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PART 2

PRE-CONFERENCE EVENTS

- Listening Sessions
- Solutions Forums
- Mini-Conferences
- Independent Aging Events



Listening Sessions

Listening Sessions

Listening Sessions, which began in August of 2004, were called for and attended by the Policy Committee to further inform their discussions about the key issues around the broad agenda to be addressed by the 1200 delegates to the 2005 White House Conference on Aging

2004

- 8/18/04 **Leadership Council of Aging Organizations**
Washington, D.C.
- 8/30/04 **2004 Florida Conference on Aging**
Miami, FL
- 9/9/04 – 9/10/04 **Leadership Council of Aging Organizations and Other Organizations**
Washington, D.C.
- 10/18/04 **White House Conference on Aging Listening Session**
Boise, ID
- 10/18/04 **White House Conference on Aging Listening Session**
Birmingham, AL
- 10/19/04 **White House Conference on Aging Listening Session**
Post Falls, ID
- 10/21/05 **White House Conference on Aging Listening Session**
Idaho Falls, ID
- 12/07/04 **Indiana Governor's Conference on Aging**
Indianapolis, IN
- 12/8/04 **2004 Illinois Conference on Aging**
Chicago, IL
- 12/10/04 **Alliance for Aging Research White House Conference on Aging Listening Session at the American Association for Advancement of Science**
Washington, DC

2005

- 1/8/05 **Transportation Research Board WHCoA Listening Session**
Washington, DC
- 1/24/05 **National Coalition on Mental Health and Aging WHCoA Listening Session**
Washington, DC



Solutions Forums

Solutions Forums

“Solutions Forums” replaced the Listening Sessions beginning in February 2005. These forums helped further refine the issues raised in 2004 and in the annotated agenda adopted by the Policy Committee. The Committee sought creative, thoughtful, innovative and specific solutions to some of the challenges that we face as an aging society. Solutions presented formed the basis for resolutions considered by the delegates. Like the Listening Sessions, Policy Committee members attended these sessions.

- 3/9/05 **California Commission on Aging WHCoA Solutions Forum**
Sacramento, CA
- 3/12/05 **American Society on Aging/National Council on the Aging WHCoA Solutions Forum**
Philadelphia, PA
- 4/1/05 **WHCoA Solutions Forum hosted by the Utah Division of Aging and Adult Services and the Honorable Orrin Hatch (R-UT)**
Salt Lake City, UT
- 4/7/05 **2005 White House Conference on Aging Solutions Forum**
“The Future Needs of the Aging Baby Boomers”
Los Angeles, CA
- 4/14/05 **The College of William and Mary, The Thomas Jefferson Program WHCoA Solutions Forum**
Williamsburg, VA
- 4/21/05 **WHCoA Solutions Forum on Mental Health and Aging in Illinois sponsored by the Illinois Coalition on Mental Health and Aging**
Schaumburg, IL
- 5/6/05 **Ohio Nutrition Network Solutions Forum**
Columbus, OH
- 5/13/05 **WHCoA Solutions Forum hosted by the American Occupational Therapy Association, Inc.**
Long Beach, CA
- 5/17/05 **Leadership Council of Aging Organizations (LCAO) Solutions Forum**
Washington, D.C.
- 5/25/05 **University of West Virginia Center on Aging WHCoA Solutions Forum On Rural Aging**
Morgantown, WV

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- 6/2/05 **Schmieding/ILC WHCoA Solutions Forum on Elder Caregiving sponsored by the Schmieding Center for Senior Health and Education and the International Longevity Center in New York City**
Springdale, AR
- 6/13/05 **National Congress of American Indians/National Indian Council on Aging Solutions Forum**
Green Bay, WI
- 6/21/05 **2005 Silicon Valley Boomer Business Summit WHCoA Solutions Forum**
Santa Clara, CA
- 6/23/05 **Colorado Division of Aging and Adult Services WHCoA Solutions Forum**
Denver, CO
- 6/24/05 **WHCoA Solutions Forum hosted by the American Optometric Association “Eyecare Access: Eliminating Barriers for Seniors and Baby Boomers”**
Dallas, TX
- 7/6/05 **Nevada Solutions Forum**
Las Vegas, NV
- 7/7/05 **Nevada Solutions Forum**
Reno, NV
- 7/13/05 **WHCoA Solutions Forum hosted by the Kansas Department of Aging**
Topeka, KS
- 7/19/05 **Care Coordination Across the Continuum Solutions Forum sponsored by the Coalition for the Continuum of Care**
Washington, DC
- 7/29/05 **Texas Silver-Haired Legislature WHCoA Solutions Forum**
Austin, TX
- 8/3/05 **Tennessee Commission on Aging and Disability Solutions Forum held during the Tennessee White House Conference on Aging. “The Booming Population: Bridging Today with Tomorrow-Choosing Tennessee for a Lifetime”**
Nashville, TN
- 9/12/05 **Palm Beach/Treasure Coast Solutions Forum**
West Palm Beach, FL
- 9/22/05 **Alliance for Aging Research Solutions Forum**
Washington, DC
- 9/30/05 **Corporation for National and Community Service and Texas Department on Aging Solutions Forum on Civic Engagement**
San Antonio, TX



Mini-Conferences

Mini-Conferences

Official White House Conference on Aging (WHCoA) Mini-Conferences were coordinated by a variety of partner agencies, organizations and the WHCoA on a key topic area identified by the Policy Committee. WHCoA Mini-Conferences provided the Policy Committee with focused information on a specific issue and were intended to generate recommendations and solutions from the public and private sectors for use in the development of resolutions and implementation recommendations for delegates to the 2005 WHCoA. Policy Committee members participated in official WHCoA Mini-Conferences

4/19/05 – 4/20/05 **WHCoA Mini-Conference on Long Term Care “Creating a Comprehensive National Long Term Policy”**
Washington, DC

Planning committee members include: AARP, American Council of Life Insurers, American Health Care Association and the National Center for Assisted Living, America’s Health Insurance Plans, The National Alliance for Caregiving and the National Association of Home Care & Hospice

6/15/05 **WHCoA Mini-Conference on Caregiving**
Washington, DC

Planning committee members include: Matz, Blancato & Associates, Inc., Feinberg Family Caregiver Alliance, National Alliance for Caregiving, MetLife Mature Market Institute, National Alliance for Caregiving, AARP, Towson University

6/15/05 **WHCoA Mini-Conference on “Voice of Business on the Mature Workforce”,**
Washington, DC

Planning committee members include: U.S. Chamber of Commerce’s Center for Workforce Preparation (CWP), the Labor, Immigration & Employee Benefits Division (LIEB) and the John J. Heldrich Center for Workforce Development at Rutgers University

6/29/05 **WHCoA Mini-Conference on Nutrition**
Washington, DC

Planning committee members include: the National Association of Nutrition and Aging Services Programs and Florida International University’s National Resource Center on Nutrition, Physical Activity. Other partners include the National Council on the Aging, Meals on Wheels Association of America, Tufts University Jean Mayer USDA Human Nutrition Research Center on Aging in Boston, The Association of Nutrition Services Agencies, The National Association of State Units on Aging, and the Gerontological Nutritionists, a dietetic practice group of the American Dietetic Association, American Dietetic Association, and National Association of Area Agencies on Aging

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- 7/12/05 **WHCoA Mini-Conference on Economic Incentives To Increase Retirement Savings by Individuals and Through Employment-Based Retirement Plans**
Arlington, VA
- Planning committee members include: American Benefits Council, ERISA Industry Committee, Employee Benefit Research Institute, International Foundation of Employee Benefit Plans, National Rural Electric Cooperative Association, WorldatWork
- 7/14/05 **WHCoA Mini-Conference on Financial Literacy**
Washington, DC
- Planning committee members include: the Employee Benefit Research Institute and its Education and Research Fund Programs Choose to Save and American Savings Education Council (ASEC) and public and private Partners of ASEC
- 7/16/05 **WHCoA Mini-Conference on Geriatric Health Care Workforce**
Bethesda, MD
- Planning committee members include: Bureau of Health Professions, HRSA
- 7/21/05 **WHCoA Mini-Conference on Health Literacy and Health Disparities**
Chicago, IL
- Planning committee members include: American Medical Association, Blue Cross and Blue Shield Association
- 7/21/05 – 7/22/05 **WHCoA Mini-Conference on Disability & Aging**
Arlington, VA
- Planning committee members include: National Institute of Disability and Rehabilitation Research of the Department of Education; America's Health Insurance Plans (AHIP); UnumProvident Corporation; Paralyzed Veterans of America; Office of Disability, U.S. Department of Health and Human Services; AARP; National Council on Independent Living; American Association of People with Disabilities; Aetna; Department of Veterans Affairs; MetLife; and the U.S. Department of Labor
- 9/27/05 **WHCoA Mini-Conference: Preparing for the Boom: The Access and Development Of Health and Financial Information Across the Lifespan**
New York, NY
- Planning committee members include: ZivaContinuum in cooperation with the American Bar Association, Senior Lawyers Division and the Financial Planners Association

**Mini-Conference Reports to follow.*



Mini-Conference

*Creating a Comprehensive
National Long Term Care Policy*



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



Long Term Care Mini-Conference

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.



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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 WHC_{oA} 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.



Long Term Care Mini-Conference

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

National Association for Home Care & Hospice – Jeff Kincheloe



Long Term Care Mini-Conference



Mini-Conference

Future of Caregiving



Final Report and Recommendations

of the

Mini-Conference on the Future of Caregiving

held

June 15, 2005

The Washington Court Hotel

Washington, DC

Submitted to the 2005 White House Conference on Aging
Policy Committee

2005 WHITE HOUSE CONFERENCE ON AGING

Mini-Conference on the Future of Caregiving

Introduction

The White House Conference on Aging is convened every ten years to explore the issues affecting our nation that are related to the aging of our population. The 2005 White House Conference on Aging has defined its work as exploring a set of issues that are likely to influence the nation over the next 10 years, and to include, in all of its considerations, the Baby Boom generation in the dialogue. It can be argued that one of the most compelling issues facing the Baby Boom generation is the care of their aging parents and grandparents. Moreover, in the not-too-distant future, increasing numbers of Boomers may find themselves providing care for spouses and other family members. Family caregiving is therefore becoming a familiar activity for millions of American families with profound implications for all aspects of our family, civic, and work life.

In recognition of the above, a mini-conference on the “Future of Caregiving” was convened on June 15, 2005, to provide a forum in which these implications were discussed and a set of policy recommendations developed for presentation to the White House Conference on Aging Policy Committee. This report outlines the forum, issues discussed at the forum, and the recommendations developed by the participants.

The Process

Planning for the “Future of Caregiving” event began early in 2005 under the leadership of the representatives of the conference sponsors:

- The National Alliance for Caregiving
- The MetLife Mature Market Institute

The planning committee included the following individuals:

- Robert B. Blancato Matz, Blancato & Associates, Inc.
- Lynn Friss Feinberg Family Caregiver Alliance
- Gail Gibson Hunt National Alliance for Caregiving
- Laura Howard Matz, Blancato & Associates, Inc.
- Kathy O’Brien MetLife Mature Market Institute
- Les Plooster National Alliance for Caregiving
- Lisa Stand AARP
- Sandra Timmermann MetLife Mature Market Institute
- Donna Wagner Towson University

The planning committee developed the agenda, managed the logistics and developed the invitation list. Individuals who were invited to participate were selected to represent the following categories of expertise and advocacy: policy, practice, business, research, education, aging, population diversity, disability, technology, and philanthropy.

There were 129 participants at the event including individuals representing the general public who gained access to the event through the White House Conference on Aging website. In addition, members of the White House Conference on Aging Advisory Committee in attendance included Rudy Arredondo, Sonny Carlota, Peggye Dilworth-Anderson, Katherine Freund, Cynthia Hughes-Harris, Edward Martinez, Lawrence Polivka, and William Scanlon. Mel Woods of the White House Conference on Aging Policy Committee was in attendance, as was staff member Remy Aronoff.

The Agenda

Participants were welcomed by representatives of the sponsors of the event. Gail Gibson Hunt, President and CEO, National Alliance for Caregiving, provided an overview of family caregiver issues and the White House Conference on Aging. Expert presentations focused on the following topics:

- Emerging Issues in Family Caregiving – Lynn Friss Feinberg, MSW, National Center on Caregiving, Family Caregiver Alliance
- Employed Caregivers – Donna Wagner, Ph.D., Center for Productive Aging, Towson University
- Health of Caregivers – Richard Schulz, Ph.D., University Center for Social and Urban Research, University of Pittsburgh
- Diversity of Caregivers – Donna Benton, Ph.D., Los Angeles Caregiver Resource Center, University of Southern California.
- Legislation and Public Policy – Robyn Golden, LCSW, Rush University Medical Center and Robert Blancato, MPA, Matz, Blancato and Associates.

The Honorable Dorcas Hardy, Chair of the White House Conference on Aging Policy Committee, addressed the group about the White House Conference on Aging - to be held December 11-14 in Washington, DC - and the importance of family caregiving to the deliberations of the delegates.

A plenary session was convened to allow participants to make recommendations or raise issues that would complement those addressed in the morning session. The luncheon speaker was Senator Hillary Rodham Clinton, who highlighted the key role of family caregivers in bipartisan legislation titled the “Lifespan Respite Care Act”.

The afternoon was dedicated to small working groups to discuss the issues and develop a set of recommendations. The final plenary session, which followed these working groups’ discussion, was dedicated to reaching consensus on the four sets of recommendations emerging from the work groups.

Final recommendations/resolutions were accepted by Robert Blancato and Gail Gibson Hunt, members of the White House Conference on Aging Policy Committee.

The Recommendations

The four working groups identified several important issues central to the well-being of family caregivers and their need to play an active role in policy discussions during the next ten years. These issues included:

- the need for an expanded definition of family caregivers to incorporate the diverse caregiving situations and family configurations present in contemporary life. This includes diversity in terms of race, ethnicity, lifestyle, geography (urban/rural) and income levels as well as an expanded definition of “family” to include non-traditional families and non-kin informal caregivers.
- the need to strengthen existing government programs providing respite care and related supports, notably, the National Family Caregivers Support Program, expansion of support to caregivers of all ages with passage of the Lifespan Respite Care Act, and broadening of the Family and Medical Leave Act as well as enactment of caregiver tax credits for qualified employees and employers.
- the need for increased visibility and more research about the economic importance of family caregiving to the U.S. long-term care system, and, more broadly, caregivers’ contributions to society.
- the need for an instrument and program to assess informal and family caregivers that can accurately determine their needs for targeted services.
- the need for more flexible support for employed caregivers so that they can continue to be both family caregivers and productive members of the workforce.
- the need for caregiver experts and organizations to be closely involved in policy discussions about possible reforms of long term care programs and financing mechanisms for long-term care services to ensure that family caregivers and those for whom they care are properly supported.

The participants were passionate about all of these issues as well as others but, after discussion among the whole group, participants came up with the following three recommendations to send to the White House Conference on Aging Policy Committee.

Recommendation I

We recommend that government programs be expanded to better support the diverse population of caregivers including:

- increased funding for the National Family Caregiver Support Program through 2015 tied to an index reflecting cost of living increases and the increase in the number of caregivers
- enactment of the Lifespan Respite Care Act
- development of a national assessment program for all family and informal caregivers that can assess their need for support services and which can be integrated into the development of care plans
- enactment of tax credits for caregivers and paid family medical leave with employer tax incentives.

Recommendation II

We recommend that all employers, large and small, be encouraged to develop voluntary flexible workplace policies and programs that support employed caregivers. Government should work with employers to provide technical assistance and incentives such as tax advantages to develop and support a larger array of paid and unpaid leave options including: flex time, phased retirement and programs that are responsive to diverse caregiver populations.

Recommendation III

We recommend that a bipartisan commission on caregiving be established by the White House and Congress to bring visibility to the issues of caregiving and the importance of supporting caregivers for our families and our society. Furthermore, this commission should be charged with fostering research to improve assistance for employers and community organizations regarding outreach and support for caregivers.



Mini-Conference

*Voice of Business on the
Mature Workforce*



1615 H STREET, NW
WASHINGTON, D.C. 20062-2000

PHONE: 202-463-5525
FAX: 202-463-5308

July 29, 2005

*Ms. Dorcas Hardy
Policy Committee
White House Conference on Aging 2005
1 Massachusetts Avenue NW
Washington, DC 20001*

Dear Ms. Hardy:

On behalf of the White House Conference on Aging (WHCOA), the U.S. Chamber of Commerce's Center for Workforce Preparation (CWP), the Labor, Immigration & Employee Benefits Division (LIEB) and the John J. Heldrich Center for Workforce Development at Rutgers University organized a pre-WHCOA event on June 15, 2005 titled "Voice of Business on the Mature Workforce". This event changed the discussion on aging by adding the business perspective to the development of recommendations that WHOCA will present to the White House following its December 2005 national conference. The enclosed summary of our event offers four recommendations to the Conference as it considers opportunities for mature workers in the workplace of the future.

