousands in our state as well as a major fiscal impact for the state:

- Inpatient hospital charges related to falls for all ages, across all payers, were over \$800 million. Almost 70% of people who were hospitalized due to a fall were age 65 and up. The inpatient hospital charges related to those falls (age 65 and up), across all payers, were over \$547 million.
- Medicaid paid over \$47 million in inpatient hospital charges related to falls.
- Of those who were hospitalized due to a fall in 2012, 64% were discharged to an extended care facility.
- Total skilled nursing facility charges paid for by Medicaid a year after a fall were approximately \$26 million for people age 35 and older.

If falls were prevented through effective interventions, expenditures such as those referenced above could be reduced. While the consequences of falling (e.g., pain and suffering, loss of independence, isolation, costly treatments, premature death) can be catastrophic, many successful strategies for avoiding falls are not difficult and are often cost-saving. Fall prevention and related interventions need to be addressed in a systemic or methodical fashion in South Carolina, particularly for individuals living in home and community-based settings and for family caregivers. A comprehensive, multifaceted effort using resources that are readily available could improve fall prevention efforts, benefiting consumers, families and health care providers across the state. Evidence-based fall prevention programs exist that could be drawn on to develop a comprehensive program. Multiple states have statewide ongoing fall prevention programs (e.g., Hawaii, Michigan, California, Connecticut). Though very few are collecting quantitative data, the University of Pittsburgh Schools of the Health Sciences, which introduced a program to reduce falls among the elderly, found that their simple intervention reduced falls by 17% statewide, thereby reducing subsequent costs associated with falls.

Action steps

The Taskforce recommends the implementation of a coordinated statewide fall prevention program to improve the quality of life for South Carolinians, reduce the need for long-term services and supports and save money.

The implementation of such a comprehensive statewide fall prevention program could occur in stages and could focus initially on key target populations such as consumers receiving HCBS

through SC Prime and high risk populations (e.g., those who have previously fallen). The engagement of family caregivers would also be a means for disseminating this information.

Some of the components that are integral to a successful fall prevention program are:

- A standardized, consistent and implemented fall risk assessment process with validated screening tools;
- Consistent communication and application of an intervention when an individual has been identified as a fall risk;
- Adequate education on falls and fall risk for individuals, family caregivers and health care providers.

#### *Other preventive efforts*

Fall prevention efforts are just one example of prevention-related activities that could help older adults and people with disabilities while also saving state resource. The Taskforce supports implementation of policies and statewide education efforts that encourage the use of preventive services to promote healthy aging:

- Working through professional associations and professional training programs to educate health care providers about best practices in prevention and how those could be integrated into our current health care delivery systems.
- Working with advocacy organizations to educate individuals about the importance of preventive services, such as flu, shingles and pneumonia vaccines/shots which are covered by Medicare.
- Working with SCDHHS to prioritize preventive services, including providing enhanced payments for preventive services.



**Recommendation 23: Develop and market a comprehensive, user-friendly online information and referral resource for long-term services and supports, which will include resources for family caregivers.**

*(Responsible entities – LGOA in conjunction with advisory committee\*)*

Rationale

Consumers and families face complex issues while navigating long-term care considerations and need a place to obtain comprehensive information about available options and access resources. Health care and other service providers also require access to information to help them refer individuals and caregivers to appropriate community resources. Currently, there are multiple ways that individuals can find information in South Carolina. Having a more centralized, coordinated system could increase efficiency, improve timely access to services and reduce stress for those navigating long-term care issues. It is critical that information resources be easy to use, meet accessibility standards, and be consistently updated and well-publicized.

One of the major resources for LTSS-related information in the state is SC Access, which is managed by the LGOA. SC Access is a Web-based service directory that is used by Information and Referral/Assistance specialists in the Aging Network and is also available to the general public and health and human service providers. In addition to service listings, users can find a community calendar, educational resources, a personal care listing and a nursing facility/CRCF bed locator. Other information resources include: the Medicaid call center, DDSN online provider/service directory, United Way's 211, SC Thrive and other private entities. Many nonprofits serving particular target populations maintain resource directories, call-in numbers and Web pages to provide information specific to the needs of those they serve.

