REPORT

How Can States Support an Aging Population? Actions Policymakers Can Take

by Lindsay Goldman, LMSW, and Robert Wolf, JD
# Table of Contents

**Acknowledgments** .................................................................................................................... 1

**Foreword** .................................................................................................................................. 2

**Introduction** ............................................................................................................................... 3

**Overview of Aging in America: Key Demographics and Issues**
  - The Active Aging Framework .......................................................................................... 4
  - Financial Security and Older Adults .............................................................................. 10

**Critical Topics in Aging Selected by State Health Policy Leaders**
  - Long-Term Services and Supports .............................................................................. 13
  - Workforce Shortage and Palliative Care ..................................................................... 18
  - Dementia ......................................................................................................................... 21
  - Innovations in Technology ............................................................................................ 24

**Notes** ......................................................................................................................................... 29

**The Authors** .............................................................................................................................. 36
Acknowledgments

The authors would like to thank Jo Ivey Boufford, MD, President of The New York Academy of Medicine, as well as all of the speakers who presented at the Reforming States Group fall meetings on aging. Their affiliations at the time of the presentation are listed.

G. Lawrence Atkins  
Executive Director  
Long-Term Quality Alliance  
Washington, DC

Crispin Baynes  
Co-director NY Chapter  
Aging 2.0 Advisor  
New York, NY

Patti Killingsworth  
Assistant Commissioner  
Chief of Long-Term Services and Supports  
Bureau of TennCare  
Nashville, TN

Jed A. Levine  
Executive Vice President  
Director, Programs and Services  
Alzheimer’s Association, New York City Chapter  
New York, NY

Helen B. McNeal  
Executive Director  
The California State University  
Institute for Palliative Care  
San Marcos, CA

Jewel Mullen  
Commissioner  
Connecticut Department of Public Health  
Hartford, CT

Marlene Nagel  
Director of Community Development  
Mid-America Regional Council  
Kansas City, MO

Jennifer Wallace-Brodeur  
Interim Lead, Livable Communities, Education & Outreach  
AARP  
Washington, DC
Foreword

It is projected that by 2050, there will be 83.7 million Americans over the age of 65, almost double the number who were that age in 2012. This generation of older adults will not only have increased longevity, but will be different from previous generations in that they will be better educated, more racially and ethnically diverse, and more widely dispersed from their families. Taking into account these characteristics, state health policy leaders are looking at ways to help this population live long and healthy lives—often while remaining within their communities.

What can states do to support an aging population? The topic is of such importance to state health policy leaders that the Reforming States Group (RSG) devoted its 2015 fall meetings to the topic. Supported by the Milbank Memorial Fund since 1992, the RSG is a bipartisan, voluntary group of state health policy leaders from both the executive and legislative branches who, with a small group of international colleagues, work on practical solutions to pressing problems in health care and, more broadly, in population health.

The goal of the meetings was to help state leaders better understand the specific needs of an older population—and to uncover some of the promising solutions that states and local agencies are implementing to support this population.

Written by Lindsay Goldman, LMSW, and Robert Wolf, JD, MUP, of The New York Academy of Medicine, the report highlights topics from the 2015 fall RSG meeting. The first part of the report provides an overview of aging in America, including key issues. It uses the World Health Organization’s Active Aging Framework as a model of healthy aging.

The second part of the report examines topics selected by state health policy leaders, based on their relevance. These topics include improving long-term services and supports, how the impending workforce shortage affects palliative care, innovations in technology, and dementia. For each of these topics, suggestions for state-based policy initiatives are culled from the discussions among state policymakers at the meetings.

It is our hope that this report will provide a framework for discussion among state and local policymakers as they develop policies and programs that support the aging population in their communities.

Representative John O’Bannon
Virginia House of Delegates
RSG Steering Committee Member

Nick Macchione
Director of Health and Human Services for the County of San Diego, California
RSG Steering Committee Member
Introduction

Population aging is a global phenomenon rapidly occurring in both developing and developed countries. Advances in medicine, coupled with reductions in fertility and infant and childhood mortality rates, have led to significant gains in life expectancy. By 2050, the number of people aged 65 and over will total just under 1.5 billion, or 16% of the global total. In 1950, it was only 5%.1

Life expectancy in the United States is 78.7 years, up from 47.3 in 1900.2 The population aged 65 and over is growing at a faster rate than the total American population. While people aged 65 and over currently comprise 14.5% of the total population, by 2030, they are expected to comprise 20%.3 State and local governments play a vital role in helping health, human services, housing, transportation, and other agencies support an aging population. They do this by identifying needs, coordinating programs, and providing financial, policy, and program resources.

To this end, the Reforming States Group (RSG) dedicated part of its fall 2015 meetings to the subject of aging—specifically, how states can best plan for and support an aging population. Improved population health depends in part on enlightened, evidence-based state policies. The RSG believes that leadership is essential to the health of our communities and works to develop leadership among participants for the benefit of the states.

During its fall 2015 meetings, the RSG partnered with The New York Academy of Medicine to develop sessions focused on some of the major challenges and opportunities facing states as they work to support an aging population.

The topics for the meetings were chosen by state leaders, based on their relevance and the emerging trends in the engagement and care of older people. The session focused on an overview of issues in aging, including the socio-demographic composition of the population, the World Health Organization’s framework for active-aging and age-friendly communities, and the financial security of older Americans.

Reforming States Group

Supported by the Milbank Memorial Fund since 1992, the Reforming States Group (RSG) is a bipartisan group of state executive and legislative leaders who, with a small group of international colleagues, meet annually to share information, develop professional networks, and commission joint projects. The meetings provide trusted forums for health care policymakers in states and other jurisdictions to candidly share experiences and discuss common challenges.

RSG meetings are unique in several ways:

- They focus on state policymakers. The health of our communities depends on state leadership to balance competing priorities and advance health policy.
- They are nonpartisan. The group’s strict adherence to principles of nonpartisanship enhances the RSG’s credibility as a source of good information. “Milbank Rules” apply during meetings—state leaders discuss policy ideas and learn how their peers address challenges, while adhering to the idea that “what’s said here, stays here.”
After the overview, presentations focused on four topics of interest to state leaders:

- **Long-term services and supports**—What are the key challenges facing states? What are the ways states can improve the system of care?
- **Workforce shortage and palliative care**—What is palliative care? How will the impending workforce shortages affect adequate and quality care?
- **Dementia**—What is the prevalence and what are the associated costs of the disease? What innovative programs can states learn from?
- **Innovations in technology**—What are the future technology trends that can support older people?