This year's conference takes place as the concerns of older workers are gaining nationwide attention. The U.S. Bureau of Labor Statistics estimates that the number of individuals aged 55 or older in the workforce will increase from 18.4 million in 2000 to 31.8 million in 2015. Further, given significant increases in longevity and a decline in birthrates, the number of current workers supporting the population of individuals over age 65 has declined from 7 to 1 in 1950, to 5 to 1 in 2000, and is projected to decline further to 3 to 1 by 2050. In addition, today's aging population is very diverse, encompassing people with a wide variety of education and skill levels, income, ethnic and racial characteristics as well as attachment to the labor force over time. For many older Americans, poverty and a lack of private retirement benefits are a reality. These demographics present

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extraordinary challenges for the United States, both today and in the future, in terms of its economy, workforce, social and health insurance programs, and competitiveness in a global economy.

At our June 15 event, over 100 executives from business, chamber, association and nonprofit organizations discussed their business perspectives and policies on mature workers. These leaders are actively involved in addressing workforce development issues in their communities and understand the importance of a skilled workforce to the nation's economy. Nationally recognized experts such as, Susan Meisinger, president and CEO of Society for Human Resource Management (SHRM), Bill Novelli, president and CEO of AARP, Ken Dychtwald, president of Age Wave, The Honorable Larry Craig (R-ID), former chair of the U.S. Senate Special Committee on Aging, and Steve Law, deputy secretary of the U.S. Department of Labor, presented their innovative and futuristic ideas on both the older worker options and the policies that will need to be put in place to support those options.

The first part of our pre-conference event focused on employment and education options for older workers, especially those that will provide a planned transition of retiring worker knowledge and skills. The second half of the event explored pensions and health care policy by studying their impact on employers that hire older workers and seniors seeking employment. The attached policy recommendations were developed using the Meridia Audience Response Polling system. Over 100 executives were asked and answered questions regarding their top 5 recommendations for effective change and opportunities for mature workers in the workplace of the future.

We recognize that the first Conference on Aging of the 21st Century is a significant opportunity to address the issues of today's seniors, and to focus on the 78 million baby boomers whose aging will change the face of America. The U.S. Chamber of Commerce and its partners are pleased to contribute to the development of 55 policy recommendations for consideration by the President and Congress. Again, thank you for the opportunity to participate in this important dialogue.

2005 WHITE HOUSE CONFERENCE ON AGING

FINAL REPORT APPENDIX

Sincerely,



Nataché Muschette
Director

Name of Event: “The Voice of Business on the Mature Workforce”

Date of Event: June 15, 2005

Location of Event: U.S. Chamber of Commerce, 1615 H Street, NW,
Washington, D.C. 20062

**Number of Persons
Attending:** 100

**Sponsoring
Organizations:** Center for Workforce Preparation
Labor, Immigration and Employee Benefit Division
U.S. Chamber of Commerce

AARP, Society for Human Resource Management, Monster,
American Public Transportation Association, CVS/Pharmacy,
Spherion, John J. Heldrich Center for Workforce
Development at Rutgers, The State University of New Jersey,
Meridia Audience Response

Contact Name: Natache Muschette, Director, Center for Workforce
Preparation

Telephone Number: 202-463-5781

Email: nmuschette@uschamber.com

Priority Issue #1: Flexibility in Retirement Plan Design and Management

Preserving and enhancing the private retirement system in the United States is important to the long-term financial security of the nation's ever-increasing older population, and to the ability of companies to remain competitive. A viable and workable national retirement income policy is not possible unless American employers have the flexibility to choose a retirement plan that is right for its business and workers.

Almost half of all American employers provide retirement benefits voluntarily to their employees. Today, traditional defined benefit pension systems help millions of Americans achieve retirement security by providing voluntary employer-funded retirement income that is guaranteed for a lifetime. These plans also provide employers with strong financial incentives that can be used to attract and retain talented workers. As of 1999, nearly 19 million retirees were receiving benefits from defined benefit plans with over \$119 billion in benefits paid out in that year alone. Given the low American personal savings rate, and the modest balances in American 401(k) plans, many U.S. workers rely on defined benefit plans for much of their financial security in their retirement years. But, as businesses and worker demographics change, employers are finding that their retirement plans, especially traditional defined benefit plans, need to change with the times.

Barriers:

Over the past year, more large employers have resorted to the termination or freezing of employer pension plans. In a study released in June 2005 by Wyatt Worldwide, about 11% of America's 1,000 largest companies offering traditional pensions terminated their plans or froze accrual of new benefits to workers in 2004, up from 7% in 2003. Nearly two-thirds of these large companies still sponsored pension plans, but 71 froze or terminated plans last year. While employers are increasingly exiting the traditional defined benefit system for a variety of reasons, many policymakers, employers, and government officials agree that inaction in addressing this need, as well as a lack of legal clarity and flexible solutions to retirement plan design, are large barriers to moving forward.

Proposed Solutions:

As the workplace, the economy, and businesses change, employers need more, rather than less, flexibility in the design and management of private pension plans, including support for new and possibly emerging "hybrid" defined benefit plans. Currently designed hybrid plans are viable solutions that offer defined benefit pensions that also incorporate features of defined contribution plans. They also offer the security of employer funding and assumption of investment risk, but with federal guarantees and required lifetime and spousal benefit options. Under Cash Balance Plans, employers provide annual pay credits to an employee's hypothetical account and interest credits on the account balance. Under Pension Equity Plans, employers provide credits for each year of service and these credits are multiplied by an employee's final payout to produce a lump-sum figure. Overall, cash balance and other hybrid plans are increasingly an important part of the defined benefit plan system and should be clarified and strongly endorsed.

Priority Issue #2: Removal of unnecessary and burdensome rules and regulations in the private pension system

Over the past year, serious concerns about the long-term solvency of private defined benefit pension plans — along with a desire to promote and strengthen private benefit plan sponsorship by business — have prompted legislative and executive branch interest. Recent attention to the aging workforce and a looming Social Security and pension crisis offers a unique opportunity to undertake meaningful pension reform to strengthen employer-sponsored retirement systems, and thus offer considerably more American families the stability that such plans provide. The value of employer-sponsored benefit plans to many American families is undeniable. A recent Heldrich Center (2005) study of American workers found that employees look to employer-sponsored pension plans for important financial support following retirement. It is clear that certain demographic and economic factors are changing the way Americans view retirement and work — factors that now require a new way of thinking and new public policies that appropriately address these changes

Barriers:

At present, pension reform and solvency are not yet possible but can still be achieved. Close to half of American employers offer voluntary retirement plans, and a majority would like to continue doing so. However, most employers feel restrained by pension and benefit regulations that get in the way. As debate continues on legislation and tax code issues, the business community is concerned that it will face increases in paperwork, reporting, and required payments through passage of new mandatory requirements and more unnecessary rules. Less flexibility and more complexity will only lead more businesses to abandon defined benefit plans, which is clearly not in the best interest of either the retirees or their companies. A significant obstacle to finding workable solutions is the failure to give American businesses enough flexibility, customization, and responsiveness to offer employees a retirement plan that balances the needs of employers and older workers.

Proposed Solutions:

For employers, addressing current disincentives, cumbersome paperwork, and removing unnecessary rules and regulations is a solution. Changes and adjustments need to be made to IRS, ERISA, and Social Security rules that match the reality of today's aging workforce and global business environment. Simplifying administrative and compliance requirements is a much needed step. For example, at present benefit plan sponsors are required to provide many different notices to participants. Streamlining these requirements would alleviate significant administrative burdens for employers. In addition, filing requirements are currently onerous and inflexible. Efforts need to be made to make filing requirements (such as paper vs. electronic) more flexible, rather than less.

Priority Issue #3: Encourage the Implementation of Phased Retirement Programs

As the baby boom generation enters retirement age, the traditional concept of retirement from work is changing. Recent surveys by Watson Wyatt (2004), AARP (2004), the MetLife Foundation/Civic Ventures (2005), and the Heldrich Center for Workforce Development (2005) show that American workers no longer believe in the work-save-retire model. Even when older workers retire, they are likely to continue working. As the demographics show, Americans will be living longer, healthier lives and therefore will be able to work longer. Consequently, many older workers are looking to make a gradual transition into full retirement by reducing their hours or job responsibilities. This gradual retirement arrangement is called “phased retirement” and has come to mean enabling older workers, through an arrangement with their employer, to reduce their work hours and responsibilities while maintaining certain full-time benefits.

Barriers:

Interest in phased retirement as an option for older workers is growing among both workers and employers, but a gap exists between what workers want and what employers choose to offer. According to the 2004 Watson Wyatt survey, more than 60% of surveyed workers are interested in working fewer hours late in their careers, but less than half expect their employers to provide this flexibility. On the employer side, a 2005 survey by the Society for Human Resource Management noted that the majority of surveyed organizations had made few or no changes to prepare for worker shortages due to baby boomer retirements, such as offering phased retirement, bridge employment, or reducing work hours. Several barriers exist that discourage phased retirement alternatives from becoming more widely accepted and implemented. These include but are not limited to pension regulations that currently prohibit defined benefit plans from offering payment benefits before normal retirement age, Social Security rules and incentives that discourage many employees from continuing work beyond traditional Social Security retirement age parameters, as well as employer and employee fears and confusion about the details of phased retirement.

Proposed Solutions:

For many mid-career workers and pre-retirees, as well as employers facing labor and talent shortages, phased retirement is a solution. Federal rules and regulations should be changed or established that allow phased retirement benefits to be implemented for employees of any age, years of service, or combination of age and service — under the terms of an employer’s voluntary retirement plan. Possible changes in federal rules and regulations include increased flexibility in several significant areas such as 1) an employer’s ability to modify a phased retirement program, allowing employers to adapt to changing economic and/or demographic trends, 2) in the age eligibility for early retirement under employer plans, so that any employees (i.e., those under the age of 59 1/2) eligible for early retirement may elect phased retirement, and 3) in the determination of the form of benefit distribution, including allowing lump-sum distributions.

Priority Issue #4: Create a National Bipartisan Commission on Aging and the Workforce

The demographics and economic situation of the aging American workforce present special challenges for U.S. employers, workers, policymakers and communities. The significant challenges that demand ongoing national attention include: 1) how to maximize ongoing workforce training and preparation opportunities for an aging population that effectively balances the requirements of employers and the income and civic/social engagement of older persons; 2) how to enable older workers with less skills and education (many of whom lack access to private retirement benefits) to participate in the labor force, especially with small and medium-sized employers in the high-growth, high-demand service sector; 3) how to systematically engage mid-career and older Americans in career counseling as well as lifetime learning and skill enhancement endeavors; 4) how to best make use of current and emerging technology to help older workers remain on the job; 5) how to effectively transform the current outdated education-employment-retirement model, including how to “phase” work and retirement so that older employees may remain active and employed through years of increasing longevity but balanced with knowledge transfer and increasing opportunities for mid-career workers and a more diverse population of younger workers; and 6) how to make workplace opportunities more flexible and desirable, and how to balance the needs of an aging workforce with the needs of employers.

Barriers:

Once every decade, the White House Conference on Aging provides an important national forum for addressing aging issues, including mature workers. Providing solutions for these challenges calls for a sustained effort, with an ongoing review of possible alternatives between sessions of the White House Conference on Aging. With the impending retirement of the baby boom generation and the challenges that generational shifts pose for employers and public policymakers, the lack of an organized effort to address these national issues will be a barrier to effective policy solutions.

Proposed Solutions:

Responding to the need for longer term attention to this issue should be a bipartisan group of 18 of the nation’s leading experts on older workers — representing the ranks of industry, government, academia, labor, and workforce development — to join together to form a National Bipartisan Commission on Aging and the Workforce. The Commission would be charged with examining the aging workforce in depth, making recommendations to improve opportunities for older workers in the American workplace over the next 10 years and suggesting active demonstration projects that would develop responsive strategies that focus on retirement, re-education and re-careering America’s mature worker population. The Commission’s work would be open to the public, and members would seek ways to keep the public involved and informed. Ten members should be affiliated with the business community. If considered, the U.S. Chamber of Commerce’s Center for Workforce Preparation is posed to develop and direct this Commission with the support of the White House.



Mini-Conference

Nutrition

2005 White House Conference on Aging Post-Event Summary Report

Name of Event: White House Conference on Aging Mini-Conference on Nutrition

Date of Event: Wednesday, June 29, 2005

Location of Event: Hotel Washington, Washington, DC

Number of Persons Attending: 250

Sponsoring Organizations: National Association of Nutrition and Aging Services Programs; American Dietetic Association; National Resource Center on Nutrition, Physical Activity and Aging; Meals on Wheels Association of America; National Council on the Aging; American Society for Clinical Nutrition; National Association of Area Agencies on Aging; Society for Nutrition Education; National Association of State Units on Aging; Association of Nutrition Services Agencies; Consultant Dietitians in Health Care Facilities; Gerontological Nutritionists; Tufts University Jean Mayer USDA Human Nutrition Research Center on Aging

Contact Name: Emily Ross **Phone Number:** (410)672-5823 **Email:** eross@matzblancato.com

Priority Issue #1:

Evaluating the cost effectiveness of the Older Americans Act Nutrition Programs.

Specific Issue: Evaluation of the cost effectiveness of the Older Americans Act Nutrition Program in terms of its roles today in health promotion, nutrition risk reduction, chronic disease management, reduction of hospitalizations, lengths of stay, and re-hospitalizations, delay of nursing home placements, and overall prevention of morbidity and mortality.

Barriers/Background & Rationale:

1. Older adults have a right to a healthful diet, with access to a broad array of appropriate, culturally sensitive food and nutrition services. Not all older adults in our country have been afforded this right.
 - a. Only 9% of poor older adults' diets are categorized as good based on the USDA Healthy Eating Index.¹
 - b. Malnutrition in older adults is estimated at 20-60% in home care and at 40-85% in nursing homes.²
 - c. About 40% of community-residing persons 65 years and older have inadequate nutrient intakes.³
 - d. There is a close connection between inadequate income and hunger. Estimates of food insecurity and hunger in community residing older adults range from 6-16%.⁴
 - i. Definitions:⁵
 1. *Food insecurity* exists when the availability of nutritionally adequate and safe foods or the ability to acquire acceptable foods in a socially acceptable ways is limited or uncertain.
 2. *Hunger* is the uneasy or painful sensation caused by a lack of food. It is a potential consequence of food insecurity.
 3. *Poverty threshold* is \$9,060 for a single individual over age 65 and \$11,418 for two-person householders over age 65.⁶
 - e. Especially vulnerable to food insecurity and hunger are the 24% of older women and 14% of older men who live below 135% of poverty,⁷ as well as the 21% of older women and 16% of older men who live alone. Women, those over age 75, and minorities are the most likely to live in poverty and alone.
2. Diet quality plays a major role in preventing, delaying onset and managing chronic diseases.⁸ Both the number of older adults and cost of health care are increasing.
 - a. Increasing health costs are related to chronic diseases in which nutrition interventions have been proven effective. About 87% of older Americans either have diabetes, hypertension, dyslipidemia or a combination of these chronic diseases. These costly conditions can be ameliorated with appropriate nutrition interventions.

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3. The Older Americans Nutrition Program, in existence for 35 years, has not been comprehensively evaluated by the Food and Nutrition Board (FNB) in relation to nutrition and health, quality of life, and independence. Since there were very few nutrition questions in recent national outcome studies, the cost effectiveness of the food and nutrition services may be underestimated.⁹ However, the cost of one day in a hospital equals the cost of one year of Nutrition Program meals, based on 2003 reported total expenditures and number of home-delivered meals provided by States.¹⁰
 - a. Other federal food and nutrition assistance programs have been regularly evaluated and re-evaluated in whole and/or in part by the FNB.
 - i. Since 2000, 7 reports were published on the USDA Special Supplemental Food Program for Women, Infants and Children, commonly called WIC. The most recent is *WIC Food Packages: Time for a Change*.¹¹ Both WIC and OAA Nutrition Program began in the early 1970s and serve similar purposes. Yet, WIC currently receives over 5 times more funding through Congressional appropriations than the OAA Nutrition Program. Other FNB studies underway or recently completed include Food Marketing and Diets of Children and Youth, Assessing Worksite Wellness Program Needs, Preventing Childhood Obesity—Health in the Balance. FNB is now evaluating the National School Food Program.
 - ii. The FNB at the Institute of Medicine, the National Academies¹² produces widely disseminated reports that provide government, industry, academia, and the public with the best available information and recommendations about food safety, food security, and nutrition, thereby promoting public health and preventing diet-related diseases. Studies have served as the basis for national policy by being thorough, balanced, and objective. National policy makers need advice on nutrition and food science in relation to health to ensure that decisions are supported by the best scientific analysis.
 - b. By 2030, the number of older adults will exceed the number of school-age children in 10 states—FL, PA, VT, WY, ND, DE, NM, MT, MA, WV. Five years ago, no state had more people 65+ than those under 18. Twenty-six states will double their 65+ population by 2030, when the oldest Baby Boomers enter their 80s. Growth in the 65+ population will equal 3.5 times the US growth as a whole. This demographic shift has enormous economic and political implications. Competition will increase between our oldest and youngest citizens for tax dollars.¹³

References: See endnotes.