Numerous stakeholders have suggested that SC Access be more frequently updated, comprehensive, user-friendly and better publicized. Furthermore, the Web platform is not compatible with emerging technology. According to a 2014 AARP South Carolina poll of registered voters age 45 and older, having information about available resources for caregivers is a top need. Twenty percent of the respondents had used SC Access and indicated that it was helpful. More than three-quarters of respondents were not aware of SC Access.

Action steps

The Taskforce recommends developing a central Web-based information and referral system that could use and expand on content from SC Access but would ultimately take its place as a more comprehensive, user-friendly resource. This system should be marketed as a one-stop shop for consumers, caregivers and health care or other service providers/agencies.

This project should be implemented by a public-private partnership and led by an advisory committee that will oversee the process of developing the content, technical components and marketing plans. The advisory committee should also make recommendations about developing the needed administrative infrastructure/processes to ensure that information is consistently updated and meets the needs of various constituents. The advisory committee should include stakeholders from across the LTC system as well as professionals with relevant technical expertise in Web-development, IT and marketing.

Identifying, compiling and preparing the content of this resource should occur in phases. It should include the following components:

- New and existing information and referral content;
- A suite of training modules for family caregivers (see Recommendation # 18);
- A link to a registry of direct care workers (see Recommendation # 11);
- Information on available technology that supports aging in place;
- Other potential special features targeting areas of identified need.

To address sustainability, an action plan for further public-private funding opportunities should be developed.

\*Progress note: In the fall of 2014, the Duke Energy Advisory Committee allocated up to \$250,000 for development of the infrastructure and promotion of an enhanced website. An advisory committee of the aforementioned stakeholders has been appointed to work with the LGOA.

**Recommendation 24: Institute an ongoing informational campaign to educate consumers about the need to save and plan for long-term care expenses.**

*(Responsible entity – LGOA)*

Rationale

Long-term care services are expensive, and the majority of people will need these services at some point in their lives. According to the US Department of Health and Human Services, “[s]omeone turning age 65 today has almost a 70% chance of needing some type of long-term care services and supports” at some point. Despite how widespread this need is, people are generally uninformed about the costs of long-term services and supports and lack understanding about what public programs will fund.

People need to be actively planning and saving for their potential needs for long-term services and supports, and research indicates that they are doing neither. According to a 2014 Associated Press-NORC poll, 67 percent of Americans 40 or older have done little or no planning at all for their ongoing living assistance needs, and only 35 percent indicate that they have put aside any savings for these needs. In South Carolina, 51 % of adults reach retirement with \$50,000 or less in savings. Recognizing that people have competing priorities when making decisions related to their financial resources, planning and saving for potential needs related to long-term services and supports should be an important part of their considerations. Planning ahead and being financially prepared could enable individuals to make better use of their resources, providing them with greater autonomy and choice as well as increased security.

A broad-based campaign is needed to raise awareness about planning for potential needs for long-term services and supports. This campaign should include information about the full range of services and possible financing options (e.g., medical spending accounts, long-term care insurance, general trusts, Medicaid-qualifying trusts and reverse annuity mortgages). It is especially important to target efforts to reach younger audiences to encourage planning and saving earlier in life. Therefore, a diverse group of partners, beyond those in the aging field, is necessary to plan and implement the campaign.

Action steps

The LGOA should partner with a diverse collaborative representing the business sector, providers, professional associations, advocates and other stakeholders to:

- Develop an informational campaign to raise awareness among younger adults about the importance of preparing privately for retirement and LTC costs in the future;
- Provide education for the health care, social services and legal professions about their roles in providing information to consumers on financing options for LTC;
- Develop an information campaign to disseminate educational materials to consumers at their first point-of-contact with the system;
- Work with employers to raise awareness about the need to include information on LTC financing options in their established retirement planning sessions;
- Explore grant opportunities to help fund these efforts.

**Recommendation 25: Strengthen the state’s infrastructure to provide greater supports to consumers and families regarding options to maintain independence.**

*(Responsible entity – The SC Statewide Independent Living Council)*

Rationale

Individuals and families should have access to information about what resources are available to maximize independence and support living in the least restrictive setting. They also may need access to peer support and training opportunities to enable them to develop the skills needed to live independently. Such information may be particularly difficult to access for individuals residing in nursing facilities, assisted living facilities or other residential programs who desire to live in a more independent, less restrictive setting.

