Financing Long-Term Services and Supports for Individuals with Disabilities and Older Adults: Workshop Summary

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Financing Long-Term Services and Supports for Individuals with Disabilities and Older Adults

WORKSHOP SUMMARY

Tracy A. Lustig and Steve Olson, *Rapporteurs*

Forum on Aging, Disability, and Independence

Board on Health Sciences Policy

Division of Behavioral and Social Sciences and Education

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Reviewers

This workshop summary has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published workshop summary as sound as possible and to ensure that the workshop summary meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the process. We wish to thank the following individuals for their review of this workshop summary:

MAUREEN FITZGERALD, The Arc
CONSTANCE GARNER, Foley Hoag, LLP
ALICIA H. MUNNELL, Boston College Carroll School of Management
DONALD L. REDFOOT, AARP Public Policy Institute

Although the reviewers listed above have provided many constructive comments and suggestions, they did not see the final draft of the workshop summary before its release. The review of this workshop summary was overseen by **CHRISTINE K. CASSEL,** National Quality Forum. Appointed by the Institute of Medicine, she was responsible for making certain that an independent examination of this workshop summary was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this workshop summary rests entirely with the rapporteurs and the institution.

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Introduction and Themes of the Workshop[1]

The financing of long-term services and supports has become a major issue in the United States. These are the services and supports that individuals with disabilities, chronic conditions, and functional impairments need in order to live independently, such as assistance with eating, bathing, and dressing.[2] Long-term services and supports do not include the medical or nursing services required to manage health conditions that may be responsible for a disabling condition.

At least 11 million adults ages 18 and over receive long-term services and supports (Kaye et al., 2010). Only a little more than half of them—57 percent—are ages 65 or older. The services that these adults need vary greatly. Some need just supportive services to remain in their homes, while others require much more intensive medical care. For this latter group, paying for long-term services and supports can be a great burden. One study found that about 6 percent of people turning 65 in 2005 could expect to

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[1] The planning committee's role was limited to planning the workshop, and the workshop summary has been prepared by the workshop rapporteurs as a factual summary of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants, and are not necessarily endorsed or verified by the Institute of Medicine or the National Research Council, and they should not be construed as reflecting any group consensus.

[2] "Long-term services and supports" are also referred to as "long-term care," but the former term is now preferred as a more accurate and comprehensive description of the kinds of assistance needed by people with disabilities. This workshop summary generally uses the term long-term services and supports, but it refers to long-term care in contexts where the term has become standard, as in long-term care insurance.

have expenses of more than $100,000 for long-term services and supports (Kemper et al., 2005–2006).

In 2011, according to one study, $210.9 billion was spent on long-term services and supports, which accounted for about 9.3 percent of personal health care spending (O'Shaughnessy, 2013). About 62 percent of that spending came from Medicaid ($131.4 billion), nearly 22 percent came from out-of-pocket spending by individuals and their families ($45.5 billion), and nearly 12 percent ($24.4 billion) came from other private sources, including private long-term care insurance. With the projected aging of the U.S. population, these numbers are expected to increase substantially.

Most of the services and supports received by people with disabilities is provided by families and friends without compensation. Various studies have estimated the value of these services at hundreds of billions of dollars, yet this is usually not counted when thinking about the financing of long-term services and supports. Other important issues in this area include inadequate planning and personal savings for long-term care needs by individuals, intergenerational transfers, the role of income support programs such as Social Security Disability Insurance and Supplemental Security Income, and the role of private long-term care insurance.

Given the magnitude of the challenge posed by the financing of long-term services and supports, the Forum on Aging, Disability, and Independence of the Institute of Medicine (IOM) and the National Research Council (NRC) held a workshop on the topic on June 12, 2013, in Washington, DC. The workshop covered both older adults who acquire disabilities and younger adults with disabilities who may acquire additional impairments as they age, the target population of the Forum's work. The challenges associated with financing long-term services and supports for people with disabilities impacts all age groups. While there are important differences between the characteristics of programs developed for different age groups, and specific populations may have different needs, this workshop addressed the financing sources for long-term services and supports in general, noting specific differences as appropriate.

Box 1-1 provides the workshop statement of task. Appendix A contains the workshop agenda and Appendix B contains biographical sketches of the speakers. The workshop was undertaken as part of the forum's mission to foster dialogue and confront issues of mutual interest and concern within the long-term services and supports system.

ORGANIZATION OF THE REPORT

After this introductory chapter, Chapter 2 provides an overview of the challenge posed by the financing of long-term services and supports,

BOX 1-1
Statement of Task

An ad hoc planning committee will plan a 1-day public workshop to examine the financing of long-term services and supports for working-age individuals with disabilities and among individuals who are developing disabilities as they age. The workshop will feature invited presentations and discussions that will

- Provide an overview of the scope and trends of current sources of financing for long-term services and supports for working-age individuals with disabilities and older adults aging into disability, including income supports and personal savings.
- Consider the role of families, business, and government in financing long-term services and supports.
- Discuss implications of and opportunities for current and innovative approaches.

including workforce needs, the use of technology, and personal preferences for care. Chapter 3 considers the role of individuals and families, both as caregivers and as purchasers of long-term services and supports. Chapter 4 looks at the role of government in paying for long-term services and supports, while Chapter 5 examines the role of the private sector in providing long-term care insurance and helping employees save for retirement. Chapter 6 concludes this summary of the workshop by offering reflections on several of the most prominent topics that arose during the day's presentations and discussions.

THEMES OF THE WORKSHOP

Chapters 2 through 6 each begin with a box that lists the important points made by the presenters whose remarks are summarized in that chapter. The following points are drawn from those boxes as an introduction to the themes of the workshop, with the names of the presenter indicated.

The Challenge

- Most of the 11 million people who need long-term services and supports are living at home and in the community and rely solely on informal or family caregiving for all their care (Feder).

- The costs of long-term care services exceed most families' ability to pay (Feder).
- A "care gap" is emerging as the population ages, and the workforce for long-term services and supports continues to have serious capacity problems (Stone).
- The need for extensive and expensive long-term care is a highly variable and unpredictable event that is well suited for insurance (Feder).

The Role of Individuals and Families

- About 30 percent of households in the United States provide unpaid care to family members with disabilities (Hunt).
- The costs to families and businesses incurred by the provision of long-term services and supports range into the trillions of dollars (Hunt).
- A relatively small portion of the population ages 65 and older spends down to become eligible for Medicaid, and those who do tend to have relatively little income or wealth (Johnson).

The Role of Government

- Medicaid is the primary payer for long-term services and supports, with elderly beneficiaries and nonelderly beneficiaries with disabilities accounting for the majority of enrollment and expenditures for these supports and services (Musumeci and Reaves).
- The United States lacks a universally available insurance-based approach that would spread the financial risk of aging and living with a chronic illness or disability (Goldberg).
- A social insurance program could gain political support if it was self-financed, reduced Medicaid spending, and complemented private insurance (Goldberg).
- Bold innovations might slow the growth of expenditures while also improving the economic status of people with disabilities, but the evidence base to support such innovations is often inadequate (Stapleton).

The Role of the Private Sector

- Relatively few people have purchased long-term care insurance, and many of the companies that have offered coverage are leaving the market (O'Leary).

- Automatic enrollment in 401(k) plans by employers can substantially increase participation rates, and automatic escalation of contributions would substantially increase savings (VanDerhei).
- Public subsidies for long-term care insurance currently benefiting the upper end of the income spectrum could be redirected to the middle of the spectrum to make long-term care insurance less costly (Frank).

2

The Challenge

Important Points Made by the Speakers

- Most of the 11 million people who need long-term services and supports are living at home and in the community and rely solely on informal or family caregiving for all their care. (Feder)
- Many people with impairments have high levels of unmet needs. (Feder)
- The costs of long-term care services exceed most families' ability to pay. (Feder)
- The need for extensive and expensive long-term care is a highly variable and unpredictable event that is well suited for insurance. (Feder)
- A "care gap" is emerging as the population ages, and the workforce for long-term services and supports continues to have serious capacity problems. (Stone)
- The provision of long-term services and supports for an aging population will require a highly trained and competent workforce across all care settings. (Stone)
- Technologies for communication, engagement, safety, security, health, and learning can all help people age successfully in their locations of choice. (Orlov)
- If the long-term services and supports system is committed to consumer-centric care, it needs to find a way to accommodate the decisions made by people with disabilities. (Iezzoni)

During the first session of the workshop four speakers provided a broad overview of the challenges posed by the financing of long-term services and supports in the United States. Judith Feder, professor of public policy at the Georgetown Public Policy Institute, provided an overview of the financing of long-term services and supports. Robyn Stone, executive director of the Center for Applied Research and senior vice president of research for LeadingAge, examined workforce issues, which are related both directly and indirectly to funding. Laurie Orlov, founder of Aging in Place Technology Watch, described the potential of technology to help meet the needs of older adults. Lisa Iezzoni, director of the Mongan Institute of Health Policy at Massachusetts General Hospital and professor of medicine at Harvard Medical School, discussed the choices people with disabilities make and the need for society to respect those choices.

THE FINANCING OF LONG-TERM SERVICES AND SUPPORTS: AN OVERVIEW

Judith Feder
Georgetown Public Policy Institute

The vast majority of the 11 million people who need long-term services and supports are living at home and in the community, Feder said. Only about 1.5 million, mostly older people, are in nursing homes. In addition, 80 percent of the people living at home rely solely on informal or family caregiving for all their care, she said. A very small percentage rely solely on formal care. Reliance on families is a good thing, Feder said, in that families care about their loved ones and want to support them. It is not a good thing, however, if the care is inadequate, if the burden on caregivers is excessive, or if care at home is a family's only choice.

Surveys indicate that people with impairments have high levels of unmet needs. These unmet needs are associated with significant consequences such as falling, an inability to dress or toilet, or going without meals. Families are doing what they can, Feder said, but in many cases it is not enough.

Evidence also indicates that the costs of long-term services and supports exceed most families' ability to pay. This suggests that the care provided by family members is not just a labor of love but is a financial necessity for many people. Caregivers, in turn, can incur costs of their own or negative health consequences as a result of the care they are providing.

The Affordability of Long-Term Care

Most people cannot afford formal long-term care. A nursing home costs on average more than $80,000 per year (MetLife Mature Market Institute and LifePlans, Inc., 2012). Assisted living, in which a facility provides some supports but not nursing care, costs an average of about $40,000 per year. Intensive home care or daycare for people who have considerable needs costs an average of somewhere around $20,000 per year.

Most people do not have enough money to afford such care for long, Feder said. Young people who are disabled tend to be on the low end of the income spectrum, and most young people have not yet had a chance to save much money. Among older Americans, fewer than one-third have incomes greater than four times the poverty level, which is about $42,000 for an individual or $53,000 for a couple, and only one in three seniors has savings as high as the annual cost of a nursing home.

Some people argue that a lack of savings reflects poor planning and insufficient personal responsibility. But that argument assumes that everyone will eventually need long-term care, which is not the case. Though a commonly quoted statistic is that 70 percent of people now turning age 65 will need long-term care before they die, that number includes informal or family care, and some people included in the 70 percent will require just a little care while others will require a lot. While 4 in 10 65-year-olds will need 2 or more years of care, 3 in 10 will die without needing any long-term care.

The reality is that the need for extensive and expensive long-term care is a highly variable and unpredictable event. Thus, Feder said, it is "exactly the kind of event for which insurance is suited."

Long-Term Care Insurance

Private long-term care insurance has not been a success (see Chapter 5). Only 7 million to 8 million people have policies. Coverage is available only to people who do not have long-term care needs and is not available if someone is likely to need care. Policies generally are affordable only for people with relatively high incomes. The premiums are not guaranteed and can rise unexpectedly despite rules trying to limit such increases. These increases can lead people to conclude that they no longer can afford the insurance and thus to drop their coverage. Insurers are retreating from long-term care insurance, Feder said, because they have not found a way to make it a useful, viable product. Getting people in their 40s and 50s to plan for their living expenses in retirement is a higher priority than buying long-term care insurance, Feder argued, particularly given the limited value of such insurance.

Medicare and Medicaid

By law, Medicare does not cover custodial care. Even in cases where Medicare does cover home health care and skilled nursing facility care, restrictions limit access to benefits. These limits can be the subject of contention, but they generally keep Medicare from being used for long-term supports and services.

Medicaid covers long-term supports and services for people who do not have any resources. According to Feder, it is a last-resort financing mechanism for people who exhaust their own resources. It does not provide protection against financial catastrophe; it helps only after financial catastrophe strikes.

The level of protection that people get from Medicaid varies dramatically across states, particularly with respect to long-term services and supports. According to estimates by AARP, Feder said, only one in five low-income people in need of long-term supports and services gets Medicaid in the least generous states, compared with two-thirds in the most generous states. Similar variation occurs in the amount of spending per person.

Home- and community-based care is often unavailable under Medicaid, though such care has expanded in recent years for the younger disabled community and, especially, the intellectually disabled community. For seniors, nursing homes continue to dominate the landscape, Feder said.

Health care reform is focused on improving primary care rather than on people who need long-term care. But the chronic conditions that create high costs in the health care system also create a need for long-term care, Feder noted.

The Future

The number of people over age 65 in the United States will double over the coming decades. Furthermore, the burden across states will vary greatly because of differences in the ratio of the low-income disabled population to the working-age population. According to Feder, the result is likely to be a decrease in the adequacy and equity of services.