This report provides a review of the topics discussed, as well as suggestions for state-based policy initiatives that emerged from discussions among state policymakers at the meetings. These suggestions can be found in charts throughout this report.

This report is intended to provide a framework for state policymakers to identify potential areas for action. It is important to note that this report does not present an exhaustive review of aging issues nor does it capture all of the work being done across states to meet the needs of older populations. All of the presentations mentioned above can be found on the Fund’s website.

**Overview of Aging in America: Key Demographics and Issues**

**The Active Aging Framework**

In the United States, policy decisions and funding mechanisms are predominantly grounded in a medicalized approach to aging. This approach focuses on health care treatment rather than prevention, and it does not maximize the social, physical, and economic participation of older adults to prevent disability and physical frailty.

Aging, however, is not a medical condition but a developmental stage. While half of all physical impairments after age 65 are due to arthritis (often leading to falls), heart disease, and diabetes, the majority of older people live independently while managing these chronic conditions. Moreover, the new generation of older Americans is unlike previous generations. More people are working much later in their lives, some as a result of insufficient retirement savings or economic uncertainty. While in the past, older Americans might have moved to Florida or Arizona, most now maintain ties with where they currently reside and expect to remain in their communities.

The active aging framework, developed by the World Health Organization (WHO), recognizes all of the determinants of healthy aging. (See Figure 1.) The framework offers an alternative paradigm centered on “adding life to years” not simply “years to life.”
Grounded in evidence, the active aging framework posits that a person’s disability trajectory can be slowed or reversed through increased engagement in his/her community, which is associated with better physical and mental health, as well as well-being. To enable older people to remain in their homes and communities, the WHO age-friendly communities model was created to identify and address barriers faced by older people throughout the course of daily life within the following eight domains:

1. Outdoor spaces and buildings
2. Transportation
3. Housing
4. Social participation
5. Respect and social inclusion
6. Civic participation and employment
7. Communication and information
8. Community support and health services

Through qualitative and quantitative data collection methods, feedback from older people is gathered and used to make improvements within each of the eight domains. While the provision of health care and supportive services is certainly important, it is only one of eight domains within this framework, which posits that aging must become the business of all sectors and disciplines, including but not limited to architecture, planning, arts and culture, business, and real estate. When viewed through the active aging framework, an aging population is an opportunity to improve communities for people of all ages and to delay or reduce disability and dependence.

Aging is not a medical condition; it’s a developmental stage.
As of April 2016, the WHO age-friendly communities model had been implemented in 287 communities, 86 of which are in the United States. While communities as diverse as New York City; Henderson, Nevada; Atlanta, Georgia; Fayetteville, Arkansas; Des Moines, Iowa; and Bowdoinham, Maine, have different approaches to governance and implementation, the model is most successful when political leadership and the private sector are engaged. For example, Age-friendly NYC is a partnership between the city council, the mayor’s office, and The New York Academy of Medicine. Adhering to the WHO model, Age-friendly NYC has engaged thousands of older people throughout the city since 2007, resulting in notable improvements to policy, programs, and practices developed in response to feedback, including:

- **Improvements in pedestrian safety**
  New York City saw a 10% reduction in pedestrian fatalities among older people through mitigation measures at the most dangerous intersections, including extending pedestrian crossing times at crosswalks to accommodate slower walking speeds, constructing pedestrian safety islands, widening curbs and medians, narrowing roadways, and installing new stop controls and signals.

- **Transportation that supports aging in place**
  New York City added 4,000 bus shelters and 1,300 benches specially designed to enhance the comfort and safety of older people.

- **Improved consumer experience at local businesses**
  Age-friendly NYC educated 30,000 storefront businesses about age-friendly business practices, catalyzing improvements such as the addition of seating in stores, more legible signage, and new senior discounts.

- **More opportunities for exercise**
  The parks department designated senior-only swim hours and provided water aerobics for older people in 16 public pools, as well as discounted rates for other exercise programs.

- **Shared use of public resources**
  A Market Ride program uses school buses to transport older people in underserved areas to supermarkets.

Currently most age-friendly initiatives, also known as “livable community” initiatives, are developed at the city or community level; however, some states, such as Connecticut, are beginning to pass livable community legislation requiring state agencies to collaborate with another to ensure that older people can access resources, services, and amenities needed to remain independent. Improvements made through age-friendly initiatives often benefit people of all ages. For example, extending street crossing times also helps families with one small children and younger people with disabilities.
Activities Policymakers Can Consider to Support Age-Friendly Communities

<table>
<thead>
<tr>
<th>Goals</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incorporate age-friendly communities into funding decisions and requests for proposals (RFPs).</td>
<td>Encourage all state agencies and beneficiaries of state funding to consider how their policies and programs will affect older people and to take the development of age-friendly communities into account when making state funding decisions. Modify RFPs to reflect this priority.</td>
</tr>
<tr>
<td>Promote and support agency collaboration and planning.</td>
<td>Convene meetings of state agencies, including, but not limited to, health, aging, and transportation, to promote collaborative planning and use appropriations to promote cross-sector collaboration.</td>
</tr>
<tr>
<td>Provide communities with age-friendly resources.</td>
<td>Post age-friendly tools and resources on state agency websites. See the New York State Office for the Aging.</td>
</tr>
<tr>
<td>Leverage resources to assess, improve, and track the age-friendliness of communities.</td>
<td>Leverage state area agencies on aging (AAAs), state colleges and universities, and regional planning efforts to assess the age-friendliness of communities, make required improvements, and track outcomes. See Age-friendly Portland and Age-friendly Philadelphia.</td>
</tr>
<tr>
<td>Seek out lifelong learning opportunities for older adults.</td>
<td>Encourage state colleges and universities to offer free or low-cost opportunities for lifelong learning for older people, as well as access to amenities such as fitness centers and pools. See The City University of New York (CUNY).</td>
</tr>
</tbody>
</table>

Resources


**Aging & the National Prevention Strategy.** Philadelphia Corporation for Aging.

CDC Community Health Improvement Navigator. US Centers for Disease Control and Prevention.