Proposed Solution: The Food and Nutrition Board at The National Academies should conduct an evidence-based study of the cost effectiveness of the Older Americans Act Nutrition Program.

Priority Issue #2: Nutrition and Physical Activity Resource Center

Specific Issue: Resource Center(s) for Nutrition and Physical Activity through the Older Americans Act

Barriers/Background & Rationale:

1. Older adults are at great risk of malnutrition and sedentariness.¹⁴ Diet quality and physical activity play major roles in preventing, delaying onset and managing chronic diseases.^{15,16} About 87% of older Americans either have diabetes, hypertension, dyslipidemia or a combination of these chronic diseases. These costly conditions can be ameliorated with appropriate nutrition interventions and more active lifestyles.
 - a. Both the number of older adults and the cost of health care are increasing. Increasing health costs are related to chronic diseases in which nutrition and physical activity play definite preventive roles.¹⁴⁻¹⁶
 - b. The new national focus on healthy lifestyles was prompted by the American obesity epidemic along with rising health care costs. *HealthierUS* includes nutritious diets and physical activity as strategies for health promotion and disease prevention.¹⁷

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2. The Older Americans Act (OAA) Nutrition Program is the largest program administered by the US Administration on Aging. Yet, there is no requirement for the Assistant Secretary to fund a Resource Center for Nutrition and Physical Activity.
 - a. The OAA Nutrition Program is important in health promotion and disease prevention. It is cost-effective. One day in a hospital equals the cost of one year of Nutrition Program meals, based on 2003 reported total expenditures and number of home-delivered meals provided by States.¹⁸ In 2005, OAA Nutrition Program allocations for Title III C-1 (congregate meals), C-2 (home-delivered meals), and Nutrition Services Incentive Program were \$718,483,690 or **46%** of total agency funding.
 - b. Funding a Resource Center for Nutrition and Physical Activity is at the discretion of the Assistant Secretary for Aging. The current Assistant Secretary for Aging issued a competitive Request for Proposals for a National Resource Center on Nutrition, Physical Activity and Aging in 2003. Florida International University was awarded a 3-year grant ending in FY06. Previously it was funded via Congressional earmarks.
 - c. The Older Americans Act¹⁹ requires the Assistant Secretary for Aging to make grants or contracts for three Resource Centers at modest cost. OAA designated Resource Centers focus on Native Americans (Section 418), legal assistance (Section 420), and ombudsman (Section 421). Each Resource Center relates to a relatively small program area and only **1.5-3%** of total agency funding.
3. The multi-facets of food and nutrition services for older adults range from food safety, foodservice operations, nutrition assessment and care planning, culturally appropriate menus and special diets, outcome-oriented nutrition education, counseling, and other services.²⁰ Designing and promoting physical activity for older adults likewise has many facets. A Resource Center or Centers would focus on different aspects of nutrition and physical activity for older adults. More than one Resource Center should be mandated to capitalize on nutrition and physical activity for health promotion and disease prevention.
4. The lack of a food and nutrition infrastructure for the largest federally funded nutrition assistance program for older adults is in direct contrast to all USDA federal nutrition programs.²¹ The Aging Network needs technical assistance, access to the latest scientific information, guidance to establish outcome-based model programs, and help to implement newly released federal guidelines, such as the Dietary Reference Intakes (DRIs) and *Dietary Guidelines for Americans*, as well as national physical activity recommendations targeted to older adults. A Resource Center or Centers can assure that the Aging Network technical assistance needs are met. Another goal is to promote better cooperation between the food industry and the OAA Nutrition Program. Development and/or reformulation of more nutritious food products would expand menu options, food quality, and cost-effectiveness.

Thus, the recommended language for a new section in the Older Americans Act is:

(NEW) Sec xxx. RESOURCE CENTERS ON NUTRITION AND PHYSICAL ACTIVITY.

(a) ESTABLISHMENT-

(1) IN GENERAL - The Assistant Secretary shall make grants or enter into contracts with eligible entities to establish and operate one or more Resource Center(s) on Nutrition and Physical Activity (referred to in this section as "Resource Centers"), targeted to older Americans. The Assistant Secretary shall make such grant(s) or enter into such contract(s) for periods of not less than 3 years.

(2) FUNCTIONS -

- A. IN GENERAL -** Each Resource Center that receives funds under this section shall
 - i. Gather and disseminate information on nutrition and physical activity;
 - ii. Perform research and disseminate findings and best practices; and,
 - iii. Provide technical assistance and training to entities that provide services to older adults.
- B. AREAS OF CONCERN -** In conducting the functions of subparagraph A, the Resource Center(s) shall focus on priority areas of concern of older Americans which shall be
 - i. Health promotion and disease prevention through nutrition and physical activity;
 - ii. Home and community-based services to help rebalance long term care and reduce Medicare and Medicaid costs;
 - iii. Special population needs, including persons with obesity, diabetes, heart disease, osteoporosis, minorities, ethnicities, and any other populations determined by the Assistant Secretary.
 - iv. Food safety, food insecurity and food service operations; and,

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v. Other problems or issues the Assistant Secretary determines are of particular importance to older individuals.

(3) PREFERENCE - In awarding grants and entering into contracts under paragraph (1), the Assistant Secretary shall give preference to institutions of higher education that have conducted research on, and assessments of, the nutrition and physical activity characteristics and needs of older Americans, and those that have the expertise of registered dietitians. Preference will be given to those institutions of higher education serving minorities

(4) CONSULTATION - In determining the type of information to be sought from, and activities to be performed by the Resource Center(s), the Assistant Secretary shall consult with national organizations, such as the American Dietetic Association, Society for Nutrition Education, American Society for Nutrition, that have expertise in nutrition.

(5) ELIGIBLE ENTITIES - To be eligible to receive a grant or enter into a contract under paragraph (1), an entity shall be an institute of higher education with experience conducting research and assessment on the nutrition and physical activity needs of older individuals.

References: See endnotes.

Proposed Solution: The Older Americans Act shall specify one or more Nutrition and Physical Activity Resource Centers.

**Priority Issue #3:
Integration of food and nutrition into Medicaid and other state and local Home and Community Based Services.**

Specific Issue: Integration of food and nutrition into Medicaid and other state and local Home and Community Based Services as cost effective core services using new federal funds as incentives that allow state flexibility.

Barriers/Background & Rationale:

1. Food and nutrition services are essential to keeping Medicaid and Medicare recipients healthy, independent, out of nursing homes and living in the community.²² Dual Medicare-Medicaid eligibles constitute over 42% of all state Medicaid funding.
2. Medicaid reform in states is attempting to contain the soaring costs of this state-federal healthcare program for the poor. Medicaid spending increased from 8% in 1985 to 20% in 2003, making it the single largest item in state budgets.²³ Medicaid is the budget-busting program in many states today.
3. Current federal Medicaid guidelines are broad. They should be modified to include national requirements that ensure access to fundamental food and nutrition services in Home and Community Based Services (HCBS)²⁴ and provide federal funds as incentives while preserving state flexibility.
4. Some States provide food and nutrition in HCBS. State cost cutting, especially in Medicaid, threatens the provision of or expansion of these services despite their fundamental nature.²⁵
 - a. AK, IA, MD, OR and other states provide home delivered meals. IA and MD provide medical nutrition therapy (nutrition care planning, nutrition assessment and dietetic instruction) and FL provides home delivered meals, dietitian services, nutrition assessment and nutrition risk reduction.
5. The US Administration on Aging administers the largest federal nutrition assistance program for older adults, the Older Americans Act (OAA) Nutrition Program. The home-delivered component is commonly called *meals-on-wheels*. The Administration on Aging has a strategic goal of helping older adults access an integrated array of health and social support.²⁶
 - a. The OAA Nutrition Program provides on average 5 meals a week to homebound older adults.²⁷ In FY 2003, about 143 million home delivered meals were served to 1 million home bound. Over 40% of the Nutrition Programs reported waiting lists for home delivered meals.²⁸
 - b. Many older adults who qualify as "nursing home appropriate" under Medicaid Waivers have one or more nutrition-related chronic diseases and functional limitations. These often inhibit the ability to grocery shop, store, prepare, and/or independently eat nutritious safe meals.
 - c. The OAA Nutrition Program should be expanded where possible. Five meals a week is inadequate for many home-bound older adults. Yet, the cost of one day in a hospital equals the cost of one year of Nutrition Program meals, based on 2003 reported total expenditures and number of home-delivered meals provided by States.²⁹

6. States are moving away from the bias of paying for nursing home care by creating community-based options.³⁰ It is essential that food and nutrition services become part of comprehensive care in HCBS. Criteria should be established to determine the number of meals, snacks, supplements, and nutrition support that each eligible individual requires. A nutrition monitoring mechanism should be established as part of HCBS, so that the common, devastating nutritional problems (weight loss, dehydration, pressure ulcers) often seen upon admission to nursing homes and other institutional settings do not become widespread among the frail homebound in community settings.
7. A national monitoring system that uses existing state medical assistance data should be established to ensure that older adults, especially the homebound and those who live alone, have access to not only health care, but to adequate safe food and nutrition services.³¹ The monitoring system could be modeled on the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) Services that began collecting state data in 1990 under a revision of the Social Security Act. EPSDT monitors the health care of Medicaid-eligible children.
 - a. EPSDT is a comprehensive and preventive child health program for Medicaid beneficiaries under age 21. Defined by federal law in 1989, it consists of two mutually supportive, operational components³²:
 - i. Assuring the availability and accessibility of required health care resources, and
 - ii. Helping Medicaid recipients and their parents or guardians effectively use these resources.

Thus, Medicaid reform shall emphasize the fundamental nature of food and nutrition services given their essential role in health promotion, disease prevention, risk reduction, and disease management. These services are essential to maximizing independence and quality of life, and will thereby reduce Medicaid and Medicare expenditures. EPSDT can be the model for establishing a monitoring system for our aging population. The Medicaid Commission recently enacted by HHS Secretary Leavitt shall consider the cost effectiveness and preventive nature of food and nutrition programs.

References: See endnotes.

Proposed Solution: Medicaid and other state and local Home and Community Based Services shall integrate food and nutrition as cost effective core services using new federal funds as incentives that allow state flexibility.³³

RESOLUTION #1

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2005 WHITE HOUSE CONFERENCE ON AGING

FINAL REPORT APPENDIX

RESOLUTION #2

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¹⁵ Institute of Medicine, Committee on Nutrition Services for Medicare Beneficiaries. *The Role of Nutrition in Maintaining Health in the Nation's Elderly: Evaluating Coverage of Nutrition Services for the Medicare Population*. Washington, DC: Nat'l Academy Press; 2000.

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RESOLUTION #3

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Mini-Conference

*Economic Incentives to Increase
Retirement Savings by Individuals
and Through Employment-Based
Retirement Plans*

Final Report and Recommendations by the

**Mini-Conference on Incentives to Increase
Retirement Savings By Individuals
and Through Employment-Based Retirement Plans**

July 12, 2005

**Mini-conference held at the headquarters of the
National Rural Electric Cooperative Association
Arlington, Virginia**

**110 attendees representing large and small employers (both private and
public sector), unions, rural cooperatives, academia, benefits and
compensation professionals and members of the public**

Sponsored by:
American Benefits Council
ERISA Industry Committee
Employee Benefit Research Institute
International Foundation of Employee Benefit Plans
National Rural Electric Cooperative Association
WorldatWork

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Priority Issue #1

The White House Conference on Aging should support policies that promote the expansion of defined benefit pension plans as an important benefit that both offers retirement income and facilitates orderly planning particularly for older workers and their employers.

Background

A defined benefit pension plan (DB plan) is an arrangement that provides a retirement benefit calculated according to a specific formula set out in the plan document. Contributions to single-employer DB plans are made by the employer who bears the risk of investment. A defined benefit is required to be offered in the form of an annuity but may provide the option of a lump sum. DB plans provide employees funded retirement benefits that are not dependent on their ability or inclination to save nor on the fluctuations of the financial markets before, at, or after retirement. For employers, DB plans are a means of attracting and retaining employees and are an important element of workforce management.

Barriers to Implementation and Maintenance of Defined Benefit Pension Plans:

Increased Regulation and the Cost of Administration: Employee benefit plans are subject to over 2,000 pages of statutes and over 4,500 pages of regulations. DB plans consume the bulk of these directives. The complexity of excessive regulation is a significant barrier to implementing and maintaining DB plans since sponsors are subject to significant expenses in order to maintain actuarial, accounting, communication, and administrative consultants and legal counsel necessary for compliance. Increased complexity makes it more difficult for employees to understand the intrinsic value of DB plans and DB plan sponsors often face significant competitive disadvantages against companies not sponsoring DB plans. As the regulatory barriers increase, DB plans have become endangered. In 2004, for example, only 26,000 plans covered 17 percent of the private workforce compared to 1978 when 128,000 DB plans covered 41 percent.

Predictability of Funding Requirements: By far, the most critical factors in determining required contributions to defined benefit plans are the interest rates mandated by statute (e.g., 30-year Treasury bonds or corporate bond rates) that fluctuate widely from year to year. Since DB plans are long-term commitments, employers depend upon the ability to average mandated rates over a four-year period to “smooth” volatile interest rate fluctuations. As an additional safeguard, employers can accumulate credits for excess plan contributions in “rich” years to offset the inability to fund a plan in other years (e.g., credit balances). The inability to smooth fluctuations in required contributions would be a considerable barrier to implementing or maintaining DB plans because stability and predictability are critical to sponsorship of such long-term financial commitments.

Lack of Transparency and Relevance to Plan Participants: Few workers can calculate their traditional defined retirement benefit at different stages of their careers. Newer hybrid defined benefit plans express the benefit as if it were a savings plan so participants understand their benefit at any time. Hybrid plans also provide greater benefit portability to the growing number

of employees who do not spend their entire careers with one employer. While hybrid arrangements have been around for almost two decades, their validity has been questioned by a single court case contradicting other courts that have validated the plans. Unless the law clarifies that hybrid plans are valid arrangements, the legal limbo will continue to be a significant barrier to transparency, portability, and relevance of the benefits offered by defined benefit plans.

Increased Worker Mobility: Many workers would like to continue working on a reduced basis past “early” and even “normal” retirement age, especially since they are likely to live longer than earlier generations and may outlive their retirement assets. Current law places significant barriers on older workers who wish to continue working on a “phased retirement” basis.

Proposed Solutions:

- Eliminate barriers to and encourage long-term and predictable funding of defined benefit plans by permitting reasonable techniques for averaging or smoothing of contribution requirements over a four year period.
- Permit reasonable use of credit balances and smoothing of asset values in meeting funding obligations.
- Encourage plan sponsors to increase contributions to plans during favorable economic times in order to reduce funding pressures during economic downturns, in particular by eliminating tax penalties for making “excess” contributions.
- Validate that hybrid arrangements are lawful.
- Establish “clearinghouse” model plans (similar to multi-employer plans used in collective bargaining arrangements) so that workers who change jobs frequently and their employers (including those that do not directly sponsor a plan) can voluntarily contribute to one portable defined benefit or defined contribution plan.
- Eliminate the barriers in pension law that prevent older workers from choosing “phased retirement” and employers from contracting with former employees after they retire.

Priority Issue # 2

The White House Conference on Aging should support policies that allow and encourage individuals to participate more readily and effectively in 401(k) and other defined contribution retirement savings plans.

Barriers to Implementation of and Participation in Defined Contribution Plans:

Lack of Sufficient Financial Literacy: Defined contribution plans are employer-sponsored arrangements (such as 401(k) and 403(b) plans) in which the benefit at retirement consists of the cumulative contributions made to the plan plus any earnings. Often, most of the money in these plans comes from compensation the employee elects to contribute. The employee decides how to invest the money in the choices offered by the plan. Many employees strive to make informed economic and financial decisions but are not always skillful in planning for the future. Some never elect to contribute to the plan in the first place.

Obstacles to Automatic Enrollment: Studies show that automatic enrollment, under which employees automatically participate in defined contribution plans unless they opt out, significantly increases participation in these plans. Particularly among low- and moderate-income workers, automatic enrollment typically raises employee 401(k) participation rates from the 60-65 percent range to the 85 percent plus range (Choi et al, *National Tax Journal*, June 2004). Other automatic features such as systematic increases in contributions (unless the employee opts out) and allocation of contributions into appropriate investment funds can greatly increase the assets accumulated for retirement.

