S. HRG. 111–64

HEALTH CARE REFORM IN AN AGING AMERICA

HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

ONE HUNDRED ELEVENTH CONGRESS

FIRST SESSION

WASHINGTON, DC

MARCH 4, 2009

Serial No. 111–2

Printed for the use of the Special Committee on Aging

Available via the World Wide Web: http://www.gpoaccess.gov/congress/index.html

U.S. GOVERNMENT PRINTING OFFICE
50–873 PDF WASHINGTON : 2009

For sale by the Superintendent of Documents, U.S. Government Printing Office
Internet: bookstore.gpo.gov Phone: toll free (866) 512–1800; DC area (202) 512–1800
Fax: (202) 512–2250 Mail: Stop SSOP, Washington, DC 20402–0001

SPECIAL COMMITTEE ON AGING

HERB KOHL, Wisconsin, *Chairman*

RON WYDEN, Oregon
BLANCHE L. LINCOLN, Arkansas
EVAN BAYH, Indiana
BILL NELSON, Florida
ROBERT P. CASEY, Jr., Pennsylvania
CLAIRE McCASKILL, Missouri
SHELDON WHITEHOUSE, Rhode Island
MARK UDALL, Colorado
KIRSTEN GILLIBRAND, New York
MICHAEL BENNET, Colorado
ARLEN SPECTER, Pennsylvania

MEL MARTINEZ, Florida
RICHARD SHELBY, Alabama
SUSAN COLLINS, Maine
BOB CORKER, Tennessee
ORRIN HATCH, Utah
SAM BROWNBACK, Kansas
LINDSEY GRAHAM, South Carolina

DEBRA WHITMAN, *Majority Staff Director*
MICHAEL BASSETT, *Ranking Member Staff Director*

CONTENTS

PANEL I

PANEL II

APPENDIX

HEALTH CARE REFORM IN AN AGING AMERICA

WEDNESDAY, MARCH 4, 2009

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The Committee met, pursuant to notice, at 10:05 a.m. in room SD–562, Dirksen Senate Office Building, Hon. Herb Kohl (chairman of the committee) presiding.

Present: Senators Kohl [presiding], Wyden, Udall and Martinez.

Index: Senators Kohl, Martinez, Udall and Wyden.

OPENING STATEMENT OF SENATOR HERB KOHL, CHAIRMAN

The CHAIRMAN. Well, good morning to everybody. It's so good to see so many of you here today. I know many of you come quite a long distance to be at this hearing. So we express our deepest appreciation to each and every one of you who have made this trip to be with us.

We're pleased to welcome everybody here to this first hearing on the issue of national health reform. Our message today is a simple one. Any serious health reform proposal must address long-term care. With America aging at a rapid rate and with the high and rising cost of caring for a loved one, it's crucial that long-term care services are addressed.

Today we'll initiate a conversation about how we can work together to improve long-term care services while also taking steps to make them more cost effective. We all know family members, friends and neighbors who have struggled to recover from a bout of severe illness or a serious accident and need care for a prolonged period or even for the rest of their lives. These individuals need long-term care services and supports to help them with day to day activities.

But let's be clear that the ultimate goal of long-term care is to allow older or disabled Americans to live as independently as possible. However, as we know, one size does not fit all. Given the variety of circumstances requiring long-term care, any update to our current system must be flexible, and must offer choices tailored to everybody's needs. With the help of our outstanding witnesses today we're going to try to spark some creative ideas about how this can be accomplished in a way that will also get costs under control.

Today we'll be focusing most of our attention on the provision of long-term care through Medicare, a Federal program, and Medicaid, which is administered jointly by the Federal and the state governments. Some states have expressed concern that their aging and disabled Medicaid populations are swamping their budgets. This financial strain will only worsen.

Yet a handful of states, including my own state of Wisconsin, are addressing long-term care in a proactive, thoughtful manner. These states have made important strides in not only expanding the range of services, but also in controlling costs. Though it's not easy, it is achievable. It requires strong leadership and political commitment.

We will hear today from HHS about a range of innovative grant programs that the Federal Government has created to provide several states with financial resources and incentives to broaden the range of Medicaid services offered to roughly a million people in their homes and communities. However, we need to make sure that our economic troubles do not lead to diminished services. The recently enacted stimulus bill provides states with an additional $87 million dollars in Medicaid funding. I believe some of this funding should be used by states to strengthen these popular and vital home and community-based programs.

We also need to find ways to coordinate and approve care for the more than seven million beneficiaries who are eligible for both Medicare and Medicaid, which includes some of the sickest and the poorest of our citizens. The care that these dual eligibles receive is very often not coordinated well and is very costly. Today we'll examine ways to deliver more comprehensive and fully integrated care at a lower cost.

We should acknowledge that the rising costs of health care and long-term care do not only affect the government. More than one-fifth of all long-term care spending comes directly out of the pockets of individuals and their family members. We also know that tens of millions of family caregivers provide long-term care to loved ones every day, yet have little or no access to support for themselves. As part of our long-term care strategy, we need to provide support for family caregivers through entities such as the Aging and Disability Resource Centers which were pioneered in Wisconsin.

On that note, I recently introduced bicameral legislation to expand education and training opportunities in geriatrics and long-term care for licensed health care professionals, direct care workers and family caregivers. Our country is facing a severe shortage of health care workers who are well trained and prepared to care for older Americans. This too must be addressed by the President and by Congressional leaders as they move forward with national health care reform. My colleagues on the Finance and HELP Committees do not have an easy task ahead. But my hope is that the lessons we learned and the ideas we generate in this Committee will be a resource for them.

We thank our witnesses for being here. Before I turn the microphone over to the Ranking Member, Senator Martinez, I have a statement from Senator Edward Kennedy.

He writes, "A major goal of health reform must be to give our citizens a chance to lead full and independent lives. That means that reasonable health care should include services to help individuals maintain their function and prevent deterioration of their condition, just as it should cover services for acute illness and injury. So I join Senator Kohl in expressing the importance of including long-term services and supports in any health care reform initiative. I applaud him for holding this hearing today.”

We thank Senator Kennedy for that inspirational message. We turn now to Senator Martinez from Florida who is the Ranking Member.

STATEMENT OF SENATOR MEL MARTINEZ, RANKING MEMBER

Senator MARTINEZ. Thank you, Mr. Chairman. I wanted to welcome all of you who’ve joined us here today for this important hearing. I want to thank Chairman Kohl for calling this hearing and focusing attention on this very important issue. The issue of what we here at the Federal level can do to enhance and improve long-term care is a very timely subject.

The issue of sustainable quality and long-term care in America is an important issue for most states. For states like Florida it’s absolutely a vital issue. Looking at the demographic you will see the percentage of Floridians over the age of 65 is nearly 40 percent higher than the national average. The number of Floridians age 85 and older—those most likely to need more acute, long-term care services—is nearly two times the national average.

With the annual growth of Florida’s low-income elderly population at 80 times the national average, more focus has to be put on long-term care issues and ensuring that the elderly and disabled will be able to age with dignity and peace of mind. I believe Florida is a microcosm of what America will look like in the coming decades. So I look forward to working with President Obama and my colleagues in the Senate to address these issues in a bipartisan way.

While reform is desperately needed, we also need to change the way reform has been talked about in the past. The discussions of Medicaid reform both here in Washington and in state capitals tends to involve only four options, cut eligibility, cut reimbursement rates, cut benefits or ask Congress for more money. Rather than remaining focused on these limited choices I think we should begin our discussion with a focus on what is best for patients. We must look for ways to improve the consistency and coordination of care to best assist this vulnerable population.

Ultimately our goal should be to improve the health of low-income Americans and ensure that those in need of services have access to the services they need. An improved Medicaid long-term care program will be able to serve more people with better results. We should be giving state officials a range of options to pursue that will improve the delivery of care including support for innovations which prevent people in need of long-term care from spending all of their savings and then have no other option but to go onto Medicaid to access care.

I know that my state of Florida has been working on these issues and remains focused on finding new ideas to guarantee success. Florida has chosen to invest in initiatives focused on ensuring our elderly and disabled will be able to age with dignity. We must work to transform the health care infrastructure so that it is focused on the quality of life and on a person's needs rather than those of state or Federal accountants.

We ought to build on the innovation occurring in some states and ensure patients are in control of how and where they receive services. Florida, like many states, has experimented with consumer driven and nursing home diversion models of care delivery with positive results and has saved money while flattening the growth curve for nursing home bed days. Florida has one of the original cash and counseling demonstration states and now has more than 1,000 consumers managing home-based services to meet their long-term care needs. By focusing on what is best for each patient and providing flexibility, we can create a model that works for an aging population in states across the nation.

I thank you for being here. I thank you for this hearing, Mr. Chairman. I look forward to hearing the testimony from the witnesses.

The CHAIRMAN. Thank you very much, Senator Martinez. We will have the privilege today of hearing from experts as well as many experienced public officials.

Our first witness today will be Thomas Hamilton from the Centers for Medicare and Medicaid Services. Mr. Hamilton is the Director of the Survey and Certification Group within the Center for Medicare and State Operations. He previously served as the Director of CMS' disabled and elderly health programs. In that capacity he led the development of Medicaid policies for low-income elderly and adults with disabilities. For 21 years prior to joining CMS, Mr. Hamilton was one of the principal architects of the Wisconsin long-term care system.

Our second witness today will be Karen Timberlake. She serves as Wisconsin's Secretary of Health and Human Services. Ms. Timberlake provides direction for the state's health agency, which is charged with ensuring the health, safety and well being of Wisconsin citizens while also emphasizing prevention and protecting consumers.

Ms. Timberlake also chaired the Governor's task force on autism in 2004 and served on the state's group insurance board from 2000 through March 2007. We welcome you, Madame Secretary, and look forward to your testimony.

Senator Martinez, our next witness is from Florida.

Senator MARTINEZ. Yes, Mr. Chairman. I want to very much welcome Secretary Holly Benson, who is here with us today from Florida. Secretary Benson is a great Floridian and a good friend, and someone who has a long and distinguished career in public service.

She has served as Governor Charlie Crist's Secretary of the Agency for Health Care since 2008, February of 2008. She is also the former Secretary for the Florida Department of Business and Professional Regulation.

Before serving on the Governor's Cabinet, she practiced law in her hometown of Naples. She is a graduate of Dartmouth University, and has her law degree from the University of Florida.

Secretary Benson, we're so happy to have you here today. Welcome.

The CHAIRMAN. Thank you. Mr. Hamilton, we'd love to hear from you.

STATEMENT OF THOMAS HAMILTON, DIRECTOR, SURVEY AND CERTIFICATION GROUP, CENTERS FOR MEDICARE AND MEDICAID SERVICES, WASHINGTON DC

Mr. HAMILTON. Good morning, Chairman Kohl, Senator Martinez. Thank you for initiating a national conversation about improving the nation's long-term care system. Such a conversation is very timely. Within 10 years the proportion of elderly people in this country is expected to increase from the current 13 percent to 16 percent and then to 19 percent a mere 10 years after that.

To draw forth the implications of this trend for our long-term care system, the U.S. Census Bureau estimates that about 4.2 percent of elderly people require help with activities of daily living such as bathing, dressing, toileting and ambulating. But, the need for direct assistance increases more than threefold to 14.4 percent for those aged 75 plus. Among the elderly it is precisely the cohort age 75 plus that is fastest growing.

While the challenges are considerable, so too, are the opportunities for Federal leadership. So too are the opportunities for Federal partnership with States and with members of the aging and disability communities. We have seen such leadership and partnership before.

In 1981, for example, Congress observed the pioneering work of a few States such as Oregon, Wisconsin and New York as they took initiative to demonstrate the feasibility of statewide, organized, community-based, long-term care systems. Congress subsequently enacted Section 1915(c) of the Social Security Act, otherwise known as the home and community-based service waiver program, to provide Medicaid matching funds and make such community-based systems a national possibility rather than simply a local phenomenon. More recently, Congress provided states with Real Choice Systems Change Grants, year after year, and enacted a self-directed services option for State Medicaid plans.

Congress enacted the largest Medicaid demonstration program in history in 2005, the $1.75 billion dollar "money follows the person rebalancing initiative." This initiative is helping States transition to the community more than 36,000 people who have been residing in nursing homes or other institutional settings.

Have these partnerships with states made a difference? Unequivocally, yes. Consider, for example, the problem of institutional bias in Medicaid. In 1981 the national proportion of Medicaid funds devoted to community-based care ranged from 10 to 20 percent. The rest was spent on institutional care. By 2007, however, the community care proportion nationally had increased to 47 percent.

Have these partnerships with states been cost effective? Yes. To illustrate this point, as the Chairman indicated, prior to my Federal career I had the privilege of directing the Wisconsin "community options program" from its start in 1981 to 1998. During that time the elderly population in Wisconsin increased by 30 percent.

But the Medicaid population in nursing homes declined by 17 percent. Community options made a difference. An important part of the cost effectiveness of community programs is the greater involvement of family and friends in such programs, engendering a greater amount of control of the use of funds that the programs permit people who require long-term care, as in the programs indicated by Senator Martinez.

As a colleague said to me in 1980 when we were first designing our program, I don't think we can go wrong trusting the cost containment instincts of 87 year old widows. He was right. A few years later I actually found myself visiting with an 87-year-old widow who went by the nickname of Frenchie.

As we sat around her kitchen table in the trailer in which she and her husband had raised eight children—the trailer in which we were helping her age in place—her case manager asked her, Frenchie, "how's that new prosthesis working out?" Frenchie reached down and unsnapped her leg, plunked it on the kitchen table and said, "it don't fit too good." [Laughter.]

Mr. HAMILTON. "Well," beamed her young case manager, "we'll just get you another one." "No," replied Frenchie. "You've given me enough. You spend that money on someone else."

In the January 2009 issue of *Health Affairs*, Steven Kay examined this very question of cost containment overall for the long-term care system and reached a similar conclusion about the cost containment effects of community programs nationally. Sadly there remain serious problems. While a few states devote up to 73 percent of their long-term care dollars to community supports, in many other states the proportion is less than 30 percent. In one state it is a mere 13 percent.

There are also serious challenges to the ability of some community programs to function as true, effective alternatives to institutional care. Nursing homes, after all, are obliged by law to offer care that is comprehensive and reliable, and operates in a system in which complaints are investigated by independent, trained individuals with authority to require correction if the complaint is substantiated. Effective community programs match those attributes and more. They tend to be comprehensive with a wide array of potential services and supports.

These programs also tend to be organized and individually-tailored programs, organizing what can otherwise be a confusing array of community services. They offer the beneficiary a coherent package of understandable supports tailored to each person's needs and preferences. They offer the ongoing help of a case manager to access the services they need and resolve any problems that might arise.

Effective programs are community integrated. They promote active participation and community life and the maintenance of relationships with family, friends and community members. For younger people with a disability, they support employment such as helping with needed transportation to the job site.

They are person centered. The programs make the elderly person, or a person with a disability, the center of services, funding and decisionmaking. This is the essence of "money follows the person" rather than the person being required to live where the money is.

They tend to be cost effective and offer flexible funding. By maintaining the involvement of family and friends, providing flexibility in the use of funds in a manner that promotes cost effective solutions, and keeping decision-making close to the individual, community programs can provide very cost effective, long-term care that have helped states restrain the growth of Medicaid expenditures.

Last, they tend to be quality committed. The programs have internal quality improvement systems, formal mechanisms by which complaints must be investigated. A formal system by which independent, trained individuals visit with program participants in their own homes to review the quality of care, first hand.

Chairman Kohl, Senator Martinez, thank you for the opportunity to share these thoughts with you today. I would welcome any questions you may have.

[The prepared statement of Mr. Hamilton follows:]

STATEMENT OF

THOMAS E. HAMILTON
DIRECTOR, SURVEY AND CERTIFICATION GROUP

CENTER FOR MEDICAID AND STATE OPERATIONS
CENTERS FOR MEDICARE & MEDICAID SERVICES

ON

MAKING THE CASE FOR LONG-TERM CARE SERVICES AND SUPPORTS

BEFORE THE

SENATE SPECIAL COMMITTEE ON AGING

MARCH 4, 2009

Testimony of

CMS
CENTERS for MEDICARE & MEDICAID SERVICES

Testimony of
Thomas E. Hamilton

Director, Survey and Certification Group
Center for Medicaid & State Operations
Centers for Medicare & Medicaid Services

Before the
Senate Special Committee on Aging
"Making the Case for Improving Long-Term Care Services and Supports"

March 4, 2009

Good morning Chairman Kohl and distinguished members of the Committee. It is my pleasure to be here today to discuss the role of the Centers for Medicare & Medicaid Services (CMS) and other Agencies and programs at the U.S. Department of Health & Human Services (HHS) that provide services and supports to Americans of all ages who require long-term care (LTC). HHS is composed of 11 Agencies, also known as Operating Divisions, which are responsible for public health, biomedical research, Medicare and Medicaid, welfare, and social service programs.

CMS is the HHS Agency responsible for administering Medicare, Medicaid, the Children's Health Insurance Program (CHIP), and other health-related programs. CMS is the largest purchaser of health care in the United States, serving 92 million individuals through Medicare, Medicaid, and CHIP and therefore, a significant purchaser of long-term supports and services. The Agency, and in particular, the Survey & Certification Group that I direct, is also charged with oversight and quality assurance of health care facilities through the survey & certification process, including nursing homes, home health agencies, and other provider types.

The HHS Administration on Aging (AoA) works to provide home and community-based services to more than 10 million older persons through programs funded under the Older Americans Act. AoA is involved in nutrition, transportation, adult day care, and other health promotion activities. In addition, AoA has a Long-Term Care Ombudsman that provides advocacy services for nursing home residents around the country and a national caregiver support program.

In addition to the HHS operating Agencies that administer direct care programs, several different HHS research divisions study and evaluate the health and long-term care programs and policies of HHS Agencies, including HHS' Assistant Secretary for Planning and Evaluation (ASPE), CMS' Office of Research, Development and Information, CMS' Office of Policy, AoA's Office of Planning and Policy Development, and AoA's Office of Evaluation.

The Importance of Long-Term Care

The formal LTC system plays a vital role in helping people of all ages who have a chronic illness or disability to obtain the daily supports and services they need, and in supporting families to care for their loved ones at home or in the community. The community-based portion of the LTC system is also instrumental in supporting people with a disability to live in their own homes, participate in their communities, sustain their families, and often contribute to the national economy through their own employment. With $232 billion spent on LTC services in 2007,[1] the benefit structures, services, quality and financing of LTC have significant economic effects in the United States as a whole and in local communities where care is delivered.

As the two public programs of Medicare and Medicaid together comprise the single largest purchaser of long-term care, we have a serious responsibility to ensure that the LTC system provides cost-effective, high-quality care that is responsive to the public and the needs and preferences of the individuals who require care. This challenge will only increase as the number of elderly in the country, particularly those over age 85, continues to grow.

While the challenges in LTC are considerable, so too are the opportunities for Federal leadership and partnership, particularly given the substantial role of public programs in

---

[1] Calculated using 2007 OACT National Health Expenditures data.

financing LTC. Those partnerships are with States, families and caregivers, individuals who have a disability, private sector businesses, and the American worker. Progress through partnership can be seen clearly in just a few examples.

Opportunities for Federal Leadership and Partnership

Federal partnership with States. When some States took initiative to demonstrate the feasibility of statewide, organized, community-based long-term care systems, Congress acted to make such systems a *national* possibility by contributing Federal matching funds and regulations pursuant to passage of section 1915(c) of the Social Security Act in 1981.

The Federal-State partnership that resulted from that legislation has grown now to the point where all States[2] have Medicaid "home and community-based service" waivers (HCBS) and there are currently approximately 300 active HCBS waiver programs in operation throughout the country.[3] Despite the fears of critics that it would expand Federal spending, the HCBS program actually contained institutional costs and helped States moderate the growth of Medicaid spending overall.[4] Similarly, States and the private sector took the initiative to demonstrate risk-based capitation programs of all-inclusive care for the elderly (PACE). The Federal government assisted these innovations through Medicare and Medicaid waivers, and Congress later passed national legislation to make PACE a permanent entity within the Medicare and Medicaid programs.

Federal partnership with families. The home and community-based services program each year helps elderly and younger people with a disability to live in their own homes in a cost-effective manner, where they are able to maintain their family relationships, existing support networks, and friends. The waiver programs support rather than supplant families in active caregiving. Similarly, AoA makes caregiver support programs

---

[2] 49 states have Medicaid HCBS waivers. Arizona has a demonstration under section 1115 of the Social Security Act that provides equivalent services to HCBS waivers.

[3] DEHPG Desk Reference. November 2008. p. 231.

[4] See, for example, Kaye, Stephen H, LaPlante, Mitchell P., and Harrington, Charleen: Do Noninstitutional Long-term Care Services Reduce Medicaid Spending? *Health Affairs*, Volume 28 Number 1, January/February 2009, 262-272.

an important part of its agenda, particularly through the National Family Caregiver Support Program (NFCSP).

Federal partnership with individuals who have a disability. When a number of States, such as Arkansas, partnered with the Robert Wood Johnson Foundation and HHS to demonstrate *cash and counseling programs* that enable individuals or families to be in charge of managing their own budget for long-term care and making their own long-term care choices, CMS responded in 2002 with the *Independence Plus* Medicaid waivers. Congress subsequently made changes to the Medicaid personal care benefit in 2005 to permit more States to make such programs available.

Federal partnership with the private sector and American workers. The vast preponderance of LTC providers are private sector, small business, non-profit and for-profit alike. About 3 million workers are employed in direct care occupations, caring for 15 million elderly and younger people with chronic illnesses and disabilities. Every day millions of American workers with personal skills and generous hearts dedicate themselves to caring for their community members in private homes, in nursing homes, and in a variety of personal care settings. In large measure those workers determine not only the quality of care for the people they support, but their quality of life as well.

Partnership among Federal agencies in the field of long-term care. CMS and AoA, for example, combined forces and funding in 2003 that now enable 40 States, the District of Columbia and select Territories to implement "one stop shop" Aging and Disability Resource Centers (ADRCs). The ADRCs offer objective information about all long-term care options that an individual or family might consider, and actively help families sort through what can otherwise be a confusing array of agency services to be negotiated.[5] ADRCs also assist families in assessing their needs, developing care plans and connecting them to the services they need.

---

[5] More information is at: http://www.aoa.gov/prof/aging_dis/aging_dis.aspx.

Similarly, AoA built upon an existing program encouraging community-based care for disabled and elderly individuals, and has recently partnered with the Department of Veterans Affairs (VA) to provide home and community-based services to veterans.[6]

Before explaining these programs and themes in more detail, it may be useful to clarify what we mean by long-term care, who it involves, and who are main providers of long-term care.

Background

What is Long-Term Care? There is one simple definition of long-term care with which we might all resonate: long-term care is simply society caring for itself. A more technical definition would describe the term "long-term care" as referring to the services and supports needed when the ability to care for oneself has been reduced by chronic illness, disability, or aging. Long-term care services and supports maximize independence by meeting health and personal care needs over an extended period of time. Long-term care services and settings are as diverse as the people who use them. Most long-term care takes the form of personal assistance, in which a caregiver provides basic help performing everyday activities of daily living (ADLs) such as bathing, dressing, using the bathroom, getting in and out of bed or a chair, and eating. For people with cognitive impairments, such as those with dementia or with severe developmental disabilities, ADL assistance may take the form of cuing.

LTC can be provided in a number of different settings, including informal home care and supports by family and friends; formal part-time care in the community through adult day care or home health services; and around-the-clock care provided in the community through HCBS waiver programs or care provided in an institutional setting such as nursing homes. Most individuals in need of LTC services will use a combination of these types of care during the course of their lifetime.

---

[6] More information is at http://www.aoa.gov/prof/Nursing/nursing_grants.aspx.

Who Uses Long-Term Care Services? People who need long-term care are a diverse group in terms of age and functional needs. Some individuals with disabilities have developmental needs that were apparent at birth and require daily assistance throughout their life. Other individuals of all ages may need short-term rehabilitative or skilled nursing care following an injury, surgery, or illness, such as an incident of stroke. In addition, since prevalence of disability increases as people age,[7] a growing number of retirees require long-term supports to assist them as they age and begin to lose mobility or cognitive functioning.