A Self-Service Tool Kit: The AARP Network of Age-Friendly Communities. AARP.

Activities Policymakers Can Consider to Meet the Housing Needs of Older People

<table>
<thead>
<tr>
<th>Goals</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incentivize or require universal design principles to improve accessibility in the built environment through products and environments designed to be usable by all people without the need for adaptation.8</td>
<td>Evidence shows that universal design helps older people remain safe and independent in their homes.9 Mechanisms to promote universal design include financial incentives, building certification, streamlined permitting, and fee waivers. Tax incentives and deferred loan programs have also been used to help people with disabilities make minor modifications to their existing homes.10 See California and Georgia.</td>
</tr>
<tr>
<td>Support policies to increase and preserve affordable housing for older people.</td>
<td>Policy options to maximize affordable housing include creating a housing trust fund, providing rental subsidies, using tax incentives, and refinancing debts.11 See Washington, DC, Georgia, and New York City.</td>
</tr>
<tr>
<td>Provide property tax credits in exchange for volunteer service.</td>
<td>Evidence suggests that volunteering may be associated with better health as well as reduced social isolation. The Seniors Add Valuable Experience (SAVE) program in Danbury, Connecticut, is a partnership between the City of Danbury and the United Way that enables people aged 65 and older to earn a $600 property tax credit for 100 hours of service per year.</td>
</tr>
</tbody>
</table>

Resources

Housing America’s Older Adults. Joint Center for Housing Studies of Harvard University.

HousingPolicy.org. National Housing Conference and Center for Housing Policy.
Activities Policymakers Can Consider to Meet the Transportation Needs of Older Adults

<table>
<thead>
<tr>
<th>Goals</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Create volunteer driver programs through area agencies on aging and pass laws to prohibit auto insurance companies from increasing rates.</td>
<td>The Independent Transportation Network of America is a membership organization that works with volunteers to increase transportation access for older people who can no longer drive. In some states, such as Maine, elders can donate their cars in exchange for rides.(^\text{12}) To maximize volunteer participation, states can establish laws to prohibit auto insurance companies from raising rates for volunteer drivers.</td>
</tr>
<tr>
<td>Offer subsidized rides for low-income older people through partnerships.</td>
<td>Partner with Uber and other ride-sharing platforms to develop supports for older adults. The Gainesville Florida Area Agency on Aging currently has a six-month pilot project providing Uber rides to elders in two neighborhoods.(^\text{13})</td>
</tr>
</tbody>
</table>

Resources

- ITN America (The Independent Transportation Network of America)
- Federal Transit Administration grants
- National Center on Senior Transportation
Financial Security and Older Adults

According to 2014 census data, 10% of people aged 65 and over were living in poverty as defined by the federal poverty measure (FPM), compared to 16% in the general population.14 However, using the supplemental poverty measure (SPM), which more comprehensively reflects available financial resources and liabilities (e.g., benefits and entitlements, medical expenses, housing expenses, etc.), 15% of people aged 65 and over were living in poverty. This measure yields a consistently higher rate of poverty for older people across all states.15 Furthermore, women aged 65 and older were more likely to be poor than men under both the FPM (12% versus 7%) and the SPM (17% versus 12%), and this disparity increases with advanced age. Using the FPM, older Hispanics/Latinos and Blacks/African-Americans were more likely to be living in poverty than Whites (20% and 18%, respectively, compared to 7% under FPM, and 28% and 22% compared to 12% under SPM).15

In 2015, the US Government Accountability Office reported that about half of households aged 55 and older have no retirement savings (such as a 401(k) plan, defined benefit plan, or individual retirement account) and have few other financial resources to draw on in retirement.16 An analysis by the National Institute on Retirement Security found that the median retirement account balance is $2,500 for all working-age households and $14,500 for near-retirement households.17 Retirement savings and pensions need to last longer because, on average, men and women are retired for seven more years than they were in 1970. Increasingly, defined retirement plans have been frozen or terminated, and individually managed accounts are becoming the mainstay of retirement.18 This is particularly worrisome in light of the fact that elderly people exhibit low levels of financial literacy at a time in their lives where they need to make complex decisions19 and can also easily fall prey to financial fraud and abuse.18 The annual financial loss by victims of elder financial abuse is estimated to be at least $2.9 billion dollars, a 12% increase from $2.6 billion estimated in 2008.20

In 2014, over 82% of people aged 65 and older were not in the labor force.14 However, unless something is done to replenish Social Security’s shrinking trust funds, by 2035, the first pension check for older Americans might amount to as little as 27.5% of their career wages, according to calculations published last year by the chief actuary of the Social Security Administration.21 As a result, one recent analysis projected a 180% increase in the number of elderly living in poverty—from 8.9 million in 2010 to 25 million in 2050, based on current rates of population growth and assuming no improvements in what is promised in Social Security benefits.22
Activities Policymakers Can Consider to Help Increase the Financial Security of Older Adults

<table>
<thead>
<tr>
<th>Goals</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model age-smart employment practices.</td>
<td>Look at the potential to provide flexible work schedules and workplaces, job sharing, paid sick leave, caregiver support services, technology training, and the use of universal design principles to assure accessibility for state employees.²³</td>
</tr>
<tr>
<td>Allow employees to work beyond age 65.</td>
<td>Review the impact of allowing employees to work after 65 without forfeiting benefits. For example, deferred retirement option plans have been instituted in many public school districts facing teacher shortages.²⁴</td>
</tr>
<tr>
<td>Collaborate with the private sector to promote age-friendly banking practices.</td>
<td>Encourage banks to implement age-friendly policies, including expediting assistance to those who cannot wait in line; training staff on effective communication strategies with older people; delivering neighborhood workshops on topics such as financial planning, safety, and fraud; offering telephone banking and money home-delivery services; and ensuring the accessibility of all bank branches and equipment.²⁵</td>
</tr>
</tbody>
</table>

Resources

**Age-Friendly Banking: A Global Overview of Best Practices.** AARP International.

**Age Smart Employer NYC: Compendium of Strategies and Practices.** The New York Academy of Medicine.

**Pension Counseling and Information Program.** This Administration on Aging (AoA) program assists older Americans in accessing information about their retirement benefits and helps them negotiate with former employers or pension plans for due compensation. AoA currently funds six regional counseling projects covering 30 states.

