



2005 White House
Conference on Aging

Final Report and Recommendations by the
Mini-Conference on Long-Term Care

“Establishing a Comprehensive National Long-Term Care Policy”

held on

April 19 & 20, 2005

at the

Capitol View Conference Center
Washington, DC



Executive Summary of Recommendations

Developed by the White House Conference on Aging Long-Term Care Mini-Conference

1. Economic Security & Long-Term Care Financing

Congress and the Administration must:

- Provide coverage for all Americans through public and private mechanisms.
- Use current public dollars more efficiently and intelligently.
- Launch a national long-term care education campaign.

2. Health and Independence

Congress and the Administration must:

- Create financial incentives and otherwise provide for workforce training and service delivery enhancement.
- Establish a unified quality agenda for long-term care in collaboration with private sector stakeholders.
- Fund a broad initiative to incentivize and support self-directed consumers.
- Reform public and private funding programs to remove institutional biases in concert with states.
- Establish a Federal office to address long term care workforce issues.

3. Supportive Services

Congress and the Administration must:

- Fund and prioritize recruitment, training and retention of long-term care workforce.
- Establish a new agency with the U. S. Department of Health and Human Services to focus solely on long-term care.



The White House Conference on Aging

And Why it Matters to Every American

The 2005 White House Conference on Aging (WHCoA) occurs as the first wave of the 78 million-strong baby boom generation prepares for retirement. It creates an important opportunity to creatively assess aging in America and improve the lives of older Americans.

The 2005 WHCoA will be held in December, 2005 in Washington, DC. This will be the fifth in the history of our nation and the first such conference of the 21st Century.

Authorized by Public Law, this conference has, over time, served as a catalyst for the development and enhancement of national, state and local aging policies in the United States. This conference, “*Booming Dynamics of Aging ~ From Awareness to Action*” will make policy recommendations to the President and Congress, and assist the public and private sectors in promoting dignity, health, independence and economic security of current and future generations of older Americans.

About the WHCoA Long-Term Care Mini-Conference

Creating a Comprehensive National Long-Term Care Policy was a designated “mini-conference” event by the 2005 White House Conference on Aging (WHCoA). Its purpose was to provide the full WHCoA Policy Committee with recommendations specific to long-term care that could be considered for incorporation into its final policy recommendations to the President and Congress.

Organizations planning the WHCoA Long-Term Care Mini-Conference included long-term care policy representatives from:

- **American Association of Retired Persons**
- **American Council of Life Insurers**
- **American Health Care Association and National Center for Assisted Living**
- **America’s Health Insurance Plans**
- **National Alliance for Caregiving**
- **National Association for Home Care & Hospice**

This Mini-Conference took place on April 19th and 20th in Washington, DC. It was attended by more than 125 long-term care stakeholders from the public and private sectors. In compliance with WHCoA policy, public seating was available and provided. Several members of the WHCoA Policy Committee also attended and participated.

Funding for the conference came from generous contributions provided by *Beverly Enterprises, Evangelical Lutheran Good Samaritan Society, Genworth Financial, Golden Rule Insurance Company, MetLife, Mutual of Omaha, New York Life Insurance Company, Prudential Financial, UHS-Pruitt Corporation and Vetter Health Services.*

The one and a half day conference began with a thought-provoking Socratic dialogue produced by Fred Friendly Seminars of New York and moderated by Harvard Law Professor Arthur Miller.



Panelists included former administration officials, congressional leaders and private sector representatives who explored the challenges America faces in formulating and enacting comprehensive long-term care policies that can meet the rapidly growing need for quality long-term care and services for the 78 million aging baby boomers.

The dialogue session set the stage for three policy development sessions which developed recommendations in the areas of Economic Security and Long-term Care Financing; Health and Independence; and Supportive Services.

At a breakfast on the second morning, following a keynote address by Centers for Medicare and Medicaid Services (CMS) Administrator, Dr. Mark McClellan, a “draft” of the recommendations was presented to WHCoA Policy Committee Chairman, Dorcas Hardy.