It is estimated that there are currently 8 million people age 65 and older receiving paid LTC services. This number is expected to increase to 10 million in 2020. In addition, approximately 5 million people under age 65 living in the community have long-term care needs.[8]

In a recent study examining the LTC needs, use, and costs of care that current 65-year-olds will face over the rest of their lives, it was predicted that:

- 65 percent will spend some time at home needing LTC services;
- 30 percent will receive care at home for more than two years; and
- 11 percent will require care for more than five years.[9]

Furthermore, the study showed that nearly a quarter of retirees will rely on informal care provided by family members at home for at least two years.[10] Projections regarding LTC provided in around-the-clock facilities estimated that 35 percent of current 65-year-olds are likely to need such formal LTC, with five percent spending more than five years in nursing facilities in the future.

---

[7] U.S. Census Bureau, Economics and Statistics Administration. *Americans with Disabilities: 2005.* Published December 2008. Page 4. http://www.census.gov/prod/2008pubs/p70-117.pdf.
[8] Ibid.
[9] Kemper, P, Komisar, H, & Alecxih, L Long-Term Care Over an Uncertain Future: What Can Current Retirees Expect?. *Inquiry*, *42*, Retrieved April 4, 2008, from http://www.inquiryjournalonline.org/inqronline/?request=get-abstract&issn=0046-9580&volume=042&issue=04&page=0335.
[10] Ibid.

Who Provides Long-Term Care and in What Settings? Of Americans with ongoing LTC needs, 17 percent reside in nursing homes while the other 83 percent live in the community where the majority of their care is provided by unpaid family members and friends.[11] In 2006, an estimated 30-38 million caregivers provided informal care valued at $354 billion.[12] In addition, the HCBS waiver program serves over 1 million people in their homes and communities; it is the primary care system for individuals of all ages with mental retardation or developmental disabilities and is a major system serving the elderly and individuals with physical disabilities. Today nearly 1.5 million individuals are in approximately 15,800 nursing homes on any given day, and about 3 million people will spend some time in a nursing home each year.[13] Although we do not have definitive data, approximately one million people live in alternative residential settings, including assisted living facilities, which are usually privately operated and not certified by Medicare and Medicaid.[14] The Department is conducting a nationally representative survey of these places to fill a major gap in public knowledge about these settings, the services provided in them, and the people who live there.

Who Pays for Long-Term Care? Long-term care is financed in a variety of ways, but there is one thing all agree on: paid LTC by trained individuals is generally expensive. At an hourly rate of $19, four hours of daily care by a home health aide could consume more than $27,000 a year for an individual needing care in his/her home.[15] Those in need of around-the-clock facility-based care face an average of $70,000 a year for a semi-private room in a nursing home.[16] In 2007, one year of care in an intermediate care facility for persons with developmental disabilities averaged $123,565.[17]

---

[11] Georgetown University Long-Term Care Financing Project *February 2007 Fact Sheet.* Retrieved April 7, 2008, from: http://ltc.georgetown.edu/pdfs/medicare0207.pdf.

[12] "Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving," AARP Public Policy Institute, June 2007.

[13] Centers for Medicare & Medicaid Services, Survey & Certification Group, OSCAR database.

[14] Spillman, Brenda and Kirstin Black, *The Size of the Long-Term Care Population in Residential Care: a Review of Estimates and Methodology*, Report prepared for ASPE by the Urban Institute, February 2005.

[15] *Metlife Market Survey of Nursing Home and Assisted Living Costs.* October 2007. P 4.

[16] Ibid.

[17] http://rtc.umn.edu/docs/risp2007.pdf

Contrary to popular opinion, LTC is not routine health care, and is generally not covered by standard health insurance. People who pay for these services out-of-pocket account for approximately 18 percent of the total long-term care spending. Another 3 percent are covered by other sources, including the voluntary sector, and 7 percent of LTC services are paid for by private health and long-term care insurance policies.[18] In 2005, approximately 7 million private LTC insurance policies were in force, up from 1.2 million in 1990.[19] These policies are helping individuals and families shoulder the burden of the increasing costs of long-term care services.

Public sources (e.g. Medicare, Medicaid, and the VA) pay for the vast preponderance of long-term care services. However, Medicare covers only a fraction of LTC costs, 22.4 percent in 2007, and limits services to post-acute settings.[20] Many of these post-acute or skilled services are delivered by long-term care providers or in long-term care settings. Specifically, the traditional Medicare fee-for-service benefit covers care in these facilities under specified conditions:

- Skilled Nursing Facilities (SNFs): Medicare pays for SNF care for up to 100 days in a benefit period, following a 3-day minimum inpatient hospital stay for a related illness or injury.
- Inpatient Rehabilitation Facilities (IRFs): Medicare pays for stays in an IRF for beneficiaries requiring longer rehabilitation, often following a previous inpatient hospital episode of care.
- Long-term Care Hospitals (LTCHs): Certified by Medicare as acute care hospitals, LTCHs treat Medicare patients requiring hospital-level care for an average length of stay of greater than 25 days.
- Home Health (HH) Services: Medicare coverage for HH services is limited to reasonable and necessary part-time or intermittent skilled care or therapy. A beneficiary must meet certain criteria and be home-bound in order to receive HH care that is reimbursed by Medicare.

---

[18] National Health Care Expenditures Data, 2007.

[19] "Who Buys Long-Term Care Insurance." America's Health Insurance Plans, April 2007, page 11.

[20] OACT analysis of National Health Care Expenditures Data, 2007.

For those who qualify for assistance, each State Medicaid program must offer nursing facility services and HH agency services, but many forms of LTC services are optional benefits and the availability of community-based LTC services varies by State. In 2006 for example, 33 States covered personal care services; 24 States covered private duty nursing services. Cost-sharing structures for such services vary by State as well.[21] Medicaid also pays for institutional services for a group of individuals with severe intellectual or developmental disabilities whose cost of care is substantial. In 2007, all but three States operated Intermediate Care Facilities for the Mentally Retarded (ICF/MR). There were 96,527 residents in 6,419 ICF/MR; this includes a small number of large State-operated institutions, but the average ICF/MR served 15 residents and was privately operated. As of June 2007, a total of 437,707 individuals with intellectual or developmental disabilities received services in 167,857 settings, including 115,569 who were served in their own homes.[22]

Medicaid is the mainstay of long-term care financing, funding 48.5 percent of LTC payments in 2007.[23] Of the total Medicaid LTC expenditures in 2007 ($113 billion), approximately 53 percent funded institutional services (nursing homes and ICFs-MR) and 47 percent was spent on for community-based services (HCBS waivers, HHAs, personal care, etc).[24]

AoA and ASPE Initiatives to Support Long-Term Care

As stated previously, HHS, CMS and AoA have developed ongoing initiatives to strengthen long-term care and provide necessary services to those who qualify by partnering with other government Agencies and community stakeholders.

HHS' ASPE has led a number of research initiatives to examine challenges and trends to the long-term care workforce. In 2004 ASPE and the National Center for Health

---

[21] Kaiser Family Foundation Analysis available at http://www.kff.org/medicaid/benefits/index.jsp?CFID=10860190&CFTOKEN=84403082.
[22] http://rtc.umn.edu/docs/risp2007.pdf
[23] OACT analysis of 2007 National Health Expenditures Data.
[24] Ibid.

Statistics conducted the National Nurse Aide Survey and the National Survey of Home Health Aides as part of the National Nursing Home Survey. In addition, ASPE is currently conducting a nationally representative survey of residential settings (such as assisted living), to expand knowledge about the long-term care settings and services used by many Americans. HHS and the Department of Labor (DOL) are collaborating this year to examine the feasibility and design of an evaluation of the DOL's Registered Apprenticeship program for long-term care workers in which 40 long-term care employers offer registered apprenticeship employment and training to approximately 2,000 apprentices in 20 States.

For the past nine years, the AoA has operated the NFCSP providing information, assistance, training, respite care and other services to more than 700,000 caregivers each year. CMS also has efforts to support caregivers, and recently held the *Ask Medicare* caregiver initiative in September 2008. The *Ask Medicare* initiative provides information, tools and materials to assist the caregiver and their loved ones in making informed healthcare decisions.

AoA's Nursing Home Diversion Program:

As a complement to the CMS "Money Follows the Person" initiative, AoA is currently supporting State Nursing Home Diversion (NHD) programs that target individuals who are not Medicaid eligible but who are at high risk of nursing home placement and spend down. Targeting this population has important implications for Medicaid since most of the Medicaid-eligible elderly people in nursing homes entered as private paying individuals and then exhausted their private resources and "spent down" to Medicaid eligibility. By helping individuals to remain in the community, the NHD program can help individuals redirect their own resources to community-care and realize their personal preference for staying at home. Under the initiative, 20 states are assisting these at-risk individuals to arrange for flexible, service packages that they can self-direct in order to get the services necessary for remaining in a community-setting. The VA is partnering with AoA on this initiative to provide home and community-based services to veterans of all ages, including younger disabled veterans returning from the wars.

Current CMS Long-Term Care Activities

Home and Community-Based Services Waiver Program. Historically, the Medicaid program has had an "institutional bias" when rendering LTC services, because the majority of Medicaid LTC dollars went to nursing home care (as a mandatory service option) versus home and community-based LTC services. In recent years as laws have given more flexibility, there has been a shift away from the institutional bias resulting in more individuals in need of LTC supports and services transitioning back into community-based environments and utilizing HCBS waiver programs. In Fiscal Year (FY) 2007, spending for HCBS waiver programs, personal care, and home health services accounted for 47 percent of all Medicaid LTC expenditures.[25] HCBS waiver programs are currently operating nationwide. Where previous ratios of institutional to community-based spending were as high as 80/20, the more recent 53/47 ratio reflects the progress of the rebalancing efforts in the growing community-based initiatives.[26]

Home and Community-Based Services State Plan Option. Congress, through the Deficit Reduction Act of 2005 (DRA), created the Section 1915(i) Home and Community-Based Services Medicaid State Plan Option. Beginning January 1, 2007, States have the option to amend their Medicaid State plans to offer HCBS as a State plan optional benefit. On April 4, 2008, CMS published a proposed rule (73 Fed. Reg. 18,676) to further clarify this benefit. This option breaks the prior eligibility requirement that an individual can receive community services only if he or she needs an institutional level of care. At the same time, States will be able to tighten the standard for admission to institutions and refine eligibility for home and community-based waiver services without having to request Section 1115 demonstration authority. Demand in the States is strong for more HCBS options, as evidenced by the large number of beneficiaries on waiting lists for access to HCBS waiver services. As an example, the State of Iowa took advantage of the new benefit to provide statewide HCBS case management services and "psycho-social rehabilitation services" at home or in day treatment programs that can include such things as support in the workplace. Services approved under this State plan optional benefit will

---

[25] OACT analysis of National Health Care Expenditures Data, 2007.

[26] Ibid.

help individuals delay or avoid institutional stays or other high-cost out-of-home placements. The State of Nevada is also providing the HCBS State Plan option benefit.

Money Follows the Person Rebalancing Demonstration. Through the DRA, Congress also created the CMS "Money Follows the Person (MFP) Rebalancing Demonstration." This demonstration supports State efforts to "rebalance" their LTC support systems by offering $1.75 billion in competitive grants to States over 5 years. With this critical assistance, States will be able to make targeted reforms in their State to shore up the community-based infrastructure so that individuals have a choice of where they live and receive services. Specifically, the Federal government will offer the incentive of a MFP-enhanced Federal Medical Assistance Percentage rate for a period of 1-year for each person that the State transitions from an institution setting into the community.

Twenty-nine states and the District of Columbia are currently participating in MFP.[27] These participating States collectively propose to help approximately 35,000 individuals (47 percent of whom are elderly) transition themselves to community-based environments consistent with their preferences and family relationships. Under MFP, individuals will be tracked for three years to monitor their quality of life in the community and to assess their service utilization and health outcomes. The demonstration information will provide CMS with a research platform for future long-term care policy decisions.

This week, CMS held a three-day national conference on the "Money Follows the Person Rebalancing Demonstration."

Self-Directed Budgets for Personal Assistance Services. Congressional action through the DRA gave new authority for Medicaid State plans to offer a benefit for self-directed personal care services to individuals, also known as "Cash and Counseling." Self-directed personal care services have been historically provided through HCBS waivers

---

[27] Thirty States and the District of Columbia were awarded MFP grants; South Carolina has since withdrawn from the program.

and Medicaid Section 1915(c) demonstration waiver programs. With this new authority, self-directed personal care services, including self-directed personal care services provided by family members, can now be provided under Medicaid State Plan Options instead of through waiver or demonstration authority. States will also be able to provide services or items to individuals in need of LTC that maintain their independence or substitute for human assistance. Five States have been approved for 1915(j) self-directed personal assistance service State Plan option benefit: Alabama, Arkansas, Florida, New Jersey and Oregon.

State Long-Term Care Partnership Program. Lastly, the DRA allowed additional States to offer a new long-term care financing program previously available in only four demonstration States. The State Long-Term Care Partnership Program was established to help individuals take more responsibility in planning and financing their future LTC needs by providing incentives for the purchase of LTC insurance. Under the LTC Partnership Program, an individual who purchases a qualified LTC policy and uses its benefits is allowed to apply for Medicaid coverage without having to spend down all of his or her assets first. Specifically, an individual will be able to qualify for Medicaid while retaining assets in the amount of insurance benefit payments made on their behalf. These newly protected assets will also be exempted from Medicaid estate recovery provisions. To date States have responded enthusiastically; as of December 2007, 36 States offered Partnership policies in their State, had approved State plan amendments for qualified State Long-Term Care Partnership Programs, had submitted a State plan amendment, or were in the process of developing Partnership programs.

Real Choice Systems Change Grants for Community Living. Real Choice Systems Change (RCSC) grants have enabled States and other eligible organizations, in partnership with local disability and aging communities, to design and construct infrastructure to address critical elements of successful systems transformation. These grants have resulted in effective and enduring improvements in community-integrated services and long-term support systems in large and small communities across the nation. The infrastructure that has been developed as a result of RCSC grants enables individuals of all ages to live in the most integrated community setting suited to their medical needs, to have meaningful choices about their living arrangements, and to exercise more control over the services they receive.

Since FY 2001, Congress has appropriated annual funding for RCSC grants to improve community-integrated services. These system changes are designed to enable children and adults of any age, with any payer source, who have a disability or long-term illness to:

- Live in the most integrated community setting appropriate to their individual support requirements and preferences;
- Exercise meaningful choices about their living environment, the providers of services they receive, the types of supports they use, and the manner by which services are provided; and
- Obtain quality services in a manner as consistent as possible with their community living preferences and priorities.

Program of All-Inclusive Care for the Elderly (PACE). PACE is a capitated benefit for frail elderly authorized by the Balanced Budget Act of 1997 (BBA) that features a comprehensive service delivery system and integrated Medicare and Medicaid financing. The PACE model was developed to address both the acute and LTC needs of individuals aged 55 or older who are eligible to receive nursing facility care under both Medicare and Medicaid. For most participants, the comprehensive service package permits them to continue living in the community while receiving services, rather than reside in an institutional setting. Capitated financing allows providers to deliver all services participants need rather than be limited to those reimbursable under the Medicare and Medicaid fee-for-service systems. The BBA established PACE as an optional benefit under the Medicare and Medicaid programs. It is available under Medicare to qualifying Medicare beneficiaries who are living in PACE service areas and under Medicaid in States that elect to provide PACE services as a State option to qualifying Medicaid beneficiaries who are living in PACE service areas. Operationally, the PACE program is unique as a three-way partnership between the Federal government, the State, and the PACE organization.

Outreach and Education

Own Your Future Campaign. Through a partnership among CMS, AoA and ASPE, CMS launched the *Own Your Future* Campaign in January 2005 to spread the word that Medicare generally does not pay for LTC services and to clarify that Medicaid pays only for limited services for the poor and disabled. This joint Federal-State initiative is designed to help the next generation of Medicare beneficiaries prepare for their LTC needs.

Increasing Quality and Transparency

CMS takes seriously its responsibility to ensure the quality of care provided in long-term care settings. Nursing homes participating in the Medicare and Medicaid programs are required to meet over regulatory requirements that address 180 aspects of care based on expectations that Congress set forth in law to protect nursing home residents and assure optimum quality of care and quality of life. These requirements cover a wide range of topics, from protecting residents from physical or mental abuse and inadequate care, to the safe storage and preparation of food. Through the Survey and Certification program, CMS has contracts with State governments to perform health inspections and fire safety inspections of these certified nursing homes, as well as investigate complaints about nursing home care. The health inspection team consists of trained inspectors, including at least one registered nurse. These inspections take place, on average, about once a year, but may be done more often if the nursing home is performing poorly. Approximately 15,800 onsite, comprehensive ("standard") surveys are conducted each year, in addition to about 50,000 onsite complaint investigations that focus on the particular areas of complaint.

Beginning in 2004 and annually since, CMS has published on its Web site an Action Plan for Further Improvement of Nursing Home Quality to set a vision and provide the public transparency on CMS' efforts to continuously improve nursing home care.[28] The 2008 plan includes initiatives in key areas including: Consumer Awareness and Assistance, Survey, Standards and Enforcement Processes, Quality Improvement and Quality Approaches through Partnership, and Value Based Purchasing.

Beyond routine inspections, CMS continues to focus on improving the quality of care in nursing homes through quality initiatives and the evolution of its *Nursing Home Compare* Web site. In November 2002, CMS began a national Nursing Home Quality Initiative, which includes quality measures that are shown at the *Nursing Home Compare* Web site (www.medicare.gov/nhcompare). The website enables consumers, providers, States and researchers to compare information on nursing homes. Many nursing homes have already made significant improvements in the care being provided to residents by taking advantage of these materials and the support of Quality Improvement Organization staff.

CMS continues to improve *Nursing Home Compare* through increased user-friendly site functions, additional facility information (including Special Focus Facility status), and the new five star quality ratings for each nursing home. Beginning December 18, 2008, CMS made star quality ratings available on the *Nursing Home Compare* Web site for each of the nation's 15,800 nursing homes that participate in Medicare or Medicaid. Facilities are assigned star ratings from a low of "one star" to a high of "five stars" based on health inspection surveys, staffing information, and quality of care measures. This information is designed to assist consumers as they compare nursing homes in a particular geographic area. As *Nursing Home Compare* continues to evolve, long-term improvements could potentially include dynamic consumer testing, the addition of new quality measures, improved staffing data based on payroll sources and reported quarterly rather than annually, increased user interactivity to refine search capabilities, and information from resident and family satisfaction surveys.

---

[28] The 2008 plan can be found at
http://www.cms.hhs.gov/CertificationandComplianc/Downloads/2008NHActionPlan.pdf.

The Survey and Certification model is effective for the nursing home industry but is not a model that transfers to community-based long term care settings. Therefore, there are a variety of approaches to LTC quality that are important. In community-based long-term care settings, CMS requires States to provide assurances of quality in order to secure approval of each home and community-based waiver application, and has designed a quality framework to assist States. CMS is further advancing quality assurance in HCBS waivers through the MFP demonstration. Each State approved for MFP funding must ensure direct reporting to CMS on specific quality measures. State responsibilities include submission of claims data as part of quality of care indicators, a longitudinal analysis of the quality of life of participants, and fulfillment of more robust programmatic quality assurance requirements that include risk mitigation, critical incident reporting and an emergency back-up system. A required quality of life assessment provides an important opportunity for face-to-face visits with individuals who are receiving community-based long-term care. States are using a variety of approaches to this assessment, ranging from hiring a survey firm, sending State staff, to using advocacy and peer groups. CMS will analyze both data driven and operational impacts to inform future policy making.

Conclusion

Mr. Chairman, thank you for the opportunity to draw attention to the important topic of long-term care and describe what CMS and HHS are doing to address the challenges. Regardless of the care setting, timeframe, or payer, all Americans need access to high-quality, flexible and personalized LTC supports and services. HHS and its partner Agencies are committed to continuing our current efforts to engage caregivers in this discussion, while supporting the design and delivery of LTC supports and services that enable individuals with cognitive and physical impairments to have access to quality LTC in their home communities. In the end, long-term care in our country is about people – the people who need assistance and care, the people working to provide it, and their family members and friends. I am happy to answer any questions that you may have.

The CHAIRMAN. Thank you very much, Mr. Hamilton. Ms. Timberlake.

STATEMENT OF KAREN TIMBERLAKE, SECRETARY, WISCONSIN DEPARTMENT OF HEALTH SERVICES, MADISON, WI

Ms. TIMBERLAKE. Good morning, Chairman Kohl, Mr. Martinez and Committee Members. It's my pleasure to be with you today to talk a little bit about the future of long-term care. In particular what Wisconsin has been doing over a decade or more to really lead the way in this area.

I also would like to take the opportunity to thank you, Chairman Kohl, for your support of our innovative "senior care" program which offers affordable prescription drug access for Wisconsin seniors. We look forward to a partnership with you and with the new Administration to make sure that that program continues.

Mr. Hamilton has certainly set the stage for you well in terms of the demographic challenges that are facing Wisconsin, as they are every other state. What I think we have seen in Wisconsin—not only the "community options" program that Mr. Hamilton spoke so eloquently about, but also our innovative Family Care and Family Care partnership and Aging and Disability Resource Center programs, is that we can, in fact, provide more and better care to our frail elders and to people with disabilities.We can do it in a cost effective way by focusing on four really key principles.

One is consumer choice, making sure that individual consumers achieve their desired outcomes. How do they want to live? How do they want to work? How do they want to spend their time? That really is the center of what we try to do for people as we design their long-term care needs.

Second, we focus on access. The "family care program is in fact, a Medicaid state entitlement. It serves all who qualify. In Wisconsin we are well on our way to eliminating the thousands of person long waiting lists for home and community-based services.

Third, Family Care and related programs have an emphasis on quality. We want to make sure that as people are supported in the community that the care that they receive is of the highest quality, that their needs are met, and that we make sure that they are in fact achieving the outcomes that they desire for themselves.

Fourth, Family Care is cost effective. We actually are able to serve more people. We're able to eliminate waiting lists within the confines of our Medicaid long-term care budget which right now accounts for more than half of the dollars that we spend on Medicaid. So while the proportion of spending on long-term care in the Wisconsin Medicaid program is unlikely to change, the way those dollars are distributed is in fact being rebalanced from a heavy emphasis on institutional settings to a much heavier and growing emphasis on community-based settings.

Family Care does all this by combining the dollars that are available to spend on long-term care services and certain health care services like home health care, skilled nursing care where it's needed, mental health services, physical and speech therapy, putting all of those dollars, if you will, into one purse that can then be used to design a care plan for each individual consumer. That care plan is designed with the consumer's engagement and with a multi-disciplinary care team that includes in every case a social worker and a registered nurse. Where the consumer has other needs, other experts are brought into that care team.

So what we find is again, by putting consumer choice and consumer desired outcomes at the center, by bringing that multi-disciplinary care team together, we are able to identify the most cost effective ways of achieving the outcomes the individual member desires. For people who are dually eligible for Medicaid and Medicare, we also have in Wisconsin what we call the “family care partnership” program which takes the Medicaid long-term care services and also takes acute and primary care services offered under Medicare and bundles all of that into a capitated rate that can then be used to provide not only the long-term care services that people need, but also fully integrated care management of their medical needs as well. That similarly is providing excellent support for people with some of the most acute needs in our state.

The front door to all of these services, if you will, is our network of “aging and disability resource centers” that many of you have mentioned. The benefit of these centers in our view is that they really emphasize prevention. So the goal of this effort really is to make sure that we can provide all the long-term care services that people need through the publicly funded system. But a secondary goal, which is just as important, is that we help people avoid needing those publicly funded, long-term care services for as long as possible.

So we want people to remain healthy. We want people to remain independent. We want people to be able to make good choices about their own assets and how they might choose to support themselves.

So anyone in Wisconsin is eligible to come to an Aging and Disability Resource Center to get basic information about long-term care options that might be available to them. To get questions answered about prescription drug benefits, about ways to access good preventive services. They also can have a benefits counseling and assistance in enrolling in the various benefit programs that are available to this population. Then should they be eligible for Family Care or Family Care Partnership the Aging and Disability Resource Center will help them actually enroll in those programs. So we think that further expansion and further support of Aging and Disability Resource Centers would be an excellent focus for this Committee and for the Congress’ work as it considers what to do with the future of Older Americans Act funding.

So as we all know, and I think everyone in the room agrees, the future of long-term care in this country and certainly in Wisconsin is not about the nursing home of the future. It is about the community of the future. It really is a question of how can we make sure that we can provide the right care to each individual consumer in their home, if possible, in another community setting, if possible, while making sure that their health is maintained, and that their independence is maintained to the greatest extent possible.