**Planning for Retirement: Before You Claim.** The Consumer Financial Protection Bureau offers a number of tools, including retirement financial planning information.

**Savvy Saving Seniors Financial Education Tools.** National Council on Aging.

**What Can We Do to Help? Adopting Age-Friendly Banking to Improve Financial Well-Being for Older Adults.** Community Development Investment Center, Federal Reserve Bank of San Francisco.
### Activities Policymakers Can Consider to Help Reduce Financial Exploitation of Older Adults

<table>
<thead>
<tr>
<th>Goals</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leverage existing resources.</td>
<td>Incentivize and/or support legislation to appropriately train bankers to identify, report, and respond to signs of cognitive impairment and exploitation.²⁶ Area aging agencies can work to educate bankers, as well as health care professionals and other community gatekeepers (e.g., religious leaders and law enforcement), about how to identify and respond to financial exploitation of elders and create and strengthen linkages with appropriate community service providers (e.g., adult protective services).</td>
</tr>
<tr>
<td>Promote financial literacy among older adults.</td>
<td>Partner with the private and nonprofit sectors to fund and promote financial literacy and counseling programs across the age continuum that include: basic money management, budgeting, avoiding scams, maximizing benefits, reverse mortgage issues, managing credit and debit cards, and other critical financial knowledge. Institutions such as libraries, state and community colleges, and high schools are ideal settings to deliver this content. California and Delaware have done this successfully.²⁷</td>
</tr>
<tr>
<td>Strengthen linkages between services for public health, aging, and disability.</td>
<td>States—as well as some communities—have established resources and services to address financial fraud and abuse among older adults. In Missouri, Missourians Stopping Adult Financial Exploitation (MOSAFE) educates financial institutions and consumers about how to stop attempted or ongoing financial exploitation.</td>
</tr>
</tbody>
</table>

### Resources

- National Center on Elder Abuse, Administration on Aging, Department of Health and Human Services
- National Committee for the Prevention of Elder Abuse
- Financial Fraud Enforcement Task Force
Critical Topics in Aging Selected by State Health Policy Leaders

Long-term Services and Supports

Long-term services and supports (LTSS) provide assistance to people with physical and cognitive impairments who need help with activities of daily living (e.g., bathing, dressing, eating, toileting, shopping), medical attention, and assistive devices or technology over an extended time. According to a recent report to Congress, 12 million Americans use the long-term care system, which includes residential health facilities (nursing homes), adult care facilities (adult homes and assisted living), hospice (inpatient and outpatient), adult day health care centers, and home care. The rapid aging of the population, coupled with fewer family caregivers and fewer personal resources to pay for care, is projected to double the number of Americans in need of both privately and publicly funded LTSS from 12 million in 2010 to 27 million in 2050, placing a huge strain on the system. Of people turning age 65 now, it is estimated that 70% will need assistance with activities of daily living for an average of three years (3.7 for women and 2.2 for men).

Cost

With limited coverage under Medicare and few affordable options in the private insurance market, millions of Americans turn to Medicaid, the nation’s publicly financed health insurance program, when they can no longer afford to pay for LTSS. As a result, Medicaid will continue to be the primary payer for a range of institutional and community-based LTSS for people needing assistance with daily self-care tasks. In 2013, Medicaid spent over $123 billion for institutional and community-based LTSS, which represented 28% of the total Medicaid service expenditures that year.

This governmental financing burden would be even higher if not for the fact that in the United States, the majority of LTSS is provided by unpaid caregivers—relatives and friends—in home- and community-based settings. An AARP public policy brief reported that the majority of family caregivers are women aged 50 and over, caring for a parent for at least one year while maintaining outside employment. A 2006 study by the MetLife Mature Market Institute found that employers lose $33.6 billion a year in worker productivity because of caregiving responsibilities.

Service Delivery

Medicaid home- and community-based care versus institutional long-term care varies by region and population. In 2011, 80% of nonelderly beneficiaries with disabilities used home- and community-based services (HCBS) compared to 50% of elderly beneficiaries; however, many states are increasingly shifting their budgets away from institutional care for both populations as seen in data from 2013. (See Figure 2.)
Medicaid home- and community-based services include:

- Home health services, personal care services
- Section 1915(c) HCBS waivers, which allow states to provide HCBS to people who would qualify for institutional care
- Section 1115 demonstration waivers to deliver HCBS through managed care

In 2013, spending on HCBS grew to 46% ($56.6 billion) of total Medicaid LTSS spending.

States are also beginning to utilize the new and expanded federal options from the Centers for Medicare and Medicaid Services (CMS) for funding HCBS, including:

- Money Follows the Person, Rebalancing Demonstration Grant
- Section 1915(i) HCBS state plan
- Section 1915(k) Community First Choice state plan option

States are also pursuing managed fee-for-service models in an effort to improve care coordination and/or expand access to HCBS.

There are almost nine million people known as “dual eligibles” who receive Medicaid and Medicare benefits. They have substantial health needs that result in disproportionate share costs to both programs. Medicare acts as the primary payer for a range of services for dual...
eligibles; Medicaid provides cost-sharing assistance and may pay for services not covered or limited under Medicare. Under new waiver authority in the Affordable Care Act, select states are testing models to align Medicare and Medicaid financing, seeking to better integrate and coordinate primary, acute, behavioral health, and LTSS for this vulnerable beneficiary population.

Quality

Improving the quality of Medicaid HCBS programs is a growing concern for CMS, states, and all stakeholders. Monitoring beneficiaries’ care quality and outcomes will grow in importance as states increase their use of risk-based, capitated managed care to cover new populations and deliver LTSS. CMS requires that states implementing managed LTSS programs include a comprehensive strategy for assessing and improving care and quality of life for LTSS beneficiaries. In addition, CMS recently announced the Home Health Value-Based Purchasing Program, which would reduce or increase payments to Medicare-certified home health agencies in nine pilot states depending on the quality of care delivered.