This report contains the final recommendations being formally submitted to the WHCoA.



COMMON OBSERVATIONS AND CONCERNS:

There were several common considerations that emerged from each of the policy development sessions worthy of specific focus.

- There was consensus among conference participants that a true crisis exists in this country regarding the state of elder care. Emerging from this Mini-Conference, there was an unequivocal call for the White House and Congress to immediately address the state of elder care with the same commitment and energy devoted to other national crises.
- There was consensus that without strong leadership in developing long-term care solutions and policy from the highest levels of government and the private sector, the needs of this nation's rapidly aging population will, undoubtedly, not be met in the decades to come. Strong political leadership was also seen as necessary to elevate social and cultural issues around aging and disability while enacting evidence-based policies to improve quality.
- In addition to the need for national institutions to lead the reform debate, two of the three policy development groups called for creation of a new federal long-term care agency within the Department of Health and Human Services (HHS) – or a bi-partisan, federally chartered and funded national commission with strong centralized leadership and the authority needed to implement necessary reforms.
- Two policy development sessions deemed it critical to address workforce needs by enhancing the recruitment, training and retention of a stable professional and paraprofessional workforce. The need to provide support and training for family caregivers was also recognized as a workforce concern. Attention in these areas is viewed as key in the provision of quality care and services in all settings.
- Overall, there was recognition that government cannot do everything – and that a public/private approach is necessary to create and implement policies that will provide access to quality long-term care and supportive services in an economical and equitable manner.

RECOMMENDATIONS DEVELOPED FOR PRESENTATION TO THE WHCoA POLICY COMMITTEE

1. Economic Security & Long Term Care Financing:

The purpose of this session was to formulate long-term care financing recommendations to enable our nation to achieve sustainable, affordable and efficient long-term care. The session participants first discussed what they believe is an ideal long-term care system and then discussed the barriers to achieving that vision. Many financing options and barriers were considered, and three recommendations were formulated from the considered options.

Policy Options and Barriers:

Long-Term Care for Every American:

The confusion and misperceptions associated with terminology and jargon, as well as sources of financing, were identified as a barrier to achieving efficient, quality long-term care for all Americans. Participants emphasized that “long-term care” is not strictly about medical care only, but also includes services allowing seniors to continue to live healthy, socially productive lives.

Until there are commonly agreed-to definitions, it will be impossible to create an effective and efficient long-term care system for various needs and cultures – such as geriatric long-term care and long-term care for young disabled persons.

There was much debate about how long-term care should be financed. It was concluded that in order to achieve a sustainable long-term care system we must consider both private and public financing means. Through these variously configured funding streams, all Americans would be assured of having access to coverage for their long-term care and supportive service needs – in all settings.

Coordinate and Increase Public Funding of Long-Term Care:

Among other aspects of the current long-term care system, participants pointed to the lack of coordination between long-term care and acute care – as well as state and federal health policies – as causal factors leading to inefficiency in the use of public dollars. While boosting the efficient use of existing resources, funding for long-term care must be increased and distributed equitably based on need. It was suggested that long-term care be added as a long-term care benefit to Medicare or by creating a “new” federally funded long-term care program.

Long Term Care Risk Education and Promoting Individual Responsibility:

Many conference participants expressed a view that not all individuals are taking as much personal responsibility for their health and long-term care needs as they are able. It was noted that citizens need more information about: the inherent risks they face in needing long term care; the various long-term care settings that are available to them; and steps they can take to better meet their own needs for long-term care. Additionally, participants felt that employers could do more to educate their employees about these



risks; and that the importance of positive health behavior, such as exercise, healthy living and preventive health care, must be instilled in every adult.

Improving and Encouraging Personal Financing of Long-Term Care:

Research has shown that a large number of adults assume that Medicare or their health care insurance will cover their long-term care needs – and current policies encourage people to impoverish themselves in order to qualify for Medicaid.