Centers for Independent Living (CILs), authorized by Federal law, help individuals with disabilities live as independently as possible by providing the following core services: information and referral, independent living skills training, individual and systems advocacy, peer support/mentoring and transition services. Independent living skills training can include such topics as how to use public transportation or paratransit (specialized transportation services for people with disabilities), manage finances, find stable housing or employment, access necessary social services, manage personal care aides or become a proactive consumer of health care. Transition services are provided to youth with disabilities who are entering higher education or the workforce, individuals who are at risk of entering an institution and individuals who are moving from an institutional setting to living at home or in a community-based setting. South Carolina has three CILs operating in 37 of the 46 counties that serve over 3,000 consumers. Currently, SC CILs do not receive state funding but receive a total of \$949,514 in federal funding.

Action steps

- The SC Statewide Independent Living Council will be responsible for the development of an automated informational planning toolkit to promote independent living. Key stakeholders to involve in this effort include AccessAbility, Able SC, Walton Options for Independent Living, representatives from the ten Aging and Disability Resource Centers, SC Department of Health and Human Services, SC Department of Disabilities and Special Needs, AARP, Protection and Advocacy for People with Disabilities, University of South Carolina College of Nursing, individuals living with disabilities and older South Carolinians. In a parallel effort, these stakeholders should also develop a communication and public information campaign about the toolkit and the importance of maintaining independence targeted to the community, other stakeholders and health care providers.
- The Taskforce recommends that state funding be allocated to the CILs to enable services to be provided in the nine counties that are currently unserved and to expand the capacity of the three existing centers to provide additional supports that promote independence in the counties currently served.

**Recommendation 26: Support and enhance statewide public education efforts regarding advance care planning based on the needs and values of individuals.**

*(Responsible entity – TBD prior to report release)*

Rationale

Individuals with a serious, chronic or terminal illness face important decisions about their care and the options that exist regarding treatment and comfort care. Through educational efforts and input from trusted legal and health care providers, individuals should be allowed to make informed choices regarding their care and ensure that their wishes are carried out. In addition, people should be encouraged to consider these issues and options in advance of need to ensure that they have outlined their choices clearly and appropriately. Living wills and health care powers of attorney can be complicated to understand. It is important for individuals to have access to information and resources to better comprehend the legal and ethical issues involved in executing these documents and the importance of completing them.

In an effort to better inform consumers about advanced directives, the Patient Self-Determination Act (PSDA) was enacted by Congress in 1990 and became effective in 1991. The PSDA requires hospitals, nursing facilities, home health agencies, hospice providers, managed care organizations and other health care providers who accept Medicare and Medicaid reimbursement to offer information about advance directives as a part of an admissions process (physicians are excluded from this requirement).

In 2010, the South Carolina Coalition for the Care of the Seriously Ill (CSI) was established as a statewide coalition of provider associations and other stakeholders “to develop uniform processes for communication, consent, and decision-making that will be widely used regularly by physicians caring for seriously ill patient.” CSI began a pilot project in Greenville and Charleston in 2014 to test the use of a standardized form called the Physician Order for Scope of Treatment, which combines a consumer’s wishes about their treatment with a physician’s order for services. The goal is to have a portable communication form that follows the consumer throughout the treatment process so that the entire care team across the health care system (e.g., home health care, emergency room) is aware of and follows those wishes. Informing this pilot project, the coalition has four broad strategic aims, including one regarding increasing public education and awareness about advance directives and health care decision making.

Action steps

The Taskforce:

- Supports the Coalition for the Care of the Seriously Ill in providing statewide educational programs on advance directives and health care decision making, including the promotion of a Health Care Decisions Day;
- Recommends increasing awareness of the Coalition and expanding partnerships to include additional LTC interests/partners;
- Recommends that the Coalition should be a partner in efforts related to the broad-based campaign on LTC planning (Recommendation # 24);
- Recommends including advance care planning resources on relevant websites (Recommendation # 23).