We, in Wisconsin, under Governor Doyle’s leadership with Chairman Kohl’s support, are very proud to be among the leading states in this area. I thank you very much for the opportunity to speak with you briefly today.

[The prepared statement of Ms. Timberlake follows:]

State of Wisconsin
Department of Health Services

Jim Doyle, Governor
Karen E. Timberlake, Secretary

Written Testimony for the Senate Special Committee on Aging
The Future of Long-Term Care
Presented by Wisconsin Secretary of Health Service Karen Timberlake
March 4, 2009

Mr. Chairman and Senator Martinez, thank you for your invitation to talk about the future of long-term care. As Senator Kohl knows, people in Wisconsin prize their independence and expect to be responsible for their own welfare, especially our older residents -- who experienced the Depression, World War II and the economic boom that followed. These are values that need to inform our public policy. Now in their eighties, one in three of our oldest citizens need long-term care. Every year, another 30,000 people in Wisconsin reach the age of 65; more adults with disabilities are surviving into old age, and the Baby Boom is heading for retirement. At least fifty percent of our Medicaid budget is used for long-term care.

Since the creation of Medicaid and Medicare, states have led the way in the delivery of long-term care. As President Obama and the Congress tackle the huge issues of entitlements and of health care reform, the infrastructure for addressing the needs of an aging population exists within states. In Wisconsin, we are ready for change that improves choice, access, quality and cost-effectiveness.

Our internationally recognized Community Options waiver program showed that people who qualified for Medicaid nursing home care could be supported in their homes and community settings at a lower average cost. Building on this program, previous legislatures and governors invested in a demonstration project called Family Care. I am proud to be introducing Governor Doyle's **21st century model for long-term care,** a statewide entitlement to managed long-term care still known as Family Care, and the companion initiative --Aging and Disability Resource Centers.

Wisconsin has broken down the silos of individual Medicaid services and multiple home and community waivers. Family Care combines funding and benefits for social services and health care. That includes home and community supports for elders and people with disabilities as well as nursing home and related Medicaid benefits in one flexible and comprehensive package.

Putting all of the resources into one "purse" does something pretty amazing: it gives consumers the **choice** of institutional or home care, without delay, when an older person needs help. Previously, an elderly woman who took a bad fall would have the so-called "choice" of a Medicaid nursing home bed immediately, or the promise of home and community care after a long wait. Family Care is a Medicaid managed care entitlement that provides **access** to home care or nursing home care without delay.

Along with Family Care, we also offer Family Care Partnership, a component that combines Medicare and Medicaid funding and benefits for both acute health care and long-term care services. Partnership is particularly valuable for individuals with complex health care needs and disabilities. Both Family Care programs serve elders and people with disabilities with a need for a nursing home level of care. Both programs are built around the expertise of a care team that consists of a nurse, social worker, the consumer and even a family member, seeking cost-effective solutions. Vocational rehabilitation professionals and other experts help those seeking employment.

This approach results in lower monthly costs per member, and lower Medicaid costs – saving an average of $500 per month per person. Managed care organizations (MCOs) receive a monthly capitation payment for each member. MCOs set rates and contract with a network of providers to deliver individual services and supports.

An effective long-term care strategy requires getting good information to the public so people can plan ahead and understand their options. Wisconsin currently has 33 Aging and Disability Resource Centers (ADRCs) organized through county government and the aging network.

ADRCs are the visible one-stop customer service centers for people who are trying to solve problems when they do not know how to obtain critical help. The ADRCs are objective, so people receive unbiased information about assisted living, home care and especially managed care. The ADRCs give free information and assistance, warm and welcoming offices and home visitors who explain options and determine eligibility.

Older people often resist getting help. Independence is primary, as it is for younger people with disabilities. Their goal is to avoid or to exit the nursing home and return home or live in an apartment or assisted living facility that remains connected to community and faith organizations.

For an elderly widow fearful of poverty, the outcome she seeks is security. Her care team will manage all of her services and expenses and take care of her needs, protecting her dignity. The future of long-term care is not about the nursing home of the future. It's about the community of the future, where people who are very old or very disabled can live as much as possible like other people, with the best possible health and mobility.

Family Care Partnership helped Alyce and Earl stay in the farmhouse where they have lived for 60 years in western Wisconsin. Alyce has diabetes, and Earl has increasing memory loss. They both have a lot of medications and they are both hard-of hearing. With the right amount of home help, medical monitoring and an emergency response system, they can look out for each other in the place they know best.

We know a person-centered approach can work within a managed care framework. Brining it to scale for 55,000 people in Wisconsin is a challenge. We are serving more people without increasing our Medicaid costs (in 2005 dollars.) And that requires putting in place business systems, data collection and quality oversight sufficient for a $2.5 billion program serving our most vulnerable citizens. It means actuarially sound capitation rates, and regulatory partnerships with the between the department of Health Services and the Insurance Commissioner. We offer these citizens **cost-effective** solutions to their problems, and maintain quality. We are saving money in order to expand services and end wait lists, and that requires sound fiscal management at the state and local levels. Our managed care organizations are either regional public entities created by county governments, or non-profits with over a decade of managing care in the state. Their credibility overcomes the common mistrust of managed care, especially among older people.

Long-term care must be a central issue of health care reform and entitlement reform. We can offer the best care to vulnerable people within a cost-control framework. I urge you to look at Family Care and Aging and Disability Resource Centers as the model for a national reform.

The CHAIRMAN. Thank you very much, Ms. Timberlake. Now we turn to Ms. Benson.

STATEMENT OF HOLLY BENSON, SECRETARY, FLORIDA AGENCY FOR HEALTH CARE ADMINISTRATION, TALLAHASSEE, FL

Ms. BENSON. Thank you, Mr. Chairman, members, Senator Martinez. Thanks very much for the invitation to join you today. Ensuring access to quality care and empowering seniors with tools to manage their care have long been priorities in Florida. On behalf of Governor Crist, I would like to thank you for your partnership in our efforts.

Today I've been asked to give you an overview of several programs in Florida, the Cash and Counseling Program, the Nursing Home Diversion Waiver and the PACE Program. The flexibility offered by these programs has served Florida well. It has allowed us to meet the needs of a diverse range of beneficiaries.

Senator Martinez put the Florida problem in context. We're home to 18.3 million residents. Seventeen percent of our population is 65 or older as compared to 12.6 percent of the Nation as a whole.

We serve 2.3 million Medicaid beneficiaries. Fifteen percent of them are 65 or older. They account for 27 percent of our expenditures.

In order to meet the needs of the most vulnerable, Florida sought several waivers. Our goal in seeking these waivers was to empower Medicaid beneficiaries to have more control over their care. Provide them with the most appropriate and better coordinated care. Use taxpayer's resources most responsibly.

The first program I'd like to discuss is the Cash and Counseling Program. This program gives consumers who qualify for home and community-based assistance with a personal care monthly allowance that they may use to hire workers and purchase care related goods and services. The pilot began in 2000 as a Robert Wood Johnson grant and now serves over 1,100 people.

Mathematica Policy Research Institute conducted an independent evaluation of this program and they made a number of findings. But one of them is particularly important. Treatment group members those who purchased their own services were more likely than control group members to have their care needs met, to be satisfied with their care, and to report that the program had greatly improved their lives. This program has been successful in empowering our beneficiaries, increasing their satisfaction and containing costs. We're in the process of applying to expand enrollment in the waiver.

The second program I'd like to discuss is the Nursing Home Diversion Waiver. It is broader than the Cash and Counseling Waiver and is designed to provide frail elders with an alternative to nursing facility placement by offering coordinated acute and long-term care services to frail elders in a community setting. Under this program, applicants 65 and older who are dually eligible for Medicaid and Medicare Parts A and B and who meet certain facility criteria, can choose to continue living in their own homes or in community settings such as an assisted living facility.

The waiver provides case management, for acute care and long-term care services. All participants select a case manager who helps them develop a care plan with a nursing home diversion provider. These service providers are managed care organizations that are approved for each county.

Florida's Office of Program Policy Analysis and Government Accountability reviewed the diversion program and found that the program successfully delayed participants entering nursing homes. It also found that participants who entered a nursing home for an extended stay had shorter stays on average than similar non-waiver clients.

The final program that I'd like to discuss is the program of all inclusive care for the elderly, which I'll refer to as the PACE program. This program is a capitated benefit that features a comprehensive service delivery system and integrated Medicare and Medicaid financing. Within the capitated rate, providers have flexibility to deliver all services that participants need rather than being limited to those that are reimbursable under the Medicare and Medicaid fee-for-service systems.

This program allows beneficiaries to continue living at home while receiving services rather than being placed in a nursing home. PACE organizations provide primary care, social, restorative and support services for Medicaid and Medicare-eligible individuals aged 55 and older who meet nursing home level of care criteria. PACE programs provide social and medical services primarily in an adult day health center supplemented by in-home and referral services in accordance with the participant's needs.

All Medicare and Medicaid services must be available, including personal care, acute care services, recreational therapy, nutritional counseling, meals and transportation. The services also include adult day health care, home care, prescription drugs, nursing home and inpatient care.

PACE, nursing home diversion and consumer directed care represent three of the ways that we have used the flexibility you have granted us to meet the needs of our Medicaid beneficiaries. Through these programs we have allowed beneficiaries to design benefit packages that are more tailored to meet their needs and that are better integrated. We have allowed more beneficiaries to receive care in their homes and institutional settings. We've increased consumer satisfaction and we have not increased costs to taxpayers.

Thank you, Mr. Chairman, Senators.

[The prepared statement of Ms. Benson follows:]

Mr. Chairman, Senators, thank you for the invitation to address you today.

Ensuring access to quality care and empowering seniors with tools to coordinate their care have long been priorities in Florida, and on behalf of Governor Crist, I would like to thank you for your partnership in our efforts. Today I have been asked to give you an overview of several programs in Florida: the Cash and Counseling program, the Nursing Home Diversion waiver, and the PACE program and to make some recommendations on ways we can continue to foster and grow successful partnerships like these. The flexibility offered by these programs has served Floridians well and has allowed us to meet the needs of a diverse range of beneficiaries.

To put the Florida perspective in context, we are home to 18.3 million residents. 17% of our population is 65 or older as compared to 12.6% in the nation as a whole; this is the highest proportion of elders among all states. We serve 2.3 million Medicaid beneficiaries. Residents 65 and older represent 15% of the Medicaid population but account for 27% of the expenditures. We spend approximately $2.3 billion annually for nursing facility care and $1.2 billion on home and community based services which serve frail elders, disabled adults, and individuals with developmental disabilities.

In order to meet the needs of these most vulnerable, Florida has sought several waivers. Our goal in seeking these waivers was to empower Medicaid beneficiaries with more control over their care, provide them with the most appropriate and better coordinated care and use taxpayers' resources most responsibly.

The first program I'd like to discuss is the Cash and Counseling program. This program gives consumers who qualify for home- and community-based assistance with personal care a monthly allowance they may use to hire workers and to purchase care-related goods and services. The program began as a pilot under a Robert Wood Johnson Foundation grant in 2000 and currently serves 1142 people in three populations: adults and children with developmental disabilities; frail elders; and adults with physical disabilities, including brain and spinal cord injuries.

Florida's program is the most far-reaching of all states' consumer directed programs, in that it gives consumers a monthly allowance based on all of their home and community based services, rather than just personal care. Our frail elders, for example, manage 27 services.

Mathematica Policy Research, Inc. conducted an independent evaluation of this program. They made a number of findings, and their key findings included the following:

- first, treatment group members were much more likely than control group members to:
    - have their care needs met,
    - be very satisfied with their care (as measured by satisfaction with quality of care and caregivers' reliability, attentiveness, and behavior), and
    - report that the program had greatly improved their lives;
- second, despite initial concerns about safety and quality of care for the treatment group, they did not suffer any more care-related health problems than the control group;
- third, the program does not save money but is budget neutral; it provides higher levels of consumer satisfaction at the same price as traditional services; and
- finally, they found that the program does not work for everyone. Many consumers are not able or willing to take on the tasks of hiring and firing workers

> and overseeing the financial aspects of the program. Therefore, this should always remain an option but should never become a mandatory program.

We believe these results show that the program can be successful, and we are in the process of applying to expand enrollment in the waiver. This program has been successful in empowering our beneficiaries, increasing their satisfaction and containing costs.

The second program I'd like to discuss is the Nursing Home Diversion program. It is broader than the Cash and Counseling program and is designed to provide frail elders with an alternative to nursing facility placement by offering coordinated acute and long-term care services to frail elders in the community setting. Under this program, applicants who are 65 and older who are dually eligible for Medicaid and Medicare Parts A & B and who meet certain frailty criteria can choose to continue living in their own homes or a community setting such as an assisted living facility.

The Medicaid Nursing Home Diversion waiver provides case management, acute care and long-term care services to eligible participants. All participants select a case manager and a Nursing Home Diversion provider. The service providers are managed care organizations that are approved for each county. The case manager develops an individualized care plan to be used in coordinating their medically necessary acute and long-term care services.

Long-term care waiver services include adult companion, adult day health, assisted living, case management, chore, consumable medical supplies, environmental accessibility and adaptation, escort, family training, financial assessment and risk reduction, home delivered meals, homemaker, nutritional assessment and risk reduction, personal care, personal emergency response systems, respite care, occupational, physical and speech therapies, home health and nursing facility services.

Acute-care waiver services include community mental health services, dental, hearing and visual services, independent laboratory and x-ray, hospice. Services such as inpatient hospital and outpatient hospital/ emergency, physicians, and prescribed drugs are paid for by Medicare, but the Nursing Home Diversion case managers help the participants coordinate these services to ensure continuity of care.

The nursing home diversion providers are responsible for Medicare co-payments and deductibles for services to all individuals enrolled in this program.

Florida's Office of Program Policy and Government Accountability reviewed the diversion program and found that the program successfully delayed participants from entering nursing homes. Frail elders participating in the program were more likely to delay entry into nursing homes than similar frail elders who were not enrolled in any Medicaid waiver programs. In addition, Nursing Home Diversion participants who entered a nursing home for an extended stay had shorter stays, on average, than similar non-waiver clients and were more likely to leave the nursing homes and return to their homes or residential settings to continue receiving community-based care.

The final program I'd like to discuss is the Program of All-Inclusive Care for the Elderly, which I'll refer to as the PACE program. This program is a capitated benefit that features a comprehensive service delivery system and integrated Medicare and Medicaid financing. Within the capitated rate, providers have the flexibility to deliver all services participants need rather than be limited to those reimbursable under the Medicare and Medicaid fee-for-service systems.

We offer this program in two areas of the state, and for our beneficiaries, this program allows them to continue living at home while receiving services rather than be placed in a nursing home. PACE organizations provide primary care, social, restorative and supportive services for Medicaid and Medicare eligible individuals age 55 and over who meet nursing home level of care criteria. PACE programs provide social and medical services primarily in an adult day health center, supplemented by in-home and referral services in accordance with the participant's needs. All Medicare and Medicaid services must be available, including personal care, acute care services, recreational therapy, nutritional counseling, meals and transportation. The services also include adult day health care, home care, prescription drugs, nursing home and inpatient care.

PACE, Nursing Home Diversion and Consumer-Directed Care represent three of the ways that we have used flexibility in meeting the needs of our Medicaid beneficiaries. Through these programs we have allowed beneficiaries to design benefit packages that are more tailored to meet their needs and that are better integrated, we have allowed more beneficiaries to receive care in their homes than in institutional settings, we have increased consumer satisfaction, and we have not increased costs to taxpayers.

Long Term Care Insurance Partnership Program

- The majority of Floridians ages 45-plus do not understand long term care coverage or costs. (*source: AARP, The Costs of Long-Term Care: Public Perceptions Versus Reality in 2006; December 2006.)*
  - 74% of Floridians underestimate or don't know how much nursing homes cost on a monthly basis.
  - 54% incorrectly believe Medicare will pay for a long-term nursing home stay.
- The Long-Term Care Insurance Partnership Program seeks to alleviate the financial burden of long term care services on the state's Medicaid program by encouraging individuals to purchase private long-term care insurance.
  - In return for purchasing partnership insurance policies, if they later exhaust the benefits of the policy and apply for Medicaid long term care services, they get to keep more of their assets than normally would be allowed when qualifying for Medicaid.
  - One dollar of the policyholders' assets will be disregarded for every dollar of long term care insurance benefits paid out under the policy. (E.g., If an applicant received $100,000 in benefits from their partnership insurance policy, he would be able to keep $100,000 in assets on top of the normal limit of $2000 in assets and still qualify for Medicaid.)
- Florida implemented its LTCPP January 1, 2007.
- In the following 18 months, over 15,000 Floridians either obtained partnership policies by purchasing new policies or exchanging older policies for partnership long-term care policies.
- Prior to the program's implementation, 465,800 Florida residents were covered by long-term care insurance. Thus, the partnership program represents a relatively small proportion of total long-term care coverage for Florida residents.
- Several obstacles could affect the program's success, including a lack of public awareness about the need for long term care coverage, lack of knowledge about the partnership program, and the high cost of long-term care insurance.
- Recommendations:
  - Congress could fund a national campaign to promote awareness of the need for people to plan for long term care needs, including purchasing LTC insurance . A national LTC awareness campaign should explain individuals should contact their state government to find out if LTCP is offered in their state.
  - Consider a tax break for individuals who purchase LTC partnership policies, with larger tax reductions targeted to low and middle income individuals.

Congressional Action that would help FL's Efforts to Improve Long Term Care: Sharing savings between Medicare and Medicaid

- People who are dually eligible for Medicare and Medicaid are some of the highest users of health and long term care services
- Medicare pays for medical services such as hospitalization, physician services, and prescription drugs.
- Medicaid pays for home and community based long term care services such as assistance with bathing and dressing, nutrition counseling, meals on wheels, adult diapers, home modifications, and adult day health care.
- When Medicaid-funded long term care services are well-coordinated, they have the potential to prevent the need for more expensive services, like hospitalization, nursing facility care, and skilled in-home nursing care. Some examples:
    - By providing diapers and assistance with bathing for an elderly person who cannot care for themselves, we can prevent skin breakdown and decubitus ulcers, which can require hospitalization, a nursing facility stay, and in-home nursing care by a registered nurse.
    - By installing grab bars in bathrooms, we can prevent falls that lead to broken hips or head injuries, which can require hospitalization, a nursing facility stay, and in-home nursing care by a registered nurse.
    - By ensuring proper nutrition through home-delivered meals and nutrition counseling, we can prevent increasing frailty and susceptibility to serious illness.
    - Adult day health care provides daily health monitoring such as blood sugar and blood pressure checks, and review of medications, which can identify a problem so it can be treated by a physician before it gets out of control and requires hospitalization, a nursing facility stay, and in-home nursing care by a registered nurse.
- Investment by Medicaid in these preventative services can lead to savings by preventing hospitalizations, nursing home rehabilitative stays, and home health nursing. The savings from these interventions, however, primarily accrue to Medicare, rather than to Medicaid.
- We request that Congress direct the Centers for Medicare and Medicaid Services to develop a methodology for sharing such savings with state Medicaid programs.
    - This would incentivize states to better coordinate home and community based care and help states defray the costs of high quality home and community based care.

The CHAIRMAN. Thank you very much, Ms. Benson.

Senator Martinez, would you like to start the questioning?

Senator MARTINEZ. Thank you, sir. I appreciate that very much. I want to thank all the witnesses for the very good testimony you've given us today.

I wanted to just maybe follow up with Secretary Benson and ask you, Secretary, how do you believe that the Federal Government can help to better support your community-based care initiatives through Medicare and Medicaid?

Ms. BENSON. Well, Mr. Chairman you all have done a really nice job of doing that. I think you have heard that we've had a lot of flexibility. These are just some of the programs that we have offered.

Ms. Timberlake talked about some of the home and community-based services. We've seen some great success with that. We have seen that by offering those kinds of services you can also decrease the cost of the Medicaid program.

I think some of our concerns internally are how do we incentivize States to achieve those savings in our home and community-based services and share those savings with the Federal Government. So we look for ongoing partnerships in those efforts.

Senator MARTINEZ. You know I'm intrigued by the program that where you allow a case worker, a case manager, if you will. How is that working? Is that an experience, Ms. Timberlake, that you also have shared in Wisconsin? I mean, that to me seems to be a very, very good way of allowing an individual to have some flexibility in the way they get their care while at the same time keeping costs down.

Ms. TIMBERLAKE. Right. Absolutely. I think one of the common themes that's cutting across all the health care reform discussions including the discussion of long-term care reform is about doing the best possible job of care management and case management.

I think we all would agree that lots of money is being spent. The question is, is it being spent on the right services for people at the right time and in the right setting? So what we have found with Wisconsin's Family Care program and with the Partnership program is that it really is that inter-disciplinary team that works with the individual consumer, and with a family member, if that's appropriate.

As I said, it always includes a social worker and a registered nurse. Because even in the long-term care only side of the equation many of these consumers have health needs that need to be well managed and well addressed. So by putting that inter-disciplinary care team together, by working with that individual consumer, again at the level of goals and of outcomes that are desired to be achieved, the care team can then work through with the consumer what is the most cost effective way of achieving those desired goals.

I'll give you a real concrete example. We had a consumer who was living independently in her own apartment. One day she came to her care team and said she wanted to move into a more expensive assisted living facility.

The care team said well, why is that? It turns out that this consumer had a good friend who had previously resided in the apartment complex who had recently moved to the assisted living facility. She wanted to move there too, to be closer to her friend. The care team said how about if we arrange for transportation for you every day so that you can go and visit your friend. That was perfect for her, it met her needs.

So that's a simple example, an easy problem to solve. Would that they were all that easy, but in fact it's a good illustration of this idea of focusing on the outcomes that the consumer wants and then putting the right people around the consumer to help think through how to get those desired outcomes.

Senator MARTINEZ. Any comment from you?

Ms. BENSON. I think Ms. Timberlake covered it very well. But I think that we've seen in all sorts of health care people generally know what's best for them. One size doesn't fit all.

I mean, I think the Frenchie example was outstanding because frequently we find that our consumers consume less health care if they're given the power to control their care. So I think that we've covered it pretty well, Senator.

Senator MARTINEZ. Thank you. Mr. Chairman, I'll turn it over back to you.

The CHAIRMAN. Thank you. Senator Udall, would you like to make a statement, or ask a question?

Senator UDALL. Thank you, Mr. Chairman. I too want to welcome the panel. Thank you for your very insightful comments.

I did want to acknowledge the leadership of the Committee. This Special Committee on Aging will play an increasingly important role, I believe, as we all do something about getting older every day. I remember, Chairman Kohl, Robert Kennedy when he ran for President. We had been celebrating his legacy given that it was some 40 years ago that he ran for President in the 1968 cycle.

One of the criticisms of him was that he was too young to be President. He said well, I'm doing something about that every day. [Laughter.]

We all find ourselves in that boat. I did want to ask you a question that I think the next panel will also address. Which is when you look at the long-term care insurance world and the incentives that we've tried as a Congress to put in place and that society has tried to put in place, would you give us a grade on how we're doing?

I know that you interact in your various state programs with long-term care insurance policies. Maybe we can work from left to right and start with Mr. Hamilton and move across. Comments you have on ways to provide greater incentives for long-term care insurance and how important that is as one of the elements in a comprehensive policy?

Mr. HAMILTON. With regard to any form of social insurance there are hazards that people are trying to insure themselves against. There are benefits that they're trying to move toward as an alternative. So, one of the challenges for long-term care insurance is, what is it that people would get as an alternative to what they're trying to insure themselves against, and to the extent that people are really focused on being able to maintain themselves in their own homes, the challenge is that in the community system, you've got a disparate array of individualized services that are very difficult to organize. So what's so very important, I think, about what

Secretary Benson and Secretary Timberlake are doing in their states, is actually using the Medicaid program as a foundation to build an organized system.

So what individuals can purchase is not simply a little bit of home health care, a little bit of personal care, a little bit of transportation, but actually a package of coherent services that has the benefit of the case manager approach that Senator Martinez observed. So that there's a coherent package, it can come together, that makes long-term care much more feasible. In the early days of long-term care insurance, the only benefit was nursing home care. The policies didn't sell very well.

But if you've watched the evolution of the long-term care insurance industry you've seen a broadening of the benefit packages, and it's becoming much, much more acceptable to individuals. So, the more of the infrastructure and foundation that the states can create through this partnership with the Federal Government, leveraging Medicaid, the more possible those social insurance models will become.

Senator UDALL. That's helpful. Secretary Timberlake, would you like to comment?