The National Quality Forum, contracted by the Department of Health and Human Services, is convening a multi-stakeholder committee to address gaps in HCBS quality measurement. This two-year project will include the creation of a conceptual framework, a synthesis of evidence, an environmental scan of measures and measurement concepts, and recommendations for prioritization in measurement.

Simultaneously, the National Association of States United for Aging and Disabilities, the Human Services Research Institute, and the National Association of State Directors of Developmental Disabilities Services are developing National Core Indicators—Aging and Disabilities (NCI-AD), modeled on the National Core Indicators’ effort to collect data for people with intellectual disabilities. The NCI-AD aims to “support states’ interest in assessing the performance of their programs and delivery systems in order to improve services for older adults and individuals with physical disabilities.” To this end, a survey has been created and piloted in three states and will be rolled out in an estimated 30 more states over the next few years.

Activities Policymakers Can Consider to Improve LTSS

<table>
<thead>
<tr>
<th>Goals</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review and understand state scorecards on aging.</td>
<td>AARP, The Commonwealth Fund, and The Scan Foundation collaborated to create a State Long-term Services and Supports Scorecard to compare states across indicators including affordability and access, choice of setting and provider, quality of care and quality of life, support for family caregivers, and effective transitions for older adults, people with physical disabilities, and family caregivers. Policymakers can review their state’s scorecard and develop plans to improve areas of weakness in collaboration with the private and nonprofit sectors and other stakeholders.</td>
</tr>
</tbody>
</table>
## Activities Policymakers Can Consider to Help Implement Caregiver-Friendly Policies

<table>
<thead>
<tr>
<th>Goals</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consider family-leave policies for caregivers.</td>
<td>State family-leave policies have been found to improve worker productivity, recruitment, retention, and motivation. As of 2014, California, New Jersey, and Rhode Island had such policies.</td>
</tr>
<tr>
<td>Review policies to integrate unpaid caregivers into the care team.</td>
<td>Increasingly, unpaid caregivers are performing complex medical and nursing tasks in addition to providing traditional assistance with activities of daily living. In their 2012 study of a nationally representative sample of 1,677 caregivers, AARP and the United Hospital Fund found that 46% of caregivers performed tasks at home that would have been done in a hospital or nursing home in the past. Tasks included “managing multiple medications, helping with assistive devices, preparing food for special diets, providing wound care, using monitors, managing incontinence, and operating specialized medical equipment,” and caregivers reported that many of these tasks were challenging and required additional training. A model is the Caregiver Advise, Record, Enable (CARE) Act, which asks hospitals to:</td>
</tr>
<tr>
<td></td>
<td>1. Document the family caregiver’s name in the medical record;</td>
</tr>
<tr>
<td></td>
<td>2. Inform the family caregiver of discharge plans; and</td>
</tr>
<tr>
<td></td>
<td>3. Train the family caregiver on how to do the medical tasks the person being discharged will require at home.</td>
</tr>
<tr>
<td></td>
<td>As of December 2015, the CARE Act had been signed into law in 18 states and was pending in several others.</td>
</tr>
</tbody>
</table>
Activities Policymakers Can Consider to Improve Quality of Care for LTSS

<table>
<thead>
<tr>
<th>Goals</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monitor LTSS quality indicators.</td>
<td>Implement, monitor, and enforce measures of quality for LTSS that are currently under development at the federal level and regularly consult with local consumer and industry groups on additional quality measures that may be appropriate.</td>
</tr>
<tr>
<td>Review state ombudsman programs.</td>
<td>The Older Americans Act requires every state to have a long-term care ombudsman program. The ombudsman program, which is typically operated by the State Unit on Aging, provides resources and advocates for people in need of long-term care. The ombudsman addresses complaints about long-term care services and investigates elder abuse cases. Because states have the flexibility to design and fund the program as they see fit, there is variability in the capacity and quality of these programs, as well as the ratio of paid staff to certified volunteers. State policymakers should work to ensure the ombudsman program is meeting the needs of long-term care consumers in a timely and effective fashion.</td>
</tr>
</tbody>
</table>

Resources

CARE Act Map

Commission on Long-Term Care. The commission’s report to Congress outlines policy recommendations for service delivery, workforce, and financing, including establishing integrated care teams, using technology-enhanced data sharing across care settings and among providers, training family caregivers, and finding a sustainable balance of public and private financing for LTSS.
Workforce Shortage and Palliative Care

Population aging poses several challenges to the acute care and long-term care workforce. First, there are simply not enough professionals (i.e., geriatricians, nurses, administrators, and mental health and substance abuse providers) and paraprofessionals (i.e., nursing assistants, home health aides, and personal care aides) to meet the current and projected demand.\(^4\) Demand is expected to increase by 35%, while the unpaid caregiver support ratio declines from 7:1 to 4:1.\(^4\) Second, the existing workforce has not been trained to meet the needs of the system’s current and future users. The National Academy of Medicine’s 2008 report, *Retooling for an Aging America: Building the Health Care Workforce*, states, “The education and training of the entire health care workforce with respect to the range of needs of older adults remains woefully inadequate.”\(^4\) Meeting this increased demand will require strategies to attract new workers to health care professions as well as to encourage the retention of current workers, including those who are older. (See Figure 3.) For direct-care workers (3.4 million in 2014 and projected to increase to nearly 5 million by 2022),\(^4\) who deliver an estimated 70% to 80% of long-term care,\(^5\) noncompetitive wages, challenging work, difficult schedules, and poor working conditions (e.g., rigid hierarchies with lack of collective decision-making and respect for expertise) contribute to low rates of recruitment and retention,\(^4\) which are estimated to cost state Medicaid programs $6.4 billion annually.\(^6\) There are few training requirements\(^7\) and limited opportunities for career advancement,\(^8\) and increased training does not necessarily result in higher wages.