Feder drew several key lessons from her overview:

- Long-term care needs to be treated as a social responsibility, not just a personal responsibility.
- Savings are not a solution because the risk varies at all ages.
- An inability to plan ahead means that risk needs to be spread though some kind of public insurance mechanism, especially given the failure of private industry to provide a workable solution.

Her own preference, Feder concluded, would be an equitable, adequate financing system for everybody who needs long-term care. Policy makers may be concerned that greater funding for long-term services and supports will displace family caregivers. But the existing evidence indicates that when supports are available, family caregivers provide other kinds of services rather than going away. Also, some displacement of responsibilities would be welcome. Some family caregivers are ruining their own health, and some cannot do an adequate job.

WORKFORCE ISSUES

Robyn Stone
LeadingAge Center for Applied Research

The workforce for long-term services and supports has serious capacity problems. Recruiting staff is difficult in every segment of the workforce, including administrators, physicians, nurses, social workers, aides, and ancillary staff. The field has rapid turnover and high vacancy rates. The professional and direct care staff are aging, and the preparation of potential candidates is inadequate for current and, especially, future realities. Finally, a poor image and a lack of financial incentives exacerbate recruitment and retention problems.

To this list of negative trends, Stone added a positive one: Given the aging of the population, long-term services and supports will provide a growth area for jobs if financing is available. She also said that many workers love these jobs, even though some may not admit that they work in long-term care.

Beyond the capacity of the workforce, other issues bedevil the field. The pay and benefits in the field are lower than in hospitals or the primary care sector, and working conditions tend to be poor. Long-term services and supports have a much broader set of demands than is the case in health care. Relatively little is being invested in education or training or in adding new personnel. Though the Affordable Care Act mentions geriatrics, its focus is on hospitals and on primary care. Few data are available on supply and demand imbalances, either now or in the future.

The result of all these trends is an emerging "care gap," Stone said, which is going to grow as the population ages and as more young people with disabilities live into old age and need services. In the future, more care will be delivered in homes and in the community, but most of the work on developing a workforce for long-term services and supports has concentrated on the nursing home setting. For their part, nursing homes are focusing more attention on post-acute care, which means that home- and community-based settings will provide more traditional long-term services and supports. But the workforce may not be available to provide such services.

Greater Diversity

Older adults are becoming more ethnically and racially diverse. By 2040 about one-third of the elderly population is going to be non-white, Stone said. Cultural competence issues between caregivers and their clients will become even more complex than they are today. Already, Stone said, some of the most significant issues in workforce development involve how various cultures, groups, and individuals work together in organizations.

The next cohort of elders will include more highly educated and wealthier older adults, who are likely to put greater demands on the workforce. Also, some clients will have many more resources than others, which could create a two-tiered system. Meanwhile, the expansion of consumer-directed service systems is complicating the training of the workforce because some clients may not want more training and credentials for the workforce.

Immigration issues have a direct bearing on long-term services and supports. According to Stone, immigrants already provide the foundation for the frontline workforce in many parts of the country. The debate over immigration reform that was ongoing in Congress at the time of the workshop therefore has important implications for long-term services and supports.

As the population ages, retirement could undergo a redefinition, Stone said. Older adults may remain in the workforce, and one possibility is that some of these older workers will find new careers in long-term care. Changes that could make this more likely include the development of technologies that help to retain older staff; the redesign of work, such as the introduction of job-sharing options; the use of retired providers as mentors or coaches for younger staff; and the use of retired geriatric professional caregivers as educators.

Mental Health Issues

About one in five older Americans—more than 8 million altogether—have some type of mental health or substance use condition, and older veterans are even more likely to fall into this category than the general older population. Depressive disorders and behavioral problems secondary to dementia are the most prevalent mental health issues.

In the future, more adults are expected to have dementia and associated behavioral and psychological symptoms. The use of illicit drugs is likely to increase, Stone said, especially the illegal use of marijuana and the nonmedical use of prescription drugs. The workforce is in general not trained to deal with these issues.

Potential Actions

Stone made several recommendations related to workforce issues. The provision of long-term services and supports for an aging population will require a highly trained and competent workforce across all care settings, including direct care workers, clinicians, managers, and administrators, she said. Geriatric and gerontological competencies are essential, including an understanding of not only medical but also social needs. Interdisciplinary team approaches have been linked to the quality of care, as has geriatric training, and both will need to be emphasized.

To meet current and future demands, the supply of personnel entering the field needs to be augmented, Stone said. She argued that wages and benefits need to be increased or redesigned to create more competitive positions, and that working conditions and the quality of jobs need to be improved, with larger and smarter investments in the formal and continuing education of the workforce. Because Medicare and Medicaid are large payers in this area, their actions have major implications for the development of the workforce.

New models for the organization and delivery of long-term services and supports need to be developed, Stone said, with an emphasis on moderating the demand for personnel. Technology has a role (as pointed out in the next section of this chapter), but she added that it needs to complement and work with human caregivers. Other countries have started to grapple with workforce problems, Stone said. For example, Germany has an apprenticeship program for home caregivers which recognizes the need to develop professional competencies and skills.

Stone asserted that the licensing and certification of health care providers should require the demonstration of competencies in basic geriatric care and that schools and training programs should expand geriatric and gerontological coursework. Appropriate content needs to be developed to teach needed competencies across all settings. More clinical placements in community-based settings are needed, she said, along with the creation of geriatric nursing long-term care specialist programs aimed at registered nurses with less than baccalaureate-level preparation. Finally, new models of care, such as managed long-term services and supports, and new integrated models provide an opportunity to think about the workforce in a different way.

Workforce issues for long-term services and supports are receiving increased attention at the state, federal, and even global level, Stone concluded. New initiatives, foundation activities, and legislation are providing new opportunities. The provision of long-term services and supports is a growing field. The challenge will be to make the jobs in this field desirable.

Comments from Workshop Participants

Stone's remarks on the workshop issues sparked several comments from workshop participants. Forum member Terry Fulmer, dean of the Bouvé College of Health Sciences at Northeastern University, noted that the size of the workforce could be almost doubled if men were represented in it to the same extent as women.

Robert Jarrin, senior director of government affairs for Qualcomm Incorporated, noted that family caregivers and people with disabilities also need education about their conditions and the options that may be available to them through technology. A workshop participant observed that the reigning medical paradigm is that if something is wrong, you take a pill. But older adults also need to change their behaviors in order to maintain their functionality. Not enough people get this message and act on it, he said.

TECHNOLOGY

Laurie Orlov
Aging in Place Technology Watch

If successful aging is defined as the ability to do things for oneself, feel safe, and be healthy as one gets older, then successful aging in place includes the ability to remain in one's home of choice, whether a private home, an assisted living facility, a shared home, or some other option. Aging in place requires connected relationships among older adults, health care providers, and families and caregivers. It also increasingly will require technology, Orlov said, especially given that the number of nursing home and assisted living facilities has dropped in recent years, even as the number of older adults has increased.

Orlov discussed four categories of use for aging-in-place technologies. (She did not discuss robots, which she termed "a fantasy much talked about in the press" but much too expensive for routine care in the near-term future.)

1. In the area of *communication and engagement*, she listed e-mail, chat, games, video, cell phones, smart phones, and various kinds of portable and desktop computers.
2. In the area of *safety and security*, she mentioned webcams, fall detection devices, home monitors, and other kinds of safety and security devices.
3. In the area of *health-related technologies*, she cited telehealth applications, medication management technologies, disease management

technologies, and fitness technologies, including those designed to improve cognitive fitness.

4. In the area of *learning and contribution*, she listed technologies for enabling education, volunteering, and work. For example, online courses can retrain older adults for a "fourth stage" of life. Even people with dementia or in nursing homes can continue to learn with easy-to-use computers.

These four categories both overlap and depend on each other, Orlov emphasized. People can become isolated and depressed if they lack access to the technologies for any particular one of these categories.

The Adoption of Technologies

All of these technologies already exist. The major question is what will drive their adoption. Orlov said that her strong belief is that the caregivers of the people who need these technologies should be the ones making choices about which technologies are developed and used.

With the exception of a few limited pilot programs, these technologies are typically paid for by the user or other private sources, Orlov said. Even telehealth technologies are rarely funded by public sources, she said. The market for these technologies is very large—as much as $20 billion by 2020—but it is fragmented.

A positive development, however, is that technologies are becoming increasingly customizable, Orlov added. Tablets, smart phones, motion sensors, and other technologies can all be modified for each individual according to his or her needs.

The Commercialization of Technologies

During the discussion period, forum member Margaret Campbell, a senior scientist for planning and policy support at the National Institute on Disability and Rehabilitation Research (NIDRR), noted that technologies need to be commercialized to reach the public. NIDRR funds research on these technologies, but it does not fund trials for efficacy or effectiveness. The pathway from research laboratory to successful product needs to be studied so that it can be improved and so that promising technologies can be applied, she said.

Orlov agreed that efforts to commercialize promising research results are extremely limited, with just a few exceptions. Ph.D.s can be earned and technologies can be piloted in assisted living or nursing homes, yet they never get beyond the pilot stage. In some cases the need for a new technology may not exist, or an existing technology may meet existing needs. In other cases, the deployment of a technology may require training of the workforce—and not just the frontline workforce, but administrators at all levels.

Jarrin also observed that payers may cover expensive technologies that have undergone a U.S. Food and Drug Administration clearance or approval process and then achieved federal reimbursement while not covering much less expensive new and innovative technologies that arguably provide the same functionality and service.

PERSONAL PREFERENCES

Lisa I. Iezzoni
Harvard Medical School and
Massachusetts General Hospital

Many people with disabilities think they have a reasonable quality of life and want to extend the lives that they have. Iezzoni, who travels in a wheelchair, mentioned a friend who is a quadriplegic and can barely move any part of his body. Yet, when she and her friend went to the Barnes Collection near Philadelphia, the odometer on his 4-year-old wheelchair clicked past 8,000 kilometers—the equivalent of traveling across the United States.

People with disabilities are just as diverse and have just as many different opinions as anyone else, Iezzoni said, and those opinions can change over time. For example, they may want a technology at one point in their lives and later not want it. They make choices that may have long-term consequences, such as whether to get married or have children, even though society sometimes discriminates against them when they try to make choices. For example, after a divorce, courts often reward custody of children to a non-disabled spouse, she said, even though the person with disabilities may be fully capable of caring for those children.

People with disabilities can make choices that are not in their best interests. For example, they may decide that they want to live at home without full-time care even though they may be unable to communicate effectively in emergencies, or someone may not want to walk with a cane or walker despite the risk of falling. If the health care system is committed to person-centered care, it needs to find a way to accommodate such decisions.

People who are born with disabilities or who become disabled early in life often have very low rates of employment and low incomes, which make it difficult for them to save, Iezzoni said. As a result, they may not have the resources to accommodate their disabilities because insurers often will not pay for assistive technologies or support services. But disabilities can be viewed as having society-mediated causes. Someone may have a functional impairment that they accommodate with a wheelchair, but a wheelchair is not effective unless sidewalks have curb cuts and subways have reliable elevators.

Some people may be so disabled that they need constant assistance to accommodate not just basic needs but quality-of-life needs. However, society may have the resources to accommodate basic needs but not quality-of-life needs. Some people may end their lives without the quality of life that they could have had if society had the resources to provide that assistance, Iezzoni concluded. Confronting this issue will require political and public will.

3

The Role of Individuals and Families

Important Points Made by the Speakers

- A relatively small portion of the population ages 65 and older spends down to become eligible for Medicaid, and those who do tend to have relatively little income or wealth. (Johnson)
- About 30 percent of households in the United States provide unpaid care to family members with disabilities. (Hunt)
- The costs to families and businesses incurred by the provision of long-term services and supports range into the trillions of dollars. (Hunt)

The role of individuals and families in financing long-term services and supports was the subject of the second session at the workshop. Richard Johnson, senior fellow and director of the program on retirement policy in the Income and Benefits Policy Center of the Urban Institute, looked at the prospects for financing from personal savings. Gail Hunt, president and chief operating officer of the National Alliance for Caregiving, considered family members and others who provide unpaid long-term services and supports. While both these sources of care are essential, neither can fully meet the needs of adults with disabilities.

FINANCING LONG-TERM SERVICES AND SUPPORTS FROM PERSONAL SAVINGS

Richard Johnson
Urban Institute

As was emphasized in the workshop's first session, many older adults face great difficulties in paying for long-term services and supports. Among adults 65 and older those with disabilities have less income and wealth on average than those without disabilities, and those with more disabilities tend to have lower income and wealth than those were fewer disabilities (see Figures 3-1 and 3-2). For people with limitations in three or more activities of daily living (ADLs), only 11 percent have incomes above four times the poverty level, and about 25 percent are below the poverty line (see Figure 3-1). Similarly, people with limitations in three or more ADLs have, on average, only about $8,000 of financial wealth that they can use to pay for long-term services and supports (see Figure 3-2).