Although current law allows employers to implement automatic enrollment features, a number of significant obstacles remain and some employers are therefore hesitant to adopt these designs. Under existing guidance, the employer may not rely on the relief provided by ERISA Section 404(c) (which places legal responsibility with the participants for investment performance in employee-directed defined contribution plans) for automatic enrollment plans with default investments. Moreover, sufficient regulatory guidance has not been provided to employers on selecting a default investment that complies with fiduciary responsibilities. Thus, many employers choose low-risk or risk-free investments, that consequently have low returns for the workers. Finally, certain state wage withholding laws potentially complicate automatic enrollment by prohibiting withholding from the workers' wages without their affirmative consent.

The current barriers could be addressed through appropriate regulatory guidance concerning default investments and also legislative clarification that state wage withholding laws do not prohibit automatic enrollment. In addition, employers would have an incentive to implement automatic enrollment if "safe harbors" were developed to avoid complex and costly testing requirements. In addition, greater efforts to promote financial literacy and knowledge about retirement income needs will permit individuals to more readily and effectively save for retirement.

Proposed Solutions:

- Encourage employers, through clarifying legislation or regulatory guidance, to implement defined contribution plans that automatically do the following unless the workers opt out:
 - Enroll workers in the plan and increase contributions over time
 - Allocate contributions to an appropriate default fund
- Provide incentives to employers to implement automatic enrollment through the use of safe harbors that will reduce administrative costs
- Clarify that state wage withholding laws do not prohibit automatic enrollment
- Clarify that default contributions may be made to a wider range of investments
- Promote knowledge about retirement income needs by encouraging employers to facilitate financial literacy programs
- Create a national emphasis in our educational system on the value of saving and on retirement income needs, through such means as making financial literacy a criteria for high school graduation

Priority Issue #3

The White House Conference on Aging should promote policies that help control health care costs and make possible the funding of retiree health care needs.

Barriers:

Persistent and Unsustainable Cost Increases: The persistent and unsustainable double-digit increase in health care costs remains a major factor eroding retiree coverage. According to the 2004 Kaiser/HRET Survey of Employer-Sponsored Health Benefits, the share of employers (with 200 or more employees) offering retiree health coverage fell from 66 percent in 1988 to 36 percent in 2004. Retiree health costs increased by an estimated 12.7 percent from 2003 to 2004 according to a recent report by Kaiser and Hewitt Associates, significantly outpacing inflation or wage growth for the same period and running slightly higher than the annual increase in active employee health costs. While employers continue to bear substantial costs, retirees are assuming an increasing percentage and many now pay the full premium.

Expanding and Unrestricted Participant Care Requirements: Numerous factors contribute to the health care affordability crisis, particularly for retirees. Some factors are difficult to influence such as the “Baby Boom” generation’s increasing health care needs as it reaches retirement age or health consumers’ expectations, regardless of cost, that services be immediately available. Another significant factor is the lack of uniform measures of the quality and efficiency of health care services. Without such measures, large health care purchasers, such as governments, employers and health plans, often waste health care dollars on unnecessary or ineffective care.

Need for Quality and Efficiency Measures: Quality and efficiency measures would also assist consumers in selecting care. Government, employer and health plan purchasers would be able to reward providers who consistently deliver appropriate care. These “value-based purchasing” or “pay-for-performance” efforts involve numerous stakeholders in the health system. They are, however, unlikely to succeed without the federal government, the largest of all health purchasers, moving to adopt this approach over the next several years.

Little Savings for Future Health Care Needs: In addition, while a small percentage of Americans will leave employment with retiree health coverage, fewer still are saving while actively employed for their future health care needs. Nor do the appropriate tax-advantaged savings vehicles yet exist to help them. According to the Employee Benefit Research Institute (EBRI), each individual who expects to live to age 85 and who retires without health care coverage will need \$223,000 for costs not covered by Medicare. (EBRI Issue Brief No. 254, *Retiree Health Benefits: Savings Needed to Fund Health Care in Retirement*, Feb. 2003.) This figure does not include coverage costs for those retiring prior to age 65 Medicare eligibility.

Tax-Advantaged Savings Vehicles Required: Those attempting to save for their retiree health care needs face additional hurdles. For example, funds accumulated in 401(k) plans or traditional Individual Retirement Accounts (IRAs) are taxed at distribution, requiring retirees to pay after-tax dollars for health insurance premiums or other medical expenses. These could be financed by pre-tax spending if these costs were incurred during working years. The tax code also contains

no provisions to directly encourage lifelong savings for individual future health care needs through tax-advantaged savings vehicles, similar to 401(k) plans, IRAs, or 529 college savings plans. Finally, newly authorized Health Savings Accounts (HSAs) potentially could help more Americans save for retiree health expenses, but strict limits on annual contribution amounts prohibit sufficient savings accumulation for post-employment health costs.

Proposed Solutions:

- Promote the development of health care quality outcome measures
- Promote the disclosure of health provider outcomes so that individual, employer, health plan and government purchasers can make decisions based upon quality, cost and efficiency of care
- Establish flexible tax-advantaged retiree medical savings vehicles
- Establish medical savings vehicles for retiree health needs that apply equally to all individuals regardless of employment status
- Permit individuals to accumulate additional funds within their employer-sponsored retirement savings account, or Individual Retirement Account, and to reallocate existing balances in these arrangements for retiree health care purposes
- Modify flexible spending accounts to encourage individuals to save for retiree health care needs by eliminating the so-called “use it or lose it” rule
- Eliminate disincentives for employers to establish or contribute to retiree medical savings vehicles due to restrictive interpretations of the Age Discrimination in Employment Act
- Allow individuals and employers to direct a portion of their retirement savings plan contributions to a subaccount that could be withdrawn on a tax-free basis after retirement to pay for qualified medical expenses



Mini-Conference

Financial Literacy



Final Report and Recommendations by the

Mini-Conference on Financial Literacy throughout the Life Cycle

July 14, 2005

Capitol View Conference Center
Washington, DC

2005 White House Conference on Aging Mini-Conference on Financial Literacy throughout the Life Cycle: Policy Recommendations:

FIRST LEVEL RECOMMENDATIONS

Issue #1:

Americans generally do not have adequate financial literacy to make the necessary complex and demanding financial decisions they face.

Background:

Americans don't adequately understand issues such as assets needed for retirement, unsafe levels of debt, or how to differentiate financial products and providers. The national savings rate is at a disturbingly low level while consumer debt is alarmingly high. Many Americans feel that consumer spending is necessary, but that planning for their financial future is not. Too many Americans are ignorant of, or have false expectations about, the benefits of government-provided retirement security programs, such as Social Security and Medicare.

Government officials, actuaries, and other professionals who are interested in Americans' financial well-being believe behavioral change is needed. However, central leadership and funding is lacking to effect this change. Government, nonprofit organizations, and business have not yet fulfilled this leadership and funding role. Employers that do recognize the need are hesitant to implement wide-scale financial education due to uncertainty about complex regulations and potential liability. Community and workplace-based programs struggle for proper funding and don't have good models of success to follow.

Recommendation:

Launch and Fund a Federal Government-Sponsored Social Marketing Campaign

This campaign should incorporate and build upon the highly successful ChoosetoSave® education program and be designed to provide financial education that fosters measurable behavioral change. The changes in public behavior should relate to the financial decisions Americans must make to achieve their hopes and aspirations. The national campaign should use consistent messages, reach people when the topic is of concern, and be segmented to be culturally sensitive so as to ensure the messages are heard and understood.

The campaign should be national in scope and begin with the establishment of a President's Council on Fiscal Fitness with a highly visible or celebrity champion. This Council should be a permanently funded federal government office with central authority to conduct the federal government's national campaign, conduct research on best practices for financial education programs, and set national financial literacy policies.

Issue #2:

Americans too often are not good at managing their hard-earned assets during retirement.

Background:

Americans today are living longer and spending much more time in retirement than ever before. As a result, they must make many more and increasingly complex financial decisions. One of the most pressing issues to address is helping Americans manage their assets to ensure income throughout retirement. People should have a permanent stream of income throughout retirement beyond just Social Security.

Recommendation:

Expand the Use of Products That Ensure a Stream of Income throughout Retirement

This could be accomplished by providing a 50 percent exclusion from income tax for life annuity payments and a safe-harbor for employer plans that offer this product as an option.

Issue #3:

Americans too often are the victims of financial fraud and exploitation.

Background:

Financial fraud and exploitation can negate the savings efforts of Americans during their working years by literally wiping out their assets. American consumers and government officials too often do not recognize that financial fraud and exploitation is a problem.

The lack of standardized information is a key problem. In addition, why Americans become more susceptible to fraud as they age is not widely studied. There is a general lack of understanding about how financial fraud and exploitation is happening, who is doing it, and which individuals are most at risk.

Due to scarce funding and inattention, those working to prevent and prosecute financial fraud lack training and support materials. Beyond that, coordination among professionals is weak or nonexistent and there is a lack of data to demonstrate what approaches are effective. As well, there are different paradigms, experiences, and professional backgrounds and values. This leads to a lack of professional expertise; uniform definitions, vocabulary, and concepts; distribution channels; and evaluation of behavior change.

Recommendation:

Establish a National Center on Financial Fraud and Exploitation

This center, in coordination with the proposed President's Council on Fiscal Fitness, should act as a clearinghouse and think-tank on financial fraud issues. It would identify, collect, and evaluate existing materials and resources, determine any unmet needs, and develop new materials and programs. It should also use research to develop model materials and laws and regulations.

SECOND LEVEL RECOMMENDATIONS

Issue #4:

Americans' lack of financial literacy has an immediate impact on both individuals and the economy while improving the nation's financial literacy and changing public financial behavior will take generations.

Background:

Currently, the personal savings rate is alarmingly low. Cultural predilection to spend and not save will be hard to correct in the short term. If that behavior does begin to change, Americans will encounter a lack of easily understandable, mass-market investment and insurance products. For those who believe they need assistance, there is no easy method for consumers to evaluate and select a financial advisor. Competent advisors for all income levels are not widely available.

One of the most effective places for Americans to save is the workplace. However, among employees who do have access to a workplace-based retirement savings plan participation is low. As changing demographics and budget deficits will put a strain on government health and retirement support programs, innovative solutions are necessary to address short-term needs while longer-term behavior is changed.

Recommendation:Increase the Prevalence of Automatic and “Opt-Out-Only” Savings Features

This should be accomplished by introducing a three-percent mandatory Social Security add-on individual account, safe-harbors for defined contribution automatic features including enrollment, escalation of contribution, and allocation to life-cycle funds, payroll deduction IRAs, and allowing tax refunds to be directly deposited in retirement accounts. Policies should increase employers’ ease of implementation, management, and control of retirement accounts in order to reduce liabilities and the costs involved.

Issue #5:

Americans too often are the victims of financial fraud and exploitation.

Background:

There is a lack of education at all ages about financial fraud and exploitation. It is perceived to be a small issue compared to other social problems. Therefore, there is little funding for or coordination in, efforts to alert Americans about new and existing financial fraud and exploitation schemes.

Recommendation:Create and Fund a National Strategy to Reduce Financial Fraud and Exploitation

This should be accomplished by instituting, within any financial education campaign coming from the proposed President’s Council on Fiscal Fitness, a specific strategy to combat financial fraud and exploitation. This strategy should include an educational program across lifespan and be conducted in schools, at workplace settings, and through faith-based organizations and interest and affinity groups. This education should come from teachers, government agencies, law enforcement officials, and financial services companies. The strategy should coordinate this education with proper law enforcement preventative and prosecutorial actions.

Issue #6:

The United States does not address financial literacy at the most important stage in life when it can be learned by most individuals: during elementary and high school years.

Background:

Early education is critical to achieving national financial literacy. Personal finance is not widely included in state curricula standards due to a variety of factors. The No Child Left Behind law encourages teaching to specific standards, but these currently do not adequately cover personal finance. Also, financial literacy is not a priority issue for the U.S. Department of Education or state and local education officials. Therefore, financial education is not given the importance or time it needs in the classroom.

Additionally, where classroom curricula do exist, there is often not adequate funding for its costs. There is a shortage of qualified and competent teachers in financial education. Training these teachers requires funding, as do the necessary classroom materials.

Recommendation:**The Federal Government Should Mandate Financial Literacy Courses as a Requirement for High School Graduation**

This mandate should include age-appropriate financial education in all school curricula and should also provide funding for teacher training and material development through the U.S. Department of Education, coordinated with the proposed President's Council on Fiscal Fitness.

This report and recommendations are submitted by the White House Conference on Aging Mini-Conference on Financial Literacy throughout the Life Cycle Planning Organization:

Employee Benefit Research Institute
Dallas L. Salisbury, President & CEO



Mini-Conference

Geriatric Health Care Workforce

**2005 White House Conference on Aging
Final Report and Recommendations by the
Mini-Conference on Geriatric Health Care Workforce Issues**
held on
July 16, 2005
at the
Bethesda North Marriott Hotel and Conference Center
Bethesda, MD

Executive Summary

The public and private sectors should take specific and directed action to address the increasing need for a well-trained geriatric health care workforce. Through Federal leadership and public and private partnerships, this effort should ensure the highest quality of life for America's aging population. The following three recommendations are proposed to address these policy goals.

Recommendation 1: Educate and train all health care professionals, health professions students, and direct care workers in the requisite knowledge, skills, and attitudes to provide patient/person-centered, evidence-based, and coordinated interdisciplinary geriatric care and aging services. This care must be available across the continuum in ambulatory, acute, home and community-based services, assisted living, and long-term care settings.

Recommendation 2: Support the recruitment and retention of an adequate number of health care professionals and direct care workers, and faculty to train the health care workforce to provide patient/person-centered, evidence-based, and interdisciplinary geriatric care and aging services.

Recommendation 3: Provide reimbursement support through the Centers for Medicare and Medicaid Services for interdisciplinary geriatric teams to provide patient/person centered, evidence-based care in ambulatory, acute, home and community-based services, assisted living, and long-term care settings.

Priority #1: Educating the Health Care Workforce

Background: Despite older Americans' huge demand for health services and resources, most health care professionals and direct care workers are unprepared to provide health care for the aging population either as a specialist in geriatrics or as a generalist with basic geriatric education and training. The current shortage of geriatricians is expected to worsen. Today there are approximately 6,600 certified geriatricians when it is projected that 36,000 geriatricians are needed by 2030. Less than 1% of nurses are certified in geriatrics and only 3% of advanced practice nurses specialize in care of the older adult. Less than one-third of one percent of physical therapists are certified in geriatrics and of the more than 200,000 pharmacists, only 720 have a geriatric certification. Social workers have no national certification for geriatric social work and registered dietitians and dietetic technicians have no formal program in geriatric nutrition. Furthermore, similar evidence of the dearth of basic geriatric education and training appears across health care professions of all disciplines. Less than 3% of current medical students take any elective courses in geriatrics. Only 23% of nursing programs had any required courses in geriatrics and only 14% had any elective courses. The majority of direct care workers have no formal training specific to geriatrics.

Recommendation: Educate and train all health care professionals, health professions students, and direct care workers in the requisite knowledge, skills, and attitudes to provide patient/person-centered, evidence-based, and coordinated interdisciplinary geriatric care and aging services. This care must be available across the continuum in ambulatory, acute, home and community-based services, assisted living, and long-term care settings.

Implementation Strategy:

- Congress and the Administration should redirect funding for Graduate Medical Education beyond reimbursement to hospitals, to support interdisciplinary geriatric training and education in other settings across the continuum to include hospitals, ambulatory, institutional, assisted living, and home and community-based settings.
- Authorizing legislation for geriatric education and training programs in the US Department of Health and Human Services, Health Resources and Services Administration, Bureau of Health Professions should be expanded to include direct care workers and family caregivers, in support of building an infrastructure that is prepared to respond to the growth of the aging population and expansion of home and community-based services.
- Accrediting bodies, educational institutions, licensing boards, professional associations, and other health care provider organizations must establish competencies in aging, geriatrics, and interdisciplinary models of care and include geriatric-related content in licensing and certifying examinations.
- The Institute of Medicine or a similar body should produce a comprehensive report and provide recommendations on education, training, and service methods the health care

workforce can employ to produce optimal, quality geriatric care that incorporates coordinated and properly trained interdisciplinary teams.