Caring Across Generations, a national policy organization on caregiving, reports that a home care worker’s average wage is only $9.57 per hour with an average annual income of about $13,000.\(^9\) For many workers, these figures are even lower due to location or erratic work schedules. For example, Florida’s minimum wage is $8.05 per hour, so a caregiver who works full time earns only $322 per week.\(^9\) Home care workers’ pay is so low that it is estimated that as many as half rely on public assistance to sustain their own families. In addition, nearly 300,000 direct-care workers have no health insurance, and many direct-care workers leave their jobs because of untreated injuries and chronic illnesses. Approximately half of all direct-care workers leave the workforce every year to find better paying work.\(^4\)
While all regions of the United States struggle to provide quality LTSS for older people, rural areas face unique direct-service workforce challenges:

- Geographic isolation means there are fewer direct-service agencies available to provide services, fewer direct-service workers available for agencies to hire, and long distances between individuals in need of services and service agencies. This results in direct-service workers spending more time traveling and less time delivering services. Lack of public transportation and difficult road and weather conditions are also barriers to care delivery.

- Rural home-health agencies serve a smaller and more dispersed client base compared with their urban counterparts. Rural home-health agencies also tend to be smaller, are more likely to be nonprofit, and generally provide fewer services.

- In many rural areas, family members, neighbors, and friends often fill gaps in caregiving services. However, migration of many adult children to larger, more urban areas reduces the number of family members available to provide care; thus, many rural elders and people with disabilities must rely on friends, religious organizations, and neighbors for unpaid services.

- Rural areas also face unique challenges in recruiting and retaining health care workers in general and constitute 85% of Health Professional Shortage Areas in the United States.
### Activities Policymakers Can Consider to Improve Recruitment and Retention of Long-term Care Workforce

<table>
<thead>
<tr>
<th>Goals</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leverage state colleges and universities.</td>
<td>In response to a projected shortfall in trained palliative care professionals, California State University created the Institute for Palliative Care to prepare the current and future palliative care workforce while also educating the community about the benefits of palliative care. The institute offers evidence-based online and in-person learning to current and future palliative care professionals working in health systems, hospices, skilled nursing facilities, case management, and physician practices.</td>
</tr>
<tr>
<td>Improve competence of workforce.</td>
<td>Health care and mental health professionals need to be able to demonstrate their competence in the care of older adults as a criterion of licensure and certification, as recommended by the Institute of Medicine in its 2008 report <em>Retooling for an Aging America</em>.</td>
</tr>
<tr>
<td>Establish state standards and funding streams for training and quality assurance.</td>
<td>Training of direct-care workers has been shown to improve quality of care and worker satisfaction and reduce turnover. Care coordinators, a new and increasingly critical segment of the long-term care workforce, are also in need of additional training. Care coordination has been found to help beneficiaries and families more effectively navigate the health system while ensuring that the proper providers and services are in place to meet beneficiaries’ needs and preferences.</td>
</tr>
</tbody>
</table>

### Resources

- **Building Health Workforce Capacity Through Community-Based Health Professional Education.** Global Forum on Innovation in Health Professional Education; Board on Global Health; Institute of Medicine.
- **The Impact of the Aging Population on the Health Workforce in the United States.** Center for Health Workforce Studies, School of Public Health, University at Albany.
- **The Mental Health and Substance Use Workforce for Older Adults: In Whose Hands?** Institute of Medicine.
- **Paraprofessional Healthcare Institute (PHI).** The PHI website offers research about direct-care workers, as well as curricula for improving quality of care.
Dementia
Dementia is the general term for a decline in mental ability, and Alzheimer’s disease is the most common cause. Alzheimer’s is a progressive disease, and though it is not a normal part of aging, the majority of people with Alzheimer’s are 65 and older and the risk factors increase with age.\textsuperscript{54} While Alzheimer’s has no cure, there are treatments that can temporarily slow the worsening of symptoms and thereby improve the quality of life for both those with the condition and their caregivers.

Prevalence (see Figure 4):\textsuperscript{55}

- Every 67 seconds, an American develops Alzheimer’s disease.
- Approximately 5.3 million Americans live with Alzheimer’s.
- While Alzheimer’s is the sixth leading cause of death in the United States, deaths from the condition may be undercounted due to the way in which causes of death are reported on death certificates.
- More Americans suffer from Alzheimer’s disease than breast cancer and prostate cancer combined.
- One of seven people with Alzheimer’s lives alone, making this a community problem.
- Baby boomers are entering the age of greatest risk.
- One of three people over the age of 85 has Alzheimer’s.
- Four percent of people with Alzheimer’s are under age 65.
- Blacks/African-Americans are about twice as likely to have Alzheimer’s and other forms of dementia as Whites, and Hispanics/Latinos are about one-and-a-half times more likely to have Alzheimer’s and dementia than Whites; however, Blacks/African-Americans and Hispanics/Latinos are less likely to be diagnosed with the disease. There are no known genetic factors that can explain the greater prevalence of Alzheimer’s and dementia in Blacks/African-Americans and Hispanics/Latinos.
Figure 4

Linked to Aging
Alzheimer’s disease becomes more prevalent as people grow older.

Age distribution of Americans with Alzheimer’s disease in 2015

Projected number of Americans age 65 and older with Alzheimer’s disease

Sources: Alzheimer’s Association (2015 age distribution); Alzheimer’s Association based on data from a 2013 article in the journal Neurology by Liesi Hebert and others (projections)

A Growing Problem
Projected increases between 2015 and 2025 in Alzheimer’s disease prevalence by state

Source: Alzheimer’s Association based on data provided by Jennifer Weuve at Rush University Medical Center and others.

Source: More Cities Aim to Be Dementia-Friendly
Cost

Dementia is the most expensive disease in the United States with a current overall cost of $226 billion, projected to increase to $1.1 trillion in 2050 with the growth of the older population. Medicare spends nearly three times more, on average, for a person with dementia than for a beneficiary without dementia, and Medicaid spends nearly 19 times more, on average, for a person with dementia than for a beneficiary without dementia.

In 2014, 15.7 million unpaid caregivers of people with dementia provided an estimated 17.9 billion hours of care at an estimated economic value of $217.7 billion. This population of caregivers is at increased risk of having their own physical and emotional challenges, including more emergency room visits and hospitalizations, reduced immune function, heart disease, and depression.