## Improving Long-Term Care in South Carolina

### FUTURE DIRECTIONS

The actionable recommendations contained in this report create direction for improving the long-term care (LTC) system in South Carolina. These recommendations and their associated action steps offer clear guidance on how to pursue needed improvements. Although the members of the LTC Taskforce addressed a diverse array of critical issues, they did not set out to create a strategic plan. However, the recommendations of this report provide a solid foundation for the development of such a comprehensive, fully integrated approach to addressing LTC in our state. As such, **the LTC Taskforce recommends the development of a formal strategic plan for providing and sustaining long-term services and supports for older adults and people with disabilities in our state.** Such a plan should address the role of government, the private sector and public-private partnerships, as well as the contributions of volunteers and family caregivers. It should also address how South Carolina will ensure community integration for older adults and people with disabilities as required by the Final Rule and the Olmstead decision (the U.S. Supreme Court decision of 1999 requiring community-based services for persons with disabilities). Data collection and progress monitoring should be put into place to support the process. The plan should cover all available funding sources (including private pay and volunteer resources as well), different levels of need and all target populations.

Although the recommendations presented in this report are comprehensive and reflect the expansive scope of the LTC Taskforce, there are areas that emerged as a part of the taskforce deliberations that were seen as beyond the focus of this effort. One such area—*transportation*—was seen as fundamentally related to long-term care in that critical inadequacies in the transportation system in our state create essential barriers to individuals living independently and hamper access to needed services and supports. The complexities of this topic, though, transcended the collective expertise of those assembled to focus on long-term care. In order to effectively address the pervasive concerns around the transportation system in our state, **the LTC Taskforce recommends the formation of a statewide taskforce on transportation that will engage experts, consumers and leaders from across South Carolina in efforts to enhance public transportation services—particularly for older adults and persons with disabilities.**

Ultimately, this report and the recommendations it contains represent a living document. This report should be used as a flexible tool in seeking needed improvements in the LTC system in our state. The desire of the taskforce members was to create recommendations that can be translated into action. In some instances, such action requires testing new approaches and determining what works. For that purpose, **the LTC taskforce also recommends the development of formal “incubator” processes to pilot new approaches and evaluate results.** Such “incubators” could allow for innovative ideas to be brought from theory into practice in support of policy, systems and environmental improvements in select communities across our state. Gauging what works would allow for promising results to be translated more quickly to communities in other areas of the state in a manner that accelerates improvements. The involvement of communities and private-sector partners is essential, as government cannot do it all. The dramatic needs that will be generated from the demographic changes that our society will experience over the next 20 years will exceed the capacity of any one entity—even government. Private-sector entities, communities, families and individuals must work alongside government to meet this demand.

In order to ensure that real improvements evolve from the recommendations of this report, it will be essential to structure an implementation phase that can engage responsible entities in progress around the action steps and allow for tracking of progress. To that end, **the LTC Taskforce recommends that there be a formal and structured implementation process that would bring collective focus, leadership and accountability to each of the recommendations presented in this report.** In addition, implementation efforts could yield further innovations as practical improvements begin to occur. Ultimately, all of this must happen in order to prepare our state to meet the vital and changing needs of all South Carolinians.

## **Appendices**



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## Overview of Long-Term Care Services in South Carolina