Ms. TIMBERLAKE. The thing I would add to that is what we've seen in Wisconsin is that the sort of myriad of long-term care insurance options that are out there are often very confusing and very difficult for consumers to go through and to make good decisions about. So we need to be careful that just as we want to help people make good decisions about managing their own personal assets over time so that they avoid becoming our customers in the Medicaid program for as long as possible. Similarly, we want to make sure that we're helping them not purchase insurance that in fact they don't need and spend lots of money up front to avoid—as Mr. Hamilton says—a risk that in fact in a cost benefit analysis is not worth it.

So I think that something we can work together on between the states and the Federal Government is making sure that we have very clear information for consumers and a very sort of methodical way to help people think through what those risks really are. What is the range of options for managing those risks and where long-term care insurance fits in that suite of solutions.

Senator UDALL. Thank you, Secretary Benson?

Ms. BENSON. Thank you, Senator. You know that majority of Floridians over 45 really don't understand long-term care coverage. AARP did a survey. They found that 74 percent of Floridians don't have any idea how much nursing home care costs on a monthly basis.

Fifty-four percent assume that Medicare will pay for a long-term nursing home stay. So there's a real lack of information out there. You all worked in partnership with the states to give us the ability to do long-term care insurance partnership programs.

Florida's legislature did the legislation to do that. My agency does that in partnership with the Office of Insurance Regulation. Our system went live in January 1, 2007. But we've only had 15,000 people take up this offer.

I think you know that really in exchange for purchasing these partnership policies, if individuals later exhaust those benefits and apply for Medicaid long-term care services, they get to keep more of their assets than normally they would be allowed to when qualifying for Medicaid. I think all the states see a problem with people spending down their assets in order to qualify for Medicaid. So, you know, while we believe Medicaid is an important part of the safety net, if we can strengthen the private sector, it matters.

Senator UDALL. Yes.

Ms. BENSON. So in terms of what you could do to help the states, I think all states are facing these challenges with budget crunches, although you've just recently made a difference on that issue for many of us. But over the long-term, it will be a challenge.

So there are two things that I think would help. I think for all the states who are trying to encourage individuals to buy long-term care insurance, and then we're all in the campaign, might make a difference. I think in addition, looking to tax credits to help those individuals and incentivize them to purchase long-term care insurance, I think that would make a difference too.

Senator UDALL. Thank you very much, Mr. Chairman.

Thank you.

The CHAIRMAN. Thank you very much, Senator Udall. Mr. Hamilton, Wisconsin as you know is one of 40 states with aging disability resource centers. Is there a model for these centers that all states to follow or are there variants between what can and cannot be done from state to state?

Mr. HAMILTON. There's a variety of models and approaches that states are taking. There's certain common elements, one of which is to ensure that the aging disability resource centers can help organize the information about all of the options available to people. This has been an area of great partnership between the Administration on Aging who are represented here in the front row and the Centers for Medicare and Medicaid services. So the two agencies have combined resources to then partner with states to develop more and more aging and disability resource centers.

At the present time these occur in particular geographical areas. But the goal is to broaden them. So eventually, more states can be on the road that I think Wisconsin is at, which is to have statewide availability of Aging and Disability Resource Centers that are available to people regardless of income or assets.

So, again, it builds that foundation that's available to the private long-term care insurance market as well as the public payers, so that every individual who needs long-term care is able to go to one good environment where they get good, free information about all of the choices available to them. In addition, in a really organized system, those Aging and Disability Resource Centers are interposed in the places of decision-making. Secretary Timberlake can correct me if I'm wrong but I believe that in Wisconsin, no one enters a home and community-based program or a nursing home without the benefit of that good, free information coming from the ADRC.

The CHAIRMAN. Would you like to expand on that, Ms. Timberlake?

Ms. TIMBERLAKE. I think that what we have seen is exactly as Mr. Hamilton has alluded to which is that the ADRCs are serving the entire range of consumers in Wisconsin. So it isn't just people who believe that they are or might become Medicaid-eligible. It literally is any person who has a question about their long-term care needs, and benefits that might be available to themselves or a family member or a friend or a colleague who has a disability that they need some assistance with.

Then at the other end of the continuum, the ADRC is in fact the place where people go through the eligibility determination process if in fact they are eligible for a Medicaid or Medicare-funded long-term care program. So as we have been able to open ADRCs across the state, we really are finding that we're addressing thousands of consumers questions every week. We believe we are doing good prevention as well as connecting people to the programs and services that they're eligible for.

The CHAIRMAN. Thank you. Ms. Benson, would you like to make a comment?

Ms. BENSON. We don't have ADRCs exactly in Florida. We have moved down the path of aging resource centers. You know, getting old and navigating the senior care system is particularly difficult.

I recently read that book, Nudge, that is out on the market that talks about the complexities of navigating Medicare Part D. So you all were great, and said we want to give people choices. But I think that in some states, the choices were more than 50 plans. You know, I had to sit down with my grandmother, and my father is a doctor, and while I'm Secretary of the Agency for Health Care Administration, and it was hard.

I just outlined three programs for you today. But that's just a small sample of what we offer in Florida. So I think everything we can do to make sure we have infrastructure in place to help people make the right choices for them will really make a difference. We appreciate your leadership on that issue.

The CHAIRMAN. Well, we thank you so much, all three of you. You've added a lot to the discussion. We appreciate your coming here. Thank you so much.

Mr. HAMILTON. Thank you.

Ms. TIMBERLAKE. Thank you.

Ms. BENSON. Thank you.

The CHAIRMAN. We will turn now to our second panel.

We're pleased to welcome first Henry Claypool. Mr. Claypool is currently the Washington liaison to the Public Health Institute and a Senior Advisor for Disability Policy to the Administrator of CMS. During his time at HHS, Mr. Claypool played a key role in implementing policies to respond to the U.S. Supreme Court's Olmstead decision and expanding Medicare's coverage of assistive technologies.

Next we'll be hearing from Melanie Bella who is a Senior Vice President of Policy and Operations at the Center for Health Care Strategies. In this position, Ms. Bella leads the organization's efforts to improve the quality of care for people with chronic illness and disabilities. She also serves as a health care advisor to the Kennedy School of Government Innovations in American government awards program. Previously, she served as Medicaid Director for the State of Indiana from 2001 through 2005, where she championed a state chronic disease management program.

Finally, we'll be hearing from Professor Judy Feder, who is currently on the faculty of Georgetown University's Public Policy Department, serving as Dean for three years. She also currently serves the Center for American Progress as a senior fellow. Ms. Feder is one of the nation's leaders in health policy and she's an expert in ways to improve our nation's health system. We thank you all for being here. We'll listen to you first, Mr. Claypool.

STATEMENT OF HENRY CLAYPOOL, WASHINGTON LIAISON, PARAPROFESSIONAL HEALTH INSTITUTE, NEW YORK, NY

Mr. CLAYPOOL. Chairman Kohl, Senator Martinez, good morning. I'm Henry Claypool, the Washington liaison for PHI, which promotes quality care through quality jobs within the elder care disability services delivery system. Thank you for inviting me to testify today to share my perspective on the importance of addressing long-term services and supports in health reform efforts.

My testimony is also informed by my personal experience as a former Medicaid beneficiary and as someone that continues to rely on the supports provided by direct care workers today. Frankly, without the assistance of others with routine and often intimate tasks, I wouldn't be able to be here today, much less work, pay taxes and lead an active life in my community. These services are, in short, are what enable many Americans like me to work and contribute to the nation's economy.

The wages paid to direct care workers likewise spur the economy. Direct care jobs constitute a $56 billion dollar economic engine fueled by personal income that over three million direct care workers spend largely on locally produced goods and services in their community. That is why we believe health reform including long-term services reform must be an integral part of our efforts to restore and revitalize the economy.

Therefore we applaud the leadership of the President, for recognizing that health reform is key to addressing the nation's economic distress and making it a priority in his budget proposal. We urge Congress to ensure that long-term services reform is addressed along with making affordable health insurance available to all Americans this year. If the needs of those who rely on long-term services and supports are not addressed in health reform, it is difficult to see how our country will ever effectively curb the rate at which medical expenses rise.

We believe health reform must include: one, reforms to make more community based, long-term services and supports available to Americans in need. Two, efforts to build capacity and a direct care workforce which provide these critical community living services.

Health reform should strengthen Medicaid long-term services by: one, ensuring that the Federal Government provides enhanced matching payments for long-term services and supports to gradually assume a greater proportion of the costs associated with long-term services. Two, require that states in return provide a certain level of service making it possible for beneficiaries to lead meaningful lives in the community. Enacting the Community Choice Act as part of health reform would be an important step in this direction. [Applause.]

Three, streamlining eligibility rules to make it possible for beneficiaries to have access to community living services when they need long-term services and supports.

Four, creating additional incentives for states to measurably reduce and gradually eliminate service access disparities that currently exist within states, across different groups of beneficiaries and throughout the country.

A needed and complementary measure that should be taken is to create the public insurance program envisioned in Senator Kennedy's CLASS Act. [Applause.]

This program would help individuals and family members safeguard their financial future against the economic devastation and hardships that often accompany the loss of certain functional abilities.

Addressing long-term services program design and financing is only part of the answer. As you've recognized, Mr. Chairman, equal attention must be paid to building and strengthening the workforce needed to provide these services. In order to provide services and supports to an increasing number of Medicaid beneficiaries in the community and develop service delivery systems that are more cost efficient and effective in promoting positive health outcomes we need: one, to improve direct care worker compensation by increasing wages and ensuring access to affordable comprehensive health care for workers.

Two, to upgrade training and advance opportunities for direct care workers by passing the Chairman's proposed Retooling the Health Care Workforce for an Aging America Act, an important next step which PHI is pleased to support.

Three, explore new health management practices that target behavior, habits and daily activities of people with chronic conditions and the direct care staff that work with them, since these individuals often see each other every day. It is likely that with the right resources, consumers and workers together can reshape habits, and promote more healthy lifestyles.

Mr. Chairman, I appreciate the opportunity to testify and be pleased to answer any questions.

[The prepared statement of Mr. Claypool follows:]

PHI Quality Care THROUGH Quality Jobs

349 East 149th Street, 10th Floor ■ Bronx, NY 10451
Tel: 718.402.7766 ■ Fax: 718.585.6852
E-mail: info@PHInational.org ■ www.PHInational.org

Testimony of

Henry Claypool
Washington Liaison
PHI
On
Health Reform in an Aging America
Before the
Special Committee on Aging
United States Senate

March 4, 2009

Chairman Kohl, Senator Martinez and Members of the Committee, Good morning.

I am Henry Claypool, the Washington Liaison for PHI—which promotes *quality care through quality jobs* within the eldercare/disability services system. PHI works with a wide range of providers, consumer groups and labor to strengthen the front-line workforce—Home Health Aides, Certified Nurse Aides, Personal Care Attendants—and with the American Geriatric Society is the co-convener of the new national *Eldercare Workforce Alliance.* My testimony today reflects only the views of PHI, however, and not that of the Alliance.

Thank you for inviting me to testify today to share my perspective on the importance of addressing long-term services and supports in health reform efforts. My comments are also informed by my own personal experience. I am a former Medicaid beneficiary and I continue to rely on supports provided by direct-care workers. I have used this personal experience to inform policy making in various roles within state and federal government. I am acutely aware of the critical role long-term services and supports (LTSS) play in maintaining one's health. I define long-term services and supports as those needed when ability to care for one self has been compromised by a chronic illness, disability or aging. Core long-term services are those that provide assistance in routine daily activities such as bathing, dressing and preparing meals.

I use the term, "long term services and supports" rather than "long term care" for two reasons. First, I believe it better captures what those of who rely on the assistance of others need and want. Second, the term "long-term care" has become synonymous with nursing home or other forms of institutional services. In fact, over 80 percent of people with significant disabilities across the age-span live in their homes or other community-based settings. The number of long-term residents of nursing homes, intermediate care facilities for persons with intellectual and developmental disabilities and mental health institutions has declined dramatically over the past several decades, which requires a shift in how Americans think and talk about this sector of the country's health care system.

I. INTRODUCTION

The nation appears poised to consider—and hopefully enact—comprehensive health reforms to provide health insurance to the nearly 50 million Americans who currently are uninsured as well as another estimated 25 million who are "underinsured." The "underinsured" are made up of individuals who like myself have insurance coverage that is insufficient to meet all of their health care needs. We have an important opportunity in our nation to improve the lives of uninsured and underinsured Americans by better streamlining, organizing, and integrating how we provide health care and related services. The conventional wisdom seems to be that all of the ills of our health care system can be remedied by addressing the issues of the uninsured and bringing about increased cost efficiencies through increased comparative effectiveness research. These are vital and necessary prerequisites for moving forward. However, I do not believe that limiting the scope of the health reform agenda to these issues will be sufficient to meet the challenge facing the American people today.

To truly meet this challenge, I believe we also must rethink and retool how we as a nation design, finance, and deliver long-term services. Health Reform must move beyond making improvements in access to acute care services and embrace interventions that improve access to on-going services and social supports that allow individuals with limitations in activities of daily living to lead better and healthier lives. People who use long-term services tend to be extensive users of health care as well. As such they are a major cost driver of the health care system. We simply cannot achieve efficiencies and cost savings in our health system unless and until we adopt and effectively implement a comprehensive approach to managing their needs.

For example, if one looks solely at Americans with Medicare over age 65, the cost to the program for treating the medical needs of those with functional limitations is three times that of a beneficiary without long-term care needs. If we do not include this population—which consumes a significant share of our nation's health care resources—Congressional efforts to address the growth rate of medical costs is likely to fall far short of its goal.

As with the acute care system, each of the major payers in our health system—private insurance, Medicaid, and Medicare—plays distinct roles in financing and delivering long-term services and supports. Medicare provides limited post-acute care through its skilled nursing facility benefit and its home health care benefit, accounting for slightly less than one-quarter of total long-term care spending. Direct out-of-pocket care spending by individuals and families accounts for 22 percent of spending.

The overwhelming majority of people who need long-term assistance and supports relies primarily on unpaid help from family and friends. This is not only for older Americans but for both children and adults who have significant disabilities as well. When such natural supports are either not present or not sufficient to meet their daily needs, however, many of these Americans and their families must turn to Medicaid. For example, most people who require extensive nursing home stays, or on-going assistance to live in their communities, exhaust their savings and become eligible for Medicaid. As a result, Medicaid is the largest single funding source in the U.S. for both institutional- and community-based long term services. Medicaid now accounts for 40 percent of total long-term services and support spending.

While it is reasonable to ask individuals to bear as much of the cost of their services as possible, we know that long-term service costs can quickly overwhelm most individuals and families. This is especially true of younger adults who have not built up a nest egg to rely on for financial support.

For working aged adults with sufficient resources or employer-sponsored benefits, private insurance can play a role. Some individuals have access to short-term disability insurance which can provide critical support following an injury. A smaller number of Americans have access to long-term disability insurance that provides an income support base for individuals who lose their ability to work due to disability. A smaller number of Americans have purchased private long-term care insurance.

The value of these insurance products varies immensely. However, if designed well and indexed for inflation, they may hold the potential to provide important support for some individuals who, due to disability, need access to long-term services and supports. It may be obvious, but it is important to note, however, that people who have already developed a disability are unable to purchase private long-term care insurance.

I would now like to offer several recommendations on financing reforms to make more community-based long-term services and supports (LTSS) available to Americans as well as approaches for building workforce capacity to meet the demand for community living services.

II. REFORM LTSS FINANCING BY STREGHTHENING MEDICAID AND CREATING A NEW PUBLIC INSURANCE OPTION

A starting point for thinking about how to improve access to LTSS is to recognize that Medicaid is the anchor of our national financing system for these supports and services. As noted above, Medicaid pays for 40% of long-term services spending in the United States and 46% of institutional or nursing home care. Medicaid is intended to assist low-income individuals with very few assets and is not available to everyone who needs LTSS. Individuals must meet both financial and functional eligibility criteria to qualify for these services.

At its inception, Medicaid was not intended to play such a large role in financing and delivering long-term services, but has come to this because of the convergence of a dearth of other financing sources for long-term services, and the high cost of long-term services and supports, which is quickly impoverishing for most Americans.

The Medicaid program makes critical LTSS available to thousands of Americans with disabilities across the age-span that receive life-sustaining support from the program. For example, persons with mental retardation and developmental disabilities rely on Medicaid for supervision and cueing services. Persons with mental illness may need supervised housing or help with medication management. Persons with spinal cord injuries and traumatic brain injuries need environmental modification for wheelchairs and other assistive technology as well as personal care services. Persons with Alzheimer's disease and dementia need long-term services due to decreasing mobility and cognitive functioning that comes with aging. They also rely on supervision and cueing services as well as transportation. And finally, persons with neuron-degenerative conditions need help with personal care.

Medicaid covers both community-based and institutional long-term services and supports, but access to community-based services is often limited as witnessed by the growing number of people on waiting lists for services (332,000 in 2007). Historically, differences in functional and financial eligibility criteria between nursing home and community-based settings have steered people with long-term services needs into institutional settings. This "institutional bias" within the Medicaid program counters consumer demand for greater access to community-based services, and contributes to inequities in eligibility across the states. While Medicaid is effective in helping many people live meaningful lives as an integral part of their community, for many others, some institutional or nursing home services are the only option available when the need of long-term services and supports arises.

Access to Medicaid long-term services should be provided in the most appropriate setting that can meet the needs of an individual, whether in an institution or the community. So long as Medicaid beneficiaries are limited to $2,000 in assets, making financial arrangements for the goods and services needed to maintain a residence in the community will be very difficult, and in many cases only possible with assistance from friends and family members. To accomplish this, asset limits for community-based services must be increased at least to the levels that a spouse is permitted to retain when their partner enters a nursing home. In other words, there must be parity in asset limitations between those seeking to receive nursing home care, and those seeking to receive home- and community-based services.

Another complication created by the institutional bias in Medicaid is that the amount of community-based services that a beneficiary might receive varies from state to state and often within a state. Even though where an individual lives should not have such a significant effect on his or her ability to participate in community activities, attend religious services, seek an education, or pursue vocational goals—unfortunately, for people with Medicaid who need assistance with activities of daily living, this variation in service options is too often the case.

To strengthen our country's financing for LTSS and increase the availability and accessibility of community living services, I recommend that Congress work with President Obama to enact comprehensive LTSS reforms such as those envisioned in the Community Choice Act and the CLASS Act

1. Advance the Community Choice Act

As you know, Senator Harkin has long sponsored legislation that would address the institutional bias in Medicaid and give those in a need a real choice of community-based or institutional services. The most recent iteration of this legislation- the Community Choice Act - would advance this vital aim by providing states with additional federal resources to make community living services a mandatory part of the Medicaid benefit. In so doing, it would offer people that need such assistance a real choice between living in an institution or their community—enabling states to better meet their civil rights obligations under the Americans with Disabilities Act to provide people with disabilities with services - including Medicaid LTSS - in the most integrated setting appropriate to their needs.

The cost to the federal government associated with this proposal has been cited as a barrier to its enactment in the past. There is evidence, however, that the original estimates relied on assumptions that are now out-dated. By using recently compiled data regarding states' spending on personal assistance services, a more refined estimate from the Congressional Budget Office may allow policy makers to better weigh the benefits associated with allocating resources toward making access to community-based personal assistance services an entitlement

If the estimated cost of the Community Choice Act continues to discourage legislators from adopting this approach to address the need to make more community-based personal assistance services available through the Medicaid program, an alternative approach should be included as part of health reform. Such provisions could include providing financial incentives to states to increase the availability of community-based personal assistance services and supports over a five- to ten-year period. The federal government could establish a series of annual benchmarks to set a target for each state to measure progress toward providing a level of personal assistance services that would support an increased number of beneficiaries to live in their homes and communities.

Providing, for example, a states with a modest increase in their FMAP over a prolonged five- to ten-year period could help advance four key objectives:

- It could help states to measurably reduce and gradually eliminate service access disparities that currently exist within states, across different groups of beneficiaries, and throughout the country.
- It could provide states with a federal funding commitment to expand access to such services and to sustain such access even during one or more economic downturn. This is necessary to address the chilling effect that the countercyclical nature of Medicaid has upon state policy makers' decision-making that affects community living services in both good times and bad.
- It could provide states with the time they require to rebalance their LTSS systems and begin to realize some of the cost efficiencies and savings that can result from doing so.
- Such an approach also could provide the states and the federal government the time needed to experiment with and arrive at a consensus on what a fair and sustainable division of labor and funding responsibility for Medicaid LTSS should be.

States' participation in such a program could be voluntary. However, if a state refused to participate or take good-faith effort to make meaningful progress in rebalancing its LTSS system, it could be compelled to comply with the integration requirements of the ADA and the Olmstead decision.

2. The CLASS Act

Another important component of health reform should be the inclusion of Senator Kennedy's Community Living Assistance Services and Supports (CLASS) Act. Designed as a program that would pay for itself through premiums, the CLASS Act would allow Americans to enroll in a broad-based public insurance program to prepare for the eventuality that they might experience an inability to perform certain activities of daily living. This program would help individuals and families safeguard their financial future against the economic devastation and hardships that often accompany the loss of certain functional abilities.

Employed individuals would pay monthly premiums; there would be a vesting period; and there would be no exclusions based on health or disability status. People would be eligible for cash benefits based on functional need - not diagnosis. Benefits could be used to purchase assistance based on the individual's and family's circumstances. This insurance plan would provide access to long-term services and supports without the need to "spend down" to become eligible for Medicaid; as a result, beneficiaries would not need to become impoverished for life to have their needs met.

The CLASS Act would have the added effect of slowing the demand for Medicaid services by the number of Americans that were able to meet their needs with the distributions from this program. Individuals could supplement their coverage with private insurance, if desired. If enacted, this program could eventually help thousands of Americans take steps to close crucial gaps that currently exist in the nation's health care system. Acting now will make this an option in the not too distant future.

III. BUILD LTSS WORKFORCE CAPACITY

Addressing long-term care program design and financing is only part of the answer. As you have recognized, Mr. Chairman—and as underscored in the Institute of Medicine's 2008 report, *Retooling the Health Care Workforce for an Aging America*—equal attention must be paid to building and strengthening the workforce needed to provide these services. Thank you for your leadership on matters related to the direct care workforce. We also appreciate your efforts, along with Senator Wyden, to include investments in our nation's direct-care workforce in the Economic Recovery legislation.

More specifically, your legislation, the Retooling the Health Care Workforce for an Aging America Act, originally introduced last December and reintroduced at the beginning of this Congress, would address a number of issues confronting the home- and community-based workforce today. PHI is pleased to support this legislation.

As you therefore well know, Mr. Chairman, the eldercare/disability services workforce is an invisible giant. Many do not recognize just how large this workforce is. According to PHI's analysis of data from the U.S. Bureau of Labor Statistic, the direct-care workforce—which includes home health aides, personal care aides and certified nurse aides among others—now numbers 3,000,000, and demand for these jobs is projected to grow to 4,000,000 by the year 2016. At 4,000,000 workers, this workforce will outnumber teachers who educate our youth; nurses; and law enforcement and public safety officers.

Two direct-care worker occupations in particular—Personal and Home Care Aides and Home Health Aides—are expected to be the second and third fastest-growing occupations in the nation, increasing at rates of about 50 percent from 2006 to 2016.

As our country invests in providing greater choices for receiving eldercare/disability services and expanding the availability of community-based services, we must support the workforce to meet the growing demand this creates. I have called for an enhanced federal financial effort to end the institutional bias in Medicaid but ***a complementary effort by the federal government must be extended to address the workforce capacity challenges that our nation faces in the realm of LTSS.***

Further we must recognize that the direct-care workforce—deployed in hundreds of thousands of homes and tens of thousands of facilities around the country every day—is a tremendously valuable, yet underutilized, asset in our health care infrastructure. We absolutely must seek ways to leverage this resource toward our reform goals of improving access, promoting quality, increasing efficiency, and controlling costs.

In order to provide services and supports to an increasing number of Medicaid beneficiaries in home- and community-based settings—and to develop service delivery systems that are more cost efficient and effective in promoting positive health outcomes—our country must make advancements in three areas:

1. Improve direct-care worker compensation
2. Upgrade training for direct-care workers
3. Explore new health management practices that target behavior/habits/daily activities of people with chronic conditions and the direct care staff that work with them.