Activities Policymakers Can Consider to Help Adults with Dementia

<table>
<thead>
<tr>
<th>Goals</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop and fund state plans on Alzheimer’s disease.</td>
<td>The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships is a plan created by the Alzheimer’s Association and the Centers for Disease Control and Prevention outlining specific action items that states, local public health agencies, and partners can take in promoting cognitive functioning, addressing cognitive impairment, and helping to meet the needs of caregivers. Currently, 23 of 52 states, the District of Columbia, and Puerto Rico are implementing one or more road map actions. Forty-one states have a state plan to address dementia, and another seven are developing plans. However, funding is required to implement many of the action items on these plans. For example, New York allocated state funding in 2016 for Alzheimer’s disease, including: $25 million for Alzheimer’s disease care and support services $4 million for Alzheimer’s disease community assistance programs $4 million for Alzheimer’s disease centers of excellence $15 million for respite and caregiver services grants ($75 million over five years)</td>
</tr>
</tbody>
</table>
Activities Policymakers Can Consider to Help Adults with Dementia

| Support non-pharmacological interventions. | Numerous interventions can improve the quality of life for people with dementia and their caregivers. For example, the Music & Memory program trains professionals to set up personalized music playlists delivered on iPods and other digital devices for those in their care. |
| Create “dementia-friendly” communities. | The US movement to create “dementia-friendly” initiatives began in Minnesota and grew out of a legislative working group to prepare the state for the growing impact of Alzheimer’s. This led to the ACT on Alzheimer’s initiative, which focused on two main goals: finding the best examples of dementia-friendly practices globally and developing community implementation models. Minnesota now has 36 local communities implementing dementia-friendly measures. A national initiative, Dementia Friendly America, modeled on Minnesota’s efforts, has prompted five pilot communities, including ones in Arizona and West Virginia. |

Resources

ACT on Alzheimer’s: Dementia-Friendly Toolkit
Dementia Friendly America
The Healthy Brain Initiative. Developed by the Alzheimer’s Association and the Centers for Disease Control and Prevention’s Healthy Aging Program.
Music & Memory.

Innovations in Technology

Emerging technology has the potential to maximize social and economic participation, manage health conditions, and compensate for changes in cognitive and physical ability among older people. Older adults use technology to connect with family and friends, facilitate employment and volunteerism, and to access information and resources.

In 2013, 65.1% of people aged 65 and over lived in homes with computers, and over half of all older adults aged 65 and over reported using the Internet. However, there are disparities in usage among older people by age, race and ethnicity, level of education, and region. Black/African-American and Hispanic/Latino older adults have significantly less access to high-speed Internet connections than their White or Asian counterparts. Younger, high-income, and more educated seniors use the Internet and broadband at rates approaching that of the general population. Of older adults with an annual household income of $75,000 or more, 90% reported going online and 82% reported having broadband at home. In ad-
dition, 87% of older adults with college degrees reported going online, with 76% adopting broadband at home. This sharply contrasts with the utilization rates of low-income older people and those who did not attend college. Of older adults earning less than $30,000 annually, only 39% reported going online and 25% reported having broadband at home.

Internet, broadband, and cellular phone use drops off significantly after age 75. As of April 2012, only 34% of those 75 and over reported use of the Internet, 21% reported using home broadband service, and 56% reported using a cell phone. In an increasingly digitized world, older people who are not connected are at a significant disadvantage in accessing information about employment, housing, finances, government benefits, opportunities for socialization and enrichment, and emergency preparedness and response, all of which are required to maintain health, well-being, and security.

Older adults can also use technology to maintain functional independence and manage health conditions.

Information and communications technology has the potential to help older adults maintain functional independence by providing assistance with activities of daily living, such as meals, home and personal care, home repair, and delivery and transportation. Robotics and wearable technologies are emerging to address mobility and cognitive challenges, and monitoring devices are increasingly being used to transmit information about an elder’s safety, health, and well-being to family members and health care professionals.

Technology will become especially critical because the projected number of both paid (5 million) and unpaid (45 million) caregivers will not keep pace with the projected number of people who will require assistance (119 million) by 2020. This huge demand represents a $279 billion revenue opportunity over the next four years. However, for information and communications technology to be leveraged to its full potential, the technology must be user-friendly and flexible to adapt to changes in capacity and support activities of daily living without being intrusive or infringing on basic notions of privacy.

A 2014 report, *The New Era of Connected Aging: A Framework for Understanding Technologies that Support Older Adults in Aging in Place*, provides a valuable and utilitarian framework for thinking about these technologies by defining four categories reflecting the purpose and primary location of the technology:

- **Body**: Products that support monitoring and management of an older adult’s physiological status and mental health.
- **Home environment**: Products that support monitoring and maintaining the functional status of older adults in their home environments.
- **Community**: Technologies that enable older adults to stay socially connected.
- **Caregiving**: Technologies and products that support both informal and formal caregivers in providing timely and effective assistance.
The report anticipates further growth in development and adoption of technology as the costs continue to drop dramatically, the number of technologically capable older people increases, and simpler interfaces are used, such as voice recognition. The ability to analyze enormous amounts of data through connected aging technologies will drive additional innovation to improve health promotion, disease prevention, diagnostics, and health care delivery.

In 2016, the President's Council of Advisors on Science and Technology released the report, *Independence, Technology, and Connection in Older Age* to address the intersection of aging and technology and to recommend solutions to reduce barriers to the scale and spread of technology at the federal level to support healthy aging. State policymakers can also help ensure that older people benefit from technological advantages by identifying and addressing barriers at the state level.

**Barriers to Technology Adoption among Older People: Broadband Availability**

Broadband Internet availability varies substantially between urban and rural areas of the United States. Overall, urban areas have much higher availability of broadband Internet services compared to rural areas (99.6% have availability in urban areas versus 81.8% in rural areas).

- **Affordability**
  Manufactured technology products, as well as data consumption and connectivity, may be cost prohibitive for seniors. Accessing broadband Internet through home and cellular data networks such as like 3G and 4G will be a new cost for many older adults who may not immediately recognize the value.