Priority #2: Recruitment and Retention of Health Care Providers and Faculty into Geriatrics

Background: The projected growth in the numbers of the older adult population has created an unparalleled urgency for qualified geriatric health care providers. The United States has a limited number of health care providers that have been recruited and retained to provide geriatric health care. The lack of educational opportunities and career mobility, and inadequate employment policies, has created a high annual turnover rate of nurse's aides in nursing homes, which range from 40 percent to more than 100 percent. The United States is also faced with a severe nursing shortage. The number of new nurses entering the profession is insufficient to replace those nurses who are retiring or leaving the field for other reasons and this is particularly evident in the area of geriatric nursing. Limited reimbursement has hampered board certification in geriatrics by many physicians and psychiatrists. Many board certified geriatricians and geropsychiatrists are retiring and there is a paucity of fellows who are entering the field to replace them. Educational debt has also negatively influenced physicians from entering the geriatric workforce. In addition, the educational system's ability to address the need for geriatric health care practitioners is compromised by a severe shortage of health care faculty trained in geriatrics who are capable of teaching health care providers to care for the elderly. There are currently only 600 physician faculty teaching geriatrics, but estimates are that more than 1,450 will be needed to prepare physicians to care for older individuals. Other health care fields such as nursing have similar deficits. For instance, of the approximately 670 baccalaureate nursing programs in existence, 58% had no full-time and 80% had no part-time faculty certified in geriatric nursing. Of the 88 accredited schools of pharmacy, less than one-half include any full-time faculty who specialize in geriatrics; most have practice-based or adjunct faculty who teach experiential courses with some geriatrics content.

Recommendation: Support the recruitment and retention of an adequate number of health care professionals and direct care workers, and faculty to train the health care workforce to provide patient/person-centered, evidence-based, and interdisciplinary geriatric care and aging services.

Implementation Strategy:

- Congress and the Administration must provide financial incentives in the form of educational loan forgiveness, student stipends, training grants, and fellowships to attract health professions students from diverse backgrounds to provide patient/person-centered, evidence-based, and interdisciplinary geriatric care and aging services.
- States must provide financial incentives in the form of continuing education and career ladders to attract and retain direct care workers to provide patient/person-centered, evidence-based, and interdisciplinary geriatric care and aging services.

- Congress, the Administration, States and the long-term care industry must work together to develop mechanisms to improve recruitment and retention of direct care workers through improved wage, salary, pension, and health care benefit packages, and improve work place policies.
- Congress and the Administration must provide funding mechanisms to recruit and retain faculty in geriatrics through career development programs in clinical teaching or research for academic geriatricians and doctorally-prepared non-physician academic health care professionals in their early, middle, and senior careers.

Priority #3: Interdisciplinary Team Reimbursement

Background: Currently, 82% of the Medicare population has at least one chronic condition and more than two-thirds have more than one chronic condition. Two-thirds of all Medicare spending is attributed to 20% of beneficiaries with 5 or more chronic conditions. Evaluation and management of multiple chronic health problems in older individuals require significantly longer office or home visits and coordination of additional medical or supportive services. However, health care providers are not adequately compensated for the extra time needed to properly assess and coordinate care for older adult patients, making their care financially unattractive. Furthermore, the current Medicare program does not adequately reimburse health care professionals for providing interdisciplinary, integrated, and coordinated health care across the continuum of care settings. Alternatives to institutional care, such as home and community-based services, provide health care to older adults who want to stay in familiar surroundings, retain autonomy, and maintain a maximum level of physical, social, and cognitive function.

Recommendation: Provide reimbursement support through the Centers for Medicare and Medicaid Services for interdisciplinary geriatric teams to provide patient/person centered, evidence-based care in ambulatory, acute, home and community-based services, assisted living, and long-term care settings.

Implementation Strategy:

- Congress should mandate that the Centers for Medicare and Medicaid Services conduct demonstration projects to evaluate reimbursement structure for interdisciplinary geriatric team care.
- Congress should mandate that the Centers for Medicare and Medicaid provide reimbursement for best practices in interdisciplinary geriatric team care across the care continuum.
- Congress and the Administration should increase Older Americans Act funding for the State Units on Aging to develop replicable model(s) of coordinated interdisciplinary care in partnership with academic institutions.



Mini-Conference

*Health Literacy and
Health Disparities*



PROCEEDINGS

Mini-Conference on Health Literacy and Health Disparities

July 21, 2005 / Chicago



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American Medical Association

Executive Summary

The White House Conference on Aging occurs once a decade to make aging policy recommendations to the President and Congress, and to assist the public and private sectors in promoting dignity, health, independence and economic security of current and future generations of older persons.

Past White House Conferences on Aging have contributed to the establishment of many key aging programs such as Medicare and Medicaid, the Older Americans Act, the Supplemental Security Income Program, Social Security reforms, and establishment of the National Institute on Aging. Past Conferences also led to creation of a national nutrition program for older persons, and establishment of the national aging network.

The 2005 White House Conference on Aging (December 11-14, 2005) is the first WHCOA of the 21st century and is intended to produce policy recommendations to guide national aging policy over the next decade through 2015. The leading edge of the baby boomers will begin to turn 60 in 2006, and for the next three to four decades, the 60+ population will be significantly larger than today. The 2005 White House Conference on Aging will focus on opportunities and challenges presented by the “new” 60+ population of 78 million, as well as consider issues that impact the mature older population.

In addition to the nearly 400 events held across the country to provide input to the 2005 White House Conference on Aging (WHCoA), the Policy Committee identified key areas they felt needed more focus and requested several Official White House Conference on Aging Mini-Conferences to be developed with a variety of partner agencies and organizations.

In particular, the Policy Committee wanted to explore the issue of vulnerable elderly populations that were at risk for a disproportionate burden of disease, injury, premature death and disability due, in part, to their limited abilities to understand and participate in the 21st century health care system. These are the populations that experience low health literacy and increased

health disparities. The American Medical Association and Blue Cross Blue Shield of America were invited to co-host this WHCoA Mini-Conference on Health Literacy and Health Disparities. With the assistance of a national program planning committee, a conference was developed to explore these two rapidly growing areas of concern, and held in Chicago on July 21, 2005.

The Conference brought together experts in the fields of health literacy, adult learning and literacy, medicine, nursing and public health, law, patient safety, pharmacy, health services and systems management, quality improvement, public and private health care plans. After the general overview of the issues by David W. Baker, MD, there were three panels to explore in greater depth the following issues: 1) what is known about how to improve communications for better understanding with these vulnerable populations, 2) how to reduce the risk of medication errors by simplifying and standardizing prescription labels, warning labels, and patient instructions and making them available in the patient’s language, promising practices to address patient safety health literacy issues through the drug plans and the new Medicare Part D benefit, and 3) examining a variety of health system efforts to improve quality and health outcomes for elderly patients with limited literacy skills and/or limited English proficiency.

In preparing a final report for the Policy Committee of the WHCoA, the planning committee, panelists and experts stressed the overall theme of the conference as the need to “Ensure that all patients understand health care information”, and set forth the following:

Problem:

Patients have the right to understand healthcare information that is necessary for them to safely care for themselves, and to choose among available alternatives. Health care providers have a duty to provide information in simple, clear, and plain language and to check that the patients have understood the information before ending the conversation.

Background:

Currently, the health care system in the United States demands full participation of patients in their own care. While health professionals determine what care is needed, it is up to the patients to provide most of their own care. The instructions for such care are often complex, poorly written, and use unfamiliar concepts appropriate for medical textbooks and not easily understood by patients. While the average American reads at the 8th grade level, medical information is usually written at the college level. This puts 50% of the adult population at risk for misunderstandings, medical errors, excess hospitalizations and poorer health outcomes. Research has found that patients with limited literacy skills are twice as likely to be hospitalized and stay in the hospital longer. The excess annual costs to the health care system have been estimated to range from \$50-73 billion.

This situation is most serious for the elderly, many of whom have to cope with problems such as loss of vision and hearing, loss of family support and social isolation, fatigue, pain, chronic illness and cognitive decline, in addition to the multiple instructions for care of multiple illnesses and medications. Seniors, ages 65 and older, account for 40% of all medication use and the average 65 year old has nearly 31 prescriptions filled per year. All medications have the potential of causing harm as well as benefit, the incidence of adverse medication events increases with the number of medications. Medication errors are the most common medical mistakes – some as a result of misread or misunderstood prescription labels – causing up to 7,000 deaths each year and costing the health care system nearly \$73 billion annually. Improving communications on medications can improve care, reduce errors, and save lives.

The decline in social support compounded by chronic illness also makes this population increasingly vulnerable to fraud.

The unrealistic expectations of health care providers that brief oral instructions and lengthy written materials will be sufficient to educate their patients in carrying out unknown and complex self-care tasks pose serious (and unnecessary) safety risks. Low literacy skills affect not only a patient's ability to safely and successfully navigate the many layers within

the health care system, but even their ability to gain access to the health care system at all.

While a majority of the 90 million Americans who have inadequate literacy skills are native-born, white and educated in American schools, there are increasing numbers of recent immigrants who need to access the health care system before they become proficient in English. They face almost insurmountable challenges in receiving health care from providers who cannot communicate with them. One recent study found that when family members or untrained interpreters are used to assist with communication, an average of 31 translation errors per visit are made.

Repeated research studies have found that both these populations – those with inadequate literacy and those with limited English proficiency – experience unexpectedly poor health outcomes, excess hospitalizations, longer lengths of stay in hospital and emergency rooms, and higher costs of care.

Proposed Solutions:

- Training in communication strategies (to include giving clear instructions and assessing patient understanding) should be implemented for all health care staff (professional and administrative) to ensure that all patients can accurately summarize the information they need in their own words and demonstrate how the information can be applied in their daily life.
- Public health messages and community outreach should use simple, clear, plain language.
 - Messages should be field-tested with consumers for accuracy and understandability.
 - Special attention should be paid to multicultural media such as radio, local newspapers, community and faith-based organizations.
 - Health literacy efforts should work with social service agencies, libraries, adult education and local literacy programs.

- Third party payors (Medicare, Medicare + Choice, VA, DOD, Tricare, etc) should make all health information they provide available in simple, clear, plain language (field tested by consumers with limited literacy and limited English proficiency).
 - Payment should be provided for the necessary one-on one patient education, as well as other services, to ensure patients understand information provided to them and are able to safely care for themselves. (Other services may include: interpreters, group education sessions, telephone education follow-up, home health care, disease management or chronic care coordination/management programs).
 - Simplifying and standardizing written and oral communications to improve patient understanding, to improve patient safety and to reduce medication misuse.
 - All U.S. prescription drug labels should be standardized. Congress should establish a public-private expert panel to develop the uniform format (similar to nutrition labels) which should be validated by consumer focus groups (including consumers with limited literacy and limited English proficiency). Accurate translations in multiple languages should be available for all retail pharmacies to use as needed. Make side-by-side translations available.
 - Standardize basic patient medication information leaflets. Pharmaceutical companies should submit simple, accurate information for consumers about the drug at the time that the FDA is considering approval (this is the procedure in Europe). The patient leaflets should be translated under supervision of the pharmaceutical companies and reviewed by an FDA panel that includes practicing physicians, to ensure the accuracy, fair balance and clinical appropriateness of the information. Consumer focus groups should validate the leaflets for the ease of understanding the information.
- Congress should establish a public/private expert panel to develop a basic standard set of questions about any medication and educate consumers to ask these questions of their physicians, nurses and pharmacists. These standard questions should be validated by consumer focus groups including consumers with limited literacy and limited English proficiency. Public Health messages and patient education programs should disseminate the information. Educate health professionals through their professional associations and institutions to respond clearly to these basic safe medication questions.
 - The Center for Medicare and Medicaid Services (CMS), as it begins to implement the new Medicare prescription drug program, should track the utilization of prescription drugs, the potential for adverse events, the source of purchase of the drug, the frequency of drug substitutions/changes, the results of appeals processes, the availability and accuracy of patient education materials (in multiple languages), the utilization of pharmacy counseling practices to improve patient understanding. This research should be available to health care providers to improve safe prescribing practices and lead to better health outcomes.

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- The number of minority students going into health professions should be increased through public/private partnerships of government, grants, and outreach to these communities.
- Training and certification programs for interpreters should be developed and these health professionals should be recognized as an essential part of the health care team, and payment should be provided for their services.
- The Center for Medicare and Medicaid Services and the Agency for Healthcare Research and Quality should support research to identify and evaluate successful practices that ensure patient understanding and eliminate health disparities.
- All health care providers and third party payors should commit themselves to improving health outcomes, ensuring patient understanding, and eliminating health disparities; all federal agencies regulating and studying the health care system should also so commit themselves and agree to report annually on the progress their agencies and programs are making to achieve this goal.
- The final report summary and recommendations were submitted to the WHCoA Policy Committee for inclusion in the materials to be considered by the delegates during the December, 2005 conference.

Welcome and Introductions

Joanne G. Schwartzberg, MD

Director of Aging and Community Health,
American Medical Association and Senior
Science Advisor on Health Literacy, American
Medical Association Foundation

Michael D. Maves, MD, MBA

Executive Vice President and Chief Executive
Officer, American Medical Association

Michael Maves: I want to welcome you to this conference on behalf of the American Medical Association. Like many of you in the audience I get credit for things that other people do; I certainly want to recognize Dr. Joanne Schwartzberg and her staff for all the work that they have done, including this mini-conference.

The AMA has a strong commitment to addressing two issues that we are going to discuss today—health literacy and health disparities—and how they affect our patients. But what does it mean when I say we have a commitment? The AMA was the first national organization to create a formal policy on health literacy. We were the first to recognize that limited literacy creates a barrier to effective medical treatment and diagnoses. As a follow-up to that policy — with support from our AMA Foundation — we developed a number of tools to help physicians better care for patients with low health literacy. Those tools include educational programs for physicians, faculty training with a full curriculum and the first textbook in this field. Working with organized medicine, the AMA has also sponsored the training of multi-disciplinary teams from 19 state and specialty physician organizations. The teams have presented more than 200 educational programs to physicians and to other health care professionals. These teams have raised the awareness of health literacy across the nation and given health care providers the tools they need to recognize and begin to address this problem.

Similarly, the AMA is no less committed to ending the problem of health disparities. Last January, the AMA, in conjunction with the National Medical Association and the National Hispanic Medical Association, helped create the Commission to End Health Care Disparities. This Commission now has over 40 medical and health organizations among its members. All of them have committed to work together to do three things: first, to increase awareness among physicians and other health professionals of the problem of health disparities; second, to provide physicians with tools to improve the status quo; and third, to advocate for action, including governmental action, to eliminate health disparities in health care.

I hope this gives you an idea of the AMA's dedication to these issues and the work that we've done on behalf of organized medicine to help address both of these problems.

I also hope that this conference, which is co-sponsored by the AMA and the BlueCross BlueShield Association, will help all of us break new ground and discover new avenues for thought and action. We've brought researchers and clinicians, health administrators and patients, businesspeople, government representatives and even a few lawyers together today. We've done all of this so that we can better understand where we stand today and so we can map out where we need to go in the future.

We will look at some major changes to the health care system that are coming our way, such as the upcoming Medicare Part D Drug Benefit and the trend toward pay-for-performance models of care, both at the federal and local level. We will examine what happens to patients as these systems evolve, and we'll consider what we can do in response to promote increased equity in health care.

Again, we at the AMA are delighted to be leading the dialogue about these critical problems and how we can address them. We are also delighted that our colleagues from the BlueCross BlueShield Association have joined us here today.

Allan Korn, MD, FACP

Senior Vice President and Chief Medical Officer,
BlueCross BlueShield Association

Allan Korn: One of the greatest pleasures I've had is to restore a very cordial and meaningful relationship with the American Medical Association; we look forward to many more sessions after this one. On behalf of the BlueCross BlueShield Association, thank you for joining us today to focus critical attention on health literacy and health disparities, particularly among America's seniors. BlueCross BlueShield is delighted to be co-hosting this very important forum with the American Medical Association and is fully committed with the leadership in addressing these issues in the provider community and working to ensure they're at the forefront of the national health care policy agenda. Likewise, as part of our core commitment to enhancing the quality and safety of health care in America, BlueCross BlueShield plans are actively dedicated to improving health literacy and to tackling health disparities.

Improving care for millions of seniors means overcoming cultural and communications barriers to appropriate care. BlueCross BlueShield plans across the country are implementing many innovative programs in care management and providing important tools to help consumers make informed health care decisions for themselves and for their families. According to the Institute of Medicine, missed opportunities to deliver quality care because of cultural and communications barriers are tremendously costly, in terms of dollars and, more importantly, in terms of the pain and suffering of our patients. For example, medication errors alone, some as simple as a result of misread or misunderstood prescription labels, are the cause of 7,000 deaths each year and cost the health care system \$73 billion. This toll threatens to escalate as our population ages and grows more fragile and diverse. Seniors in today's health care

environment, especially those with disabilities and impaired cognition or communication and those with low English proficiency inevitably face the potential for miscommunication, misunderstanding and missed opportunities to receiving appropriate care.

Therefore, a culturally competent, integrated approach to involving all health care participants is essential to improving health literacy and resolving the health disparities. By offering diverse perspectives from clinicians, patients and others in the health care community, today's mini-conference is poised to generate meaningful recommendations on health literacy and health disparities to bring before our nation's leaders.