1. Improve direct-care worker compensation

Our long-term care system faces a huge recruitment and retention challenge - one made more difficult by the poor quality of many direct-care jobs. In 2007, most direct-care workers earned just over $10 an hour. This is only two-thirds of the median wage for all US workers, which is about $15 an hour. With wages this low, it should come as little surprise that over 40 percent of direct-care worker households rely on some type of public benefit such as Medicaid or food stamps in order to make ends meet.

But not all direct-care jobs are the same. Direct-care workers who work in nursing homes generally have a higher hourly wage than their counterparts providing services in the community. In fact, if we look back over the last decade—at a period of time when the federal government and states have been trying to rebalance our long-term care system to provide greater access to community-based services—our payments to workers have gone in the opposite direction. Over the last eight years, when adjusted for inflation, wages for Nursing Aides, Orderlies and Attendants have seen a modest increase in their real wages while real wages for Home Health Aides and Personal and Home Care Aides have actually declined.

Access to health insurance is also a critical concern for direct-care workers. While two-thirds of Americans under age 65 receive health coverage through their employer, only about half of direct care workers have employer-based coverage. Community-based workers are particularly affected. Nearly one-third of home care aides have no health coverage.

Providing decent paying jobs and health benefits for direct-care workers is the key to ensuring quality of life and quality of care for millions of Americans with disabilities and chronic illnesses. Without competitive compensation for direct-care workers, consumers will be forced to go without needed services, and quality of care will continue to be undermined by turnover as direct-care workers leave the field for higher paying less demanding occupations.

Community-based workers support clients with complex service needs—individuals who could only have been served in nursing homes years ago—and most of these workers are doing so without the benefit of on-site support from supervisors or peers. If we truly wish to end the intuitional bias in Medicaid, we must pay workers in the community the same as those who work in institutions. By doing so, we will bring real choice to workers who may prefer to work with people in their homes or other community settings.

Finally, in the area of setting better compensation policies and standards for direct-care workers, policy makers are hampered by a lack of ongoing, reliable state-based information about the wages and benefits that are financed with public dollars. Indeed, most states are unable to identify how many workers are employed in delivering public LTSS. The federal government can play an important role in encouraging states to collect and publicly report a "minimum data set" of information on their direct-care workforces across the full range of eldercare / disability service settings.

2. Upgrade training for direct-care workers

The training that direct-care workers receive is important and needs to be relevant to the worker's experience, knowledge base and responsibilities. Mr. Chairman, as your bill recognizes, our training programs for direct-care workers have not kept pace with the changes in our eldercare / disability service system.

In many states, the only training that is available for direct-care workers is Certified Nurse Aide (CNA) training programs, which primarily prepare workers to assist older adults in nursing homes—and as the IOM report on the eldercare workforce noted, even this CNA training is outdated and should be re-designed to meet the service needs of today's far more complex long-term service and support consumers. In addition, the IOM report called for an increase in the minimum federally mandated training requirements from the current 75 hours to at least 120 hours.

However, even less public policy attention is paid to teaching how to provide services to consumers living in their homes or other community settings, or to younger consumers with disabilities. Training standards for personal care workers vary widely between states, and even between programs within states. In fact, in many places these workers have no training opportunities at all.

Many advocates from the disability community have strong opinions about training and training requirements. This may be due to a negative experience having hired workers who have gone though a poorly designed training course that provided little information on how to interact with a person who has significant disabilities. Bad experiences with poor-quality training have led some beneficiaries, particularly those in consumer directed or self-directed personal assistance programs, to seek the opportunity to train, as well as hire, their own workers.

We submit, however, that best-practice forms of training are now available that prepare workers explicitly for working within a consumer-directed model, and that these, more "relationship-based" forms of training can directly support the aspirations of self-directed consumers to in turn further train, employ and supervise their direct-care workers.

Consistent with the direct-care worker training provisions of your bill S. 245, we must upgrade current training programs and expand their relevancy to a greater range of workers. We can enhance the content of entry-level and advanced training for direct-care workers by identifying the competencies required for workers to provide quality services to long-term care consumers in any setting.

Training would also be improved by developing competency-based curricula designed around a system-wide review of the skills and knowledge needed to provide quality services to address the physical, emotional, and cognitive needs of older Americans and individuals with disabilities. Finally, training should include a greater emphasis on communication and interpersonal problem-solving skills to strengthen service and support relationships, ensure delivery of person-centered services, and coordinate with family caregivers.

3. **Explore new health management practices that target the behavior, habits, and daily activities of people with chronic conditions and the direct-care staff who work with them.**

As I noted earlier, I believe that it is critical that health reforms embrace interventions that improve access to on-going services, as well as social supports that allow individuals with limitations in activities of daily living to lead better and healthier lives. People who use LTSS tend to be the cost driver of the health care system, and we cannot achieve efficiencies and cost savings in our health system unless and until we embrace a comprehensive approach to managing their needs.

The direct-care workforce is ideally positioned to help manage chronic conditions, ensure compliance with medication and health care regimens, and introduce wellness and prevention education, thus resulting in better health status for consumers and lower medical costs for our health care system. Recent efforts to involve home care workers in monitoring the chronic health conditions of the individuals they are serving have great promise as a building block for new disease management practices.

While monitoring certain health statistics (*e.g.*, blood pressure, blood sugar level, adherence to medication regiment) are critical functions that can be performed by direct-care workers, changing the behaviors that bring on many chronic conditions may present the greatest challenge to lessening the impact of these conditions on overall health status. Since the root cause of many chronic health conditions is human behavior, it is important to explore how direct-care workers might support healthier behavior of the people they serve.

By providing a mix of education and modest incentives, direct-care workers may be able to support certain health-related behaviors, and thus certain conditions, that are acquired or exacerbated by poor eating habits, lack of physical activity, and social isolation. For example, providing a direct-care worker with a basket of produce to prepare a meal for their client, along with a video on food preparation, may create a learning experience for both the consumer and the worker.

Since direct-care workers themselves often come from communities where the incidence of certain chronic conditions is high, it may make sense to think of the worker and the consumer as a health dyad where resources could be focused to change behavior and improve health status of the two, together.

In closing, I would like to thank the committee for its efforts to ensure that long-term services and supports are included in health reform. The Americans that rely on these crucial services are often people with multiple chronic health conditions. Without a concerted effort to address simultaneously the acute and long-term services needs of this population, efforts to curb the growth in cost of health care overall may unintentionally result in undermining access and quality within our nation's long-term care system.

The CHAIRMAN. Thank you very much, Mr. Claypool. Ms. Bella.

STATEMENT OF MELANIE BELLA, SENIOR VICE PRESIDENT FOR POLICY, CENTER FOR HEALTH CARE STRATEGIES, HAMILTON, NJ

Ms. BELLA. Thank you, Mr. Chairman, Senator Martinez. My name is Melanie Bella. I'm the Senior Vice President for the Center for Health Care Strategies which is a non-profit health policy organization in New Jersey.

We do considerable work with state Medicaid agencies. One of the main areas of our work has to do with integrating care for complex and special populations. So I'm delighted to be here today to talk to you.

You've heard from Secretary Timberlake about one of the most innovative managed long-term care programs in the country, Wisconsin's Family Care. So I'm going to focus on two other areas of opportunity. One being fully integrated care for dual eligibles and the second being person-centered community-based home and community service programs for individuals.

For many in the field of publicly financed care, myself included, fully integrated care for dual eligibles represents the most important and the greatest policy opportunity for health care reform that we could possibly tackle today. It's been pursued literally for decades with an evolution of programs, starting with PACE and On Lok, going into social HMOs, moving into Medi/Medi demonstration programs, now with the Special Needs Plans that have recently been created.

The problem remains that very few people are benefiting from these types of programs. I want to just tell you a quick story about the type of person that needs this type of program. I'm indebted to a good friend, Bob Master, who runs a program called Commonwealth Care Alliance in Massachusetts which is a fully integrated program. One of his patients, and she's very representative, is a woman named Maddie.

She's 77-years-old. She has diabetes. She has hypertension. She has depression and she suffered from multiple strokes. She has many different caregivers, has frequently been hospitalized and was facing institutionalization in a nursing home primarily because it was so difficult for her and her caregivers to navigate the fragmented system that she receives her care in.

Thankfully, she found this fully integrated program, Commonwealth Care Alliance. Now instead of three separate identification cards, one for Medicaid, one for Medicare and one for her drugs, three different sets of benefits, three different provider networks, she gets all of that in one place.

She has a multidisciplinary care team as Secretary Timberlake talked about. Her wishes drive her care plan. Some of the key components that Henry talked about and because of that, decisions are based on what she needs. She's been able to reduce hospitalizations and stay at home.

So not only is it good for Maddie. It's cost-effective for both the state and Federal taxpayers. We need to get programs like that to scale.

There are only 120,000 people like Maddie in fully integrated programs today. That's in large part because of the difficult financial and administrative challenges that exist between the Medicaid and Medicare programs. However there are many innovative states out there that are making great progress in these areas. I would call your attention to a little chart that shows you ten examples of what states are doing that have fully integrated programs.

I also should mention although the primary driver for this is obviously getting consumers what they need and where they need the services, we're also spending a tremendous amount of money on the fragmented system for dual eligibles. There are only seven million full dual eligibles, out of Medicaid's over 55 million beneficiaries. But they drive 42 percent of cost in total Medicaid expenditures and 24 percent of Medicare expenditures. In 2008 that will equate to about 250 billion dollars.

So there is an imperative to do better for the people we're serving. There's a fiscal imperative to do better than we're doing today.

So what could Congress do? You could dramatically accelerate progress in this area by requiring CMS to test ways to overcome some of the fragmentation in the system. There's a very innovative demonstration underway that North Carolina is pursuing that would address some of the financial misalignments between the two programs. It would be nice maybe even to get out of demo status and to have a certain core set of elements and safeguards in place to help push states along in this arena to fully integrate care while removing some of the barriers for doing so.

I also want to talk about Medicaid's progress in home and community-based services. These actually have gotten to scale over the past 30 years, although more could be done. Development of HCBS is a tremendous example of states serving as laboratories of innovation, if you will.

You've maybe heard of Vermont's program. It's called Choices for Care. It has established different tiers based on people's needs. For some folks nursing home care is no longer an entitlement, but there has been increased access to home and community-based services.

Tennessee recently launched a bold new act to rebalance its long-term care system. Again, all of these efforts share the core features of increasing access to home and community-based services and decreasing institutional care. Small steps Congress has taken in the past including the Money Follows the Person, Real System Change grants and the Long-Term Care Partnership with CMS.

Those things are great. More substantial changes are necessary which might include consolidating waivers, allowing states to manage HCBS services in totality. Modifying some of the outdated payment and benefit structures would allow innovation like this really to blossom across the country.

So I appreciate the opportunity to share some of these ideas with you. I would gladly answer any questions or fill your ears with all sorts of little and bigger changes that could really make a difference in this arena. Thank you very much.

[The prepared statement of Ms. Bella follows:]

CHCS Center for
Health Care Strategies, Inc.

Thank you, Mr. Chairman and Senator Martinez.

My name is Melanie Bella. I am Senior Vice President at the Center for Health Care Strategies, Inc. (CHCS), a non-profit health policy resource center near Princeton, NJ. CHCS has three priorities:

1) to close the gap in the quality of care received by Medicaid beneficiaries;
2) to build the leadership capacity of state Medicaid directors and other key Medicaid stakeholders; and
3) to integrate care for low-income beneficiaries of publicly financed care, especially those with the complex chronic conditions associated with advanced aging and disability.

CHCS promotes innovation, evaluation, and dissemination of best practices in each of these areas and most of our work is in cutting-edge states like Colorado, New York, Pennsylvania, Washington, Wisconsin, and others.

Because Secretary Timberlake has already described Wisconsin's managed long-term care (LTC) program, Family Care, one of the more exciting and innovative programs in LTC nationally, I will spend my time with you highlighting two other major areas of opportunity in caring for those with chronic medical and long-term supports and services needs:

- fully integrated care for the dual eligibles; and
- coordinated patient-centered home and community-based services.

For many in the field of publicly financed care, myself included, integrated care for the dual eligibles represents the single most important opportunity for reforming the current U.S. health care system. It is tantamount to a Holy Grail that has been pursued literally for decades. The first efforts to integrate care for dual eligibles began in the early 1980s with efforts like the On Lok/Program of All Inclusive Care for the Elderly (PACE) program and social HMOs, and eventually the state-based Medicare-Medicaid integration waivers in Massachusetts, Minnesota, and Wisconsin.

While there are gems among all of these programs, after 30 years most remain relatively small in scale. More that 95 percent of the dual eligibles who could benefit from fully integrated approaches are still in various forms of *un-integrated* and *un-managed* care. Even among those who could benefit the most, the highest risk duals with multiple acute and long-term care needs, the percentages in integrated care are truly discouraging. This is the case, although most experts you could bring here to testify would assert that truly integrated care could significantly improve the lives of beneficiaries and reduce the growth in Medicare and Medicaid costs for taxpayers. To underscore that last point, the seven million full dual eligibles (about 18 percent of all Medicaid beneficiaries) consume over 42 percent of Medicaid resources and 24 percent of Medicare resources. That is more than $250 billion in FY2008.

What do I mean by truly integrated care? In its purest form, it is where one entity is programmatically and financially responsible for providing all Medicare and Medicaid reimbursable services. That means both acute care and long-term supports and services as is the case with PACE, Wisconsin's Partnership Program, New Mexico's Coordination of Long-Term Services, Minnesota's Senior Health Options, and a limited number of other model programs. There are a set of core elements in each of these programs:

- Patient-centeredness;
- Hands-on care coordination;
- Direct linkage between primary care and other clinical, behavioral, and supportive services;
- An emphasis on home and community-based services rather than institutional care;
- Performance measurement; and
- Risk adjustment and other ways of aligning financing to incentivize appropriate care.

Each of these elements has been forged and tested in the groundbreaking work being done in the states I have mentioned. I call your attention to the chart attached to my prepared statement that provides more detail on some of the model programs.

As policy makers, I imagine that your major interest is in understanding how to help spread these good works to benefit more than three or four percent of dual eligibles. Under current law, the most promising option, though not "true integration," is to promote virtual integration through Medicare Special Needs Plans (SNPs), wherein dual eligibles enroll in the same managed care organization for their Medicare services and, given a contract between the SNP and the state Medicaid agency, their wrap-around acute *and* long-term care supports and services. In addition to the original Medicare-Medicaid integration states (MA, MN and WI), others like Arizona and New Mexico have made substantial progress along these lines. Even so, these virtually integrated plans are providing a full set of Medicare-Medicaid services to only about 120,000 beneficiaries.

Why are the numbers so low? In part because SNPs are relatively new to seniors and, as well, to state Medicaid agencies. Further, Federal Medicare and Medicaid officials have not been able to overcome many of the countless regulatory and administrative barriers that continue to separate these two programs even when it would be in the interest of both the beneficiaries and federal and state government to do so. With support from the Robert Wood Johnson Foundation and, more recently, The Commonwealth Fund, CHCS has worked closely with Centers for Medicare and Medicaid Services (CMS) and state officials to identify and address these barriers (e.g., ranging from different marketing and enrollment rules to divergent grievance procedures), and hopes to see even greater opportunities for doing so in the new Administration. Finally, SNPs and managed care in general are not prevalent in a number of states and in more rural regions of other states.

True—or even virtual—integration in states without vibrant managed care markets will require alternative, non-SNP based solutions. Under current law, they will also quite likely require running the complicated federal waiver and/or demonstration gauntlet with CMS and OMB. One very exciting proposed innovation, the 646 Demonstration (under the Medicare Modernization Act) in North Carolina, appears to be on the brink of approval. It presents an enormous learning opportunity on a number of fronts, but perhaps most important, it would test a gain sharing arrangement between the federal government and a non-profit entity connected to the state Medicaid agency. What is so significant herein is that it could pave the way for win-win financial realignments between Medicare and Medicaid, and between the federal government and the states. It could even lead to consideration of Medicare contracting directly with states for the risk-based management of all Medicare services for the duals—something that has been proposed under the label, "Medicaid Duals Demonstration," in a number of venues over the past several years.

Congress could dramatically accelerate progress in this arena by requiring CMS to test ways of overcoming the fragmentation of care for the dual eligibles. A reinvigoration of existing demonstration authority could certainly accelerate the pace of change. Or Congress could specifically request that CMS demonstrate progress in replicating "good" fully integrated care models by establishing the appropriate standards and safeguards and working with states to balance front-end funding needs with longer time horizons for achieving budget neutrality.

In the meantime, as I observed at the outset, states that start the ball rolling toward greater coordination of care by creating managed long-term care program's like Wisconsin's Family Care and Arizona's Long Term Care System should be encouraged by both Congress and the Administration. These programs do not get to scale overnight, so facilitating experimentation in the other states like Florida, New York, and Texas is crucial. These states and others are focusing their attention on this issue because the nation's current system of fragmented long-term supports and services is simply not good for beneficiaries or for state budgets.

Finally, it will be no news to the members of this Committee, but I must say that most of the scalable progress made in Medicaid's long-term care programming over the past 30 years is in the arena of Home and Community Based Services (HCBS). In many states, including my home state of Indiana where I served as Medicaid Director for three years, nursing homes still consume the lion's share of the funding. But a recent Kaiser Family Foundation paper reported a very encouraging statistic: 41 percent of Medicaid long-term care expenditures in 2007 were for HCBS, up from only 19 percent in 1995.

The development of HCBS is a tremendous illustration of Justice Brandeis' observation about states as laboratories for innovation. The ground-breaking work of states like WI, KS, OR, and WA, among others, has enabled the nation and frail-elders to shift away from overreliance on institutional care—even to the point of compelling nursing facilities to become more and more home-like, e.g., the Greenhouse model. Vermont, for example, launched its Choices for Care program, which establishes different tiers of need as a mechanism for rebalancing the system to increase access to HCBS services and decrease use of nursing homes. More recently, Tennessee has embraced efforts to expand access to HCBS as part of a fundamental change to its LTC delivery system. It is pursuing a fully integrated, mandatory, statewide LTC program designed to move people out of institutions and into the community.

Across the nation states are experimenting with ways to rebalance their systems; however, much more remains to be done to increase access to high quality, accountable home and community based services. Small policy changes by Congress to encourage the replication of successful past efforts such as Money Follows the Person and Medicaid Transformation Grants would be a significant start. More substantial changes might include consolidating waivers so that a different one (with a different time horizon and different cost effectiveness test) is not required for each group of individuals, allowing states to manage all HCBS services (state plan and waiver) under waiver authority; and modifying some of the outdated payment and benefit policies. One might even imagine a world some day where a waiver is not required for a person to stay at home to receive needed services.

Today, across the country, there are many small pockets of innovation in states that -- out of necessity and ingenuity -- are doing their best to work around administrative and financing hurdles to deliver better and more cost-effective services and supports for those with chronic long-term care needs. But with the myriad of "boutique" programs and with no clear path for long-term care, there is not a strong sense of knowing what kinds of care work best when, where, and for whom. In medical care, an Institute of Medicine report spurred policy makers and clinicians alike to demand that the nation deliver the right care, to the right people, in the right setting, at the right time, and for the right price. It is time for similar expectations to be applied in caring for those with chronic medical and long-term supports and services needs. There is a gold mine of opportunities to improve health outcomes, better people's lives, and curb escalating costs related to fragmented and poorly coordinated care.

Thank you for the opportunity to testify.

The CHAIRMAN. Thank you very much, Ms. Bella. Ms. Feder.

STATEMENT OF JUDY FEDER, SENIOR FELLOW, CENTER FOR AMERICAN PROGRESS ACTION FUND, WASHINGTON, DC

Ms. FEDER. Chairman Kohl and Senator Martinez, it is a pleasure to be part of the hearing you're having on such an important issue; the need for public action to improve long-term care services and supports.

We hear a lot today about the need for health reform as critical to restoring the nation's economic and fiscal health and that is a really good thing. But you know that we can't achieve health or fiscal security unless health and entitlement reform address the need for affordable long-term care. People who need health and long-term care don't distinguish between the two. They need both. Our Medicare and Medicaid programs devote substantial resources as you just heard to people who need both. We've got to fix both our health and long-term care financing systems and delivery systems to promote economic stability for our nation and our families.

Unfortunately, ignorance about long-term care has long impeded effective long-term care policy. The facts are, as you've heard and can see today, that young as well as older people need long-term care, and that even among older people the need for extensive long-term care, extensive and expensive, is an unpredictable, catastrophic risk. Families are giving their all to providing the bulk of care at home that people who need long-term care are receiving.

Contrary to what is sometimes claimed, the problem with today's long-term care system is not that individuals and families fail to take enough responsibility. Rather they just don't have enough to give. That's why we need better public support, support that spreads the risk and the burden of long-term care financing rather than as in our current system, concentrating it so heavily on the people, the individuals and the families, who actually need care.

As you've heard today, we are fortunate in that there are many ways to move forward. We can only do better. So let me give you very briefly four examples. Two focus on the low-income population and improving Medicaid while lowering costs, which we've heard much about this morning. Two would phase in broad public long-term care insurance for the future.

First on my list and on the list of many here today is to assure broader Medicaid support for care at home where people want to be rather than in nursing homes where they don't. There are lots of different proposals to do this in different ways. The Community Choice Act is one such proposal. [Applause.]

Recent research suggests that, once established and accompanied by policies to reduce nursing home use, broad availability of home care through Medicaid programs can actually slow the growth of total spending on long-term care. If supported by Federal dollars, changes in Medicaid can assure better service at potentially lower cost no matter where people live in every state and within states all across the country.

Second on my list, as Melanie has been talking about and affect in both Medicaid and Medicare, is to better integrate acute and long-term care for the Medicaid/Medicare or dual eligibles who depend on both. Dual eligibles are the poster children for what we can achieve in terms of coordinating acute and long-term care to promote better quality, reduce waste and gain greater efficiency in our health care system. Models exist using a single delivery system, as in Wisconsin as we heard earlier.

We can build on and extend those models while remembering, as we've heard this morning, that it's not enough or can be actually not so helpful just to change financing. What we need is to assure that we're developing and supporting delivery systems that are really effective in providing quality care.

For the future I've got two more options. Both would phase in public insurance protection across the income scale to prevent underservice or impoverishment for all Americans. One would add a long-term care benefit to Medicare for the future—phased in, that is not available to current beneficiaries over the age of 60, and prefunded, that is, with contributions today put into a trust fund so that future elderly would be financing their own benefits—paying now to support future needs.

A second option, the CLASS Act, would create a new long-term care program—again starting with the working age population and financed through voluntary deductions from payroll. Unlike Medicare, the CLASS Act would provide a cash benefit, which we've heard about today as well, that would allow people maximum flexibility in using their dollars to meet their needs, supported by good public policies.

Mr. Chairman, Senator Martinez, assuring efficient, adequate and equitable long-term care financing is part and parcel of building our nation's economic future and assuring economic stability. The need to address this problem will only grow as our nation ages and as younger people with disabilities live longer. Living longer is a good thing, if we match that accomplishment with policies that enhance the quality as well as the duration of life.

Given the scope of the demographic changes before us, we cannot consider ourselves stuck with the inadequate long-term care system we have. We should consider ourselves on the ground floor of the long-term care system we want to build. Now is the time—with new national leadership, a powerful need to invest in rebuilding our nation's prosperity, and a new excitement about our nation's and our government's potential, to build a better future—now is the time to confront the policy, political and fiscal challenges of building a better long-term care system.

I applaud your effort to do just that. I look forward to working with you to achieve it. Thank you. [Applause.]

[The prepared testimony of Ms. Feder follows:]

Testimony of

Judith Feder, Ph.D.
Professor of Public Policy, Georgetown University
and Senior Fellow, Center for American Progress
and
Harriet L. Komisar, Ph.D.
Research Professor, Georgetown University

on

Health Reform in an Aging America

before the
Special Committee on Aging
U.S. Senate

March 4, 2009

Chairman Kohl, Senator Martinez, and members of the committee, I am pleased to testify before you today on the need for public action to improve long-term care services and supports. I know you share my view that the nation's economic stability depends on the well-being of its families and that support for people impaired in the tasks of daily life is key to that well-being. Sadly, that support is sorely lacking under current policies.

Both during the presidential campaign and since the election of President Obama, we've heard much about the need for health reform as critical to restoring prosperity for families and the nation's economic and fiscal health. Health reform is not only essential to assuring all of us affordable health care; it is also essential to slowing cost growth in our health entitlement programs, Medicare and Medicaid.