Accordingly, participants found the current system lacks sufficient incentives for most individuals, who can, to pre-fund long-term care. Thus the expansion of private long-term care financing by offering incentives for savings or purchasing long-term care insurance and other financial vehicles is recommended.

It was generally agreed that fostering innovation within the private market would encourage growth in private spending for long-term care. Suggestions included enhancing the current tax treatment of long-term care insurance, expanding public-private partnerships, or requiring payroll deductions to be put directly towards long-term care. However, it was noted there is a very strong anti-tax sentiment in this country, making a mandatory tax assessment for long-term care a challenge.

Improving Research:

Long-term care is a complex policy issue requiring substantial analysis. Conference participants generally agreed policy-related research that identifies “best practices” or conducts cost-benefit analyses of policy options should be funded.

The group also identified the need for a Congressional or Presidential Commission to evaluate the policy options discussed at the meeting, as well as the many options that were not mentioned. It was noted that increasing funding for research dealing with chronic health conditions could help decrease long-term care costs in the long-run.

Making Long-Term Care a Dominant National Policy Issue:

The lack of high visibility for long-term care on Capitol Hill or in the White House was identified as a major barrier to improving the financing of long-term care. Participants called for bi-partisan political leadership to push this issue into mainstream politics, and more dialogue among the various interest groups and also between the political parties.

Investing in the Long-Term Care Workforce and Family Caregivers:

Participants discussed the following options to address the current decline in the long-term care workforce: elevating the value of working in the long-term care industry; increasing wages; ensuring all in this field receive benefits; creating career ladder options for caregivers; improving compensation and training for caregivers; and opening U.S. borders for more immigration of health and long-term care professionals.

To support and encourage more people to provide informal family care – currently the main source of long-term care – national policy should provide better caregiver supports through respite services, training and financial assistance.



Improving Access to Information on Consumer Choice:

Participants remarked that the high costs of certain services and lack of transparency about costs and quality all serve to reduce access to a wide range of care options. Thus the conference identified the need for a comprehensive information source provided at the consumer level, as well as comparable cost differentials between care options to better facilitate the way in which to financially prepare for and choose a care setting.

Improving care coordination and management:

Discussions about financing included the need for improved management of health and long-term care. Efficiency and quality reporting among providers and payers should be encouraged and utilized. Some participants emphasized that regulatory requirements are creating too much paperwork and taking time away from actual caregiving. It was suggested that over-regulation of the long-term care industry hinders the coordinated, efficient operation of long-term care facilities, services, and programs.

Recommendation: *Coverage for all Americans through Public AND Private Mechanisms*

It is recommended that Congress and the Administration take steps to achieve long-term care coverage for all through participation in public and private risk pools. With respect to expanding public risk pools for long-term care, Congress must establish a new public program that provides **basic** services for chronic care to all Americans.

With respect to expanding private risk pools for long-term care, Congress must enact laws to encourage private participation by individuals and families for long-term care services, such as tax incentives for the purchase of long-term care insurance and/or other private options for financing long-term care.

Recommendation: *Use Current Public Dollars More Efficiently, Intelligently*

It is recommended that Congress and the Administration improve the use of health and long-term care dollars across programs by leveraging current funding to maximize efficiency, and to employ best practices from demonstration projects and private sector initiatives on long-term care.

Recommendation: *Launch a National Long-Term Care Education Campaign*

It is recommended that Congress and the Administration develop and launch a national educational campaign on long-term care that focuses on the risks, costs, and need to pre-fund long-term care.

The campaign must be premised upon a credible advocate or group of advocates to elevate national focus on long-term care issues and awareness.

Additionally, a Congressional or Presidential Commission should be formed to address the nation's long-term care needs and to formulate steps to reform our long-term care financing system.



2. *Health and Independence:*

In crafting solutions to identified problems related to health and independence, participants attempted to balance concerns about health quality in a medical context with concerns related to quality of life for consumers of non-medical long-term services and supports. Policy implications and priorities may diverge – contingent upon the preferences and needs of distinct disabled populations.