<b>Agency/Program:</b>	<b>Overview/Organizational Placement/Structure</b>	<b>Major Funding</b>	<b>Target Populations</b>	<b>Major Services</b>
South Carolina Department of Health and Human Services	<ul style="list-style-type: none"> <li>• Designated State Medicaid Agency</li> <li>• Cabinet level agency</li> <li>• 11 regional Community Long Term Care Offices and county eligibility offices</li> </ul>	<ul style="list-style-type: none"> <li>• Medicaid (Federal/State)</li> </ul>	Persons of all ages who meet: <ul style="list-style-type: none"> <li>• Income and resource limits</li> <li>• Medical necessity requirements for some services like NF or HCBS</li> </ul>	<ul style="list-style-type: none"> <li>• Nursing facility care</li> <li>• HCBS waivers</li> <li>• Home health</li> <li>• Hospice</li> <li>• Optional State Supplementation &amp; OSCAP</li> </ul>
Lieutenant Governor's Office on Aging	<ul style="list-style-type: none"> <li>• Designated State Unit on Aging</li> <li>• Division within the Lt. Governor's Office</li> <li>• Leads Aging Network comprised of 10 Area Agencies on Aging/Aging and Disability Resource Centers, county-level Councils on Aging &amp; other private providers</li> </ul>	<ul style="list-style-type: none"> <li>• Older Americans Act</li> <li>• Other federal</li> <li>• State</li> </ul>	<ul style="list-style-type: none"> <li>• Persons 60 and older with greatest social and economic need</li> </ul>	<ul style="list-style-type: none"> <li>• Congregate meals</li> <li>• Home delivered meals</li> <li>• Transportation</li> <li>• Respite</li> <li>• Information &amp; referral</li> <li>• LTC Ombudsman Services</li> </ul>
South Carolina Department of Disabilities and Special Needs	<ul style="list-style-type: none"> <li>• Designated State Mental Retardation Authority</li> <li>• Free-standing state agency with Commission</li> <li>• 4 regional centers (ICF-IIDs), County-level Disability &amp; Special Needs Boards and other contracted private providers</li> </ul>	<ul style="list-style-type: none"> <li>• Medicaid (Federal/State)</li> </ul>	Persons of all ages with: <ul style="list-style-type: none"> <li>• Intellectual disabilities or related disorders</li> <li>• Pervasive Developmental Disorders</li> <li>• Head and/or spinal cord injuries or similar disabilities</li> </ul>	<ul style="list-style-type: none"> <li>• Home and community-based waiver programs</li> <li>• Residential programs</li> <li>• Community-based services</li> <li>• Service coordination</li> <li>• ICF-IIDs</li> </ul>
South Carolina Department of Mental Health	<ul style="list-style-type: none"> <li>• Designated State Mental Health Authority</li> <li>• Free-standing state agency with Commission</li> <li>• Operates inpatient psychiatric hospitals, 3 nursing facilities, community mental health centers</li> </ul>	<ul style="list-style-type: none"> <li>• Medicaid (Federal/State)</li> <li>• State</li> </ul>	Persons of all ages with mental illness	<ul style="list-style-type: none"> <li>• Nursing facility care</li> <li>• In-patient psychiatric services</li> <li>• Community mental health services</li> <li>• Case management</li> <li>• School-based services</li> </ul>
South Carolina Department of Social Services – Adult Protective Services Program	<ul style="list-style-type: none"> <li>• Child welfare agency &amp; also administers other federal programs for low-income individuals &amp; families</li> <li>• Cabinet-level agency</li> <li>• County offices</li> </ul>	<ul style="list-style-type: none"> <li>• Federal (TANF, SNAP, SSBG)</li> <li>• State</li> </ul>	<ul style="list-style-type: none"> <li>• Vulnerable adults in need of protective custody due to abuse, neglect or exploitation</li> </ul>	<ul style="list-style-type: none"> <li>• Adult protective services</li> </ul>

## **List of Acronyms**

AAA – Area Agencies on Aging

ADRC – Aging and Disability Resource Center

APCC – Adult Protection Coordinating Council

APS – Adult Protective Services

CLTC – Community Long Term Care

CRCF – Community Residential Care Facilities

CNA – Certified Nursing Assistant

DCW – direct care worker

DHEC – SC Department of Health and Environmental Control

DDSN – South Carolina Department of Disabilities and Special Needs

DMH – South Carolina Department of Mental Health

DSS – SC Department of Social Services

FCSP – Family Caregiver Support Program

HCBS – home and community-based services

LAC – Legislative Audit Council

LGOA – Lieutenant Governor’s Office on Aging

LLR – Department of Labor, Licensing and Regulation

LTC – Long-Term Care (also referred to as LTSS)

LTSS – Long-Term Services and Supports (also referred to as LTC)

OAA – Older Americans Act

OAPA – Omnibus Adult Protection Act

OSA – USC Arnold School of Public Health’s Office for the Study of Aging

OSS – Optional State Supplementation Program

OSCAP – Optional Supplemental Care for Assisted Living Participants Program

PACE – Program of All-inclusive Care for the Elderly

PART – Preventing Avoidable Readmissions Together

RFA – South Carolina Revenue and Fiscal Affairs Office

SCDHHS – South Carolina Department of Health and Human Services

SCHA – South Carolina Hospital Association

SNF – skilled nursing facility

SCRC – South Carolina Respite Coalition