Recent research has found that about 12 percent of the population ages 65 and older spends down to the Medicaid eligibility level during a 10-year period (Wiener et al., 2013). The people who spend down to this level tend to have relatively little income. These individuals also are likely to have had lower cumulative earnings during their lifetimes than people who do not

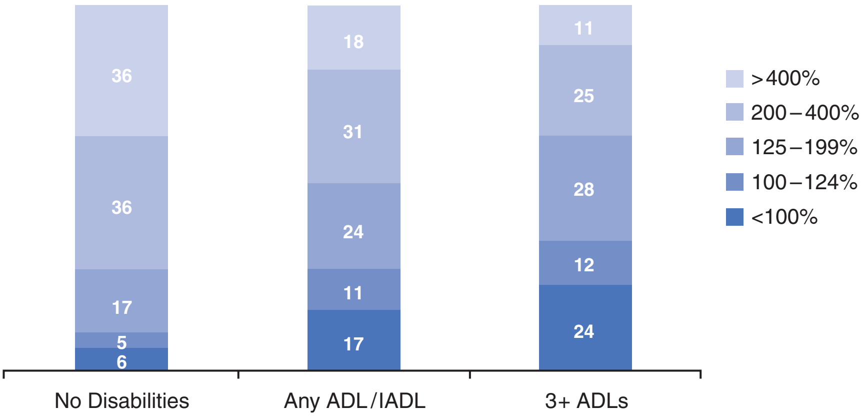

FIGURE 3-1 Household income of the noninstitutionalized older population relative to the poverty level by disability status, 2001.
NOTE: Data are for average, 45th to 55th percentile (similar to median). ADL = activity of daily living; IADL = instrumental activity of daily living.
SOURCE: Johnson and Wiener, 2006.

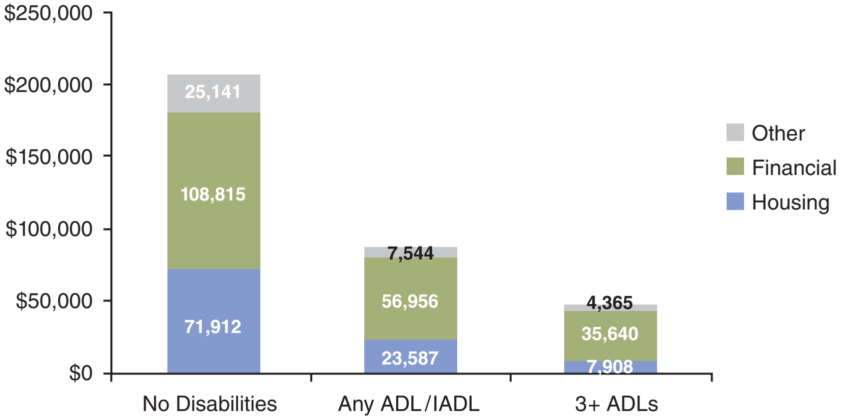

FIGURE 3-2 Average household wealth of the noninstitutionalized older population by disability status, 2002 (in dollars).
NOTE: Data are for average, 45th to 55th percentile (similar to median). ADL = activity of daily living; IADL = instrumental activity of daily living.
SOURCE: Johnson and Wiener, 2006.

spend down, Johnson said. Although some households in the top quintile of earnings eventually receive nursing home care paid for by Medicaid, more than 60 percent of those who receive such care are in the bottom two quintiles of lifetime household earnings (Johnson and Mermin, 2008).

People who become disabled in their 70s are more likely to spend down their wealth than are people in their 70s who do not become disabled, Johnson said (Johnson and Wiener, 2006). Furthermore, people who became disabled during their 70s had less wealth and income at the beginning of that period than people who did not become disabled, suggesting that the onset of disability was linked with factors, such as education or race, that also influenced wealth and income.

Projections for the Future[1]

Johnson also discussed how these numbers are likely to change in the future. A dynamic micro-simulation model developed at the Urban Institute (DYNASIM3), which simulates demographic events, economic trends, income, benefits, wealth, disability, and the use of long-term services and

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[1] The data in this section result from the DYNASIM3 model developed by the Urban Institute. A description of the model can be found at http://www.urban.org/UploadedPDF/410961_Dynasim3Primer.pdf (accessed October 17, 2013).

supports at older ages indicates that two-thirds of women born in the 1970s who survive to age 65 will live past age 85 and one in five will live past age 95—numbers that are significantly higher than for previous cohorts. Similarly, almost three-fifths of men born in the 1970s who survive to age 65 will live past age 85, and 15 percent will live past age 95.

The model also indicates that fewer older women will be widowed in coming decades, though more will be divorced, Johnson said. Men are living longer, but husbands and wives are divorcing more frequently than in the past. However, about one-third of women born in the 1960s and 1970s will be widowed for more than 10 years (compared with 49 percent and 44 percent of women born in the 1920s and 1930s, respectively), and the time spent unmarried among older women will not change much because of the increase in divorce, with about 60 percent of women spending more than 10 years alone after age 65. Fewer older men will be married in coming decades, which will affect their prospects for receiving care from their wives, Johnson said. As a result, later cohorts of older men will spend more time unmarried than in previous generations, with about 40 percent of those born in the 1960s and 1970s spending more than 10 years unmarried, up from 27 percent and 29 percent of those born in the 1920s and 1930s, respectively.

By 2040 about one-third of the population ages 65 and above will have a 4-year or higher college degree, compared with only about 16 percent today. The older population in the United States also will become more racially and ethnically diverse.

More recent cohorts of women have been working and earning more, which will improve their financial well-being in older age. As a result, women born in the later part of the baby boom (from 1956 to 1965) will receive about 50 percent more Social Security income than women born before the baby boom, although they still will receive less than men. Meanwhile, median earnings for men have stagnated in recent decades. In addition, a reduction in pension wealth will cause people born late in the baby boom to have less pension wealth in retirement than people born early in the baby boom, although defined contributions have compensated for this reduction.

Early baby boomers will have more housing equity on average than those born 10 years later or 10 years earlier. Taking everything into account, Johnson said, members of the baby boom generation will receive somewhat higher retirement incomes than their predecessors and their successors.

The results of these modeling efforts depend on critical assumptions regarding such issues as wage growth, further increases in longevity, and the returns on savings. In particular, Johnson said, the model may be overly optimistic in projecting wage growth. Also, reducing the annuity value of assets reduces retirement incomes by about 15 percent.

Major questions that remain unanswered are how savings will grow and whether people will leave that money untouched until it is needed for long-term services and supports. Also, as Johnson observed, only about 10 percent of people are contributing the maximum to their 401(k) retirement plans. One of the most hopeful recent developments in pensions is auto enrollment, in which employees are automatically enrolled in 401(k) plans unless they specify otherwise. In firms with auto enrollment, contributions have risen dramatically—to 70 to 80 percent of the workforce. But while such programs have become common among large employers, they are less common at small companies. Also, people tend not to contribute the maximum amount they can, which limits the amounts they are saving for retirement. Can these individuals be persuaded to put money into a narrower savings vehicle, such as long-term care insurance? (This question is examined in more detail in Chapter 4.)

In response to a question, workshop participant Joshua Wiener, who did the research referenced by Johnson, said that people who spend down have much lower income and assets on average than those who do not spend down. This research also found that those people who spent down transferred their assets to their children at about half the rate of people who did not spend down. Wiener pointed out that the large amount of intergenerational transfer of money that goes on in the overall society is not fully appreciated. Wiener noted that the spend-down population may not transfer money as often as the non-spend-down population because they have a lot fewer assets to transfer. In addition, various studies have found that fairly small amounts of money are transferred, which are not enough to change the cost curve for long-term care.

FAMILY CAREGIVING

Gail Hunt
National Alliance for Caregiving

The National Alliance for Caregiving, which is a nonprofit coalition of more than 40 national organizations focused on family caregiving issues, has done a series of studies on caregiving in the United States, the most recent of which showed that about 66 million people provide family care; these 66 million people represent 29 percent of the U.S. population and 31 percent of households (National Alliance for Caregiving and AARP, 2009). Seventy-two percent of those are caring for somebody of age 50 or above, 14 percent are caring for a person with disabilities who is between the age of 18 and 49, and an additional 14 percent are caring for children with disabilities who are under 18.

Caregivers have been in their role for an average of 4.6 years, with three in ten having given care for five years or more. About two-thirds are women. More than half of them help their care recipient with at least one ADL, including bathing, dressing, feeding, toileting, and transferring. These can be intense, personal, and stressful responsibilities, Hunt emphasized.

The Costs to Businesses and Families

Caregiving costs U.S. employers between $17 billion and $34 billion a year in lost productivity (MetLife Mature Market Institute and National Alliance for Caregiving, 2006). The top three costs to employers are replacing employees, workday interruptions such as coming in late or leaving early, and absenteeism. Workers also take leaves of absence, reduce their work hours, take less demanding jobs, give up working entirely, turn down promotions, lose job benefits, or choose early retirement.

Caregiving employees have health care costs that are 8 percent higher than those of employees who are not providing care, which costs employers an estimated $13.4 billion per year (MetLife Mature Market Institute, 2010). Younger caregivers (18 to 39) cost employers 11 percent more for health care than non-caregivers, and male caregivers cost employers 18 percent more for health care than female caregivers. Providing care also may be associated with high-risk behaviors such as smoking and alcohol consumption, Hunt said, and these behaviors may lead to disability-related absences. For example, people who were giving care had a higher rate of diabetes, depression, hypertension, and heart disease than people who were not giving care. About one-quarter of the males providing care reported that they had moderate or severe symptoms of depression, compared with 8 percent of males who were not caregivers. In addition, employed caregivers were less likely to manage their own health or to take part in preventive screenings offered by their employers.

In one study the average annual out-of-pocket expense for caregiving families was found to be about $5,500, which represented more than 10 percent of the median household income (Evercare and National Alliance for Caregiving, 2007). Long-distance care tended to be more costly because caregivers were paying for services to be performed. Items being purchased included medical expenses, food, meals, household goods, travel costs, additional services that were needed, and nursing homes or assisted living. Strategies for managing these expenses included cutting back on vacations, reducing leisure activities, and deferring major purchases.

The total estimated aggregate lost wages, pensions, and Social Security benefits of people ages 50 and older providing parental caregiving is nearly

$3 trillion (MetLife Mature Market Institute, 2011). For women leaving the workforce early for caregiving responsibilities, the total individual amount of lost wages equals $142,693 on average, with a somewhat lower number for men. In addition, adult children 50 and older who work and provide care to a parent are more likely to have just fair or poor health than those who do not provide care to their parents.

Experiences in Other Countries

Hunt briefly compared experiences in the United States with those in other countries. Australia provides non-means-tested payments to caregivers of $115 every 2 weeks, plus an annual payment of $600 per year. Australia's Carer Recognition Act of 2010[2] formalized a statement to recognize and encourage support for caregivers, and the country has a national respite-for-caregivers program (Australian Government, Department of Health and Ageing, 2013).

The United Kingdom offers replacement care, respite care, and breaks for caregivers through an assessment of need. A program launched in 2009 advocates for caregivers by helping companies retain employees who are providing care for a family member. Informally, a program in the United Kingdom helps people resume their careers when they stop providing care, although no legislation guarantees getting a job back.

Germany's long-term care program provides support for caregivers, while Japan has a public long-term care program that offers support to adult caregivers, almost all of whom are daughters.

The Limits to Family Care

During the discussion period, one workshop participant cautioned against labeling long-term services and supports a "social responsibility" because that term tends to be interpreted as "family responsibility." Families are interested in taking care of their members, he said, but they may not be able to serve as safety nets in the future. With people living into their 90s, their own children are elderly and have needs of their own. Furthermore, with the high rate of divorce in recent decades, families are more diffuse and voluntary, and family responsibilities may be less clear cut than is the case with more traditional family structures.

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[2] See http://www.comlaw.gov.au/Details/C2010A00123 (accessed January 15, 2014).

4

The Role of Government

Important Points Made by the Speakers

- Working-age people with disabilities are more likely to be poor than others, despite high and rising federal expenditures for this group. (Stapleton)
- Bold innovations might slow the growth of expenditures while also improving the economic status of people with disabilities, but the evidence base to support such innovations is inadequate. (Stapleton)
- Medicaid is the primary payer for long-term services and supports, with elderly beneficiaries and nonelderly beneficiaries with disabilities accounting for the majority of enrollment and expenditures for these supports and services. (Musumeci and Reaves)
- The United States lacks a universally available insurance-based approach that would spread the financial risk of aging and living with a chronic illness or disability. (Goldberg)
- A social insurance program could gain political support if it was self-financed, reduced Medicaid spending, and complemented private insurance. (Goldberg)

The third session at the workshop examined the government's role in financing long-term services and supports. David Stapleton, a senior fellow at Mathematica who directs Mathematica's Center for

Studying Disability Policy, spoke about public income support programs for working-age people with disabilities. MaryBeth Musumeci, associate director at the Kaiser Commission on Medicaid and the Uninsured for the Henry J. Kaiser Family Foundation, and Erica Reaves, policy analyst with the Kaiser Commission on Medicaid and the Uninsured, together discussed Medicaid as a funding source for long-term services and supports. Lee Goldberg, vice-president for health policy at the National Academy of Social Insurance, made a broad-based argument for the importance of social insurance as a practical and moral necessity.

PUBLIC INCOME SUPPORT PROGRAMS FOR WORKING-AGE PEOPLE WITH DISABILITIES

David Stapleton
Mathematica

Working-age people with disabilities fare poorly in the workplace compared with workers without disabilities, Stapleton said. In 2012 only about 27 percent of workers with disabilities were employed, compared with 71 percent for those without disabilities, and their poverty rate was 31 percent in 2012 versus 12 percent for their peers.[1] Among those who were beneficiaries of Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI), 48 percent had household incomes below the poverty level (Wright et al., 2011). Two-thirds of people who have been in poverty for 3 or more years have a disability (She and Livermore, 2009). At equivalent income levels, people with disabilities are much more likely to experience various types of hardship than people without disabilities, and people with disabilities have been falling farther behind those without disabilities in income and employment for the past three decades (von Schrader et al., 2011).