But we cannot achieve health or fiscal security unless health and entitlement reform address the need for affordable long-term care. People with health problems that create both acute and long-term care needs do not distinguish between the two when it comes to finding or paying for care. Both threaten their health and financial well-being. Our current entitlement programs serve people who need both sets of services. About 16 percent of Medicare beneficiaries are eligible for both Medicare and Medicaid ("dual eligibles"), more than half of whom need long-term care.[1] More than a third of Medicaid expenditures are devoted to long-term care services—at home and in the community as well as in nursing homes.[2] We cannot effectively address the needs of people served by these entitlement programs—or their costs—without addressing responsibility for financing long-term care.

Unfortunately, mythology about long-term care has long impeded effective long-term care policy. It is frequently claimed that the need for long-term care only arises when people get old, that it happens to just about everybody, and that it is the responsibility of individuals and families simply to "plan ahead" and take care of themselves or their family members "when the time comes."

Such claims egregiously misrepresent the reality of long-term care needs and the extraordinary commitments families make to address them.

- The need for long-term care is not limited to older people. Of the just over 10 million people estimated to need long-term care in 2005, about four in ten were working-aged adults or children.[3] Simply telling families to "plan ahead" is useless for the millions of people who experience disability at a young age.

- Even among older people, the need for extensive long-term care varies considerably. Among the population turning age 65 today, three in ten are expected to die without

---

[1] Kaiser Commission on Medicaid and the Uninsured, *Dual Eligibles: Medicaid's Role for Low-Income Medicare Beneficiaries*, February 2009; and Centers for Medicare and Medicaid Services, "2003 Section 8. Medicare Dually Eligible Population," *The Characteristics and Perceptions of the Medicare Population,* 2003, http://www.cms.hhs.gov/MCBS/Downloads/CNP_2003_dhsec8.pdf.

[2] Kaiser Commission on Medicaid and the Uninsured, *The Medicaid Program at a Glance,* November 2008.

[3] Judith Feder, Harriet L. Komisar, and Robert B. Friedland, *Long-Term Care Financing: Policy Options for the Future* (Washington, DC: Georgetown University Long-Term Care Financing Project, 2007), http://ltc.georgetown.edu/papers.html.

needing any long-term care.[4] By contrast, one in five will need five or more years of care. Looked at in terms of expenditures, half the people turning age 65 today can be expected to live their lives without spending anything on long-term care; another quarter are expected to spend less than $10,000 (in present discounted value). At the other end of the spectrum, 6 percent can expect to face over $100,000 (in present discounted value) in long-term care expenditures.[5]

- Far from avoiding responsibility for long-term care, it is families whom most people who need long-term care count on for support. Unpaid care provided by family and friends accounts for an estimated 85 percent of the care people are receiving at home.[6] That care comes at enormous cost to overtaxed caregivers, both in economic opportunities foregone and in health burdens associated with caregiving.

  And, despite substantial effort, even extensive family care too often leaves significant needs unmet. The last public survey of unmet need for long-term care found one of every five individuals at home and in need of care going without care they needed—and facing increased risk of serious health consequences as a result: falling, being unable to eat, bathe, or dress, or soiling themselves.[7]

The problem with today's long-term care system is not that individuals and families fail to take enough responsibility. Rather, they simply do not have enough to give. The need for extensive long-term care is an unpredictable and catastrophic risk. Typically, as, for example, in health care, we rely on insurance to "spread" such risks—having a large population contribute to a fund that is then distributed to the minority for whom catastrophic risk becomes a reality. For long-term care, however, instead of insurance, costs are concentrated on the individuals and families of those who use service, backed only by a public program (Medicaid) that finances care—primarily nursing home care—as a "last resort"—only after they have spent virtually all they have.

Despite considerable recognition among experts of the need for better insurance against the risk of extensive long-term care needs, policy action to develop better insurance has been stymied by endless debate about whether our long-term care financing system should be "public" or "private". Such ideological rhetoric obscures the facts. The reality is that we already have a mixed public-private long-term care financing system and that we will always have a mixed public-private long-term care financing system. The real policy choice is whether we want a public-private system that works, or we want to retain today's dysfunctional combination.

We currently dedicate substantial public and private resources to long-term care—but we do not use our resources effectively. Instead of insurance we have a combination of out-of-

---

[4] Peter Kemper, Harriet L. Komisar, and Lisa Alecxih, "Long-Term Care Over an Uncertain Future: What Can Current Retirees Expect?" *Inquiry* 42, no. 4 (winter 2005/2006):335-350.

[5] Ibid.

[6] Mitchell P. LaPlante, Charlene Harrington, and Taewoon Kang, "Estimating Paid and Unpaid Hours of Personal Assistance Services in Activities of Daily Living Provided to Adults Living at Home," *Health Services Research* 37, no. 2 (2002):397-415.

[7] Judith Feder, Harriet L. Komisar, and Robert B. Friedland, *Long-Term Care Financing: Policy Options for the Future* (Washington, DC: Georgetown University Long-Term Care Financing Project, 2007).

pocket private financing (very little private long-term care insurance) and last resort public financing (mostly through Medicaid).

In 2005, we spent over $200 billion in public and private dollars on long-term care supports and services.[8] Three quarters of those dollars were public—about half through Medicaid, which explicitly covers long-term care, and about another quarter through Medicare, which covers long-term care-like services, but for relatively short periods, typically associated with acute illness. But private financial contributions grossly understate the private role in today's financing system—in part because of the enormous contribution of unpaid family care and in part because of the enormous contribution—as a share of income—made by affected families.

No one likes this system. Individuals in need face financial catastrophe, too often do not get care at home where they want it, and, even when they do, too often get inadequate care. Families face overwhelming care-giving burdens. State and federal governments face growing fiscal burdens, leading them to focus more on how to limit what they spend—simply shifting burdens to individuals and families—than on how to build a system that works.

We can and must do better. With current leadership committed to investment in our future, now is the time to exert public leadership to build an effective public-private long-term care system—one that assures sufficient public and private resources to spread risk for people of all ages, supports access to quality care at home as well as in institutions, protects people who need care now as well as in the future, and shares financial responsibility fairly across taxpayers and affected individuals and families.

A better system will require a clearer, more effective public role. Fortunately, we have many ways to move forward. Today I will outline four—drawing on some of the proposals experts developed for our Robert Wood Johnson-funded Georgetown University Long-term Care Financing Project (http://www.ltc.georgetown.edu/), as well as proposals under discussion in the Congress.

The first two options focus on better long-term care services for people least able to protect themselves—low income people eligible for Medicaid. By extending Medicaid support for home and community-based care and improving services for low income Medicare/Medicaid beneficiaries ("dual eligibles"), policy can promote better access to services at potentially lower costs than the current system. Such policy changes are an obvious target for immediate action in the current fiscal environment.

But our current fiscal problems should not obscure the importance of building a long-term care system that goes beyond the low-income population. Now and into the future, reliance on a means-tested program will continue to leave modest and even better-off people of all ages at risk of impoverishment and under-service if they need extensive long-term care.

---

[8] Judith Feder, Harriet L. Komisar, and Robert B. Friedland, *Long-Term Care Financing: Policy Options for the Future* (Washington, DC: Georgetown University Long-Term Care Financing Project, 2007).

The third and fourth options therefore look at proposals for phasing-in broad public long-term care insurance that will spread the risk of needing long-term care across a broad population, assuring access to better support for people who need care.

MORE EFFECTIVE, EFFICIENT MEDICAID LONG-TERM CARE

Extending Medicaid Support for Home and Community-Based Care

First on the list is a proposal to broaden Medicaid coverage of long-term care supports and services at home. We start here for two reasons: first, because as a safety net, Medicaid focuses on people least able to protect themselves, because of limited resources, and second, because evidence suggests that expanding home care in Medicaid can efficiently improve access to needed care where people prefer to receive it—at home, rather than in nursing homes.

Despite its enormous value to people who need help, Medicaid is frequently and legitimately criticized for inadequate support for long-term care outside of nursing homes. Medicaid gives states the primary role in defining the scope of both eligibility and benefits. States vary substantially in their investment in all long-term care services, but particularly in investment in home and community-based care. In 2005, spending per low-income resident in the five highest-spending states ($1,137) was nearly three times the national average ($383) and nearly eight times the average spent in the five lowest spending states ($145).[9] Research at Georgetown shows that differences in state policies have enormous consequences for people who need long-term care. A person who is financially eligible and sufficiently disabled to receive Medicaid services in one state might not be eligible for Medicaid in another and—even if eligible—may receive a very different mix or frequency of services.[10] Further, research on unmet need indicates that states with a broader use of home-based services had a lower incidence of unmet need than states with narrower use.[11] This result is consistent with a large body of research showing that use of paid services eases the burdens of, but does not replace, family caregivers.

While Medicaid's support for home and community-based care has been growing, nursing homes still absorb the bulk of Medicaid's long-term care spending in most states.[12] Medicaid's emphasis on institutions flies in the face of the desire expressed by people of all ages who need long-term care: they would far prefer to remain at home or in the community. Research also suggests that investing resources in home and community-based care not only can provide services that people prefer but over time actually slow the growth in total long-term care spending by reducing reliance on costly institutional care.

---

[9] Judith Feder, Harriet L. Komisar, and Robert B. Friedland, *Long-Term Care Financing: Policy Options for the Future* (Washington, DC: Georgetown University Long-Term Care Financing Project, 2007).

[10] Laura Summer, *Choices and Consequences: The Availability of Community-Based Long-Term Care Services to the Low-Income Population* (Washington, DC: Georgetown University Long-Term Care Financing Project, 2003)

[11] Harriet L. Komisar, Judith Feder, and Judith D. Kasper, "Unmet Long-Term Care Needs: An Analysis of Medicare-Medicaid Dual Eligibles," *Inquiry* 42, no. 2 (summer 2005):171-182.

[12] Enid Kassner et al., *A Balancing Act: State Long-Term Care Reform* (Washington DC: AARP Public Policy Institute, 2008).

In an analysis of Medicaid long-term care spending from 1995-2005, researchers at the University of California San Francisco found that overall long-term care spending grew more slowly in states with extensive, well-established home and community-based care than in states with few such services—actually reducing total inflation-adjusted "non-MR/DD" long-term care spending over time.[13] While support for home and community-based care initially boosted total spending (and served more people), the researchers argue, over time the availability of care at home and policies to control nursing home use actually reduced reliance on costly nursing home care.

Different approaches would expand the availability of home and community-based services in Medicaid in different ways. For example, the *Community Choice Act*, S. 799, introduced in the 110th Congress, would require all states to make home and community-based personal attendant services available as an option to people eligible for Medicaid nursing home services. States would receive enhanced federal matching rate for attendant care services during an initial period, as they developed these programs.

Another approach, proposed in the *Empowered at Home Act,* S.3327, in the 110th Congress, would allow states to extend income eligibility standards for home and community-based care to nursing home and home and community-based services waiver levels (that is, income up to 300 percent of the supplemental security income, SSI, benefit level) and allow people to retain more assets, so they could actually afford to stay in their homes. States could also extend disability-based eligibility for home and community-based care to people whose conditions have not yet deteriorated to a nursing-home-equivalent level of need so they are actually able to manage in their homes.

These changes would overcome restrictions that have limited states' interest in amending their state Medicaid plans (as allowed under the Deficit Reduction Act of 2005) to broaden long-term care services in the community. For states that choose to expand in these ways, the bill would also eliminate states' ability to cap enrollment and waive state-wideness requirements. If states take up the option, these changes could assure far broader availability of home and community-based care in many states. If made mandatory, or funded more extensively by the federal government, people in need of long-term care could be better and more efficiently served in all states.

Improving Service Delivery for Medicare-Medicaid "Dual Eligibles"

A second proposal, similarly aimed at the population least able to protect themselves, focuses on measures to promote more efficient service delivery for acute as well as long-term

---

[13] "Non-MR/DD" long-term care spending does not include spending for services specifically aimed at people with mental retardation and other developmental disabilities (MR/DD). In the analysis, "non-MR/DD" spending consists of nursing home, personal care, home health, and non-MR/DD waiver spending. Stephen Kaye, Mitchell P. LaPlante and Charlene Harrington. "Do Noninstitutional Long-Term Care Services Reduce Medicaid Spending?" *Health Affairs* 28, no. 1 (January/February 2009):262-272.

care for low income older and disabled people who are beneficiaries not only of the Medicaid but also of the Medicare program.

Approximately 8.8 million Medicare beneficiaries, poor enough to qualify for Medicaid, have their acute care services financed by Medicare.14 Medicaid pays the cost-sharing associated with their Medicare benefits and, if they need long-term care, it is Medicaid that pays for their services. Although together the two programs provide a broad set of benefits, except for some state demonstration programs, neither program bears responsibility for coordinating services within or across programs. Neither program, for example, assumes responsibility for assuring support services following a Medicare-financed hospitalization that might prevent a Medicaid-financed admission to the nursing home. And, if Medicaid were to invest in such support and prevent a hospital admission, its administrators often point out it is Medicare and the federal government that would reap the savings from lower hospital spending, while Medicaid and the state would bear the expense for in-home care.

Coordination of acute and long-term care services for dual eligibles has the potential to promote both more efficient use of resources and better quality care. Some models currently exist that use a single delivery system to provide the full range of Medicare and Medicare-covered services, in return for payment from both programs.[15]

For example, in Wisconsin, The Family Care Partnership Program is a voluntary program, available in some regions of the state, for dual eligibles who have a nursing home level of long-term care need. Participants receive integrated care from a health plan that has contracts with both Medicaid and Medicare. The plan receives monthly per-person payments from Medicaid and Medicare for each participant to pay for all services its enrollees receive.[16]

Payment based on capitation, rather than fee-for-service, can encourage efficiency and enable a delivery system to use savings from reduced hospitalizations or other acute-care services to offset costs of coordination and long-term care. However, capitation also can reward an organization that delivers too little service—delivering less but not better care and simply reaping greater profits. Use of capitation rates on the assumption that the result will be greater efficiency can risk harming the very disabled patients coordination is aiming to help.

Efforts to encourage coordinated care must therefore begin with the development and assurance of effective delivery arrangements—not with payment of a capitation rate. Providers and plans can be encouraged to develop those mechanisms through demonstrations and rewarded for reducing unnecessary services with mechanisms that pose less risk than full capitation—for example, the opportunity to share in and reallocate "savings" from lower than projected use of hospital care. Even for a sophisticated organization, payment based on fixed budgets, which depend on the actually delivery of services (of whatever mix), may be preferable

---

[14] Kaiser Commission on Medicaid and the Uninsured, *Dual Eligibles: Medicaid's Role for Low-Income Medicare Beneficiaries,* Fact Sheet (Washington, DC: Kaiser Family Foundation, February 2009).

[15] Center for Health Care Strategies, Inc., "States with Fully-Integrated Care Programs for Dual Eligibles," http://www.chcs.org/usr_doc/ICP_State-by-State_Dashboard.pdf; and David C. Grabowski, "Special Needs Plans and the Coordination of Benefits and Services for Dual Eligibles," *Health Affairs* 28, no.1 (2009): 136-146.

[16] Wisconsin Department of Health Services, "Program Overview," Family Care Partnership Program, http://dhs.wisconsin.gov/wipartnership/2pgsum.HTM.

to payment of capitation payments, which are made whether or not services are delivered. Finally, quality monitoring and beneficiary choice can help assure that delivery systems are actually delivering better value, not simply lower costs.

PUBLIC CORE OF INSURANCE FOR LONG-TERM CARE

Adding a Long-term Care Benefit to Medicare

Medicare's health insurance protection is of enormous value to the seniors and people with disabilities who are its beneficiaries. But Medicare's gaps—especially in financing for long-term care—leave even its beneficiaries at risk of financial catastrophe and inadequate care when their illnesses or impairments create the need for long-term care services and supports.

As we look at reforming our entitlement programs—Social Security, Medicare, and Medicaid—in the face of an aging population, it is essential that we look at the full range of people's financial and health care needs and equitable, efficient ways to support them. Adding a long-term care benefit to Medicare—with a financing stream to support it—is therefore worthy of our attention.

One such proposal was developed for our Robert Wood Johnson-funded Long-Term Care Project by Leonard E. Burman and Richard W. Johnson.[17] The proposal would provide long-term care benefits alongside health benefits through a pre-funded, phased-in, progressively-financed program—in which resources are accumulated in advance of service needs and individuals who earn more, contribute more. The proposal is aimed at the working-aged population, should they become disabled and eligible for Medicare, and the future older population when they become eligible for Medicare.

The proposed Medicare benefit would cover nursing home services and up to 100 hours per month of home care for persons meeting specified disability criteria. Cost-sharing and deductibles would be required, up to a maximum out-of-pocket ceiling and would be subsidized for low-income beneficiaries. In order to allow revenues to accumulate to support the benefit, the new Medicare benefit would not apply to current Medicare beneficiaries aged 60 or older. All individuals under the age of 55 would participate, with individuals aged 55-59 given the option of participating by paying an additional lifetime surcharge. Five years after the program begins, participating Medicare enrollees would be eligible for benefits, and Medicaid would cover the cost-sharing and deductibles for low-income beneficiaries.

The proposal's financing would be designed to replicate the current distribution of long-term care financing across income groups, but to spread it across the full population, rather than concentrate it on users. General revenues currently support Medicaid; the new Medicare benefit would replace most of Medicaid and rely on equivalent general revenues for part of its financing. Current private long-term care spending, the authors show, increases with income, whether

---

[17] Leonard E. Burman and Richard W. Johnson, "A Proposal to Finance Long-Term Care Services Through Medicare with an Income Tax Surcharge," working paper no. 8, Georgetown University Long-Term Care Financing Project, 2007, http://ltc.georgetown.edu/forum/8burmanjohnson061107.pdf.

through Medicaid spend-down for people with low and modest incomes or through self-financing for the better-off. The new Medicare benefit, which would replace the bulk of that spending, would be financed with a surtax on the income tax that similarly varies with income.

The financing mechanisms used to support the proposal stand out in their attention to pre-funding and progressivity. To assure pre-funding, dedicated revenues would be placed in a trust fund, as currently in Medicare. But unlike Medicare, contribution rates would be designed and the trust fund structured to pre-fund future expenses by investing in nongovernmental securities, "so that", in the authors words, "revenues raised would be exactly offset by outlays and could thus not be used to mask budget deficits." The financing mechanism is not only promoted as a mechanism for more equitably and adequately supporting long-term care but also as a means to raise national savings—or to pre-fund future expenses. By establishing and investing the trust fund, it is designed to "improve the nation's ability to cope with the long-run fiscal imbalances that will start with the retirement of the baby boom generation." Essentially, this proposal allows future generations to finance their own benefits—paying now to support future needs.

Adding a long-term care benefit to Medicare builds on and strengthens our existing universal public program for health insurance, and is therefore designed to accommodate an American system. But it is interesting to note that other industrialized nations are moving toward universal public protection for long-term care financing. According to analysis of 19 Organization for Economic Cooperation and Development (OECD) countries this movement does not imply the absence of private obligations (cost-sharing and other out-of-pocket spending) nor does it imply unlimited service or exploding costs.[18] Rather, in general, it reflects an effort to balance public and private financing in a way that relates personal contributions to ability-to-pay and targets benefits to the population with the greatest need for care. Because so many of these nations already have the larger elderly populations that the U.S. is moving toward, their experience can provide important lessons for our design of a more effective long-term care system.

Establishing a Voluntary Public Long-term Care Insurance Program

Another option for broad public insurance protection for long-term care is to create a new program, specifically designed for this purpose. One such proposal is the *Community Living Assistance Services and Supports Act* (*CLASS Act*), S. 1758 introduced by Senator Kennedy in the 110th Congress. This proposal is similar to the proposal for a new Medicare benefit in promoting a broad (if not universal) spreading of risk and in phasing in coverage as its participants age, rather than covering those who are currently elderly or disabled. It differs from the Medicare proposal not simply in creating a new administrative mechanism but in its financing structure and in its offer of a specified cash benefit, rather than the coverage of a defined set of services.

---

[18] Organization for Economic Cooperation and Development (OECD), *Long-Term Care for Older People,* OECD Health Project, 2005.

As introduced in 2007, the *CLASS Act* would provide an initial cash benefit of $50 or $100 per day, depending on disability level, for people to use on non-medical services and supports. Dollar amounts would increase with inflation.

A cash benefit has been advocated—particularly by the working aged disability community—as providing greater flexibility for beneficiaries to tailor services and other purchases to suit their particular needs—including the ability to pay family caregivers, make home modifications, or make other eligible expenditures on non-medical services and supports that make life easier in ways that a pre-specified benefit package might not accommodate. Demonstrations using cash or vouchers within Medicaid suggest the importance of accompanying a cash benefit with information and counseling to help people identify and arrange their hiring or purchases, as well as with arrangements to assure that workers are both qualified and paid adequate benefits.

All employed individuals and their spouses would be eligible to participate in the new benefit, contingent on the payment of a monthly premium (subsidized for low-income participants)—and people who had previously joined could continue to participate if no longer employed. The goal would be to have a person's premium remain constant over time. But the commitment to self-funding would allow premiums to rise if necessary to assure program solvency.

Participants would first become eligible for benefits ("vested") after 5 years of payment. Premiums would be voluntary but deducted from workers' paychecks—with workers' of participating employers automatically enrolled—unless they explicitly opted out. This "opt out" approach has also been applied to employment-based savings programs, and produced substantial, albeit not universal, participation rates.[19]

The cash benefit and voluntary participation of the *CLASS Act*, illustrate the potential for creating an optional, self-funded, phased in, limited long-term care benefit—starting with the working aged population among whom the need for long-term care is relatively rare. Over time the benefit would apply to the very old, who are most likely to need long-term care. Providing a substantial portion of the population, younger and ultimately older, a core of financial protection against long-term care needs, this approach has the potential to spread the risk of long-term needs and assure better access to care.

THE IMPORTANCE OF ACTING NOW

At this time of economic hardship and fiscal stress, many will argue that improving our long-term care financing system is a low priority—that we cannot afford to address financing for long-term care. The facts are that long-term care costs, like health care costs, undermine families' financial security, and that the costs of dual eligibles—especially those who need long-term care—are driving up federal and state expenditures for existing entitlement programs,

---

[19] The Retirement Security Project, *Automatic IRAs: Extending Savings Opportunities to 75 Million More Workers* (Washington, DC: The Retirement Security Project, February 2007).

Medicare and Medicaid. Assuring efficient, adequate, and equitable long-term care financing is part and parcel of building our nation's economic future.

The need to address this problem will only grow as our nation ages. In the next forty years, the population over age 65 will roughly double—growing from 39 million and 13 percent of the population to 80 million and 21 percent of the population. The proportion aged 85 or over, who are most likely to need long-term care, will more than double—from 2 percent to 5 percent—and from 6 million to 21 million people. At the same time, people under age 65 who need long-term care are living longer, with their numbers expected to grow from 4 million to 13 million over the same period.[20]

This is not bad news—having more people living longer is a major accomplishment for our society. We must match that accomplishment with policies that enhance the quality as well as the duration of life. And, given the scope of the demographic changes before us, we do not have to consider ourselves stuck with the inadequate long-term care system we have; we should consider ourselves on the ground floor of the long-term care system we want to build.

Now is the time—with new leadership, a powerful necessity to invest in rebuilding our nation's prosperity, and a new excitement about our nation's and our government's potential to build a better future—to confront the policy, political, and fiscal challenges of building a better long-term care system. I look forward to working with you to do just that.

---

[20] Judith Feder, Harriet L. Komisar, and Robert B. Friedland, Long-*Term Care Financing: Policy Options for the Future* (Washington, DC: Georgetown University Long-Term Care Financing Project, 2007).

The CHAIRMAN. Thank you so much. Alright. Senator Martinez, go ahead.

Senator MARTINEZ. Mr. Chairman, thank you so much. You're unusually deferential for a Chairman, but thank you. [Laughter.]

Ms. Bella, I wanted to ask if you could enlighten us a little more on the case for fully integrated care for dual eligibles. I was very intrigued by some of what you had to say and for coordinated patient centered home and community-based services. It is enticing to consider that these two approaches will help better serve the vulnerable dual eligible population. It might even save money for the taxpayers.

How do you recommend that the Federal Government approach this particular challenge and do you have any solution besides the current waiver system that's in place today?

Ms. BELLA. Well I could go on forever on that. So I'll try to be brief. Really the only option a state has today to do fully integrated care and it's actually virtually integrated is through the Special Needs Plan program created under the MMA. It that allows the state Medicaid agency to contract with one of those SNP plans. That plan is also serving that individual on the Medicare side. So that plan gets both streams of funding and is able to combine the dollars to provide all of the services from Medicaid and Medicare.