Some participants stressed that certain inadequacies in the current health delivery system – the absence of coordinated skilled care and absence of uniform quality standards across settings where acute care is provided, for example – tend to compromise quality for older or frail persons whose chronic illnesses and aging-related conditions impair their functioning.

However, others highlighted inadequacies in the “non-system” of long-term care that have serious social and economic consequences among persons with disabilities. Participants generally agreed many of our disabled citizens do not have high acuity medical needs; rather they require regular supports and services in order to work and participate in social life – consistent with their civil rights under the U.S. Constitution.

Policy Options and Barriers:

Assuring Quality of Care, Quality of Life

Recognizing the different policy prescriptions appropriate to overcoming different barriers, participants nevertheless agreed that resolutions to the White House Conference on Aging should be comprehensive in addressing gaps in quality of life for all – as well as health quality.

Thus, one recommendation reflects a concern for inclusive policies on quality measurement and quality improvement. Another addresses gaps in the workforce through a concerted federal effort to respond to the widest range of significant challenges: the need for training, recruitment and retention across professions, and on the front-line; meaningful support for unpaid caregivers; and culture change in all care settings to emphasize interdisciplinary approaches.

Re-aligning Incentives to Drive Quality

Concerns were expressed that existing models of care and its financing will not move delivery toward the ultimate objective of comprehensive quality that encompasses consumer empowerment and preventive care, as well as medical treatment.

Participants suggested the need for a combination of different policy initiatives, and crafted recommendations accordingly.

Specifically, they called for financing strategies to expand home and community-based options and eliminating the current policy and financing bias toward institutional care, while concurrently strengthening access to high-quality institutional settings as an option for those requiring around-the-clock care and supervision.

Creating and Disseminating New Tools and Supports

Participants were in broad agreement that additional tools and supports must be developed for consumers to direct their own care to the extent they wish and for family members to better participate in the caregiving process.

The resulting recommendations recognize that improvements in these areas will involve public education and awareness as well as investment in innovative, cutting-edge technology and improvements in the health literacy of all consumers.

Recommendation: *Federal and State policymakers should create financial incentives and otherwise provide for workforce training and service delivery that reflects the following priorities:*

- Maximizing consumer self-direction, independence and health in homes and communities;
- Promoting models of coordinated, multi-disciplinary, continuous care and support across all settings and throughout the life spans (in contrast to a model of intermittent, episodic care);
- Emphasizing secondary and tertiary prevention for clients (risk assessment, early identification and intervention).

Recommendation: *Establish a Unified Quality Agenda for Long-Term Care*

Congress and the Administration, in collaboration with consumers, providers and other stakeholders, should establish a unified quality agenda for long-term care and supportive services, including unified measurement and reporting across the continuum of services and settings; performance-based payment; consumer satisfaction and expectations; addressing health literacy and cultural disparities.

Recommendation: *Fund Broad Initiative to Incentivize, Support Self-Directed Consumers*

Congress and the Administration should fund a broad initiative to develop new tools and supports for self-directed consumers as well as family caregivers – including public education efforts to elevate issues of importance to consumers; development of technological interventions to involve family members in the caregiving process; and interventions that promote consumer self-direction of care.

Recommendation: *Reform Public, Private Funding Programs to Remove Institutional Biases*

Congress and the Administration, in concert with states, reform public and private funding programs to remove institutional biases by: aligning incentives to promote continuity, choice and quality of care across all settings; integrating acute and long-term care and maximizing health and independence in homes and communities; and specifically balancing the Medicaid entitlement to cover home and community-based services.

Recommendation: *Establish Federal Office to Address Long Term Care Workforce Issues*

Congress and the Administration should establish a federal office to address professional and paraprofessional long-term care workforce issues and provide recommendations to improve the recruitment, training, retention and practice of a strong long-term care workforce.