Despite these indications of unmet needs, federal expenditures for working-age people with disabilities are high and rising rapidly, Stapleton said. When the more than 60 federal programs that provide support for this group are combined, federal support for this population was estimated to be $357 billion in fiscal year (FY) 2008, having increased by 30 percent in real terms over the previous 6 years (see Table 4-1). Income maintenance and health care account for 90 percent of the spending, which is split about equally between the two. The total spending on working-age people with disabilities represented 12 percent of all federal outlays in FY 2008,

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[1] These statistics are from the Annual Disability Statistics Compendium, a Web-based tool available at http://disabilitycompendium.org (accessed October 17, 2013).

TABLE 4-1 Federal Expenditures for Working-Age People with Disabilities by Major Expenditure Category, Fiscal Year (FY) 2008

Category	FY 2008 Expenditures (in billions of dollars)	Percentage Change, FY 2002–2008 (adjusted for inflation)
Income maintenance	169.8	29.5
Health care	169.1	34.4
Housing and food assistance	11.6	17.9
Education, training, and employment	4.3	–2.6
Other services	2.5	2.3
Total	357.4	30.6

NOTE: Totals are rounded.
SOURCE: Livermore et al., 2011.

although the magnitude of these expenditures is not readily apparent because it is spread across so many different programs.

The number of people who rely on these benefits has been growing rapidly (see Figure 4-1). In 1980 about 2.8 million people under age 65 were receiving Social Security disabled worker benefits; by 2010 this number had risen to 7.8 million. Part of this increase can be accounted for by the growing size of the labor force, the aging of the baby boom, and the increased participation of women in the labor force. But 30 percent of the

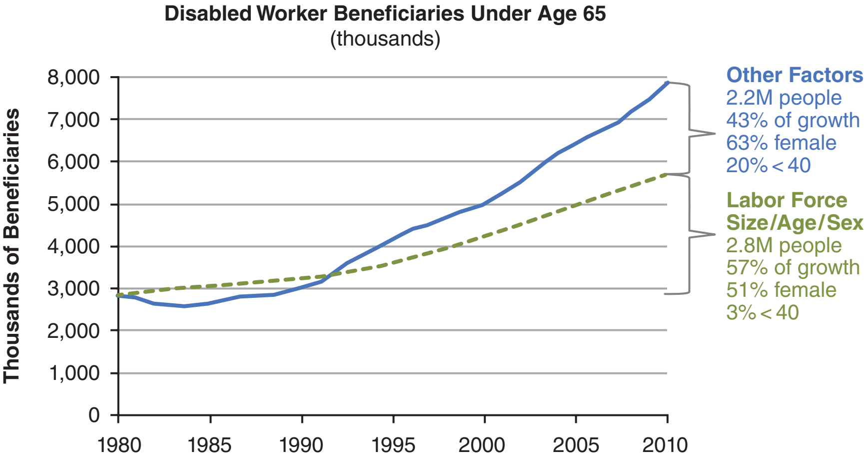

FIGURE 4-1 Growth in the total number of working age Americans receiving SSDI benefits due to demography and other factors.
SOURCE: Reprinted with permission from David Stapleton, Mathematica.

increase—about 1.2 million people—was due to other reasons. One reason is that the disability prevalence rate for female workers is now close to what it is for men. The number of people with disabilities under age 40 also has increased disproportionately.

In response to a question, Stapleton pointed out that SSDI has changed somewhat since it began. Originally designed for older workers who experienced the onset of disability, it now provides benefits to workers of any age. More younger people are enrolled, and they are more likely to have psychiatric problems or developmental problems. It also has become more sensitive to the business cycle, suggesting that it is functioning in part as an unemployment insurance program for people with disabilities. During recessions, many more people apply for the program, and some are accepted, in which case they may stay on until retirement age. Stapleton labeled that trend a significant problem.

The Need for Bold Innovations

With the Social Security Disability Trust Fund projected to be exhausted in the year 2017, potential changes in the program have generated great interest. Stapleton offered several options for bold changes in the SSDI program. One option, he said, is to tighten eligibility standards and reduce benefits in order to limit the growth of expenditures. Another option would be to engage in bold innovations designed to slow the growth of expenditures while also improving the economic status of people with disabilities. According to Stapleton, this second option could potentially work because of the many inefficiencies in the current system. For example, Stapleton argued that the current system discourages people with disabilities from working. It also is extremely fragmented, he said, with many different agencies and funding streams directed at the same populations.

Stapleton briefly described three proposals he suggested could lead to large-scale change:

1. One would require that employers provide a mandatory 2-year private disability insurance program for their employees. Having employers pay for the first 2 years of SSDI benefits would give them more incentive to keep their employees on the job.
2. A second proposal would use an experience-rating approach to the SSDI payroll tax, which would give employers additional incentive to keep people off SSDI, and also to turn SSI into a program of block grants so that states would have more flexibility to improve the well-being of the SSI population.
3. A third proposal would convert almost all federal programs into block grants, including SSDI and SSI. This proposal would also

turn all means-tested programs into block grants, such as the Supplemental Nutrition Assistance Program.

Stapleton argued that it could be disastrous to go forward with any of these programs. They are all untested and extremely risky, he said. They may cost less or they may cost more—no one can be sure which—and they could do harm to vulnerable people.

Stapleton added that some evidence points in more productive directions. Private disability workers' compensation insurers have been successful in keeping employees at work following the onset of medical conditions. The welfare reform for low-income families carried out in the 1990s offers numerous lessons—some positive, others cautionary. Other countries such as the Netherlands and United Kingdom have moved forward with reforms.

Stapleton judged the evidence available today as "clearly not adequate" to support major reform legislation in the United States. Rather, he said, a foundation for reform needs to be developed first in order to build trust within the disability community that vulnerable people will be protected and that transparency and accountability will be achieved.

A Reform Process

Stapleton described one possible reform process featuring a management structure that would address barriers to reform and build trust. It would have full and transparent financial accounting and would employ "super waivers" that cut across agency and federal–state boundaries. A federal disability policy board would be created with a charter to

- Lead a reform process with positive objectives.
- Grant super waivers to federal agencies, states, localities, and private entities for positive reforms.
- Coordinate cross-cutting activities under the waivers.
- Rigorously monitor disability population outcomes.
- Support continual improvement through evaluation, dissemination, and technical assistance.
- Make midcourse adjustments.

Under this proposal every state would have its own disability policy board, with consumers represented through an independent consumer review board. State and local chapters of the review board would monitor changes, and a federal appeals process could be in place for individuals who think they are being harmed by the waivers being granted. The policy board would develop a budget that encompasses all federal expenditures aimed at supporting the working-age population with disabilities. Annual rolling 10-year budget projections would reflect fiscal reform objectives, encompass federal and state expenditures, and provide benchmarks for expenditure growth. State-level expenditures could also be projected and tracked, including state matching dollars. Responses to the waiver process and budget projections could vary. The default response would be no response and a continuation of current programs, while the preferred response would be for federal agencies, states, localities, and private entities to propose waivers designed to improve economic and other outcomes and reduce expenditures relative to budget projections.

These waivers could help accomplish various goals, Stapleton said. For example, they might allow for a single source for all their needs (e.g., income benefits, health benefits, social services) with integrated eligibility determination. They could also be structured to avoid individuals' need to stop working in order to receive benefits, and also to encourage savings and support community living. These super waivers could address the integration of SSDI with workers' compensation and private disability benefits, he added. Finally, Stapleton suggested these types of waivers could help build transition programs for youth and young adults with disabilities. The pace of reform could be accelerated by making the projected budgets binding, but that would need to be balanced against the risk that too rapid adjustment will harm those the reforms are intended to help, he said.

Stapleton concluded that establishing a target for a collection of programs could encourage those programs to meet that target through innovations designed to help people with disabilities. The benchmarks then could be lowered to reduce spending. Policy makers will likely refrain from reductions that are perceived to damage people with disabilities, he said. Many promising options cut across federal, state, local, and private jurisdictions, which implies that these sectors will need to work together to experiment with reforms. Benchmarks would encourage overall budgeting for programs and rational decisions rather than the piecemeal cuts that are being made today.

MEDICAID[2]

MaryBeth Musumeci and Erica Reaves
Henry J. Kaiser Family Foundation

Medicaid is the primary payer for long-term services and supports (LTSS) such as nursing home care, home health services, and home- and community-based waiver services (see Figure 4-2). While LTSS users ac-

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[2] The data presented in this section resulted from analyses carried out by the Kaiser Commission on Medicaid and the Uninsured.

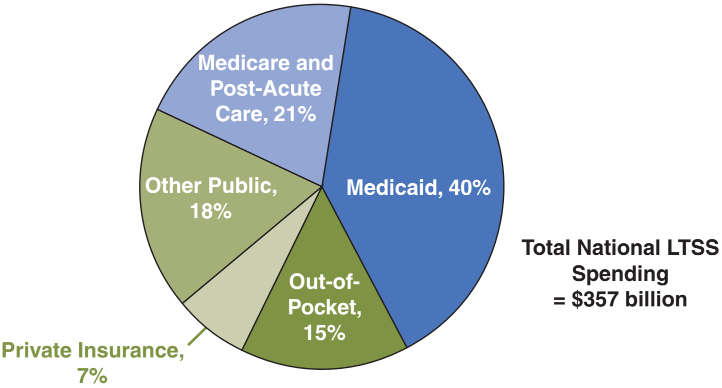

FIGURE 4-2 Sources of expenditures for long-term services and supports (LTSS), 2011.
NOTE: Total long-term care expenditures include spending on residential care facilities, nursing homes, home health services, and home- and community-based waiver services. Long-term care expenditures also include spending on ambulance providers. All home- and community-based waiver services are attributed to Medicaid.
NOTE: Total in 2011 = $357 billion
SOURCE: KCMU, 2013a.

counted for almost one-half (46 percent) of Medicaid expenditures in 2009, they represented only 6 percent of total Medicaid enrollment. The Medicaid LTSS beneficiary population is diverse, with enrollment and spending that varies disproportionately across beneficiary subpopulations. Elderly beneficiaries (people of age 65 and older) account for 52 percent of Medicaid LTSS enrollment and about 45 percent of Medicaid LTSS expenditures, nonelderly beneficiaries with disabilities represent 40 percent of enrollment and 51 percent of expenditures, and nondisabled adults and children account for 8 percent and 4 percent of enrollment and expenditures, respectively.

Institution-based LTSS account for 45 percent of Medicaid LTSS expenditures, with home- and community-based LTSS accounting for 29 percent of all Medicaid LTSS expenditures.[3] While 61 percent of elderly beneficiaries rely on institution-based services, only 21 percent of nonelderly beneficiaries with disabilities access institution-based LTSS. Total Medicaid long-term care per capita expenditures are highest for nonelderly

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[3] The balance of Medicaid expenditures for LTSS attributable to mixed long-term care (4 percent); inpatient care (7 percent); drugs (4 percent); physician, lab, X-ray, outpatient/clinic, and other acute services (9 percent); and rehabilitation therapy and other supportive services (3 percent).

beneficiaries with disabilities ($37,394), followed by the elderly ($34,007), and then by nondisabled adults and children ($14,918).

More than two-thirds (68 percent) of Medicaid beneficiaries who use LTSS qualify separately for Medicare. Medicaid LTSS expenditures for these "dually eligible" beneficiaries represent 65 percent of total Medicaid LTSS spending. Fifty-one percent of dually eligible beneficiaries use institution-based LTSS, and 33 percent access LTSS in the community.[4]

Expenditures for Medicaid long-term services grew from $54 billion in 1995 to $123 billion in 2011, with considerable growth in the share of Medicaid LTSS expenditures devoted to home- and community-based services (HCBS) over that time period. Spending for HCBS for elderly beneficiaries as a percentage of total Medicaid long-term care expenditures for the elderly varies dramatically across the states, from less than 10 percent in seven states to more than 40 percent in seven states and the District of Columbia. For nonelderly people with disabilities, Medicaid HCBS spending as a percentage of total Medicaid long-term care expenditures for nonelderly people with disabilities ranges from less than 50 percent in six states to greater than 80 percent in eight states.

Long-Term Services and Supports Offered by Medicaid

Medicaid covers a wide array of long-term medical and supportive services, with home health, personal care, and Section 1915(c) home- and community-based waiver services being the most widely used benefits. Every state that participates in Medicaid (currently, all 50 states choose to do so) must offer home health services, which accounted for 11 percent of the $50 billion spent on Medicaid HCBS in 2009. Expenditures for personal care services and home- and community-based waiver services, each provided at state option, accounted for 22 percent and 67 percent of total 2009 Medicaid HBCS spending, respectively.

Section 1915(c) waivers were developed to give states the flexibility to cover services and supports that people need in order to live independently in the community (e.g., case management, adult day health care) and to directly address the bias toward institutions that has been traditional in the Medicaid program.