While that's an interesting model and some of the plans are very good because they understand this population well, there are a lot of those plans that don't necessarily understand this population so well and/or there are a lot of places across the country where Special Needs Plans will never be an option.

So for example, what I mentioned in North Carolina. North Carolina has decided to start providing care management to its dual eligibles. In the past, North Carolina hadn't done that because any financial benefit from that would accrue to Medicare. The state would be paying for these services but wouldn't be seeing any of the benefit.

In partnership with CMS, North Carolina and the Federal Government have entered into an agreement to remedy some of that financial misalignment. As a result, all of the dual eligibles in North Carolina will get the services that will move toward an integrated benefit. So that's an example of some other alternatives that could be explored for states that are interested, particularly states with rural areas and some provider or plan challenges.

I think at a minimum what you would probably find is consensus on the types of elements you want to see in an integrated care program. That has to do with patient centeredness, the multidisciplinary care teams, strong performance standards, consumer governance, and involvement in the benefit and in the structure of the plans.

Those are elements that you could see would form some structure for what you would want to see in states across the country that Congress and CMS and states could work on in partnership to say these are the things that we expect to see. In return for seeing these we can eliminate some of these barriers or consolidate some of the authorities that it takes today to do some of these things.

In return, again, for putting the bar pretty high at what we expect these programs to look like and for having a core level of accountability in performance standards and measurements and those types of incentives even getting rid of some of the barriers to doing that today. For example, some of these states, New Mexico for example, has a very innovative integrated care program. It had to get two different waivers to do that on the Medicaid side alone.

Those two different waivers have different time periods. They have different financial tests. They require different paperwork. They require showing some cost demonstrations that don't take into account anything on the Medicare side.

So without getting into too much detail, it's some administrative things like that that could be changed that would free up a lot of the inability for states to go forward. But then more broadly and, I think, a bigger vision would be working with consumers of these services, providers of these services, states and the Federal Government to establish those core elements and safeguards and providing incentives for states to implement such programs.

Senator MARTINEZ. Just to follow up. What type of front end funding do you envision to move toward a goal like budget neutrality for integrated care?

Ms. BELLA. Well part of the challenge today as has been demonstrated especially in some recent articles is, as you know, it costs money up front to get the money back. But until we make those investments we're never going to start getting the money back. So the way the Federal/state match is structured, states may need a little help getting over that initial funding hurdle.

So, for example, I don't think we would be suggesting that the budget neutrality concept would change. But if we're looking at a five-year period, perhaps the Federal Government share is higher in the first years and the states' becomes higher in the fourth and fifth years. So on balance you get the same outcome, but you're helping states who have to spend a dollar before they can get the dollar.

You're helping them get over that hurdle of the initial investment. There are other mechanisms that would allow states to count some of the savings that Medicare might experience through some of these programs for the Medicaid waiver cost effective test as well. So those are two examples.

Senator MARTINEZ. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you very much, Senator Martinez. We're joined today by Senator Wyden from Oregon. Senator Wyden.

Senator WYDEN. Thank you very much, Mr. Chairman. I very much look forward to working with you and our colleague from Florida on this. I'm sorry that I've missed much of what has happened already.

We're down in the Finance Committee talking with the Treasury Secretary on this very subject as well. I think what is so constructive about the leadership of you, Mr. Chairman and Senator Martinez and all of the people who have come here today is this helps ensure that long-term care is not an orphan in this health care reform debate. What has been so troubling about the discussions in the past is you see volumes and volumes written on everything except long-term care.

I'm interested in doing following up on the good work of Chairman Kohl and Senator Martinez are exploring with the three of you some of the ways that we can actually start tomorrow at the Summit. Because we're all going to be at the White House tomorrow focusing on health reform making sure that our hope now of getting long-term care reform into the reform package goes forward. My real question, and perhaps we'll start with you, Ms. Feder, is financing the improvements that are so critical. In the Healthy Americans Act, the first bipartisan universal coverage bill we've had in the history of the Senate, we take two baby steps.

One is we make improvements in the various public programs so that folks who need long-term care have more choices. I think that's critically important—to have flexibility, so if you're seeking adult day care or in-home services that you empower the individual and their families to be able to make those choices.

The second thing we do is on the private side with respect to long-term care insurance. We put in place consumer protections for people who buy these private long-term care policies. A lot of them end up not worth the paper they're written on because inflation eats away any coverage.

Can we take additional steps to make it more attractive to buy these policies? Now you have been at this for a number of years. I want to start with something that really began with somebody that you and the people on this panel admire very much from Senator Martinez's home state and that is the late Claude Pepper's idea.

What Claude Pepper suggested on a number of occasions is starting a model so that people on a voluntary basis could start putting aside money for private, long-term care coverage. Perhaps through pools that would be organized by the government, so that the person who purchased it when they needed it would get more for their money. It would be private coverage.

They would have private choices. But the money would be pooled, so that the older person when they needed it would get more for their money. You've been looking at these ideas for funding long-term care in the past. What about this idea of setting up a voluntary model that people could start setting aside money for at a relatively early age?

Ms. FEDER. Well, Senator Wyden, it's a pleasure to see you today. I appreciate your wanting to highlight long-term care at the Summit tomorrow, so it's not forgotten in the health reform debate. The ideas you've mentioned are important ones.

I have some questions. I would have to look in greater detail at what Senator Pepper actually proposed, although I trust your rendition. Definitely the first part of it makes a great deal of sense, allowing people to put aside resources into a pooled fund. In fact that is the model that is included or embodied in the CLASS Act that Senator Kennedy has introduced.

I think that putting it into a fund and relying then on building a public insurance program has more promise than trying to build private, long-term care insurance. Private long-term care insurance policies are there and will play a role in our system. But we've been calling them new kinds of policies for 20, 30 years and we know from the health insurance market—and looking at long-term care and acute care together helps us—that private insurance is a really risky basis for building a system. It's kind of why in part we're in the mess we're in today in terms of our health insurance system. We're having to stitch it together and make better rules.

So my view is that the voluntary, approach say putting aside of funds and pooling of risk is a very good approach. But that if we want a strong foundation in long-term care, the public insurance system has to be at the core. Then the private insurance comes around it.

Senator WYDEN. Let me get your colleagues into this topic. Ms. Feder goes right to the heart of the philosophical debate here in the Congress. I think it is fair to say that I wouldn't have any Republican sponsors on the Healthy Americans Act if I had tilted this effort to the public side.

What has attracted bipartisan support for the Healthy Americans Act has in fact been that it is largely a private delivery system which of course is what Members of Congress have. In other words, Ms. Feder has made a very good point. It goes right to the heart of this philosophical discussion about what's the right role for government? What's the right goal for the private sector?

But there is a group of people who don't complain at all about their health coverage in this country and that's Members of Congress. They have private health choices. So as we try to grapple about this role of a public/private partnership, Ms. Feder is certainly right that there's an important role for government. We certainly recognize that for low-income people.

How do you all see integrating private coverage and the public role? Mr. Claypool.

Mr. CLAYPOOL. Well, building off Ms. Feder's comments about the CLASS Act, I think having a public insurance program like the CLASS Act really does build a very solid base. If individuals desire greater insurance they could seek a policy to wrap around the benefit that might be available to them should they need the CLASS Act. But it's vital to have a large pool that really is only available through a public program to make sure that we can safeguard, frankly, other Americans from what we're experiencing now in this country.

Unfortunately, people are being economically devastated. A large public program may hold up better under the test that we're currently experiencing. I think Ms. Feder's comments about what we're witnessing in the health care arena also back that up.

Senator WYDEN. The only thing I would say—and let's go to Ms. Bella, is Members of Congress belong to large pools as well. I mean it is possible to have large pools and do that in the private sector. You see it with Members of Congress. I think that's what this debate is going to be all about.

I mean you saw, particularly in the Presidential campaign, the debate about the individual market. I wouldn't send a soul into that broken individual market because you look at the kind of discrimination people face if they've had a preexisting condition or something like that. Nobody is talking about that.

But Members of Congress belong to very large pools. They're in the private sector. They make choices among the various kinds of coverage that they have. As I say, there's a group of people in this country who don't complain a bit about their health care coverage. It's families of Members of Congress, Ava Rose Wyden, 15 months old, William Peter Wyden, 15 months old—pictures available after the hearing on my I-phone. [Laughter.]

They can get health care through a private plan, a private plan. So I just want to go to you, Ms. Bella. We're going to obviously follow up on this and Judy Feder, in particular, is just as good as it comes as it relates to these kinds of issues.

Ms. FEDER. Thank you.

Senator WYDEN. Finding this right niche on the public and private side is going to be key.

Ms. Bella?

Ms. BELLA. I'm not sure how much I have to add to what my colleagues have said. My bias obviously is that you need to have a strong public system. I would argue that all of the markets are broken today.

Senator WYDEN. Sorry, I couldn't hear that.

Ms. BELLA [continuing]. That all of the systems are broken today.

Senator WYDEN. You won't get much disagreement on that.

Ms. BELLA. It is interesting when we look at the foundation for coverage expansion. In this country right now, we're looking at Medicaid. While Medicaid can certainly be shored up it is, as, you know, a vital anchor to the healthcare system. The market fails for some of the folks who need it the most if we rely only on, I think, some of the private choices that you and I might have.

So I guess it's not mutually exclusive, obviously. It has to all be part of a well-functioning system. But at its core again, my bias is that a strong public system is what's going to really give us the foundation we need for those who need it most.

Senator WYDEN. Could I ask one other question, Mr. Chairman? How would you three propose paying for it?

Ms. FEDER. The proposals that are on the table that we talked about, the CLASS Act and the option that I offered this morning from our Robert Wood Johnson Project on a new Medicare benefit, propose different mechanisms of financing. In the CLASS Act it's voluntary deductions from payroll. The future elderly are paying for ourselves, as I said in my testimony.

One other proposal was to redistribute resources whether it's general revenues or other sources now going to Medicaid and other spending to actually fund the benefit for the future, phased in—so that actual resources are built up in advance before the services are needed. I think you will find some promising potential funding mechanisms associated with these proposals.

I can't resist one word about when you were talking about what Members of Congress have and Federal retirees or wives of Federal retirees have. In the health insurance system we absolutely can build on our private insurance system. That is what we've got. When you look at long-term care, as I said earlier, we're on the ground floor. We don't have to accommodate a system that already exists. We can build something that is a public/private partnership—inevitably—but that has public benefits at the core.

Senator WYDEN. You know what it is striking about this is it's almost a question of semantics as opposed to anything else, because what Ms. Feder has just described through the Federal employee system has a role for a public type of function. Because the government is playing a role in ensuring consumer protections and the like, and the people are getting private choices. So to some extent this is really about nailing down the details.

You all have a very good case. I'm just hoping that after 60 years of yakking about the subject and having wonderful people like the advocates we have here in the audience, that this is the time when the health care needle gets threaded. My sense is that, and I've talked with the Chairman and Senator Martinez about this, there's something of a philosophical truce coming about in the country.

Both political parties have been right. Democrats have been right about the idea that you cannot fix this system unless you expand coverage. You've got to expand coverage to stop costs shifting and to meet these unbelievable human needs that we're seeing in areas like long-term care.

Republicans have a valid point about how you can't turn it all over to the government. You can't just have a government-run operation. That is why we're talking about things like the Federal Employee Health Benefit Plan that has a role for government and a role for the private sector.

So you all are doing good work. Senator Kohl and Senator Martinez, you have two of the best allies in the business. Starting tomorrow, starting tomorrow at the Health Care Summit I want you three and the advocates who have come here today to know that we're going to have some advocates at the White House tomorrow prosecuting your case. I'm going to be one of them.

Thank you, Mr. Chairman. [Applause.]

The CHAIRMAN. Well to just sum it up: We'd like to ask all three of you health care reform, long-term care—what are the principles, two or three principles that we must not forget? Who is first? Ms. Feder?

Ms. FEDER. Everybody needs protection. We've got to have quality care. It's got to be affordable to all of us.

The CHAIRMAN. Ms. Bella?

Ms. BELLA. I would say two. Fragmented, unintegrated, uncoordinated systems cost money and are bad for people. The second thing I would say is I would urge you to keep asking yourselves why are we talking about waivers to keep people at home or in their community when it's so easy to go into nursing homes?

I think that's a fundamental question we have to ask ourselves.

The CHAIRMAN. Thank you. Mr. Claypool. [Applause.]

Mr. CLAYPOOL. I would echo Melanie's comments. I really do think we have a challenge in terms of integrating the delivery systems. As long as we keep long-term care separate from acute care, we're never going to be able to tame these costs. We really have to look at people holistically.

Second, I think it does require to answer a question from Senator Martinez earlier an investment on the front end by the Federal Government to make sure that this happens.

The CHAIRMAN. Thank you. Well, the importance of this topic is illustrated by the enthusiasm and the energy that all of you who've traveled to be here with us today have demonstrated. You make it very clear that this is a subject that needs our urgent attention. You can take, I think, a lot of conviction from what you've seen this morning in terms of what our witnesses have said as well as we Senators who are sitting up here have also said. We'll take care of your needs. That's a promise and a pledge that we make to you. Thank you so much for being here. [Applause.]

[Whereupon, at 11:30 a.m., the hearing was adjourned.]

A P P E N D I X

PREPARED STATEMENT OF SENATOR ROBERT P. CASEY, JR.

I would like to thank Chairman Kohl for calling this important hearing on Health Care Reform in an Aging America. For the first time in over a decade the Senate will be taking a close look at the American health care system and enacting reforms to help improve coverage, access, and quality of care for all Americans. Long term care will be an important part of this debate.

Over ten million Americans need long-term services and support to assist them with the activities of daily living. That's 5 percent of the total adult population. The cost of this care is high. A year in a nursing home costs $70,000 on average. Assisted living facility expenses can be $36,000 per year, not including home health care aides who are paid about $29 an hour. These are astronomical costs that our older citizens are not always aware of or able to pay for. We've seen this first hand in Pennsylvania.

The proportion of Pennsylvanians aged 85 and older—those most likely to need assistance in daily living—is growing at a rate 20 times faster than our overall population. We've seen an aging boom that most other states will not see for another 10 to 15 years. We've also helped the 162,000 Pennsylvanians under the age of 60 that need similar assistance. I look forward to working with my colleagues in the Senate to turn dire predictions of financial disaster and human tragedy into a unique opportunity for change.

Last year, the Penn State Center for Survey Research interviewed nearly 3,000 individuals to determine how prepared they were for long-term care. Nearly all believed Medicare will pay for their long-term care expenses. Over half believed they wouldn't need any long-term care services. This research reveals unreasonable expectations that could become a harsh reality when discussed with their families and health care providers.

As we all know, while Medicare provides limited home health benefits after injuries or hospitalizations and some coverage for skilled nursing home care, state Medicaid agencies pick up the tab for 40% of long-term care expenses—and only after personal life savings are depleted. Financial and family pressures all too often result in nursing home placement even though over 90% of older citizens wish to remain in their homes.

For these and other reasons, Pennsylvania has been a leader in federal-state partnerships to help seniors and consumers have more options—and more knowledge about these options—so they can plan ahead with their families. I look forward to hearing more about other state programs and other ideas from our impressive list of expert witnesses, so we can incorporate their work into the Senate's health care reform activities.

US Senate Special Committee on Aging Hearing March 4, 2008

Health Reform in an Aging America

Testimony submitted by Assisted Living Federation of America (www.alfa.org)

Mr. Chairman,

My name is Richard Grimes, the President and CEO of the Assisted Living Federation of America (www.alfa.org). Thank you for giving me the opportunity to submit testimony on health reform in an aging America. My comments today are focused on the need for health reform to address the long term care needs of this nation's elderly and younger disabled citizens.

Currently there are approximately 10 million adults in American who need long term care services and supports. Sixty percent of those adults are over the age of 65. The risk of needing long term care increases with age. By the year 2020 an estimated 15 million Americans will need long term care support and as many as 12.1 million will be over the age of 65.

While Medicaid, Medicare, private insurance and consumers all share in the cost of long term care, nearly half of all funding for these services is through Medicaid. However, there is an institutional bias in the Medicaid system that directs two thirds of all funding to nursing homes versus home and community based settings such as assisted living.

Assisted living is a philosophy of care that embraces choice, independence and the opportunity for seniors to live enriching lives with dignity, respect and privacy. We are convinced that assisted living is popular because of the bedrock principle of choice. And we firmly believe that any long term care reform proposal must also be founded on this principle of choice.

Aging in America has changed. Thanks to advances in pharmacology and health care and the benefits of our affluent society, people are living longer than they ever imagined. The US Census bureau reports that the fastest growing demographic in our nation are those 85 and older. Study after study show that older Americans want to remain in their communities as they age and stay near friends, family and the familiar. Virtually no one wants to go into an institutionalized setting.

Assisted living is the resident-centered alternative to institutional care. More than one million seniors call assisted living communities' home. Our residents are frail seniors who need assistance with activities of daily living and can no longer (or choose not to) live in their family home. Our typical resident is an 85 year old widow. She takes eight to 10 different prescription drugs each day, and her medications enable her to manage chronic health conditions and live in her own room or apartment. She lives surrounded by caring staff and friends and maintains control over her own life, deciding when to go to bed, when to get up, when to bathe and when to eat. Institutional settings do not allow these choices.

ALFA supports the person's decision on how and where to live and receive services. Many of you are grappling with the challenge of caring for aging parents and grandparents. There are many home and community based options._Ideally everyone should have a choice regardless of age or income.

Home and community based settings, such as assisted living, are not only the preferred choice for consumers, but a cost effective choice as well The cost of assisted living is about half as much as skilled nursing home care. Medicaid saves between 50 and 66 percent when a resident can live in an assisted living community instead of a nursing home.

ALFA believes there needs to be a comprehensive integrated long term care solution, that encourages personal responsibility and incentives to encourage individuals of all ages to save and prepare for future long term care needs.

To us, the public policy challenge you face as you consider long term care needs is helping Americans save for retirement and afford the type of housing and care they need as they age. ALFA strongly supports the Community Living Assistance Services and Supports (CLASS) Act which would create a nationwide public insurance program to help pay for Americans with significant functional needs. The CLASS act keeps control in the hands of the individual and guarantees choice in long term care options.

The growth of assisted living, a largely private enterprise, in the last 25 years means that the long term care industry is no longer monolithic and nursing homes are not the only option. An institutional bias in government programs lingers against home and community based settings. That is because Medicaid and Medicare, the twin safety net programs for the poor and aging, were created by Congress long before the private assisted living industry existed in the United States. Indeed, when the prescription drug benefit was added to the Medicare program, it inadvertently charged a co-payment for poor seniors who live in assisted living communities, so called dual eligible recipients of both Medicare and Medicaid. We are pleased that lawmakers are trying to correct that inequity.

We are fortunate to live in a time when the average lifespan is steadily growing longer and the quality of life for older Americans is improving. The advances made since the creation of Social Security during the Great Depression are astonishing. As you grapple with health care reform, we urge you to take the broadest possible look at long term care and make certain your plans give maximum flexibility and choice to aging Americans.

ALFA and its members welcome the opportunity to provide more information to the committee as it considers this challenging topic. We are grateful for the chance to submit this testimony and look forward to working with committee members.

The Assisted Living Federation of American is the largest national association serving companies operating professionally managed assisted living communities for seniors. ALFA is the voice for senior living and advocates for informed choice, quality care and accessibility for all Americans needing assistance with long term care. For more information visit www.alfa.org.

Written Testimony of

Charles W. Gould

Chief Executive Officer, Volunteers of America

Submitted to the Special Committee on Aging
United States Senate

Hearing on "Health Care Reform in an Aging America"

March 4, 2009

I want to thank Chairman Kohl for providing the Volunteers of America with the opportunity to submit written testimony and his leadership in making sure that traditional acute health care costs and the health care costs associated with long term care services and supports are linked in the minds of Congress and the nation. Further, I would like to thank Senator Martinez on his continued work on the "Silver Alert" legislation that would be a useful tool in allowing people to remain in their homes and serve as a vital location system for those seniors in need. Additionally, I would like to thank Senator Wyden for his promise to take that message with him as he attended the White House Summit on Health Care.

Volunteers of America was founded in 1896 by social reformers Ballington and Maude Booth. The purpose of Volunteers of America was and continues to be, "reaching and uplifting" the American people. The Booths pledged to "go wherever we are needed and do whatever comes to hand." In this spirit, Volunteers of America has provided a variety of services to help shelter Americans from the storms of life. The services provided have changed as the needs of society have changed. In light of the anticipated unprecedented growth in the number of older Americans and the resulting strain on existing, traditional resources, Volunteers of America has made a strategic decision to focus its efforts more directly on serving the aging population and those who support them.

Much of the long term services and supports delivery system in the United States is currently designed to accommodate and access Federal and State reimbursement and regulations, rather than provide what the older individual desires or needs to remain independent, and to live in the setting of his or her choice. Demographic and economic storms are gathering which will decrease the government's ability to continue to provide services in the traditional manner. Government funds available for programs are shrinking, while the number of aging individuals is growing at the highest rate in our history.

Responses to a survey recently conducted by Volunteers of America indicate that once a serious illness or disability has occurred, an older person has fewer choices regarding care and housing, and becomes more dependent upon others to make decisions. The results also show that adult children are more concerned about safety when making health care and housing decisions for their parents, while the older people are more concerned about independence and choice when making decisions for themselves. Volunteers of America envisions the development of a senior service program which goes beyond the historic model of aging services, by designing, providing, and coordinating a constellation of services which will give older Americans the opportunity to live productively and with dignity in the setting of their choice. *Aging with Options* is designed in a way that will allow Volunteers of America to reach older people and become a trusted advisor, guide, and resource before a major health event occurs.

Developing the *Aging with Options* program nationally will allow Volunteers of America to leverage gifts and talents which already exist within the organization; will help to create a sustainable and desirable service for our clients and help spread the availability of home and community-based supports throughout the nation. The program will also enable Volunteers of America to better serve our traditional beneficiaries, as age-related issues arise. Volunteers of America is uniquely positioned to offer this program because of our national footprint, our experience in providing services to older Americans, and the passionate commitment of our employees to those we serve.

Services

The heart of the *Aging with Options* program proposed by Volunteers of America is the home of the older American. The definition of home in this program is determined not by the service provider, but by the person who desires services. Home might be a private house or apartment in the community-at-large; a dwelling in a naturally-occurring retirement community; a room or apartment in the home of a relative or care-taker; or an apartment in a low income housing development.

Community Engagement Programs

Many older Americans need help from time to time with issues that are not necessarily health care related. Even a sudden minor illness may make it difficult to get to the store, prepare meals, or walk the dog. Older people who live quite successfully in private homes may be lonely, and seeking socialization. The Community Engagement Programs within *Aging with Options* will be developed to meet those needs. By working with and coordinating existing support programs, and creating new programs where there is an identified need, Volunteers of America will help older people to obtain services they need to remain independent and outside of an institutional setting. Community Engagement Programs may be established in naturally occurring retirement communities, or in the community-at-large.

According to Senior*resource*.com, 27% of older Americans live in naturally occurring retirement communities (NORCs). These are neighborhoods of private homes or apartment buildings into which people moved, and stayed as they grew older. The density of the older population in NORCs makes them attractive venues for starting Community Engagement Programs.

Volunteers of America plans to offer social programs and service coordination to older people, with the purpose of enabling participants to continue to live safely and joyously in their homes. People who wish to participate will be charged a monthly membership fee. In return for the fee, Volunteers of America will provide classes and lectures; cultural activities; wellness and fitness programs; religious services; and volunteer service coordination. Volunteers of America may establish senior centers, in markets where needs are identified. Volunteers of America will work with professional organizations as well as volunteers to ensure resident access to high quality, dependable services. Services to be coordinated include pet care; minor housing repair; yard work; shopping; transportation; household chores; budget assistance; assistance with medical claims management; assistance with transition back to home after hospitalization; computer support services; health screenings; car repair; nutritional services, including education and screening as well as meal delivery; and other health and beauty services. Volunteers of America will collaborate with churches, providing assistance in systematizing existing church-based community engagement programs.

Some services and goods, such as personal emergency response systems or electronic medication dispensing devices, can be provided directly on a fee-for-service basis by Volunteers of America, while others will be provided through organization screened by Volunteers of America, which agree to provide high quality member services at discounted rates. Approved vendors will also agree to participate in a quality assurance program administered by Volunteers of America. The bulk of the funding for the program will come from monthly dues and fees. However, AoA, state, county, local and private grant funding will be sought as well.