3. *Supportive Services:*

Supportive Services is a broad category for policy change consideration and the Conference attendees identified critical areas to be addressed and barriers to be overcome. There was consensus in this policy session that the frail, elderly and disabled, their family members and friends must be empowered in a revamped system that provides clear choice in how and where care is provided – and that provides the necessary resources to support individual choice.

Policy Options and Barriers:

The group identified a range of barriers to improving supportive services for long-term care including: the lack of political will on the part of government policymakers to make comprehensive changes in long-term care; and the failings of our current system of antiquated laws and regulations.

The group identified a variety of specific problems including: the inefficient provision of care and services through funding “silos”; the lack of public education on most aspects of long-term care; the need for increased use of technology in all care settings; the need for financial supports for family caregivers; the need for adequate reimbursements to cover the costs of care by providers; incentives to promote preventive health programs; and the need to consider changes to immigration laws to increase the number of qualified healthcare workers in the U.S.

In one way or another, these barriers directly – or in inter-related fashion – impact care quality. There was consensus among conference attendees that the top priority in the creation of a comprehensive national long-term care policy involves ensuring a strong long-term care workforce be built and maintained – and that resources are made available to assist and support family caregivers.

Recommendation: *Fund and Prioritize Recruitment, Training and Retention of Long-Term Care Workforce*

Congress and the Administration must ensure that all levels of government and the private sector work collaboratively to effect policy changes that will enhance the recruitment, training and retention of a strong professional and paraprofessional workforce.

This would include policies that will ensure:

- The infrastructure for educating nurses, doctors, therapists, nursing assistants, and other health care professionals is strongly supported and adequate financing is available to resolve the shortage of professional and paraprofessional caregivers;
- Government reimbursements for care will cover the costs of care so that providers in all settings are able to provide higher salaries, benefits and a valued career path.
- Government will elevate the status of family caregivers by providing financial resources to provide training and financial supports to family caregivers.

Recommendation: *Establish a New Agency within HHS to Focus Solely on Long-Term Care*

Congress and the Administration must pass and enact a law creating an agency within the Department of Health and Human Services (HHS) focused solely on long-term care.



This agency and its director would be empowered with sufficient authority to analyze and make recommendations to Congress and the Administration on all aspects of long-term care – particularly delivery system reforms, design, accountability, and financing.

This agency would be tasked with defining realistic strategies the Administration and Congress can use to accomplish goals that include, but are not limited to:

- Creating a seamless long-term care continuum from acute to chronic care.
- Removing Medicaid institutional biases that deny consumer choice and removing the silo mentality in the delivery of care and services.
- Creating a basic-level long-term care benefit under Medicare (e.g., a Part E).
- Establishing a delivery system that is consumer friendly and provides for strong public education and care/case management through all settings.
- Ending middle-class Medicaid manipulation to better preserve this resource for the truly impoverished.
- Creating incentives to encourage individuals to take planning responsibility for their own long-term care needs. This would include tax incentives to encourage individuals to purchase long-term care insurance or other financial products that pay a long-term care benefit and; improved access to reverse mortgages which can allow individuals to stay at home with supportive services.
- Balancing disparities between actual costs of care and government reimbursements and level the playing field for all provider settings to ensure continued consumer access to quality care and services.
- Redesigning Medicaid to allow dollars to follow the person across all settings, while ensuring that access to quality long-term care and services can be received in the settings of choice.
- Increasing utilization of technology (telehealth, home-mods, monitoring devices, electronic medical records, etc.) in all care settings – particularly in rural settings.
- Supporting consumer and caregiver needs as related to transportation, housing, services like meals-on-wheels and other volunteer programs.

This report and recommendations are submitted by the WHCoA Long-Term Care Mini-Conference Planning Committee. Committee members include:

AARP – Lisa Stand

American Council of Life Insurers – Lynn Boyd & Shannon Carroll

American Health Care Association & National Center for Assisted Living – Todd Smith

America's Health Insurance Plans – Susan Coronel

National Alliance for Caregiving – Gail Hunt & Les Plooster

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