In general, Medicaid benefits are an entitlement. If people meet the eligibility requirements, they are entitled to receive the services. However, as a cost-control measure, states can cap HCBS waiver enrollment "slots"; many states maintain "waiting" or "interest" lists, which serve as a proxy for the level of unmet need. Significant demand exists for home- and community-based waiver services, driven by beneficiary preferences to live in the com-

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[4] The remaining dually eligible beneficiaries do not use LTSS.

munity. Pressure on states to reduce their HCBS waiver waiting lists has increased, especially after the U.S. Supreme Court's Olmstead decision,[5] which found that unjustified institutionalization of people with disabilities, when they are able to live in the community, is discrimination under the Americans with Disabilities Act. In 2009 individuals with intellectual or developmental disabilities accounted for 62 percent of individuals on waiver waiting lists nationwide, while older adults (with or without disabilities) represented 29 percent, with the remaining 8 percent consisting of children, people with physical disabilities, people with HIV/AIDS, people with mental health needs, and people with traumatic brain and spinal cord injuries.

Medicaid LTSS Options and the Affordable Care Act

In addition to home health services, personal care services, and HCBS waivers, the Affordable Care Act (ACA) offers six new or enhanced options for states to provide community-based Medicaid LTSS (KCMU, 2013b). To date, the most popular option is the Money Follows the Person (MFP) demonstration program, which was expanded by the ACA and now has 46 states participating. Under MFP, states receive enhanced federal Medicaid matching funds for qualified HCBS for people transitioning from an institutional setting to a community-based setting. The health homes state plan option, which 25 states are implementing or have planning grants for, is a new Medicaid benefit aimed at allowing states to coordinate care for individuals with chronic conditions; states electing this option receive 90 percent enhanced federal funding for the first 2 years. The new Balancing Incentive Program provides enhanced federal matching funds for states that spent less than 50 percent of their Medicaid long-term care dollars on HCBS in 2009; the goal is to increase the proportion of long-term care spending devoted to HCBS in these states, and 15 states are currently participating in the program. Fourteen states are pursuing the HCBS state plan option, expanded by the ACA, which allows states to offer HCBS as Medicaid state plan services instead of through waivers. Nine states are pursing the Community First Choice state plan option, established by the ACA, which allows states to provide home- and community-based attendant services and supports with 6 percent enhanced federal matching funds. Finally, 26 states submitted proposals to implement a demonstration, under new authority in the ACA, to align the administration and financing of acute and long-term care services for dually eligible beneficiaries; to date the Centers for Medicare & Medicaid Services has approved memoranda of understanding with six states.

In response to questions from the audience, Musumeci and Reaves

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[5] Olmstead vs. L.C. 527 U.S. 581 (1999).

noted that state take-up of the six new or expanded ACA LTSS options varies, with three states not pursuing any option and numerous states pursing three or more options. Specifically, with regard to the financial alignment demonstrations for dually eligible beneficiaries, Musumeci said that states may face challenges in implementation given that these demonstrations are seeking to integrate two disparate complex programs that were not necessarily designed to work together, that dually eligible beneficiaries are among the most vulnerable, and that some states and health plans have limited experiences with managed LTSS to date. Many important details about the demonstrations in areas such as enrollment processes, continuity of care, and beneficiary protections remain to be specified.

States are still in the implementation stages of the ACA, so it is too early to determine the full impact of the various LTSS options. The Kaiser Commission on Medicaid and the Uninsured will continue to track states' activities, given the potential of these options to lower the growth of long-term care spending and to increase beneficiary access to HCBS.

SOCIAL INSURANCE

Lee Goldberg
National Academy of Social Insurance

The demand for LTSS will rise in coming decades, but not much spare capacity exists in informal sources of long-term care. Most families continue to need two wage earners, said Goldberg. Record numbers of people are living alone—28 percent of households consist of a single person—which increases the demands on caregivers. And changes in state Medicaid programs are expected to put extra demands on informal care as people avoid going into institutions and opt for HCBS, where the absence of 24-hour care requires that family members make up the difference.

The government funds long-term services and supports for those with low incomes in addition to subsidizing LTSS indirectly through the tax code. But Medicaid, which is the de facto governmental system for long-term care, is a safety net program. The United States lacks a universally available insurance-based approach that would spread the financial risk of aging and living with a chronic illness or disability.

The Rationale for Social Insurance

Social insurance mimics private insurance, but it can also serve broader societal goals. According to Goldberg, social insurance is flexible in that it can change in order to address unforeseen developments, whereas private contracts tend to be overly specific and rigid. However, social insurance needs to be universal in order to avoid adverse selection, the situation in which only those who will need the insurance are enrolled in the program. Either a governmental mandate or strong economic incentives, as in Medicare Part B, can compel participation, suggested Goldberg. With universal participation, he said, the government does not displace private insurance, and premiums are not tied to an individual's risk.

Goldberg stated that social insurance is compatible with private insurance. With Social Security, the financial services industry has prospered as people have sought ways to supplement their income over the course of their lives. Medigap is another example of the compatibility between social insurance and private insurance, he said. France has one of the highest rates of private long-term care insurance despite a strong social insurance program with an HCBS benefit and a cash benefit. Many governments rely on mandatory social insurance not just for LTSS but also for pensions, Goldberg said, whereas the United States continues to rely on means-tested programs and tax expenditures.

According to Goldberg, pooling risk and spreading the cost of care over a large number of people is efficient and increases community resources because people can save for the average cost of LTSS rather than for the maximum potential cost. It also has a moral justification. The English philosopher John Rawls described a just society as one in which the rules are established before anyone knows where they will be in that society. When operating behind this "veil of ignorance," a well-run insurance program is the most just system, Goldberg said.

Types of Benefits

Social insurance benefits fall into two categories. A defined set of benefits, as is provided by Medicare, can help ensure the availability of complex services that require clinical knowledge and advanced technology. This is the indemnity model familiar from health insurance. Such benefits can be monitored and controlled and are familiar to most Americans. If this model were pursued, expanding Medicare would be one possible way to provide LTSS, although Goldberg argued it would be politically difficult. The other category is cash benefits, as are provided by Social Security, which are designed to improve economic well-being rather than to provide a defined set of services. According to Goldberg, cash benefits are useful for supplementing services, and they provide consumer flexibility in selecting combinations of goods and services. However, cash benefits make it difficult to monitor how funds are spent or to ensure the quality of care. Goldberg argued that both models are needed for LTSS. The population needing this care is heterogeneous and needs both kinds of benefits, he said. The question then becomes whether expanding both is politically feasible.

Research has shown that mandatory social insurance programs with monetary benefits could provide significant Medicaid savings (Tumlinson et al., 2013). This research posited that benefits would be limited to just a few years, but even a 2-year benefit would cover almost half of people with disabilities for the duration of their need for long-term care, and a 1-year benefit would help about one-quarter of the people for the duration of their needs.

Experiences in Other Countries and in the United States

Goldberg asserted that most OECD[6] countries other than the United States have replaced means-tested programs with insurance-based programs. In some cases, prices have been higher than expected, but the programs generally have been popular and manageable, Goldberg said.

In Britain the government is currently pushing for reforms in long-term care that would limit people's lifetime out-of-pocket costs and raise income eligibility on means-tested HCBS, with financing through a freeze on the inheritance tax. Despite being proposed by a conservative government, the fate of this proposal was uncertain at the time of the workshop.

The United States does not address long-term care as part of its health system, as most other countries do, Goldberg said. But the states have a history of experimentation that continues today. For example, Hawaii is considering a social insurance program, and "quiet" discussions are going on elsewhere, Goldberg said. Pension reforms in California, where a new pension law has created an opt-out system that allows people to contribute part of their paycheck to a private-sector pension program, could provide a framework for legislation elsewhere.

The Need for Change

The current system needs to be changed, Goldberg concluded. It is a disease-dependent and income-based system. Support for social insurance among policy makers could be bipartisan, he said, if the system were self-financed, if it reduced Medicaid spending, and if it complemented private insurance. Such a program would not need to address all of the risks a person faces. In addition, social insurance lends itself to starting small, Goldberg argued. Some things could be done at the state or federal level that could have political appeal. According to Goldberg, a groundswell

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[6] "The mission of the Organisation for Economic Co-operation and Development (OECD) it to promote policies that will improve the economic and social well-being of people around the world. The OECD provides a forum in which governments can work together to share experiences and seek solutions to common problems" (OECD, 2013).

of political support will be needed to achieve universal coverage for long-term care, but such support will need to be carefully built. Federalizing the program would lift a substantial burden from the states, he said, while also providing a greater uniformity to benefits. It also would enable even more far-reaching reforms, such as integrating the program with Medicare.

Given the political climate, incremental changes in LTSS where states are willing to move ahead in the face of federal paralysis may be the best approach. One thing is certain, said Goldberg: With long-term care costs projected to double by 2040, keeping the current system on autopilot is not a good option.

5

The Role of the Private Sector

Important Points Made by the Speakers

- Relatively few people have purchased long-term care insurance, and many of the companies that have offered coverage are leaving the market. (O'Leary)
- The long-term care insurance industry will need to innovate in order to balance the risk to carriers with the needs of consumers. (O'Leary)
- Public subsidies for long-term care insurance currently benefiting the upper end of the income spectrum could be redirected to the middle of the spectrum to make long-term care insurance less costly. (Frank)
- Automatic enrollment in 401(k) plans by employers can substantially increase participation rates, and automatic escalation of contributions would substantially increase savings. (VanDerhei)

The private sector plays a role in the financing of long-term services and supports both through the provision of long-term care insurance and through participation in employee retirement plans, and three speakers at the workshop discussed this role. John O'Leary, president of O'Leary Marketing Associates, discussed private long-term care insurance and the difficulties it has faced in recent years. Richard Frank, the Margaret T. Morris Professor of Health Economics in the Department of

Health Care Policy at Harvard Medical School, described policy initiatives that could increase the use of long-term care insurance while easing the pressures on Medicaid. Jack VanDerhei, research director of the Employee Benefit Research Institute, explored how the private sector can help ensure that employees have enough money for retirement.

PRIVATE LONG-TERM CARE INSURANCE

John O'Leary
O'Leary Marketing Associates

Long-term care insurance is an $11 billion business serving more than 7 million consumers, but the penetration of the overall market remains low. Group long-term care insurance covers about 2.3 million people, and individual policies cover 4.8 million. Together this represents only 5.8 percent of the U.S. population above the age of 45.

Furthermore, many of the companies that have offered coverage are leaving both the group and the individual markets. According to O'Leary, only one insurance carrier is in the group market, and it has moved to longer-form underwriting rather than guarantee issues, which will reduce the appeal of its policies. Most group policies are now in what are called closed blocks, in which the product being administered is no longer being offered. Meanwhile, individual policies have undergone rate hikes as high as 90 percent.

The companies that have remained in the business are seeking to aggressively manage risks through premium hikes, more restrictive underwriting, limiting benefits, and reducing discounts and agent commissions. They are not trying to grow because, as O'Leary said, they have determined that making money in the long-term care insurance business is very difficult.

Several factors are behind this retrenchment, O'Leary said. First, historically low interest rates make it difficult for companies to profit from invested premiums, which was not the case when many of the policies were written. Also, the initial actuarial assumptions proved to be too optimistic. Fewer policies were dropped than expected, mortality rates were lower, and morbidity rates were higher. In addition, the initial plan designs were costly for companies. The result has been a "perfect storm" of problems for long-term care insurance, O'Leary said, with high risks and low rewards for companies offering plans.

As O'Leary pointed out, more than 23 million families are in the top quintile of income in the United States, with mean annual incomes above $114,000 per year. This constitutes a sizeable market for long-term care insurance, which historically has been purchased predominantly by higher-income consumers. People in the lowest quintile are closer to qualifying for Medicaid. The people in the middle are the ones who fall through the cracks.

A Tipping Point

Long-term care insurance is at a tipping point, O'Leary said. Current actions reinforce a "niche" positioning for the industry. The most important question, then, is whether the industry will undertake the innovation that will be necessary to meet a broader range of consumer needs. The affordability of policies is the number one barrier to more sales, but it is not the only barrier.

What the industry needs, O'Leary said, is a way to balance the risk to carriers with the needs of consumers. It needs to broaden the appeal of long-term care insurance beyond "healthy/wealthy" consumers, which will require new thinking and better marketing and distribution. But the problems facing the industry have not yet been solved.

The health care system is also in the midst of dramatic changes, and health care is inextricably related to long-term care, O'Leary observed. How people take care of their health earlier in life helps determine whether they will need long-term care later in life, although, of course, the correspondence is not precise. In the future people are going to manage their own care more than they do today, O'Leary predicted. Higher deductibles and copays will be part of the reason, but innovative wellness programs also are becoming ubiquitous, as is the recognition that earlier knowledge and intervention can ameliorate later problems.

Future Options

O'Leary outlined three approaches that he suggested the insurance industry could take to limit risk:

- First, companies can offer a life or annuity product with a long-term care rider.
- Second, by creating policies with flexible inflation designs, companies can share the risk with consumers while making insurance more affordable.
- A third approach would be to offer more modest protections while reducing premiums and streamlining the underwriting process.

Each approach holds promise but has potential barriers, such as typically not being available to groups. Consumer feedback, marketing analysis, and consumer research and segmentation may make it possible to hone future modifications.

According to a survey of actuaries conducted by a policy planning group to which O'Leary belongs, the approach most favored by actuaries includes both private insurance and a government-sponsored safety net or a social insurance program. Respondents to the survey disagreed on whether a mandate will be necessary or what the required coverage levels would be.