We have an impressive group of speakers here today, ranging from health service researchers to leading literacy advocates to clinicians and health administrators who are taking innovative steps to improve the health and well-being of Americans and America's seniors. BlueCross BlueShield commends you for your efforts and we thank you for being a part of this mini-conference. We also express our thanks to fellow members of the mini-conference planning committee for your dedication to these issues and for making this event possible.

I look forward to the valuable discussions that are sure to take place today and especially to the critical recommendations that will come out of this conference.

Alejandro Aparicio, MD, FACP

Director, Division of Continuing Physician
Professional Development, American Medical
Association

Alejandro Aparicio: It is a pleasure for me to convene the 2005 Mini-Conference on Health Literacy and Health Disparities in my own hometown of Chicago. On behalf of the 2005 White House Conference on Aging Policy Committee, I want to thank the American Medical Association and BlueCross BlueShield Association and the entire planning committee for putting this mini-conference together. I particularly want to thank the leadership of Scott Serota, who chairs the Health Subcommittee with me, for his leadership and mission in

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helping these two organizations put this conference together. On a personal note, I am especially proud of being part of this meeting. As a 20-year member of the American Medical Association, it is the work that we do in health disparities and health literacy that brings me the most pride as a member.

I bring you greetings from Dorcas Hardy, the 2005 White House Conference on Aging Policy Committee Chairman, who was unable to juggle her busy schedule to be here with us. I am accompanied today by one of my colleagues on the Policy Committee, Clayton Fong, Executive Director of National Asian-Pacific Center on Aging, and Professor Rodolfo Arredondo, Professor of Neuropsychiatry and Director, Southwest Institute for Addictive Diseases, Texas Tech University Health Sciences Center in Lubbock, Texas, who is a newly appointed member of the White House Conference on Aging Advisory Committee.

Our presence here today indicates the importance of these topics for the White House Conference on Aging and of their personal and professional importance to me and my colleagues. This conference represents a great opportunity for all of us to address major issues affecting our society today and which will increasingly affect our seniors in years to come.

Let me quickly outline the White House Conference on Aging expectations for today. We would like to see limited number of realistic, doable recommendations that the committee can take to the delegates to the conference later this year. These resolutions and the conversations that will follow will be countless, to help our nation eliminate health disparities and improve health literacy among a diverse and rapidly growing number of older persons and baby boomers.

The purpose of the White House Conference on Aging, and this is the fifth to be held since 1961, is to develop recommendations for the President and the Congress that will help guide national policy on aging for the next 10 years and beyond. The next 10 years and beyond takes on a different and much more urgent meaning this time around than it did in previous White House Conferences on Aging because of the 78 million

baby boomers who will soon join the ranks of an older U.S. population. On the stroke of midnight on January 1, 2006, less than one month after the 2005 White House Conference on Aging concludes, baby boomers will begin to turn 60 years old and will continue to do so at a rate of one every 7.7 seconds. This is an overwhelming statistic when you think about the number of older people we can anticipate in the United States over the next 10 years and beyond. By the middle of the century, there will be more than a quarter million people over the age of 100, which is about four times the current number. The number of persons over the age of 65 years will increase by 147%. We know that significant health disparities, including differences in incidence, prevalence and mortality rates, exist among minority groups for preventable health conditions and diseases like cancer, cardiovascular disease, stroke and diabetes.

Heart disease rates are more than 40% higher for African-Americans than whites. Hispanics living in the United States are almost twice as likely to die from diabetes as non-Hispanic whites. Asian-American women 50 years of age or older are diagnosed with higher rates of breast cancer than non-Hispanic white women 50 years of age or older. Stroke is the leading cause of death for Asian-American males. The diabetes rate for American Indians and Alaska natives is more than twice that for whites.

Health disparities also exist between urban and rural populations. Many social and economic challenges unique to rural areas affect that status. The average age of people in rural communities is rising as a result of youth migration, which leaves behind an older population with limited support systems. Last but not least, older women experience a high burden of chronic illnesses and disability and this burden is higher among socioeconomically disadvantaged and minority women.

As a physician and geriatrician, I feel it is critical that this country have a health care system that benefits all citizens equally regardless of race, gender and ethnicity. As Dr. Maves stated, the American Medical Association has referred to a recent Institute of Medicine report on health care disparities as a wakeup call for the medical

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profession and has suggested that physicians need to play a leadership role in the elimination of health disparities. I strongly agree and I see that as part of my role since being appointed by the President to serve on the White House Conference on Aging Policy Committee. My colleagues and I are taking our jobs very seriously because this is such an important issue to our country and its people.

Health literacy is an equally important issue that we're hearing about as we cross the country collecting information for the 2005 White House Conference on Aging. We continue to hear how older patients face many perplexing decisions as they navigate the complex health care system. For people with low health literacy skills, making those decisions can be overwhelming and frightening. We all know that the ability to communicate with a health care provider can affect the prevention, diagnosis, and treatment of acute and chronic conditions. It can also be costly due to the more frequent doctor's visits and longer hospital stays associated with low health literacy. People who cannot read or understand prescriptions or labels may take medications incorrectly or not at all. And the consequences go beyond these individuals, for in some cases these same individuals are making decisions on behalf of other family members including younger children or aging parents.

As the White House Conference on Aging continues to seek and receive input from the public on issues that are part of our agenda, we greatly appreciate the contributions being made by today's participants who address these challenges.

We're also looking forward to hearing about innovations, projects and research activities that are currently under way, which will help us close the gap in health disparities and communicate better with those who need health care and information the most. We're confident that the optimal outcome for today's conference and certainly for the White House Conference on Aging in December 2005 will be pro-health care services for the aging population. We want to address the problems of health disparities and health literacy in order to allow patients and

their families to make their own health care decisions and to obtain the highest quality, safe health care. The best health options can be achieved if we continue to work together to find realistic solutions and recommendations.

We have with us some of the best and brightest minds in the field who have been involved in this area for a very long time. This is the perfect opportunity for all of us to be a part of something so meaningful, to help draft the recommendations that will go to the states and Congress and the President early next year after the completion of the conference. Past White House Conferences on Aging have raised issues that have resulted in the development of many significant programs and policies. I have every confidence that the 2005 White House Conference in Aging will be even more successful because of all of you, and what we accomplish here today. We, Clayton, Rodolfo and I, are honored to be here today and to work with you in those efforts and we look forward to the presentations and the discussions that will follow.

Framing the Issues

David W. Baker, MD, MPH

Chief, General Internal Medicine at Northwestern University, Feinberg School of Medicine

David Baker: I want to thank the planning committee for inviting me here today. It is a pleasure and an honor to speak to this group and to point out the issues that will be discussed by the outstanding experts that we have with us today.

I want to start with this quote from Goethe: “Knowing is not enough; we must apply. Willing is not enough; we must do.” Today’s conference is going to be about action. We are going to hear from thought leaders from around the country who are talking about solutions to these problems. My challenge today is to provide a brief overview of what we know on the topics of health literacy and health disparities. Obviously, this is a broad landscape so I’m going to concentrate on the issues of literacy, language barriers, and racial and ethnic differences in quality of care and the contribution of those to health disparities.

What do we know? First, health is strongly related to socioeconomic status, race/ethnicity and language. This is partly due to differences in access to and quality of care. Obviously, there are many other factors that go into understanding health disparities, differences in educational attainment, housing, etc. Millions of Americans have limited health literacy and this is more common among elderly persons and minorities. And many people have limited English proficiency, which poses a major obstacle to optimal health care.

Finally, racial and ethnic minorities receive a lower quality of care. Care differs by race and ethnicity within hospitals, but recent research emphasizes that there are major differences in where minorities go for their care. And this is also a major contributor to differences in health outcomes.

First, let’s talk about health literacy. We’ve known for many years that there’s a relationship between education and health outcomes,

particularly mortality. And though in this country we tend to emphasize differences by race and ethnicity, education is also important. A study by a group at the University of California, Los Angeles looked at the potential years of life lost due to differences in educational attainment and race and showed the years of life lost per 1,000 members of the population. For education, there are 9,000 potential years of life lost for every 1,000 individuals in our population. This is the effect of education on health and health disparities. It is almost four or five times what the differences are by race and ethnicity. (Wong MD, et al, 2002)

We need to pay attention to this. Why is that disparity? What are the mechanisms that cause that relationship between education and health outcomes? People have wondered for years. Part of the problem is likely to be related to something as direct as whether or not people can read. Whether they can read things in their life as well as for the health care that they need. Data from the National Adult Literacy Survey (NALS) in 1993 (Kirsch IS, et al, 2003) found there were 90 million Americans who had limited reading ability; 40 million who had what we call Level 1 literacy. These are individuals who struggle to read the most basic things they need to function in their life such as filling out job applications or reading bus schedules. The NALS survey did not look at anything related to health. Nevertheless, this is a good estimate of the people with the most severe reading problems in the country.

Another 50 million people have Level 2 literacy; these are people who struggle to do more difficult tasks in their life. Their economic opportunities, etc., are limited by their reading ability. We know that literacy affects a whole variety of things in people’s day-to-day lives, but the question for us is, “How does this affect their health care?”

Can patients read and understand the materials that we expect them to read? I want you to think about what we are now asking people to do. The changes that have taken place in the last 20 years are staggering. We frequently ask people to assess their health status, so people with diabetes need to monitor their blood sugar and know how to

use a glucometer. People with asthma need to know how to use a peak flow meter to see how their asthma is doing. More and more frequently we have people with high blood pressure use home blood pressure cuffs. In terms of self-treatment, we frequently have people with diabetes adjust their dose of insulin. Somebody with asthma may periodically take steroids based on the measurement of how much air they can breathe out. People with heart failure may adjust their dose of diuretics depending on their weight.

Just using the health care system alone—like figuring out your insurance coverage—is an incredible challenge. I think most of the people in this room have struggled to do this, myself included.

Think about the new Medicare prescription benefits and the incredible challenge that poses for the average American. When to go to the emergency room? How much is that going to cost you in terms of co-payments? Can you use specialists? What we're expecting people to do now in the health care system is incredibly challenging. Here is a concrete example that occurred for a real life patient:

Imagine that you're a 57-year-old auto mechanic and you're working and you develop chest pain. You come into the hospital and you find out that you've had a heart attack. You're fortunate enough to survive the heart attack and at discharge you're given aspirin, a beta blocker, an angiotensin-converting enzyme (ACE) inhibitor, maybe a blood thinner. You're told to follow a low-fat, low-cholesterol diet. You may be given a cholesterol-lowering drug, an exercise program and, oh, by the way, your blood pressure is elevated and you have mild diabetes, which you didn't know about. Bye.

If somebody is able to do these things well, they actually have a very good chance at a long and fairly normal life. If they do these things incorrectly, then they are going to have repeat heart attacks and an early death.

About 10 years ago, Mark Williams, Ruth Parker, Joanne Nurss and I did a very simple study (Williams MV, et al, 1995) to see

whether patients can do the things that we expect them to do to function in the health care system. This included giving them a reading test as well as giving them actual materials from our own hospitals. Thirty-nine percent of people could not read a prescription bottle that described how to take a medication on an empty stomach and tell us how they would take the medication. And 24% of people could not find the date and location on an appointment slip.

This is what we call document literacy, this ability to sort through a document and find key pieces of information. It's a tremendous challenge for some people. We gave people a normal blood sugar range and said, "Your blood sugar is actually out of range." We gave it a value and they had to interpret that and say, "Is my blood sugar normal today?" Thirty-seven percent of people couldn't do this. We call this quantitative literacy or numeracy. People frequently can't do the numerical tasks that we ask; for example, determining whether their weight is normal for somebody who has congestive heart failure.

We also had people read the Medicaid rights and responsibilities form, which is written at a fourth-grade level; 34% of people couldn't comprehend those materials. So clearly, there's a huge problem, a huge gap between what the health care system expects and how people are able to function within that health care system.

Many Patients Cannot Perform Basic Reading Tasks

Incorrect	%
Taking medication on an empty stomach	39%
When is your next appointment?	24%
Interpret blood sugar	37%
Medicaid rights and responsibilities form	34%

Williams MV, et al, 1995

All of these problems are greatly magnified among the elderly. (Kirsch IS, et al, 1993) Data again from the National Adult Literacy Survey show Level 1 literacy, the people who have the highest reading problems, the greatest difficulties, and the relationship between that and age. About 15% of people in the younger age groups

have Level 1 literacy, but it jumps up for the group 55 to 64 years old and among people 65 years and older. Forty-four percent of people over age 65 in the United States, a nationally representative sample, have that lowest reading ability. Who in the United States has the most chronic conditions? Who's taking the most medications? Who's at highest risk for adverse health outcomes? The people at that lowest reading level.

Based on what we saw in the NALS, we worked with Julie Gazmararian and others in her group and did a large study of over 3,000 Medicare managed care enrollees in four cities in the United States. (Gazmararian JA, et al, 1999) We found that about a third of people had significant difficulty reading health care-related information. We categorized people into a couple of different categories based on a test that we developed. People with inadequate literacy were not able to read the most basic prescription bottles or appointment slips. People with marginal literacy are able to read some of the simplest materials but struggle with some of the more difficult information on prescription bottles; for example, reading instructions on how to take a medication on an empty stomach. In our study population, about 25% had inadequate literacy; about 10% had marginal literacy. When we tested Spanish speakers with a test that was developed in Spanish, not a translation, a markedly higher proportion of people—about half of the Spanish speakers—had significant difficulties. That is true with national data, as well.

One of the questions in looking at the NALS is whether this is just a cohort effect: that older individuals have had less education and that's why they have a higher prevalence of reading difficulties, of Level 1 literacy. We looked at this within the large Medicare managed care enrollee study. We looked at the reading scores of these different groups on a scale from zero to 100, and the different age categories in the study, ages 65 to 69, 70-74, 75-79, 80-84 and 85 and older. Then we broke things down into four different groups, based on how much schooling people have. For all of these groups, there was a steady decline in their reading ability, their reading comprehension, as they age. This is consistent with a large body of literature that talks about

progressive cognitive difficulties, difficulties with information processing, as we age. Unfortunately, this is a common if not inevitable process that happens with aging. (Baker DW, et al, 2000)

This means that as our population ages, we are going to have more and more people who have difficulties understanding health-related information. The problems we have now are only going to become greater and this problem will probably never go away, regardless of changes that we make in the educational system.

When we looked at the proportion of people with inadequate literacy across those age groups, we saw an incredible jump. It's sort of a linear increase between ages 65 and 80, and then you begin to see the contributions of cognitive decline. We measured cognitive function using the Mini-Mental State Examination; it starts to curve up and go up almost exponentially as we get above age 80, so this is a major challenge.

I could show volumes of information about the relationship between literacy and knowledge, patients' understanding of their diseases and what they need to do. I'm not going to go over that today because what we care about is action. Can patients do the things they need to do to care for themselves?

We did a study on people with asthma. (Williams MV, et al, 1998) We watched patients use the little puffer that people with asthma use, the metered dose inhaler, and we scored the number of items they did correctly. There are different steps that people have to do. We broke things down based on their reading level. As reading level declines, the proportion of people who are using their inhaler correctly, the number of steps correctly performed drops very dramatically. So, it's not just an issue of knowledge. People with more literacy problems actually have worse skills for managing their chronic conditions.

Now, what does this translate into? It translates into higher rates of hospitalization. In another study we followed patients at Grady Memorial Hospital for two years and we looked at their hospitalization rates according to the three different levels of literacy—adequate, marginal and inadequate. For the people in the adequate and marginal group about 15% to 16% were

hospitalized but it was over 30% for the people with inadequate literacy. The inadequate literacy group was older; they had the worst health status. But when we adjusted for all of those things, patients with inadequate literacy had about a 52% higher risk of admission. (Baker DW, et al, 1998) In another study among Medicare managed care enrollees, it was about a 30% higher rate of admission after adjusting for all these differences.

The bottom line is, individuals with low literacy, even after taking into account all of their other differences, are more likely to be hospitalized. Much of that is due to lack of understanding about their condition and their self-management. We don't understand all of the mechanisms but clearly that has to be the major hypothesis. David Howard at Emory University translated this into medical care use and costs and found, as you would expect, low literacy costs dollars. (Howard DH, et al, 2005) It costs billions of dollars, so anything we do to improve outcomes should be cost-effective and has the potential of cost savings. Low literacy also means worse health outcomes, worse quality of life. Dean Schillinger at the University of California, San Francisco, has shown that diabetic patients with inadequate literacy are more likely to have eye disease, kidney disease, more likely to undergo amputation, have a stroke or have a heart attack. (Schillinger D, et al, 2002)

What can we do about this problem? The first thing is just write materials in plain language. Terry Davis, who will speak later in this program, took polio immunization information that was developed by the Centers for Disease Control and Prevention, which was written at about a tenth-grade level. She rewrote the information at a sixth-grade level using graphics, etc. She then compared the reading level for the individuals, according to a test called the REALM (Rapid Estimation of Adult Literacy in Medicine), with their knowledge after reading this new brochure. The good news is that this low literate brochure increased knowledge for all of the groups. It's not just the low literate people who benefit, everybody appeared to benefit. The bad news, however, is that there are still significant gaps in knowledge, so even these individuals who are

reading at the seventh or eighth-grade level had only about 65% to 70% comprehension of those materials. (Davis TC, et al, 1996) If you are reading a novel, 65% comprehension is pretty good. For informed consent, that's probably not good enough.