It is Volunteers of America's goal to establish Community Engagement Programs in 80 communities within five years, and 160 programs within ten years.

Home and Community Based Services

[1]The Home and Community Based Services program within *Aging with Options* encompasses services related to hands-on health care or assistance with activities of daily living. Services which are included are personal care; medication management; hospice; home health care; home medical equipment; advanced assistive technology; adult day care; mental health counseling; Alzheimer's disease management; assisted living-at-home; and respite care. People who receive home and community based services may also continue to receive services through the Community Engagement Program described above.

The role of Volunteers of America in providing home and community based services will vary by market. For example, in some markets it may be advisable for Volunteers of America to acquire a hospice or private-pay home health care agency, or to build an adult day care/senior center. In other markets or for services not provided directly, Volunteers of America will act as a central repository of information on services which are available, and coordinate and screen services.

There are several categories of home and community based services, including those funded under HCBS waivers in each state, Home Health and Hospice care and in some states, an assisted living model. Each of these funding streams ties to the complex area of Medicaid and Medicare alternatives that states have developed to support people who are aging. The vast majority of these programs serve to divert people from nursing homes and offer seniors the

---

[1] The Economic Crisis and its Impact on State Aging Programs

option to age in place in the least restrictive setting possible. Under federal initiatives like Money Follows the Person, states have been encouraged to rebalance their supports for people who are aging to move from institutional care (nursing homes) to community alternatives. The array of services offered in HCBS programs may include case management, assistance with ADLs, transportation, and various forms of assisted living in community based residential options. The private pay market is also growing as the supports offered are the same for the frail elderly regardless of the ability to pay. Some of the services offered people who are aging in the community are based on health care supports, focusing on diagnosis or an individual's need for medical oversight in order to maintain their independence.

Payment sources for the services vary, including Medicare, Medicaid, private insurance, and private pay. Because of the complexity of service provision and billing at this level of care, it will be critical for a centralized information technology platform to exist as the program is implemented.

It is Volunteers of America's goal to establish 30 home and community-based service programs within five years of beginning implementation of the strategic plan, and 60 within ten years.

Program for All Inclusive Care for the Elderly (PACE)

PACE is designed to allow people who would otherwise be placed in nursing homes to choose to remain in their own homes, with comprehensive supportive services. PACE programs require the support of both state and federal government agencies, and have not been implemented in all states. However, some states which do not support the PACE initiative, do support PACE-like programs, such as Medicare Special Needs Programs for people who have specific chronic illnesses. Volunteers of America has set the goal of establishing 14 PACE or PACE-like programs within five years, and 30 programs within ten years.

PACE is designed to serve Medicare beneficiaries who qualify for nursing home care, many of whom are also Medicaid beneficiaries. PACE is a service program which allows the older person to remain at home, rather than enter a nursing facility. PACE providers receive a capitated monthly payment funded by the federal and state governments, which is intended to pay for every aspect of health care needed by the enrollee. The adult day care center is the hub of the program. Services included in PACE are: adult day care that offers nursing, physical, occupational and recreational therapies, meals, nutritional counseling, social work and personal care; medical care provided by a PACE physician who is familiar with the history, needs and preferences of each participant; home health care and personal care; all necessary prescription drugs; social services; medical specialists as needed; respite care; hospital, nursing home and assisted living care as needed; and transportation. PACE organizations provide services either directly or through contractual agreements. For example, a PACE organization may own an adult day center, and directly employ its workers, including the PACE physician.

The creation of *Aging with Options* will allow Volunteers of America to leverage our organizational gifts and talents; we have a proven track record as a government contractor. *Aging with Options* will allow us to use that expertise, but we will also serve older people who are willing and able to pay for services, bringing us a new source of revenue.

One of the treasured characteristics of Volunteers of America is that our organization serves a diverse group of people in a variety of ways. *Aging with Options* is a flexible program which will help us to serve older people in unique ways which are compatible with our culture of diversity. In venturing out in our new direction, we would hope that you consider supporting all applicable legislation that supports seniors and persons with disabilities to have as much choice and independence as possible. Two such pieces of legislation include Senator Kennedy's CLASS Act and Senator Harkin's Community Choice Act.

Thank you again for this opportunity and I look forward to working with you in the future to ensure that seniors and those with disabilities have true choices for their care.

AARP

STATEMENT FOR THE RECORD

SUBMITTED TO THE

SENATE SPECIAL COMMITTEE ON AGING

ON

HEALTH REFORM IN AN AGING AMERICA

March 4, 2009

AARP
601 E Street, NW
WASHINGTON, DC 20049

For further information, contact:
Rhonda Richards
Government Relations & Advocacy
(202) 434-3770

On behalf of AARP's 40 million members, thank you for holding this critical hearing today. Addressing the needs of individuals with multiple chronic conditions is a cornerstone of comprehensive health care reform, which Congress and the Administration must enact. We cannot achieve needed quality improvements or cost savings without addressing this population. Uncoordinated care results in poor quality and high costs to individuals, their family and other informal caregivers, and both public and private payers. Poorly coordinated care can lead to both costly medical errors and unnecessary hospital stays. Family caregivers, who often serve as "de-facto" care coordinators, are trying to help their loved ones get the care they need, while risking their own health and financial security. Congress must act now -- and AARP stands ready to work with you -- to help those with multiple chronic conditions and their caregivers in comprehensive health care reform legislation.

Chronic conditions impact millions of Americans of all ages, and the risk for chronic conditions increases with age. Four out of five older adults have at least one chronic condition, according to the Agency for Healthcare Research and Quality (AHRQ). Eleven million older adults live with five or more chronic conditions. Some chronic conditions, such as diabetes and stroke, disproportionately impact minorities. In many cases, chronic conditions affect the ability of individuals to carry out essential daily activities, such as eating, bathing, dressing, and getting around inside or outside of the home.

High Costs of Multiple Chronic Conditions

Individuals with multiple chronic conditions have high health care costs, in part due to their high use of care. The Congressional Budget Office (CBO) observes that about 75 percent of Medicare spending pays for the care of beneficiaries with five or more chronic conditions who see an average of 14 different physicians each year. A study by Kathryn Anne Paez, Lan Zhao, and Wenke Hwang recently published in *Health Affairs* noted that individuals with multiple chronic diseases have the most substantial out-of-pocket spending.

Individuals with chronic conditions often have more hospital stays and emergency room visits, and they use more prescription drugs. Surveys have also shown that many individuals with chronic conditions have potentially unnecessary hospital readmissions, according to a forthcoming report on chronic care to be released by AARP's Public Policy Institute (PPI) on March 23. Unnecessary or potentially preventable hospital readmissions are very costly, reaching $12 billion in 2005, according to the Medicare Payment Advisory Commission (MedPAC). The high health care costs of individuals with multiple chronic conditions also are incurred by Medicaid, including some of the high costs of those eligible for both Medicare and Medicaid, the dually eligible.

Focusing on multiple chronic conditions alone, however, gives an incomplete picture of both health care costs and of the types of services and supports needed to improve quality and contain costs. In fact, health spending has been shown to spike sharply among persons age 50 and older when such conditions are accompanied by severe limitations in functioning, according to *Beyond 50.03: A Report to the Nation on Independent Living and Disability* by AARP's Public Policy Institute. Other research has indicated that people with both chronic conditions and activity limitations have more physician visits, many more home health care visits, and are twice as likely to have an inpatient stay as individuals with chronic conditions and no activity limitations.

While elderly Medicare beneficiaries who receive help with three or more daily activities only make up 7 percent of the Medicare population, they account for nearly 25 percent of Medicare spending, according to data prepared by Avalere Health for the SCAN Foundation. Medicare spends nearly 4.5 times more per person for these individuals than for individuals who do not need help with daily activities ($18,902 versus $4,289).

In addition, the dually eligible -- who are often in poor health and need help with daily activities -- increase Medicaid (and Medicare) costs. According to a recent report by the Kaiser Family Foundation, almost nine million dual eligibles accounted for 18 percent of Medicaid enrollment and 46 percent of all Medicaid expenditures for medical services in fiscal year 2005. Significantly, 1.6 million of these dual eligibles "who had per capita Medicaid spending of $25,000 or greater in 2005 accounted for more than 70 percent of all dual eligible spending." Multiple chronic conditions, a need for assistance with daily activities, and the presence of both of these characteristics clearly are significant drivers of high health care costs.

Quality Problems and Lack of Care Coordination

Individuals with chronic conditions and/or disabilities also can experience serious quality problems and medical errors that negatively impact the quality of care and further increase health care costs. Since individuals with multiple chronic conditions often see many providers, take many medications, need assistance with daily activities, and receive services in multiple settings, adequate care requires continuity and coordination among a wide array of providers in a wide variety of settings. Too frequently, such coordination and continuity does not occur and the quality of care breaks down.

Individuals with multiple chronic conditions often experience multiple transitions across settings, seeing many different types of providers. For example, in addition to a primary care provider and any specialists that an eighty year-old woman with four chronic conditions might have, she will likely have different providers during a hospitalization. Then she may be discharged to a skilled nursing facility for rehabilitation after the hospital stay and finally return home where she may receive some home health care or home care to help ensure that she or she and her caregiver can take care of her needs.

Research has shown that she is vulnerable to breakdowns in care at each transition point. Among the factors that contribute to gaps in care during critical transitions are poor or incomplete communication and transfers of information, inadequate education and support for older adults and their family caregivers and the “absence of a single point person to ensure continuity,” according to an article by Mary Naylor and Stacen Keating in the *American Journal of Nursing*. All too frequently, family members, partners, friends, or neighbors find that they are the sole care coordinators.

When providers across settings do not sufficiently and regularly communicate and coordinate among themselves and with the individuals and their caregivers, quality of care suffers. Lack of communication and coordination produces quality problems, such as:

- Medical errors;
- Duplicative or unnecessary tests;
- Hospital readmissions due to poor follow-up care, inadequate discharge planning or assessments, and/or lack of appropriate care and support upon return to the home;
- Unmet needs for services to enable independent living in the home rather than in a nursing home; and
- Adverse drug interactions causing further health problems due to lack of knowledge about a patient’s medical history and current medications.

According to the upcoming AARP PPI report, surveys have found that a significant percentage of patients with chronic conditions report experiencing medical errors. Individuals and their caregivers may also receive conflicting information from providers who did not communicate with one another. In addition, individuals and their caregivers may not always understand the information they receive from providers for a number of reasons, including poor communication, dementia or other conditions that impair understanding of the information, and language access or literacy barriers. Accurate and objective assessments of individuals and their needs are important, as well as the communication of this information. Improvements in quality of care for individuals with multiple chronic conditions will require improved communication to help prevent gaps in care as individuals transition across settings. Additional transparency and information about providers could also help individuals and their families make more informed choices about care providers at different points in the care process.

Care Coordination: Critical to Reducing Costs and Improving Quality

Care coordination is critical to reducing costs and improving quality of care and quality of life for those with multiple chronic conditions. Better care coordination is especially important for older adults, who are more likely to have chronic conditions and have family or other informal caregivers struggling to coordinate their care. Due to their high use of the health care system and frequent care transitions, individuals with multiple chronic conditions are likely to benefit disproportionately from quality improvement efforts. Better coordinated care can help individuals avoid unnecessary treatment and better assure timely treatments that can avoid unnecessary and more costly care. Improving quality means a person- and family-centered system that would, in part:

- better coordinate and manage care for individuals with multiple chronic conditions;
- improve communication among providers and across all settings, including the implementation of interoperable health information technology;
- improve communication among providers and individuals and their caregivers as important parts of an interdisciplinary care team; and
- address the needs of the whole person and their caregivers to improve quality of care and quality of life and potentially reduce costs.

Good chronic care coordination includes keeping individuals with multiple chronic conditions out of often more costly institutional settings whenever possible. Providing the supports to live independently, as well as supporting family caregivers -- who often provide much of the care coordination -- can help delay or prevent institutional care. For example, providing individuals and their caregivers with necessary supports can help prevent or delay unnecessary hospitalizations, emergency room visits, and nursing home placements, while decreasing overall costs.

Supportive services or home and community-based services (HCBS) can often be provided more cost effectively than care in an institutional setting. For example, on average, Medicaid dollars spent on HCBS can support nearly three older adults and individuals with disabilities for every person in a nursing home, according to a report released by AARP last year. Recent research indicates that states that make long-term commitments to increasing HCBS while diminishing their reliance on nursing home services can realize long-term savings. However, such a commitment requires short-term transitional costs that states can have trouble paying for, especially in these troubled economic times. Enhanced federal Medicaid matching funds for HCBS could provide the incentives to make short-term investments that result in long-term budget savings and improved lives for older adults and people with disabilities who need services.

Family and other unpaid caregivers are often critical to the care of individuals with multiple chronic conditions, especially for those with cognitive or functional impairments. Caregivers can play a critical role in providing quality care to their loved ones and potentially save money by keeping their loved ones out of often more costly settings, such as nursing homes and hospitals.

Assistance by family caregivers can delay or prevent the use of nursing home care. A study published in 2002 found that frequent help with basic personal care from children reduces the likelihood of nursing home entry among persons age 70 and older with disabilities over a two-year period by about 60 percent. Other research demonstrates that providing services to support family caregivers reduces the likelihood of institutionalization.

Further, people who have family caregivers tend to have shorter hospital stays, while the absence of a family caregiver has been linked to more frequent hospital readmissions. Informal care by adult children has been found to reduce Medicare inpatient expenditures of single older persons, as well as expenditures for home health and skilled nursing facility care. Other research has shown that interventions focusing on the roles of family caregivers during care transitions produce positive results, ranging from better patient outcomes in functional status and quality of life to reduced hospitalizations. In addition to these benefits of caregiving, the AARP Public Policy Institute has estimated the economic value of family caregivers' unpaid contributions to be about $375 billion in 2007.

Family caregivers can be a critical part of an interdisciplinary care team helping to meet the needs of an individual with multiple chronic conditions. Caregivers who accompany individuals during care transitions provide continuity of care by sharing knowledge of the individuals' past health and support needs. Caregivers help navigate the system to get their loved ones needed services and supports, help with daily activities and even complex medical conditions, and provide other vital mental and emotional support.

However, caring for loved ones can take a physical, emotional, mental and financial toll on caregivers that is well documented. Caregivers face challenges ranging from chronic stress and physical and mental health problems to high annual out-of-pocket costs and economic insecurity caused by loss of wages, health insurance and other job benefits, retirement savings, and Social Security benefits. These challenges are felt even more acutely in the current economic crisis.

To continue in their caregiving role, help ensure the provision of quality care, and reduce costs to public and private payers, caregivers need additional support. This support should come in a variety of forms, such as an assessment of the caregiver's needs to help connect them to needed services such as information, training, and respite care; better discharge planning, navigational assistance, and information about providers and the quality of care they provide to support decisions about care options; training to help caregivers care for their loved ones; respite care; better communication with providers as members of the care team helping their loved ones; and support from nurses and social workers.

Finally, improvements in our nation's health infrastructure and other health care reforms should be designed to facilitate care coordination for persons with multiple chronic conditions and/or disabilities, whose needs span multiple settings and providers. For example, interoperable health information technology and electronic health records should be accessible to all providers across the continuum of care, including long-term services and supports providers who are often involved in the management of chronic conditions. The need for information sharing and coordination of care goes far beyond acute or primary care providers, such as doctors and hospitals. Another example is that the health care workforce at all levels should be competent and adequately trained to meet the needs of older adults, those with multiple chronic conditions, and people with disabilities.

Steps Congress Should Take

Congress must take some important steps to improve chronic care coordination as part of comprehensive health care reform to improve the quality of care and enhance the quality of life of consumers and their families, while potentially reducing health care costs. AARP has identified below and in the attached fact sheet a number of solutions that Congress should consider in heath care reform. These include, but are not limited to:

- Improving chronic care coordination for individuals with multiple chronic conditions, such as through the use of assessments and individualized care plans. These goals would be furthered by including in health reform legislation provisions like those in the Independence at Home Act (Wyden/Markey/Chris Smith, S. 3613/H.R. 7114). Other models, such as the medical home, should also be encouraged.

- Enabling people to remain in their homes and communities and out of often more costly hospital and nursing home settings by measures such as:
  - Establishing a Medicare pilot program for a transitional benefit within the existing Medicare home health benefit to improve beneficiary/quality outcomes. For example, permitting a limited number of home health aide visits for those no longer requiring skilled services, but who require additional assistance, may reduce hospital readmissions and result in cost savings to Medicare and Medicaid;
  - Improving the Medicaid home and community-based services (HCBS) state plan option including by raising the income eligibility level and broadening the scope of services to support individuals in their homes and communities (Kerry/Grassley/Pallone/DeGette Empowered at Home Act, S. 434 [111th Congress]/H.R. 7212);
  - Providing incentives to states to use the state plan option and/or expand access to HCBS to help people remain at home, such as an enhanced FMAP for HCBS (Empowered at Home Act);
  - Requiring Medicaid spousal impoverishment protections for HCBS, just as for institutional care (Empowered at Home Act);
  - Raising the asset limits for Medicaid HCBS to improve Medicaid support for those living in the community (Empowered at Home Act); and
  - Eliminating or modifying the homebound restriction for Medicare home health care.

- Coordinating care more effectively for persons who are eligible for both Medicare and Medicaid to improve quality and reduce costs, by measures such as:
    - Improving information sharing between Medicare and Medicaid, such as claims data and Part D utilization information, and improving data collection on persons who are dually eligible;
    - Making improvements in Special Needs Plans (SNPs), including stronger relationships and contracting with state Medicaid programs; and
    - Using demonstrations and/or waivers to test new and promising care coordination or integration models and replicating successful models as appropriate.

- Supporting family caregivers, who often act as care coordinators for those with multiple chronic conditions and help delay or prevent institutional care, by such measures as:
    - Establishing a Medicaid Family Caregiver Assessment Demonstration Program to improve quality outcomes for individuals receiving Medicaid HCBS, assess needs of family caregivers when they are critical to the HCBS provided, connect them to needed supports, and help determine the best way to assess caregivers' needs;
    - Establishing a Medicaid state option or requirement to offer an assessment of family caregiver support needs where an HCBS beneficiary is dependent upon the assistance of a family caregiver (Kohl/Schakowsky

Retooling the Health Care Workforce for an Aging America Act, S. 245/H.R. 468 [111th Congress]);

- Developing family caregiver training materials to help them provide care ("Retooling" bill);
- Developing and requiring the use of information and referral protocols for providers to assist family caregivers of Medicare beneficiaries upon admission to or discharge from a hospital, emergency room, outpatient surgery, or post-acute care setting, including to make sure that individuals are aware of different alternatives for care ("Retooling" bill); and
- Ensuring the appropriate inclusion of and support for family caregivers in any chronic care coordination model.

The specific bills noted above have provisions similar or identical to the described needed solutions.

Conclusion

The time has come for Congress and the Administration to enact comprehensive health care reform. Comprehensive reform should include addressing the needs of persons with multiple chronic conditions and reducing the strains on their families. AARP looks forward to working with members of the House and Senate on both sides of the aisle and the many stakeholders to enact comprehensive health care reform legislation that will truly improve the nation's health and financial security, including individuals with multiple chronic conditions and/or disabilities.

Chronic Care and Health Care Reform

Policymakers must address the needs of people with chronic conditions by improving care coordination and disease management – this is a cornerstone of comprehensive health care reform. We cannot achieve needed quality improvements or cost savings without addressing this population. Uncoordinated care results in poor quality and high costs to individuals, their caregivers, and both public and private payers. People have costly and debilitating medical errors. Family caregivers risk their own health and financial security to provide care for their loved ones. Congress must act now, and AARP stands ready to work with you.

Eleven million older adults live with five or more chronic conditions. Individuals with multiple chronic conditions often see many providers, take many medications, and need assistance with daily activities, which results in high costs to them and to public programs. Multiple needs require continuity and coordination of care among a wide array of providers in a wide variety of settings. In the absence of such coordination, older adults -- who are more likely to have chronic conditions -- often turn to family or other informal caregivers who struggle to coordinate their care. Individuals with multiple chronic conditions and/or needs for assistance with daily activities are frequent and costly health care users and often transition across multiple care settings, resulting in more quality problems or medical errors. Improved quality through better coordinated care could yield major dividends by helping individuals avoid unnecessary treatment and assuring more timely treatments that can avoid unnecessary and more costly care. A person- and family-centered system would, in part:

- ✓ better coordinate and manage care for individuals with multiple chronic conditions;
- ✓ improve communication and coordination among providers and across all settings, including the implementation of interoperable health information technology;
- ✓ improve communication among providers and individuals and their caregivers as important parts of an interdisciplinary care team; and
- ✓ address the needs of the whole person and their caregivers to improve quality of care and quality of life and potentially reduce costs.

Good chronic care coordination includes keeping individuals with multiple chronic conditions out of often more costly institutional settings whenever possible. Providing the supports to live independently, as well as supporting family caregivers, who often provide much of the care coordination, can help delay or prevent institutional care. For example, providing individuals and their caregivers with necessary supports can delay or prevent unnecessary hospitalizations, emergency room visits, and nursing home placements.

Congress must take some important steps to improve chronic care coordination as part of comprehensive health care reform to improve the quality of care and enhance the quality of life of consumers and their families, while potentially reducing health care costs. Specific steps include:

- Improving chronic care coordination for individuals with multiple chronic conditions, such as through the use of assessments and individualized care plans. These goals would be furthered by including in health reform legislation provisions like those in the Independence at Home Act (Wyden/Markey/Chris Smith, S. 3613/H.R. 7114). Other models, such as the medical home, should also be encouraged.

- Enabling people to remain in their homes and communities and out of often more costly hospital and nursing home settings by measures such as:
  - Establishing a Medicare pilot program for a transitional benefit within the existing Medicare home health benefit to improve beneficiary/quality outcomes. For example, permitting a limited number of home health aide visits for those no longer requiring skilled services, but who require additional assistance, may reduce hospital readmissions and result in cost savings to Medicare and Medicaid;
  - Improving the Medicaid home and community-based services (HCBS) state plan option including by raising the income eligibility level and broadening the scope of services to support individuals in their homes and communities (Kerry/Grassley/Pallone/DeGette Empowered at Home Act, S. 434 [111th Congress]/H.R. 7212);
  - Providing incentives to states to use the state plan option and/or expand access to HCBS to help people remain at home, such as an enhanced FMAP for HCBS (Empowered at Home Act);
  - Requiring Medicaid spousal impoverishment protections for HCBS, just as for institutional care (Empowered at Home Act);
  - Raising the asset limits for Medicaid HCBS to improve Medicaid support for those living in the community (Empowered at Home Act); and
  - Eliminating or modifying the homebound restriction for Medicare home health care.
- Coordinating care more effectively for persons who are eligible for both Medicare and Medicaid to improve quality and reduce costs, by measures such as:
  - Improving information sharing between Medicare and Medicaid, such as claims data and Part D utilization information, and improving data collection on dual eligibles;
  - Making improvements in Special Needs Plans (SNPs), including stronger relationships and contracting with state Medicaid programs; and
  - Using demonstrations and/or waivers to test new and promising care coordination or integration models and replicating successful models as appropriate.
- Supporting family caregivers, who often act as care coordinators for those with multiple chronic conditions and help delay or prevent institutional care, by such measures as:
  - Establishing a Medicaid Family Caregiver Assessment Demonstration Program to improve quality outcomes for individuals receiving Medicaid HCBS, assess needs of family caregivers when they are critical to the HCBS provided, connect them to needed supports, and help determine the best way to assess caregivers' needs;
  - Establishing a Medicaid state option or requirement to offer an assessment of family caregiver support needs where an HCBS beneficiary is dependent upon the assistance of a family caregiver (Kohl/Schakowsky Retooling the Health Care Workforce for an Aging America Act, S. 245/H.R. 468 [111th Congress]);
  - Developing family caregiver training materials to help them provide care ("Retooling" bill);
  - Developing and requiring the use of information and referral protocols for providers to assist family caregivers of Medicare beneficiaries upon admission to or discharge from a hospital, emergency room, outpatient surgery, or post-acute care setting, including to make sure that individuals are aware of different alternatives for care ("Retooling" bill); and
  - Ensuring the appropriate inclusion of and support for family caregivers in any chronic care coordination model.

The specific bills noted have provisions similar or identical to the described needed solutions.
AARP Government Relations and Advocacy, March 2009