Other innovative ideas include a long-term care health services account, mutual long-term care, or shorter-term coverage. O'Leary was uncertain whether any of these would work, but people are exploring options and are open to change, he said. For example, he described a managed wellness program that would combine a wellness lifestyle program with financial protection so that, for example, premiums or deductibles would be tied to information on health status in a health record in the same way that automobile insurance rates are tied to driving records.

The key questions regarding long-term care insurance are who is going to offer it and what is going to be offered. O'Leary concluded by saying that funding is limited and that people are unlikely to get as much as they might want.

EXPANDING PRIVATE LONG-TERM CARE AND STRENGTHENING MEDICAID

Richard Frank
Harvard Medical School

A major problem with long-term care insurance, Frank said, is that people do not know much about it—what it costs, what it covers, or whether they will need it. They also have difficulty understanding the future implications of today's choices, given their uncertainties about their risks and future. Furthermore, the products are complex and can be unpredictable, as when premiums go up unexpectedly. Frank offered four policy measures that might offer remedies for these problems.

The first, he said, would be to simplify and standardize products. Choices could be limited to 5 to 10 products with no limit on the number of sellers. Such an approach could reduce confusion and aid comparison shopping while also saving money on selling costs, Frank said. Electronic markets and decision aides could help people navigate the marketplace. State regulations could be altered to allow high-deductible plans to be part of the choice set, which could reduce premiums by 35 percent. This would appeal to the market, Frank said, because people could protect themselves against catastrophic outcomes at a premium discount.

The second approach, Frank suggested, would be to expand the employer role. Employers have many advantages in offering long-term care insurance, including lower selling costs, reduced concerns over adverse selection, and the ability to filter products for their employees, he said. One possibility would be to offer simple low-cost products through employers. Another would be to mandate availability, so that the benefit would be offered to employees if they want it. Though politically difficult, this approach has been effective in some health care markets.

The third policy approach described by Frank would be to develop reinsurance pools. Many of the greatest risks and uncertainties for long-term care insurers are common to all participants and are hard to spread. As a result, insurers limit coverage or exit the market. Publicly organized and privately funded (or publicly and private funded) reinsurance pools have been used successfully in flood and earthquake insurance and are being proposed for some financial markets. By reducing the risk to insurers and stabilizing the industry, such a program could improve confidence by assuring consumers that the people who have qualified to buy into the program have met publicly agreed upon standards, Frank said.

The fourth option offered by Frank would be to provide targeted public subsidies for long-term care insurance.

Redirecting Subsidies

Frank described four kinds of federal tax incentives that provide such subsidies: itemized deductions of medical expenses (which include long-term care insurance premiums), self-employed deductions, employer-sponsored long-term care insurance, and long-term care insurance purchased through health savings accounts. In addition, states have their own credits and deductions, besides carrying through the federal deductions.

Frank estimated very roughly that the medical deduction amounts to a subsidy of $1.4 billion, the self-employed deduction $1 billion, and state deductions $100 million. Furthermore, more than 40 percent of the medical deduction goes to the top quartile of the income distribution of older adults. Some of the other subsidies, such as the one covering self-employed individuals, go to younger people with higher incomes.

Frank asked whether it would be possible to target these more than $2.5 billion in subsidies to expand protection, encourage more private spending on long-term care insurance, and reduce the burden on Medicaid. He noted that the 40 percent of households in the United States in the middle of the income distribution had an average of less than $80,000 in total assets at age 65. Therefore, the potential for people to spend down their assets and quality for Medicaid is large, regardless of how many are actually doing so. And even if they do not spend down to qualify for Medicaid, their consumption levels and well-being are vulnerable to health and disability risks late in life. They have lived average American lives only to be left on the verge of destitution if anything goes wrong, he said. If the subsidies currently directed toward the upper end of the income spectrum could be redirected to the middle of the spectrum to make long-term care insurance less costly, Frank argued that people's lives could be improved, as could the prospects for Medicaid.

Redirecting these subsidies has both a technical component and a political component, Frank observed. Both raise hard issues, but the possibility should be explored.

During the discussion session, one workshop participant observed that simplifying and standardizing a product can quickly generate litigation directed at collusion. He also pointed out that requiring that long-term care insurance be offered is likely to increase adverse selection risk, which will make companies even less likely to offer policies, and that reinsurance pools face the problem of large deductibles. Frank countered that simplification would have to be sanctioned by government to avoid litigation, so attracting a larger pool of people is most likely to reduce, rather than increase, selection, and that many insurance companies are in favor of reinsurance, especially if the government sets standards so that companies can have more confidence. Frank also mentioned the possibility of indexing premiums to reduce the likelihood of unexpected increases and of using 401(k) savings or non-refundable tax credits to pay for premiums without penalties.

IMPROVING RETIREMENT INCOME ADEQUACY

Jack VanDerhei
Employee Benefit Research Institute

According to a research program conducted at the Employee Benefit Research Institute, 60 percent of the households in the lowest income quartile will run short of money in retirement. They will still have Social Security, but they will have depleted their defined contribution and individual retirement account (IRA) assets and any housing equity. Moreover, 41 percent of households in the lowest income quartile will deplete those assets within 10 years of retirement. However, the vast majority of this saving shortfall disappears if largely unpredictable and substantial health expenses not covered by Medicare, usually from nursing homes, are not included.

One thing that employers can do to help stave off this future is to change the 401(k) plans they provide, VanDerhei said. Since 2006 more and more employers have begun offering automatic enrollment plans, which automatically enroll employees on their first day of work. Employees can opt out if they want, but few do. As a result, participation rates among lower income employees have more than doubled since 2006.

The automatic escalation of contributions would make such plans even better, VanDerhei said. Very few people put into retirement accounts the amounts they should be putting in—10 to 15 percent—and employers are very reluctant to start their employees at this level. With automatic escalation, a 3 percent contribution might go up to 4 percent after 1 year, 5 percent after 2 years, and so on, until the maximum was reached or the employee chose to opt out of further increases. According to VanDerhei, such a plan substantially increases the likelihood of replacing a significant portion of pre-retirement salary from Social Security and 401(k) accumulations upon retirement, depending on whether and when employees decide to opt out.

Education of employees can help convince them not to opt out of automatic escalation too soon. Also, when they change jobs they should be encouraged to keep their contributions at what they were in their previous job rather than starting anew at a low percentage. Finally, the escalation rate can be set at a 2 percent increase per year rather than a 1 percent increase, which would increase the chance that people will retire with an adequate replacement rate.

Employees also can purchase long-term care insurance. VanDerhei described a study showing that the people who have the most to gain from long-term care insurance are those in the second and third income quartiles (VanDerhei, 2005). The lowest income quartile are the closest to being eligible for Medicaid, and the highest income quartile generally have enough assets to self insure.

Asset allocations should be age appropriate, VanDerhei said. Young employees should not have zero equity exposure, employees close to retirement should not have equity allocations that are too high, and employees should not have an excess concentration in company stock (VanDerhei, 2009). In addition, working to age 70 instead of age 65 can increase the probability of success in retirement by 24 percent (VanDerhei, 2012), and annuitization at age 65 can reduce the replacement rate needed for 90 percent probability of success by as much as 24 percent (VanDerhei, 2006).

In the discussion session, one workshop participant asserted that the estimates of life expectancy generated by the Social Security Administration and the Census Bureau are too conservative. He noted that other estimates indicate that people will live as many as 5 years longer and said that this difference causes a dramatic difference in model outcomes. VanDerhei agreed that life expectancy has a "huge influence" on whether a household will run short of money in retirement but that most people run out of money in the first 10 years of retirement, which is reflected in the results of the models he described.

6

Reflections on the Workshop

Important Points Made by the Speakers

- With better training, people with disabilities could perform many needed services, often for others who have chronic health conditions and functional limitations. (Claypool)
- A program focused on relatively young individuals with significant disabilities could provide for their long-term services and supports and wrap around their health care coverage. (Claypool)
- Continued increases in the federal debt will place increased pressure on investments in the future productive capacity of the United States. (Hoagland)
- If new technologies could increase personal responsibility for health, demands on public resources could be less onerous. (Hoagland)
- Social insurance can spread the costs of long-term services and supports and ensure that everyone is covered, including younger people with disabilities who cannot obtain private long-term care insurance. (Wiener)

In the final session of the workshop, three speakers reflected on several of the prominent topics that arose over the course of the day's discussions. Henry Claypool, executive vice president of the American Association of People with Disabilities, returned to the topic of people younger than

65 with disabilities and the difficult financial prospects most of them face throughout their lives. G. William Hoagland, senior vice president at the Bipartisan Policy Center, reminded workshop participants of some of the fiscal realities facing the nation. Joshua Wiener, distinguished fellow and program director for aging, disability, and long-term care at RTI International, rounded out the discussion by asking what society can afford to pay for long-term services and supports and what it wants to pay.

PEOPLE WITH DISABILITIES

Henry Claypool
American Association of People with Disabilities

Many people with disabilities are living in dire circumstances, Claypool said. They often do not have access to long-term care insurance, and they do not have many options for meeting their future needs.

Claypool said he considers long-term services and supports to be health care–related services because these services and supports have a significant influence on health outcomes. The interactions between people's disabilities and the society in which the people with those disabilities find themselves constitute the social determinants of health, he said.

Better skills and better training are essential for this population, Claypool said. Society has a huge opportunity to invest in a relatively low-wage workforce that can perform needed services, often for others who have chronic health conditions and functional limitations. Individuals who are given training can promote basic health literacy while at the same time benefiting from that information. They can become more integrated into the community while engaging in exercises that will improve their quality of life. Together, the direct-care workforce and the people they serve can become a laboratory for future investment.

Several initiatives in the Deficit Reduction Act were designed to move state Medicaid programs toward greater balance—that is, toward providing more home- and community-based services (HCBS) for the beneficiaries of the program. States have embraced this option as a way to make a limited pot of money serve more people. Turning Medicaid into a program of block grants will not address the central issue, Claypool said, because it will put all the responsibility on states to meet the needs of their populations.

Misaligned Incentives

Modest work incentives for the working-age Medicaid population have been instituted in the past. Many individuals with significant disabilities could earn fairly significant incomes—say, $30,000 per year or more—with a stable work attachment over time. But current incentives are not set up to encourage working, Claypool said. Younger disabled people have grown up after the Americans with Disabilities Act. When Claypool was young and wanted to go out, he had to worry whether he was going to be able to use the restroom wherever he went. People no longer have to worry so much about such difficulties. Younger people have not dealt with the isolation and segregation that previous generations experienced, he said. They have been mainstreamed in school and have grown up with their peers. They have been much more integrated into the community, and communities recognize the barriers they face. People with disabilities have allies who are actively working on reducing barriers and increasing access to their communities and society.

However, the systems that support these individuals desperately need modernization, Claypool said. The current job readiness program is a legacy of World War I and was designed to serve people who were injured in combat or while working. Many policies do not yet acknowledge the transformative power of technology, which has become a great equalizer for people in the workforce. Medicaid is a poverty program caught in the midst of state-by-state decisions concerning whether to extend health care coverage to low-income populations.

The Affordable Care Act bars pre-existing conditions from being a reason to deny the purchase of private health insurance. This provides a huge opportunity for people with disabilities, Claypool said. Being able to buy health insurance is a monumental advance. But more is needed. A program focused on relatively young individuals with significant disabilities could provide for their long-term services and supports and wrap around their health care coverage. Such a program could provide the types of services and supports that these individuals need, Claypool concluded.

THE FISCAL PROSPECTS

G. William Hoagland
Bipartisan Policy Center

Hoagland reminded the group of the fiscal realities facing the United States. Throughout the 21st century the federal budget has run a deficit. Although the deficit is currently getting smaller, it is projected to start growing again in 2016, as the baby boomers start to retire in greater numbers.

As a result, the total public debt will continue to grow in absolute numbers and will stabilize at around three-quarters of gross domestic product (GDP), which is well above the historical average. The fastest growing component of the federal budget will then be paying the interest on the public debt, which will grow at about 19 percent annually between 2015 and 2020.

In 2023, according to the Congressional Budget Office (2013), domestic discretionary spending by the federal government will be only 12 percent of the federal budget—less than Medicare (15 percent), Medicaid and other health programs (13 percent), Social Security (23 percent), defense (12 percent), and interest on the federal debt (14 percent). Yet domestic discretionary income, which includes all non-defense research and development, is the seed corn for the future. Without changes in health care and other programs, even more pressure will be placed on federal investments in the future productive capacity of the United States.

Hoagland ended on an optimistic note, however. He said that right before he gave his presentation, he checked his blood pressure with his iPhone. New technologies could help people take more personal responsibility for their health, he said. The incentives built into many current policies, though well intentioned, have the effect of discouraging responsible long-term planning, which contributes to the demands being placed on federal programs. If new technologies could increase personal responsibility for health, demands on public resources could be less onerous.

THE CHOICES THAT SOCIETY MAKES

Joshua Wiener
RTI International

According to Wiener, the principal questions emerging from the workshop were: What can society afford to pay for long-term care, and what does it want to pay? Today, the United States and most other industrialized nations spend about 1 percent of GDP on public long-term care expenditures. In the next 40 years, because of the aging of the population, that percentage is projected to rise to between 2 and 3 percent.