And how about managing your medications? Would anybody in the room be happy if people were taking only 65% of their medications correctly, while the other 35% were taken incorrectly? We clearly need to go beyond just rewriting materials at a simple level.

One of the things that we can do is develop more pictorial communication. Graphics can improve communication. Peter Houts and colleagues at Johns Hopkins developed materials to teach caregivers how to help family members. For their different instructions they developed graphics, just simple line drawings, to portray the meaning. When they looked at recall of this information, the group that had the spoken instructions with the pictographs had a much higher recall of the information, which suggests you can activate a different part of the brain. Some use listening when hearing a message; in this study they've got a graphic, they're able to look at it as a reminder later on, and the message comes back to them more clearly. (Houts PS, et al, 1998)

Another example from the emergency medicine literature: this group (Delp C, et al, 1996) was concerned that people didn't know how to care for burns when they were discharged. They rewrote their standard, boring instructions and they put in cartoons to emphasize these different points. This example talks about suture removal and there's a little zipper there. This cartoon talks about using ice and elevation. As simple as it was, it worked pretty darn well. The first question for people, did they actually read it? Ninety-eight percent of people read the cartoons, it got their attention; they said, "This is different". Ninety-seven percent of people were satisfied with the instructions compared to 66% of the people who were satisfied with standard text. But the more important thing was retaining knowledge. When they called people afterwards and asked them, without looking at any materials, what they knew about the wound care instructions, 46% of people

who had seen the cartoons got all four of the questions correct compared to only 6% of the control group. What an enormous improvement in knowledge. But again, what we really care about is patients doing the correct thing. So they looked at compliance with daily wound care and asked people what they were doing. Seventy-seven percent of people who read the cartoons followed the recommendations compared to 54% who read the standard text. Some of these very simple, low-cost interventions can make a big difference.

Pictographs Improve Knowledge and Compliance with Wound Care Instructions

	With cartoons	Without cartoons
Patients who read instructions	98%	80%
Patients who were very satisfied with instructions	97%	66%

Patient knowledge of wound care:

All 4 questions correct	46%	6%
2-3 questions correct	51%	61%
0-1 question correct	3%	33%
Patient compliance with daily wound care	77%	54%

Delp C, et al, 1996

Let's talk about language barriers. As we said earlier, there are millions of people in the United States who do not speak English fluently and as they are aging they're coming in contact with the health care system. This is a tremendous challenge that we face.

In a study that we did about 10 years ago (Baker DW, et al, 1996), we asked people coming into the emergency room, "How well do you speak English—good, fair, or poor? How well did the person who examined you speak Spanish? Was an interpreter called?" Even when there was only fair concordance (speaking each other's language reasonably well) an interpreter was called only about 20% of the time, even though there were clearly language barriers. In the group with serious concordance problems—the examiner's Spanish was poor and the patient's English was poor—an interpreter was called only 60% of the time. Forty percent of the time people struggled through. What does that mean?

We looked at people who said they had no need for an interpreter. In other words, there was good language concordance. We also looked at people who said that an interpreter was needed but was not used. The group that did not get an interpreter was twice as likely to have fair or poor understanding of their diagnosis and about three times as likely to have fair to poor understanding of their treatment plan. Almost all of these patients said they wished their examiner had explained things better. They were less likely to know their diagnosis and more likely to describe

Communication Problems with Extreme Language Discordance

	No need for interpreter (n=240)	Interpreter needed but not used (n=102)
Fair/poor understanding of diagnosis	34%	62%
Fair/poor understanding of therapy plan	14%	42%
Wish examiner explained better	34%	90%
Described diagnosis incorrectly	36%	50%
Described medication directions incorrectly	31%	45%

Baker DW, et al, 1996

their medication instructions incorrectly. (Baker DW, et al, 1996)

There is a wealth of evidence now showing that we can clearly overcome language barriers. This study (Jacobs EA, et al, 2001) had two groups, people with limited English proficiency and people who spoke English. They looked at different preventive care measures: Pap smear, fecal occult blood testing for colorectal cancer screening, rectal examination and influenza vaccination. Between year one and year two, they instituted a retained interpreter program. There was a big jump in the proportion of people who had the indicated preventive service after the interpreters program was created; you'll see that this comes pretty close to eliminating the disparities. At year two, the limited English proficiency and the English-speaking group were nearly equivalent.

This study (Lee LJ, et al, 2002) looked language arts. Many times, it's difficult to have an interpreter for every different language. I heard someone speak yesterday at a conference; at their hospital there are 147 different languages. You can't have an interpreter program on site for all of those languages. This study looked at people who had a language concordant relationship with their physician or examiner, people who used the AT&T telephone interpretation, and people who used a family member or an ad hoc staff member for interpreters. They looked at satisfactory communication with the patient's assessment of how well the examiner listened, answered the questions, explained things, and the skills of the examiner. The AT&T telephone interpretation was pretty much equivalent to a language concordant relationship. This is something that is available throughout the country. There is a significant cost to this, but the technology is available.

There is also a program that Francesca Gany at New York University is developing on remote simultaneous interpreters; the examiner and the patient are wearing headsets; it's the United Nations-style interpretation, so it's a very natural conversation. It saves a significant amount of time and has a very high satisfaction rate with these physicians and their patients. The technology is out there; we need to figure out incentives to get people to use it.

Finally, I'll say a few words about racial and ethnic differences in quality of care. This cartoon says "National Academy of Science's Institute of Medicine report finds that minorities are less likely to receive proper medical care than whites." And the driver is saying to the black patient, "Back of the ambulance..."

I want to mention an example of a disparity that is almost impossible for me to explain with differences in communication. Why are there differences in the rates of curative surgery for lung cancer for whites and blacks? In this study, (Bach PB, et al, 1999) 64% of the black patients with lung cancer had a curative procedure performed, compared to 77% of the white patients. Well, maybe that's differences between the populations, so the researchers broke it down by a whole variety of things. For the people 65 to 69 years of age, whites had substantially higher rates of surgery. For the next oldest group, whites had substantially higher rates of surgery. For this oldest group, again about a 20% difference. Maybe the African-American patients were sicker. Maybe the surgeons felt the risk was too high. So the researchers broke it down by the severity of the illness. Even for the group that had no major comorbidities (in other words, they were good surgical candidates), 82% of white patients had surgery, compared to only 60% of black patients.

They also looked at the follow-up. What happened to these patients? White patients with surgery, black patients with surgery, and white and black patients who did not have surgery. Bottom line was, if people receive the same treatment, they have the same outcomes. These differences in surgical procedures are a major cause of disparities in this country. (Bach PB, et al, 1999)

We're also learning that there are very large differences in where people are going for their care and differences in the quality of care. It's not just the individual physician or provider who's caring for them; it's where people go for their care. This study (Bach PB, et al, 2004) found that African-American patients were almost 10% more likely to be cared for by a physician who is not board certified, board certification being a decent indicator of training, qualifications, and quality of care.

This data is from a study I'm working on with Romana Hasnain-Wynia at the Health Research and Educational Trust; we are looking at disparities both within hospitals and across hospitals in terms of differences in quality of care for cardiovascular disease. These are quality indicators for myocardial infarctions which we can track. Were patients given smoking cessation counseling? Were they given aspirin at the time of arrival? Were they given aspirin at the time of discharge? Did they receive percutaneous coronary intervention, angioplasty, within 120 minutes of arrival if they were a candidate? We looked at hospitals based on their overall quality of care and we stratified patients into four different groups and we looked at the percentage of minority patients at those hospitals. We found that the hospitals that did the worst in the quality of care measures were far more likely to be caring for minorities. (Hasnain-Wynia R, et al, 2005)

Can we do something about this problem? Yes. Quality improvement programs that try to improve standards of care so that everyone is receiving the same care can improve outcomes and reduce disparity. Ash Sehgal did a quality improvement program for patients with dialysis; we know there are problems with quality of care for everyone but it was worse for African-American patients. He looked at the adequacy of hemodialysis done during this period of time with quality improvement efforts and found that the adequacy of hemodialysis for whites went steadily up during this period. At the start, there was about a 10% gap with blacks being more likely to not receive an adequate amount of hemodialysis, and this went up as well, so that by the end the disparities were pretty much eliminated. (Sehgal AR, 2003) Can we solve this problem? Yes.

I adapted this from Dr. Anne Beal of the Commonwealth Fund. If you're thinking about racial and ethnic disparities, you have to say "who you are" and "where you go" make a difference. There are racial and ethnic differences in treatment by the same provider. Where you go for health care makes a difference because there are racial and ethnic differences in provider quality. And we need to solve those problems.

So where do we go? These are just a few questions for you to think about during today's talks. Who will develop better communication tools? We know that we can do this. We know that it makes a difference. Who's going to do that? Should we broaden coverage for health education? Right now, Medicare pays for diabetes education; what about payment for patient education for heart failure and high blood pressure and other conditions? How can we create incentives to increase interpreter use? What's the most cost-effective strategy? Should patients with low literacy or language barriers qualify for special services such as home health care? If someone is on a very complicated medical regimen, would it be beneficial to have someone come into the home after discharge and look at the patient's medications, help them arrange pill bottles, etc.?

How can we reduce racial and ethnic health care disparities? How do we create incentives to reduce disparities within hospitals? For example, we are now reporting our quality of care measures to Medicare in the National Voluntary Hospital Reporting Initiative (NVHRI). Should we be required to report stratified by race and ethnicity so that we actually have to report quality of care for whites and non-whites? What are the methods to improve care at underperforming hospitals and how do we create collaborations so that the best hospitals can help the underperforming hospitals improve their care? And finally, how can we create incentives to improve quality, such as pay-for-performance, without worsening disparities? We do not want to create a situation where hospitals are discouraged from caring for vulnerable patient populations because they think it's going to hurt their quality measures and decrease their pay.

I want to close with this quote from E.L. Simpson: "Getting an idea should be like sitting down on a pin: It should make you jump up and do something."

You are going to hear from an esteemed group of thought leaders today and I know that their comments will make us all jump and try and do something.

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Panel One: Improving Communications for Better Understanding

Moderator: Allan S. Noonan, MD, MPH
Director of the Public Health Program,
Morgan State University

Allan Noonan: In my previous position in the Office of the Surgeon General, I was responsible for putting together Surgeon General's reports and calls to action for the past several years. That is where I encountered these issues of health literacy. I'll start with a little story of when Dr. Carmona, the new Surgeon General, came. He pooh-poohed what we had been doing with Surgeon General's reports and said, "Nobody reads them. People just put them up on a shelf." My feelings were a bit hurt and I went back to my corner and kind of scratched my head and said, "You know, he's probably right." He asked me to look at how we could make Surgeon General's reports more useful and interesting to the population. And that was the beginning of health literacy for me.

In trying to deal with that question, I sought out the people who knew. Luckily I was at the American Public Health Association (APHA) meeting that year and saw a presentation by Dr. Rima Rudd. I said, "I don't usually go to presentations at APHA, but this one looks interesting," so I went to her presentation, got to know her, got to introduce her to the Surgeon General and learned a lot of surprising information about the literacy—or lack thereof—of our population and a lot about how to deal with it. Dr. Rudd also played a major role in Healthy People 2010, addressing the health literacy needs of the population for that 10-year public health agenda.

Rima E. Rudd, MSPH, ScD
Senior Lecturer on Society, Human
Development,
and Health, Harvard School of Public Health

Rima Rudd: A good deal of my work these days is focused on health and literacy, as well as health literacy.

I was honored to be a member of the Institute of Medicine's (IOM) Committee on Health

Literacy. We spent a good 18 months examining the field, examining the literature, and examining a great number of issues involved. One of our conclusions resonates very closely with the work that I'm doing and with the communities I have the privilege of working with. Health literacy is not a characteristic of an individual. It's not so much that an individual is health literate or not health literate. Health literacy is instead a characteristic of a society. It is an interaction. It's an interaction between what we expect of people and what people are able to do.

When we look at that interaction it's very, very important to keep in mind that we have the power to make changes in two very different ways. We can, for example, improve health literacy by lowering social demands and changing the social demands, making them more appropriate. We can also improve health literacy by increasing skills and the communications skills not only of the lay public but the communications skills of the professional group, as well.

Let me give you an example of this important interaction between the two. Consider the social factors and demands of the medical and dental health systems in our country. We make underlying assumptions about people's knowledge. For example, at the IOM committee we asked, "What assumptions can we make about the general background knowledge of the average American high school graduate?" And we found we could make very few assumptions in regard to biology and basic knowledge of the human body. There is no consistency among states and within states in regard to the number of people who take biology. After all, any high school student can waive biology and can instead take geology, earth sciences. Many programs that have an introduction to biology in junior high school also provide a waiver that a parent can sign so that a student can be absent from class without harm when there is any discussion of the human body because in discussions of the human body the reproductive organs might be discussed.

So we cannot make general assumptions about knowledge base in our society. Keep this in mind when you consider the pulmonologist who talks to a patient about inflammation of the bronchial tubes. It is very unlikely that an average patient would know that there are bronchial tubes in the body, never mind where they are.

We have context-specific characteristics such as time constraints, everyone is in a rush. As Ruth Parker once pointed out—she actually did this physically—she stood up, put her hand on the doorknob and said, “Here is the typical stance. I’m the physician, my hand is on the doorknob and I say to the patient, “Any questions?” We have processes that are complicated. We have materials that are poorly designed, poorly written. We have a language that is a fine language, the scientific language of medicine, of dentistry, of psychiatry, in health in general, public health included, and I don’t mean to exclude myself from the failure to communicate effectively by using the jargon of my trade. We also have power differentials. There’s always a power differential if you walk into a room and one person is nearly naked and the other person is overdressed by having a white coat on top of clothing and underwear.

Literacy skills are not just labeled as reading. We look at writing skills; we look at the oral exchange, being able to find the language, for example, to describe a feeling. That oral exchange is incredibly important as is the oral comprehension. Basic math skills are part of that. We make demands that people calculate dosage, that people use measuring tools and interpret charts. These are basic math skills that are sometimes well taught, sometimes not well taught, and sometimes not taught at all in our school systems. Individual factors that we must include in looking at literacy skills are:

- The patient’s emotional and cognitive state — How do you feel when you’ve just been given a diagnosis? Are you open to hearing information? Can you comprehend that information under stressful circumstances? Or when you’re nearly naked? Background

knowledge, status and efficacy all become important characteristics.

- Social demands also take place in many different contexts: at home, at work, in the community, in care settings and in the policy arena. For example, a community will vote on water fluoridation—that involves health literacy skills.
- The tasks don’t all take place within the medical encounter. They take place in different sites for promotion, protection, prevention, care and maintenance and navigation skills. We ask patients to literally navigate the hallways of institutions.
- Consider being given numbers based on varying kinds of measuring tools and being forced to comprehend and understand what those are. Looking at and understanding your medications, being able to differentiate.
- Let’s take this same thing into the community: reading labels to make decisions about the best product to purchase; looking at the weather report in a newspaper to understand whether you or your child might be at risk on a particular day because of allergies or asthma; and being aware of and taking action based on new services that are available, for example, during the flu season.
- Taking this into the health context at home: applying for services and filling out those forms is an incredibly arduous task. Using a calendar, using a clock, to plan out what you’re doing is a sophisticated task. As is using the kinds of tools,

whether it is something to test for diabetes or something like a peak flow meter for asthma, requires sophisticated skills in reading and understanding calibrations.

Here is an example from a prescription medication label. "Take one tablet, four times daily."

I'm a very good patient. I want to follow what my doctor tells me. I know I'm going to have a busy day. I take my first pill at 7 a.m., my second pill at 7:15 when I get out of the shower, my third pill at 7:30 when I sit down to breakfast, my fourth pill at 7:45 before I leave the house. I've done exactly what my doctor asked me to do. This is poorly written. This is poorly conceptualized. This is poorly designed. Whoever wrote this was functioning under the assumption that I know about titration. Nothing is being communicated here to me that would safeguard my well-being.

There are many national and international large-scale surveys of adult literacy that have looked at adults' proficiencies. I want to point out that these are all very rigorously done national samples in 22 industrialized nations. These are not reading tests and they don't yield reading scores. They look at peoples' ability to use the print material that is commonly used in their society. I was able to calculate that 191 of them specifically address health-related tasks and the use of health-related materials.