- **Lack of education and training**
  While older adults have expressed the desire to use new technologies such as computers, tablets, e-readers, and smartphones, many have difficulties learning to use technology without assistance. In a survey, only 18% of older adults reported feeling comfortable learning to use new devices such as smartphones or tablets on their own, and 77% indicated that they would need someone to walk them through the process.
## Activities Policymakers Can Consider to Improve Telehealth

<table>
<thead>
<tr>
<th>Goals</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Require private insurers to cover telehealth and telemedicine.</td>
<td>To achieve parity between what is reimbursable by Medicare and what must be reimbursed by all other insurers, consider an expansive definition of telehealth that includes telephone and remote patient monitoring and a wide range of eligible distant site providers such as physicians, physician assistants, dentists, home care and hospice agencies, nurses, podiatrists, optometrists, psychologists, and social workers. There are currently 22 states that have such laws.64</td>
</tr>
<tr>
<td>Consider participation in multistate licensure initiatives.</td>
<td>To facilitate widespread access to telehealth, participate in the Interstate Medical Licensure Compact that allows state medical boards to retain their licensing and disciplinary authority but agree to share information and processes essential to the licensing and regulation of physicians who practice across state borders. Beginning in 2015, 11 states have enacted the compact (Alabama, Idaho, Illinois, Iowa, Minnesota, Montana, Nevada, South Dakota, Utah, West Virginia, and Wyoming), and an Interstate Medical Licensure Compact Commission has been created, comprised of representatives of participating states.65</td>
</tr>
<tr>
<td>Consider aging population in broadband expansion efforts.</td>
<td>Ensure efforts to connect underserved populations include older people in addition to families with children.62</td>
</tr>
<tr>
<td>Support and promote technology training programs.</td>
<td>Encourage programs specially designed for older learners through education and training provisions within Section 415 of the Older Americans Act.66</td>
</tr>
<tr>
<td>Leverage existing federal employment and volunteer programs.</td>
<td>With programs such as AmeriCorps and RSVP, focus on recruiting older and younger people who are technologically literate to act as training instructors for older people in need of assistance.</td>
</tr>
</tbody>
</table>
Resources

Older Adults Technology Services


Consumer Technology Association Foundation. This is a public foundation affiliated with the Consumer Technology Association that has supported programs to bring technology to communities of older adults throughout the United States.

Blandin Community Broadband Program. A program of the Blandin Foundation to increase broadband utilization in rural Minnesota.
Notes


The Authors

Lindsay Goldman, LMSW, directs The New York Academy of Medicine’s work in healthy aging. She has 14 years of experience in program development and administration, aging services, philanthropy, and social policy. Goldman oversees Age-friendly NYC, the Academy’s partnership with The New York City Council and the Office of the Mayor, created to improve all aspects of city life for older people. She is the lead author of the Academy’s report, “Resilient Communities: Empowering Older Adults in Disasters and Daily Life” and the chapter, “Age-friendly New York City: A Case Study,” in the recently published book, Age-friendly Cities and Communities in International Comparison. Prior to her time at the Academy, Goldman worked at UJA-Federation of New York, where she was responsible for strategic planning and allocations to support older adults in New York City and Israel. Goldman also served as the director of the Health Enhancement Partnership at Lenox Hill Neighborhood House and received a Best Practice Award for her work from the National Council on Aging in 2008. She holds a BA from Wesleyan University and an MSW from New York University.

Robert Wolf, JD, has a long and distinguished career in aging, health, law, and philanthropy. He is currently serving as a consultant to a number of leading organizations, including The New York Academy of Medicine and the National Council on Aging. For the past 18 years, Wolf has also served as a senior adviser to the SC Group, one of the country’s most important philanthropic foundation groups in the field of geriatrics. Most recently, he served as Senior Vice President for Innovation and Development at HealthCare Chaplaincy, a national leader in the research, education, and practice of spirit-centered palliative care. Prior to that, Wolf was the director of special projects at the AARP Foundation. He has also served as the executive director of medical and geriatric programs for UJA Federation in New York City, where he managed grants and programmatic support to community agencies, medical centers, and geriatric institutions. Wolf has also had a distinguished career in law, first as a staff attorney at the Brookdale Center on Aging at Hunter College and later as a partner at Strauss and Wolf, the nation’s first law firm devoted to eldercare, where he devised legal strategies that continue to influence the practice of law and aging. He has authored and coauthored publications on aging and the rights of caregivers. He earned a BA degree from Brooklyn College, a master’s degree in Urban Planning from Hunter College, a postgraduate certificate in not-for-profit management from the Columbia School of Business, and a JD from Brooklyn Law School.
The Milbank Memorial Fund is an endowed operating foundation that engages in nonpartisan analysis, study, research, and communication on significant issues in health policy. In the Fund’s own publications, in reports, films, or books it publishes with other organizations, and in articles it commissions for publication by other organizations, the Fund endeavors to maintain the highest standards for accuracy and fairness. Statements by individual authors, however, do not necessarily reflect opinions or factual determinations of the Fund. This publication may be redistributed digitally for noncommercial purposes only as long as it remains wholly intact, including this disclaimer.

Support for this research was provided by the Milbank Memorial Fund.
About the Reforming States Group

The Reforming States Group (RSG) is a nonpartisan, voluntary group of state health policy leaders from both the executive and legislative branches who, with a small group of international colleagues, gather regularly to share information, develop professional networks, and commission joint projects—all while using the best available evidence and experience to improve population health. Supported by the Milbank Memorial Fund since 1992, the RSG brings together policymakers who usually do not meet together outside their states, to share information they cannot obtain anywhere else.

About The New York Academy of Medicine

The New York Academy of Medicine advances solutions that promote the health and well-being of people in cities worldwide.

Established in 1847, The New York Academy of Medicine continues to address the health challenges facing New York City and the world’s rapidly growing urban populations. We accomplish this through our Institute for Urban Health, home of interdisciplinary research, evaluation, policy, and program initiatives; our world class historical medical library and its public programming in history, the humanities, and the arts; and our Fellows program, a network of more than 2,000 experts elected by their peers from across the professions affecting health. Our current priorities are healthy aging, disease prevention, and eliminating health disparities.

The views presented in this publication are those of the authors and not necessarily those of The New Academy of Medicine, or its Trustees, Officers or Staff.