Some argue that an additional 1 to 2 percent of GDP is too much to spend and that long-term care programs will need to be cut. This will be problematic, Wiener said, because most observers believe that long-term care is underfunded. Others argue that an additional 1 to 2 percent of GDP is not that much, especially within the context of a health care system that spends 18 percent of GDP. Indeed, overall health spending increased by 3 percentage points between 2000 and 2010. Today, total long-term care expenditures is just 8 percent of total national health expenditures, and if it doubles to 16 percent, it will still be a small portion of total health care spending.

Today, many older adults do not have enough money to pay for their retirement, Wiener said, let alone their long-term care. Between 2005 and

2011 total median net worth among workers ages 55 and older declined by about one-third. Older people with disabilities have about half as much wealth as people without disabilities, and older people with severe disabilities have about a third as much wealth as people without disabilities. Meanwhile, the private long-term care insurance market has largely collapsed. If the private sector cannot provide long-term services and supports, the continuation of the status quo or new public initiatives are the only choices, Wiener said.

Wiener cautioned against believing that demography is destiny. Projections are largely based on the increasing number of older people, but the future is not just an extension of the past, he said. For example, slightly fewer Americans are in nursing homes than in 1990, even though the population of those ages 85 and older has almost doubled.

The Need for Social Insurance

Wiener advocated for social insurance, arguing that it spreads the costs and ensures that everyone is covered, including younger people with disabilities who cannot obtain private long-term care insurance.

The Medicaid program also will need to be examined, he said, because that is currently how long-term services and supports are publicly supported in the United States. The program could be changed incrementally without inventing a whole new system. Wiener said this could be done by altering Medicaid eligibility criteria or by expanding HCBS by making personal care services mandatory in the states that currently do not cover it.

Discussions about long-term care are not conversations about other people, Wiener concluded. They are conversations about us and our future. All Americans are getting older and will eventually face the risk of becoming disabled. In Europe, long-term care is higher on the political agenda, and many European countries are addressing the issue. Americans can learn from the successes and failures of other countries.

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Appendix A

Workshop Agenda

Financing Long-Term Services and Supports for Individuals with Disabilities and Older Adults: A Workshop

June 12, 2013

National Academy of Sciences Building
Lecture Room
2101 Constitution Avenue, NW
Washington, DC 20418

Institute of Medicine and National Research Council
Forum on Aging, Disability, and Independence

Workshop Objectives

- Provide an overview of the scope and trends of current sources of financing for long-term services and supports for working-age individuals with disabilities and older adults aging into disability, including income supports and personal savings.
- Consider the role of families, the government, and the private sector in financing long-term services and supports.
- Discuss implications of and opportunities for current and innovative approaches.

9:00 a.m. **Welcome and Opening Remarks**

Alan M. Jette, *Forum Co-Chair*
Professor of Health Policy and Management
Boston University School of Public Health

John W. Rowe, *Forum Co-Chair*
Professor
Columbia University

SESSION 1: DEFINING THE CHALLENGE

Panel Moderator: *Robert Jarrin,* Senior Director,
Government Affairs
Qualcomm, Inc.

9:15–10:30 a.m. **Overview**

Judith Feder
Professor, Georgetown Public Policy Institute
Georgetown University

Specific Challenges Key to These Discussions

Workforce

Robyn Stone
Executive Director and Senior Vice President of
Research, LeadingAge Center for Applied Research

Technology

Laurie Orlov
Founder of Aging in Place Technology Watch

Personal Preferences for Care

Lisa I. Iezzoni
Director, Mongan Institute for Health Policy
Massachusetts General Hospital;
Professor of Medicine
Harvard Medical School

Question-and-Answer Session

SESSION II: THE ROLE OF INDIVIDUALS AND FAMILIES

Each speaker will address

- Current extent of expenditures, projected trends
- Innovative solutions in their area, including necessary incentives and potential impacts on individuals
- Any relevant examples from international experiences
- Areas where further research is needed

Panel Moderator: *Lisa I. Iezzoni,* Director, Mongan Institute for Health Policy, Massachusetts General Hospital; Professor of Medicine, Harvard Medical School

10:30–11:45 a.m. **Personal Savings**

Richard W. Johnson
Senior Fellow, Director of the Program on Retirement Policy in the Income and Benefits Policy Center, Urban Institute

Family Caregiving

Gail Hunt
President and CEO of the National Alliance for Caregiving

Question-and-Answer Session

11:45 a.m.–12:45 p.m. **Lunch**

SESSION III: THE ROLE OF GOVERNMENT

Each speaker will address

- Current extent of expenditures, projected trends
- Innovative solutions in their area, including necessary incentives and potential impacts on individuals
- Any relevant examples from international experiences
- Areas where further research is needed

Panel Moderator: *Margaret Campbell,* Senior Scientist for Planning and Policy Support, National Institute on Disability and Rehabilitation Research (NIDRR)

12:45–2:15 p.m. **Innovations in Public Income Support Programs**

David Stapleton
Senior Fellow and Director of the Center for Studying Disability Policy
Mathematica Policy Research

Medicaid

MaryBeth Musumeci
Associate Director, Kaiser Commission on Medicaid and the Uninsured
Henry J. Kaiser Family Foundation

Erica Reaves
Policy Analyst, Kaiser Commission on Medicaid and the Uninsured
Henry J. Kaiser Family Foundation

Social Insurance

Lee Goldberg
Vice President for Health Policy
National Academy of Social Insurance

Question-and-Answer Session

2:15–2:30 p.m. **Break**

SESSION IV: THE ROLE OF THE PRIVATE SECTOR

Each speaker will address

- Current extent of expenditures, projected trends
- Innovative solutions in their area, including necessary incentives and potential impacts on individuals
- Any relevant examples from international experiences
- Areas where further research is needed

Panel Moderator: *René Seidel,* Vice President of
Programs and Operations,
The SCAN Foundation

2:30–4:00 p.m. **Private Long-Term Care Insurance**

John O'Leary
President
O'Leary Marketing Associates

Expanding Private Long-Term Care Insurance and Strengthening Medicaid

Richard Frank
Margaret T. Morris Professor of Health Economics
Department of Health Care Policy
Harvard Medical School

The Role of the Private Sector in Improving Retirement Income Adequacy

Jack VanDerhei
Research Director
Employee Benefit Research Institute

Question-and-Answer Session

SESSION V: LOOKING FORWARD: REACTORS PANEL

Panel Moderator: *John W. Rowe,* Professor,
Columbia University

4:00–4:50 p.m. Henry Claypool
Executive Vice President
American Association of People with Disabilities

G. William Hoagland
Senior Vice President
Bipartisan Policy Center

Joshua Wiener
Distinguished Fellow and Program Director for Aging, Disability and Long-Term Care
RTI International

4:50 p.m. **Closing Remarks and Thoughts**

5:00 P.M. **Adjourn**

Appendix B

Speaker Biographical Sketches

HENRY CLAYPOOL has 25 years of experience developing and implementing disability policy at the federal, state, and local level and also has personal experience with the nation's health system as a person with a disability. Mr. Claypool sustained a spinal injury more than 30 years ago. In the years following his injury he relied on Medicare, Medicaid, Social Security Disability Insurance, and Supplemental Security Income, which enabled him to complete his complete his bachelor's degree at the University of Colorado. In his most recent role in public service as a senior advisor to the Secretary of Health and Human Services, Claypool was a principal architect of the administration's efforts to expanding access to community living services, which culminated in the creation of the Administration for Community Living where he served as the principal deputy administrator. From 2005 to 2006 he served as a senior advisor in the Social Security Administration's Office of Employment Support Programs. From 1998 to 2002 he held various advisory positions at the U.S. Department of Health and Human Services, including senior advisor for disability policy to the Administrator of the Health Care Financing Administration at the Centers for Medicare & Medicaid Services. He is now the executive vice president of the American Association of People with Disabilities. In these roles he relies on his unique background of public service and personal experience to seek pragmatic policy solutions.

JUDITH FEDER, Ph.D., is a professor of public policy at Georgetown University and from 1999 to 2008 served as dean of the Georgetown Public Policy Institute. A nationally recognized leader in health policy, Dr. Feder has made her mark on the nation's health insurance system through both scholarship and public service. A widely published scholar, her health policy research began at the Brookings Institution, continued at the Urban Institute, and, since 1984, has flourished at Georgetown University. In the late 1980s, she moved from policy research to policy leadership, actively promoting effective health reform as staff director of the congressional Pepper Commission (chaired by Sen. John D. Rockefeller IV) in 1989–1990; as principal deputy assistant secretary for planning and evaluation at the U.S. Department of Health and Human Services in former President Bill Clinton's first term; as a senior fellow at the Center for American Progress (2008–2011); and, today, as an institute fellow at the Urban Institute.

Dr. Feder matches her own contributions to policy with her contributions to nurturing emerging policy leaders. As dean from 1999 to 2008, she built the Georgetown Public Policy Institute into one of the nation's leading public policy schools, whose graduates participate in policy making, policy research, and policy politics not only throughout Washington, but throughout the nation and the world.

Dr. Feder is an elected member of the Institute of Medicine, the National Academy of Public Administration, and the National Academy of Social Insurance; a former chair and board member of AcademyHealth; a member of the Center for American Progress Action Fund Board, the Board of the National Academy of Social Insurance, and the Hamilton Project's Advisory Council; and a senior advisor to the Kaiser Commission on Medicaid and the Uninsured. In 2006 and 2008, she was the Democratic nominee for Congress in Virginia's 10th congressional district.

Dr. Feder is a political scientist with a B.A. from Brandeis University and a master's degree and Ph.D. from Harvard University.

RICHARD G. FRANK, Ph.D., is the Margaret T. Morris Professor of Health Economics in the Department of Health Care Policy at Harvard Medical School. From 2009 to 2011 he served as the Deputy Assistant Secretary for Planning and Evaluation at U.S. Department of Health and Human Services, directing the office of Disability, Aging and Long-Term Care Policy. His research is focused on the economics of mental health and substance abuse care, long-term care financing policy, and disability policy. He is also a research associate with the National Bureau of Economic Research, and he serves as an editor for the *Journal of Health Economics*. Dr. Frank was awarded the Georgescu-Roegen prize from the Southern Economic Association, the Carl A. Taube Award from the American Public Health Association, and the Emily Mumford Medal from Columbia University's Department of Psychiatry. In 2011 he received the Distinguished Service Award from the Mental Health Association of Maryland. Dr. Frank received the John Eisberg Mentorship Award from National Research Service Awards. He was elected to the Institute of Medicine in 1997. He is coauthor with Sherry Glied of the book *Better But Not Well* (Johns Hopkins Press, 2006).

LEE GOLDBERG, J.D., M.A., is vice president for health policy at the National Academy of Social Insurance (NASI) and serves as study director of the Health Insurance Exchanges Study Panel. Prior to joining NASI in September 2010, Mr. Goldberg managed long-term care policy initiatives for the Service Employees International Union, which represents more than one-half million nursing home and home care workers. Previously, he served as a senior legislative representative and communications representative for the National Committee to Preserve Social Security and Medicare and as assistant director for health policy for United Jewish Communities. In addition to his advocacy work, he has experience working on Capitol Hill for Sen. Don Riegle and Rep. Fortney H. (Pete) Stark and as a journalist working for Inside Washington Publications. A NASI member since 2006, Mr. Goldberg received his M.A. in international economics and international relations from the Johns Hopkins School of Advanced International Studies and his J.D. from the George Washington University.

G. WILLIAM HOAGLAND, M.S., is a senior vice president at the Bipartisan Policy Center (BPC). Hoagland completed 33 years of federal government service, 25 spent as staff in the U.S. Senate. In 2007 CIGNA Corporation appointed him as vice president of public policy to work with CIGNA business leaders, trade associations, business coalitions, and interest groups to develop CIGNA policy particularly on health care reform issues at both the federal and state levels.

Hoagland is an affiliate professor of public policy at George Mason University, a board member of the Committee for a Responsible Federal Budget, and a member of the National Campaign's Public Policy Advisory Group focusing on teen pregnancy and unwanted pregnancy, the National Academy of Social Insurance, and the National Advisory Committee to the Workplace Flexibility 2010 Commission. In 2009 he was appointed to the Peterson-Pew Commission on Budget Reform examining the overall structure of the budget, authorization, and appropriations process and was a member of BPC's Debt Reduction Task Force, which published *Restoring America's Future* in November 2010. Born in Covington, Indiana, he attended the U.S. Maritime Academy and holds degrees from Purdue University (B.S.) and Pennsylvania State University (M.S.).

GAIL HUNT is president and chief executive officer of the National Alliance for Caregiving (NAC), a nonprofit coalition dedicated to conducting research and developing national programs for family caregivers and the professionals who serve them. Prior to heading NAC, Ms. Hunt was president of her own aging services consulting firm for 14 years. She conducted corporate elder care research for the National Institute on Aging and the Social Security Administration, developed training for caregivers with AARP and the American Occupational Therapy Association, and designed a corporate elder care program for employee assistance professionals with the Employee Assistance Professional Association. Prior to having her own firm, she was senior manager in charge of human services for the Washington, DC, office of KPMG Peat Marwick. Ms. Hunt attended Vassar College and graduated from Columbia University in New York. She served on the Policy Committee for the 2005 White House Conference on Aging as well as on the Advisory Panel on Medicare Education. She is chair of the National Center on Senior Transportation. Ms. Hunt is also on the Board of Commissioners for the Center for Aging Service Technology and on the Board for Long-Term Care Quality Assurance. Additionally, Ms. Hunt is on the governing board of the Patient-Centered Outcomes Research Institute.

LISA I. IEZZONI, M.D., M.S., has spent more than two decades conducting health services research focusing on three primary areas: risk adjustment methods for predicting cost and clinical outcomes of care, the use of administrative data for assessing health care quality, and health care experiences and outcomes of persons with disabilities. After spending 16 years as co-director of research in the Division of General Medicine and Primary Care at Boston's Beth Israel Deaconess Medical Center, Dr. Iezzoni joined the Mongan Institute for Health Policy (MIHP) as associate director in 2006. She is currently serving as director of MIHP.

Dr. Iezzoni has led numerous research grants with funding from the Agency for Healthcare Research and Quality, the National Institutes of Health, and the Health Care Financing Administration as well as from the Robert Wood Johnson Foundation (RWJF) and other private foundations. An internationally recognized expert in risk adjustment, she has edited *Risk Adjustment for Measuring Health Care Outcomes*, now in its third edition. Dr. Iezzoni began her disability research with a 1996 Investigator Award in Health Policy Research from RWJF, and the book summarizing this work, *When Walking Fails: Mobility Impairments of Adults with Chronic Conditions*, appeared in 2003. Another book considering disability experiences more broadly, *More Than Ramps: A Guide to Improving Health Care Quality and Access for People with Disabilities* (co-authored with Bonnie L. O'Day), was published in 2006. Dr. Iezzoni has also published numerous original articles, editorials, and commentaries in major medical and health services research journals.

Dr. Iezzoni speaks widely, and she has served on numerous committees and advisory boards of professional and governmental organizations, including the National Institutes of Health, the Institute of Medicine, the National Quality Forum, and the RWJF Clinical Scholars Program. For the U.S. Department of Health and Human Services she served on the National Committee on Vital and Health Statistics (1994–2001) and the Secretary's Advisory Committee on Health Promotion and Disease Prevention Objectives for 2020 (2008–2009). She has served on the editorial boards of the *Annals of Internal Medicine*, the *Journal of General Internal Medicine*, *Health Affairs*, *Medical Care*, *Health Services Research*, and the *Disability and Health Journal*, among others. In 2000 Dr. Iezzoni was elected to the Institute of Medicine in the National Academy of Sciences.

RICHARD W. JOHNSON, Ph.D., is senior fellow and director of the Program on Retirement Policy in the Income and Benefits Policy Center with the Urban Institute. He is an expert on income and health security at older ages. Much of his research focuses on older Americans' employment and retirement decisions. Recent studies have examined job loss at older ages, occupational change after age 50, employment prospects for 50-plus African Americans and Hispanics, and the impact of the 2007–2009 recession and its aftermath on older workers and future retirement incomes. He has also written extensively about retirement preparedness, including the financial and health risks people face as they approach retirement, economic hardship in the years before Social Security's early eligibility age, and the adequacy of the disability safety net.

Dr. Johnson's other research interest's center on medical and long-term care costs at older ages. He has testified before Congress about the family costs of elder care and about gaps in health insurance coverage among older adults who have not yet qualified for Medicare. Current projects include studies that forecast the future demand for home care and nursing home care and future out-of-pocket spending on medical care. Dr. Johnson holds a Ph.D. in economics from the University of Pennsylvania.

MARYBETH MUSUMECI, J.D., is an associate director at the Kaiser Commission on Medicaid and the Uninsured at the Henry J. Kaiser Family Foundation, where she concentrates on Medicaid for people with disabilities, including issues related to people dually eligible for Medicare and Medicaid and long-term services and supports. Prior to joining the commission staff, she held a Reuschlein Clinical Teaching Fellowship at Villanova University School of Law and spent 8 years as a civil legal aid lawyer, most recently as the deputy legal advocacy director of the Disabilities Law Program at Community Legal Aid Society, Inc., in Wilmington, Delaware, where her practice focused on Medicaid, Supplemental Security Income, other public benefits programs, and civil rights and accessibility issues. Previously she developed and taught a seminar in public benefits law at Widener University School of Law, clerked in the Delaware Family Court, and held an Independence Foundation Public Interest Law Fellowship representing women transitioning from welfare to work in Chester, Pennsylvania. She received her B.A. with highest honors from Douglass College at Rutgers University and her J.D. from Harvard Law School.

JOHN O'LEARY, M.B.A., is a marketing expert known for developing innovative and customer-driven products and marketing programs that have led to market success. Highlights of his career include senior positions at Genworth Financial, CNA Financial, and John Hancock.

At Genworth, Mr. O'Leary led the product development and marketing effort for the company's successful expansion into the group long-term care market segment. He revamped its consumer marketing campaign using segmentation and research to improve messaging and message delivery. He planned, developed, and implemented successful enrollment campaigns that achieved success rates more than double those of prior campaigns and awareness levels of more than 90 percent.

At John Hancock, Mr. O'Leary became an industry leader and spokesperson by pioneering the use of the Internet to market long-term care insurance. He worked with then Congressman Joe Scarborough's office to help successfully develop and pass legislation to provide voluntary long-term care insurance to federal workers. He also drove a public relations campaign with the National Council on the Aging that generated exposure in the *Wall Street Journal* and on *Good Morning America*, the *Today Show*, and CNN.

Mr. O'Leary's career began with consumer brand management positions at Procter and Gamble and Parker Brothers. He followed that with positions as vice president of marketing for Infocom and vice president of marketing and sales for Whistler Corporation. In those positions Mr. O'Leary was responsible for the development, marketing, and roll out of more than 100 new product introductions. He managed marketing and sales goals and budgets, directed internal marketing and external sales organizations, managed advertising and public relations agencies, and developed expertise in product and brand marketing, market research, advertising, promotion and event marketing. A strong element of his success is applying customer insights to product development and marketing innovations. Mr. O'Leary has successfully positioned products and businesses for growth and managed virtually all aspects of the marketing toolkit.

Mr. O'Leary's education includes an M.B.A. from the Harvard Business School (HBS) and a B.A. from Northeastern University. He is active with the Massachusetts Chapter of the Alzheimer's Association, is chair of the marketing track for the 2013 and 2014 Intercompany Long Term

Care Insurance conference, and is a member of the HBS Alumni of Boston Consulting Group and the HBS Health Special Interest Group.

LAURIE M. ORLOV, is the founder of Aging in Place Technology Watch, a market research firm that provides thought leadership, analysis, and guidance about technologies and related services that enable baby boomers and seniors to remain longer in their home of choice.

In her previous career Ms. Orlov spent more than 30 years in the technology industry, including 24 years in information technology and 9 years as a leading industry analyst at Forrester Research. While there she was often the first in the industry to identify technology trends and management strategies that have survived the test of time. She has spoken regularly and delivered keynote speeches at forums, industry consortia, conferences, and symposia, most recently on the business of technology for baby boomers and seniors. She has been featured on Caring.com, MatureMarkets, SilverPlanet, and Mobile Health News, and her blog entries are widely syndicated. She advises large organizations as well as nonprofits and entrepreneurs about trends and opportunities in the age-related technology market. Her segmentation of this emerging technology market and trends commentary has been presented in the *Journal of Geriatric Care Management* and the American Society on Aging's Aging Today Online. Her perspectives have been quoted in *Business Week*, *Forbes*, *Kiplinger*, the *Toronto Star*, and the *New York Times*. She has been profiled in the *New York Times* and the *Huffington Post*. She has a graduate certification in geriatric care management from the University of Florida and a B.A. in music from the University of Rochester. She has consulted for AARP and is a participating expert on the Think Tank for the Philips Center for Health and Well-Being. Clients have included AARP, Microsoft, Novartis, Johnson & Johnson, United HealthCare, and Philips.

ERICA L. REAVES, M.P.P., is a policy analyst with the Kaiser Commission on Medicaid and the Uninsured (KCMU) of the Henry J. Kaiser Family Foundation, where she focuses on long-term care policy. Just prior to joining KCMU in August 2012, Ms. Reaves was a program analyst at United Way of Central Maryland, responsible for data analysis and research support for the impact strategies and development divisions. She spent more than 3 years at the Hilltop Institute at the University of Maryland, Baltimore County, providing research and analytical support on state health reform, Medicaid home- and community-based waivers, and long-term care system transformation. Ms. Reaves holds a bachelor's degree in biological sciences and a master's degree in public policy from the University of Maryland, Baltimore County.

DAVID C. STAPLETON, Ph.D., is a senior fellow who directs Mathematica's Center for Studying Disability Policy. He is also the director of Mathematica's 5-year cooperative agreement with the Social Security Administration (SSA) for the agency's Disability Research Consortium and area leader for research sponsored by SSA, the Department of Education's Office of Special Education and Rehabilitation Services, and nongovernmental disability organizations. Since 1991 his research has focused on the impacts of public policy on the employment and income of people with disabilities.

Mr. Stapleton, who joined Mathematica in 2007, is a principal investigator for the Department of Health and Human Services Center of Excellence for Comparative Effectiveness Research on Disability Services, Coordinated Care and Integration; SSA's Benefit Offset National Demonstration; SSA's Ticket to Work Evaluation; the Rehabilitation Research and Training Center (RRTC) on Disability Statistics and Demographics; and the Individual Characteristics RRTC. He is also a senior advisor to the RRTC on employment policy and measurement; the SSA's National Beneficiary Survey; and SSA's Disability Analysis File.

ROBYN I. STONE, Ph.D., is the executive director of the LeadingAge Center for Applied Research and senior vice president of research. A noted researcher and leading international authority on aging and long-term care policy, she joined LeadingAge to establish and oversee the LeadingAge Center for Applied Research.

Dr. Stone came to LeadingAge from the International Longevity Center-USA in New York City, where she was executive director and chief operating officer. Previously she worked for the federal Agency for Health Care Policy and Research (now known as the Agency for Healthcare Research and Quality).

Dr. Stone also served the White House as deputy assistant secretary for disability, aging, and long-term care policy and as acting assistant secretary for aging in the U.S. Department of Health and Human Services under the Clinton administration. She was a senior researcher at the National Center for Health Services as well as at Project Hope's Center for Health Affairs. Stone was on the staff of the 1989 Bipartisan Commission on Comprehensive Health Care and the 1993 Clinton administration's Task Force on Health Care Reform. Dr. Stone holds a doctorate in public health from the University of California, Berkeley.

JACK VANDERHEI, Ph.D., is the research director of the Employee Benefit Research Institute (EBRI), a private, nonprofit, nonpartisan organization committed to original public policy research and education on economic security and employee benefits. He is also the director of both the EBRI

Defined Contribution and Participant Behavior Research Program and the EBRI Retirement Security Research Program, and he is the co-director of the EBRI Center for Research on Retirement Income. He has been with EBRI since 1988.

Dr. VanDerhei has more than 150 publications devoted to employee benefits and insurance, but his major areas of research focus are the financial aspects of private defined benefit and defined contribution retirement plans. He is currently analyzing a database with annual observations since 1996 of more than 23 million 401(k) participants from more than 60,000 plans.

He has also constructed a simulation model to forecast future retirement income for birth cohorts between 1935 and 1975. This model has already been used to help individual states predict the percentage of retirees (by age, gender, and family status) that will have inadequate income to provide for specific post-retirement purchases (such as housing and health care expenditures). He has also used the model to forecast the probable financial impact of modifying the existing system with respect to company stock in 401(k) plans.

He is the editor of *Benefits Quarterly* and *Search for a National Retirement Income Policy* (University of Pennsylvania Press), a member of the National Academy of Social Insurance, a member of the Board of Outside Scholars for the University of Michigan Retirement Research Center, a member of the BNA Pension and Benefit Publications Advisory Board and on the advisory board of the Pension Research Council at the Wharton School. He was a co-author of the sixth, seventh, and eighth editions of *Pension Planning: Pension, Profit-Sharing, and Other Deferred Compensation Plans* (Irwin/McGraw-Hill).

He has made numerous presentations on retirement security topics for academic as well as national professional conferences and is often called upon to provide briefings for Capitol Hill staffers and research staff for federal agencies. He has also served on or consulted for a number of working groups involved in overseeing the development of pension simulation models. He received his B.B.A. and M.B.A. from the University of Wisconsin–Madison and his M.A. and Ph.D. from the Wharton School of the University of Pennsylvania.

JOSHUA M. WIENER, Ph.D., is a distinguished fellow and program director for aging, disability, and long-term care at RTI International. He is the author or editor of 8 books and more than 200 journal articles, reports, and monographs on health care for older people, people with disabilities, quality assurance, residential care facilities, long-term services and supports, international health care systems, Medicaid, health reform, health care rationing, and maternal and child health. Dr. Wiener directed the development of the Brookings–ICF Long-Term Care Financing Model, the first comprehensive microsimulation model for long-term care in the United States. He is co-director of the Administration on Aging–funded Alzheimer's Disease Supportive Services Program National Resource Center. Dr. Wiener is currently involved in studies of quality in residential care facilities, long-term care insurance, home-based primary care, risk of institutionalization, and Medicaid spend down. Prior to coming to RTI International, Dr. Wiener did policy analysis and research for the Urban Institute, the Brookings Institution, the Health Care Financing Administration, the Massachusetts Department of Public Health, the Congressional Budget Office, the New York State Moreland Act Commission on Nursing Homes and Residential Facilities, and the New York City Department of Health.