This analysis was reported in 2005. We're about to come out with analysis that looks at Canadian statistics and a comparison between Canadian and American statistics. As David Baker pointed out, you can see how people fall out in regard to proficiency, using prose document and math skills. In the United States, the average is on the cusp of what is considered adequate for full functioning in today's society. Elders do not do as well as others; the average Health Activities Literacy Scale

(HALS) proficiency for adults in this country is about 273 for an average high school graduate. Older adults do poorly by comparison (score of 216 for elders with resources; score of 188 for elders in poverty without resources). It is evident that disparities are at play here. Look at the difference between, for example, the elders who have resources (eg, have income from dividends, a savings account, or retirement funds beyond Social Security) and those who do not have resources.

Look at those differences based on economics and look at the differences based on both economics and schooling. Elders who have more than a high school education do quite well. They're much better than the average adult in the United States. So it's not simply a matter of cognitive decline. There is something else at play here.

Findings from the international surveys show a very strong link between health and literacy skills but they also show an increased demand on people's time, energy and application of literacy skills based on the materials that people are asked to use.

We do need more research; we need to define and get a clearer understanding of what our expectations are of people, what we need them to do, what tools we offer to help them do it, and what skills they need in order to use those tools and accomplish those tasks. Once we begin to describe and understand the demands in health, we can begin to find solutions by making better tools; for example, not just lowering a reading level, but providing people with better tools as another step.

Recommendations:

Change contextual and bureaucratic demands

Remove access barriers

- Improve oral and written communication

Engage in rigorous practice

- Develop more appropriate research tools
- Engage in rigorous formative research
- Examine both mundane and innovative strategies

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Toni Cordell

Patient Advocate

Toni Cordell: I wish I had some consonants after my name because a lot of you do. High school doesn't quality you for that. It is a privilege to be here. Would you watch my hand for just a moment? I want to communicate with you in a way that I hope will make you feel insecure, inferior, or frustrated with me. Anything will do. (Ms. Cordell addressed the audience in American Sign Language)

I asked a question. Is anyone able to answer? I simply used American Sign Language to finger spell, "Can you read me?" If you don't understand that form of communication, I am in no way suggesting you lack education or intelligence. It's simply different. It's a skill, like reading. Somewhere along the line I had the opportunity and motivation to learn that. Not everyone knows American Sign Language. And not everyone gets reading right when they are in school. It does not suggest lack of education or intelligence. It suggests a lack of skill.

As a young child growing up in a home with parents who had never been nurtured, my mother's ballistic tongue and my father's ice wall were too much for me. I wanted out so very much that I refused to eat at about the age of three. This created pernicious anemia, a life-threatening illness; evidently it affects the memory process. Because of that I was hospitalized and they got me well enough to begin school. My brother and sister were academically talented. You put it in front of them and they got it like that. School didn't happen for me that way, and I'm sure my mother's intention was honorable when she said, "Toni, you are stupid." Well, excuse me. If I'm stupid, I have no more responsibility in the educational process. Leave me alone, I'm going to recess. If I am stupid, I have no hope, no purpose and no future. If I'm stupid, I'm sucking up air that belongs to you. Why would anyone want me on planet Earth?

I went on to graduate from high school, reading at about the fifth-grade level. The way I read was naming one word at a time. Words were just ink, lines and circles on the page and it was tough to get to the end of a sentence or a paragraph, much less the bottom of a page. It took me months to read a book. Now I read one a week.

As a young married woman who already had three children, I noticed something changing and determined that I needed to go see my gynecologist. During the office visit, he examined me and said, "Oh, that's an easy repair." All right, excellent. We set a surgery date. I went into the hospital and the administrative assistant or admissions clerk pushed paper after paper after paper in front of me for my signature. Not because I was a celebrity but because it was required of me. If I'm going to have this "easy repair" I've got to follow the procedure. Well, I wasn't about to tell her, "I need you to read this to me." Yeah, I can read it, but it will take all day of your time and mine. So I did what I was told. The surgery was successful. I'm grateful, and then during the six-week follow up in the doctor's office, the nurse comes bounding into the office, "Hi, Toni, how are you doing since your hysterectomy?" Not a single word could come out of my mouth for a moment because the silent shame literally grabbed me. I wasn't about to reveal to her I had no idea I had gone in for a hysterectomy. So I pretended like everything was fine. I had never asked the doctor a single question. What do you mean by "easy repair?" It's really not in the medical books, is it? "Easy repair." But, nonetheless, there was nothing to really be concerned about. I had had my children. It was not devastating on that level. I just felt horribly stupid and it was tough to walk out of there and be comfortable with who I was for a while.

I had a completely different experience five or six years ago when I was sent to Emory because additional surgeries had not gone well. And I had the great privilege of having Dr. Niall Galloway, a urologist. Well, you know, a urologist is not the person you really want to go see, not much more than a gynecologist for those of us who are female. So you know right off it's not going to be fun, but I went into his office. Dr. Galloway deserves credit for being a dynamic communicator. As he came into the examining room, I am fully dressed, underclothes and all. Chair to chair, face to face,

he asked me lots of questions. He notified me he'd be leaving the room and the nurse stayed, asked me to disrobe. He came back when I was properly draped and before he even touched my flesh he said, "Okay, I'm going to be doing this, and I'm going to be doing that." Before he moved his hand, he notified me where it was going. He even said, appropriately, "And this is not going to be comfortable." Then when he was finished with the exam, he left the room, I was allowed to dress again, so when Dr. Galloway came in to tell me what he had determined and what he thought would need to be done, we were back to chair to chair, and face to face. He engaged me in the conversation as a peer so that I could ask some questions, not that I know very many questions to ask because I come from that period of time when the doctor is God-like and on a pedestal. I immensely appreciated the way this man communicated with me.

The other factor is—I know the basic anatomy of my lower abdomen—but he drew me pictures, Picasso-ish, but pictures nonetheless. He said, "Okay, this is here, that's that, that's not supposed to be like that. It can be done like this. It will be done here. I'll cut here. I'll stitch here." So when I left his office, before I went into the hospital, I had an excellent understanding of what we were going to be doing. And thank goodness he accomplished the tasks and I'm in pretty good shape now. But emotionally, I'm in better shape because I know what he was doing. I'm deeply grateful for that.

Several years ago when my husband was dying in the latter stages of prostate cancer, I had one of the most frustrating encounters in the VA hospital. Carl was a Purple Heart survivor from World War II. A man who was kind to me, a man who deserved respect, a man I'd never seen treat anybody with disrespect. In 30 years I'd not even seen him angry five times. A good man. But in the VA hospital, the men attending him were not from the United States and I could not understand their heavy accents. I don't know how many times I had to ask the same question, over and over. I don't know if I was respected, if being female in their culture would not have put me on a high standard. But I loved this man, I could see he was dying, and I wanted to be his help. I wanted to be the person he trusted. And

I couldn't understand what they were doing. He was overmedicated with morphine. He hallucinated. He saw the enemy outside of the window on the fourth floor. He did not cooperate. He was ripping out his IVs. They actually ordered me out of the room at one point because I fell to my knees sobbing at the way he was being treated and manhandled. And one night after he called and said, "You don't know what they're doing to me," I went up at three o'clock in the morning—nobody stopped me—and I found him tied to the bed. And I untied him and never left his side again. Precious man. No reason to be treated like that. He had fought for freedom years before I was even born.

In terms of prescriptions, those of us who are not dynamic readers have never read this sheet of paper that comes out of the pill container. Those of you who are college educated, when was the last time you read one of these? Did you understand it? Thank you.

And insurance forms. During that final few weeks of Carl's life, when I was the one faced with insurance forms, my hope was that we could put the date in the same location on all the different insurance companies' forms. I would love to know the exact amount I owe you—I need to know all the other information but I get charged for things and I don't know what they are. But I do know that I need to pay for what is my responsibility. So it has been challenging at times, and I've had several experiences that have been unpleasant, based sometimes on my own lack of literacy skills and based sometimes on the fact that if the medical profession would find some way to help, it would be easier for all of us, regardless of our education level.

Wayne H. Giles, MD, MS

Acting Director, Adult and Community Health, Centers for Disease Control and Prevention

Wayne Giles: I want to give you some examples of what we have found across the country through a program called REACH, Racial and Ethnic Approaches to Community Health (<http://www.cdc.gov/reach2010/>). Nineteen-ninety was the first planning year for the program; we funded 40 communities across the country to address disparities and to do some very important

planning work around disparities and then we followed that up by intervention activities. I want to remind you—and Dr. Rudd alluded to this—the IOM report on disparities in health care concluded that disparities are among the nation’s most serious health care problems. Research has extensively documented the pervasiveness of racial and ethnic disparities in health. As we think about that today, we need to remember what the IOM concluded.

There are 40 REACH communities across the country that are doing activities around elimination of disparities. We did something that was relatively novel, I think, for the federal government. When we funded these communities, we put them in the driver’s seat. We told the communities, “You decide what racial and ethnic group you want to address. You decide among these six diseases, what are the diseases that you want to address.” And we also said, “We want you to decide the types of interventions you think are appropriate.” We did provide some guidance and some frames around the types of intervention but the communities were the ones who were in charge of deciding the types of interventions, and I think clearly one of the reasons we’ve been so successful is because of that very fact.

All of our REACH communities have three major foci. Number one, they have a community health worker component where community health workers work with folks in the community so that they know how to navigate the system. They know the appropriate questions to be asked. Number two, there’s some sort of media campaign such as posters and articles in the newspaper, and finally, number three, there’s the health care system. I’ll talk about each of those components.

I’m going to talk about two communities in detail. One is a Vietnamese community in Santa Clara, California, that’s addressing cervical cancer among Vietnamese women. The dedication and passion to the work by the members of the REACH coalition in Santa Clara has led to their success. Specifically, they want to raise awareness about cervical cancer, educate the community about the benefits and encourage women to get Pap smears. One of the things the community coalition did was to provide feedback to the Vietnamese clinic in the community. They also

worked on policy changes in the clinic. One issue was that when this clinic initially started, it had no Vietnamese female physicians. That was a huge barrier. So they recruited a woman physician. They changed the hours of the clinic so that it was open more afternoons and evenings.

In terms of the lay health worker approach, they recruited a bunch of community based organizations. They got fifty lay health workers or community health workers to do outreach and recruit patients. They compared two types of intervention: one was a media-only intervention and the other was the lay health worker/community health worker intervention.

With the media intervention, when they looked pre- and post-survey, they saw a 6% increase in knowledge about human papillomavirus (HPV) causing cervical cancer. With the community health workers helping people navigate the system, there was a 38% increase in knowledge. When they asked women “Does smoking or second hand smoke cause cervical cancer?” a 22% increase in knowledge occurred in the media group, but a 57% increase occurred with the community health worker. When they asked women, “Have you had a Pap smear?” there was a 4% increase in the media group and a 15% increase in the community health worker group.

The second community is in Massachusetts, the REACH 2010 Latino Health Greater Lawrence Family Health Center. Puerto Ricans and Dominicans in this population have about a 12% prevalence of diabetes, three times the state average in Massachusetts. There are 43,000 Latinos in Lawrence and 1,500 Latinos who know they have diabetes, diagnosed diabetes. The project aimed to eliminate disparities in diabetes and cardiovascular care. There were two components. One was a community-based intervention, with community health workers and physical activity sessions in the senior centers in Lawrence, but the other was focused on the clinic. They used a diabetes self-management education program that was modified after one done by the American Diabetes Association but they also have a registry, an electronic medical records system, which they used to provide feedback to health care providers in the community. They provide feedback to practice-wide physicians every couple of months.

They have on-site monitors who monitor what's going on. They can provide individual feedback to providers and they're doing a lot in terms of teaching physician residents. They have a family practice clinic program so they're teaching their residents the value of this self-management approach.

Some of the measures they use for cardiovascular and diabetes care are body mass index (BMI) measurement every six months, hemoglobin A1C with the goal being less than 7 and blood pressure less than 130 over 80.

Some of the results they've seen: the use of hemoglobin A1C tests between 2001 and 2005 has gone from 51% to 64% of all diabetic patients. Aspirin use has gone from 50% to 62%; annual microalbuminuria screening has gone from 46% to 60%. What is particularly impressive is a plateauing of BMIs, while BMI for the rest of the country is going up rather dramatically.

We have an independent contractor who does a survey for all of the REACH 2010 communities. Looking at the prevalence of Pap smear among Asians in the REACH communities, focusing on cervical cancer among Asians and comparing that to the behavior risk factors surveillance. This is a nationwide telephone survey. What I want you to take home from this is in 2001 when we started collecting data, there was about a 20% difference in Pap smear utilization in these Asian communities. That's decreased to about a 10% difference in 2003, the latest year we updated, so we have seen that disparity cut in half. We need to remember that this survey is community-wide. This isn't just one of the clinics that has improved its practice, but this is community-wide improvement. To see this type of disparity reduction this quickly is truly impressive.

Another example that was studied was diabetic foot examination among Hispanics. When we started there was about a 15% difference among Hispanics. That's decreased to about a 2% or 3% difference over the 2 to 3 years. These dramatic changes in these communities across the country are truly impressive.

I want to end by giving you some qualitative data about what patients who participate in the

REACH programs say. A Charleston, South Carolina, participant from a community focusing on diabetes said, "REACH classes are very helpful to those diagnosed with diabetes in general and very helpful to me in particular. I am grateful to have programs such as REACH where I can get information. In truth, my diabetes is being treated by my doctor, but at times it is not completed." I think what this person is saying is they're not getting the full picture about diabetes from their health care provider. "REACH is helpful to us because it reminds us of what we should eat, how to select our food, and the importance of exercise. There are many ways REACH is helping us, we can't mention it all. Basically, the information we receive helps minimize the risks."

Another very nice, eloquent quote, this from a patient in Seattle. The Seattle community is focusing on diabetes and cardiovascular disease. The participant talked about the value of the nutrition classes and the physical activity classes and said, "My blood pressure medicine was cut in half, my diabetes medicine was cut from two pills per day to one pill per day. I was checking my blood sugar level every day, now the doctor said I can check it twice a week." A very impressive quote. It's about empowering folks so they know what they need to be doing. The result here was that an individual had to take less medication once their disease was under control.

The final quote is probably my favorite. This also is from a REACH participant in Seattle. "I have learned to be ready for the doctor. When I go into the doctor's office and I go into the examination room, I take off my shoes and socks. I don't wait for him to tell me. On the counter I lay my monitor book with all my blood pressures and all of my sugars. So it is there so he don't have to walk out and come back. I'm getting every bit of the minutes he's supposed to be giving me." That's a very powerful quote, and that's the power of programs such as this. It's teaching folks what they need to be doing and the questions they need to be asking so that they can do exactly what this participant in Seattle did. Programs such as REACH have demonstrated that relatively quickly. By

empowering local communities, we can make dramatic differences so that patients in fact are ready for the doctor when they see the doctor.

In closing, this is not something that we can do by ourselves. This is something we all need to do together by working together in partnership. One of the things I am very excited about today is that we are doing just that. I want to thank you for inviting us here to be a part of that. I also want to acknowledge I have a colleague, Linda Anderson, from the CDC Health Care and Aging Studies Branch and the Division of Adult and Community Health here with me today.

Aracely Rosales

President, Plain Language and Culture

Aracely Rosales: (Addresses audience with a few sentences in Spanish) Are you following me? Of course, I did that on purpose. The first time I did this exercise, people in the audience got angry; a couple of people jumped out of their chairs and left the room and others who knew me, said, "Wait a minute, I know she speaks English, so why is she speaking in Spanish? I didn't know this presentation was going to be in Spanish."

I wanted to give you a little taste of what it's like and how it feels when you want to hear something and want to learn yet you can't. In this case, it's because of the language barrier. So I hope I didn't get you angry to start the morning.

Lots of evidence will be discussed throughout today about the importance of making health communications easy to understand, easy to follow, and realistic in the sense of making it culturally appropriate, and believable, so that people can act on it and feel motivated to do what they are supposed to do, and acceptable so that they know why it is important for them. That is, of course, called compliance.

There are many tools at the national and government level; there has been a lot done in the past 15 to 20 years. There are readability tools which measure reading levels by grade, there is the Suitability Assessment of Materials (SAM) to evaluate materials, and tools to assess health literacy in learners such as WRAT (Wide Range Achievement Test), the TOFHLA (Test of

Functional Health Literacy in Adults) and the REALM (Rapid Estimate of Adult Literacy in Medicine).

With the Office of Minority Health, we also have the CLAS (Culturally and Linguistically Appropriate Services) standards, which are helping a lot of organizations learn what they have to do to make their clinical services more culturally sensitive and appropriate. For example, some of these standards tell organizations that they need to train their doctors on cultural competency.

There are also publications which guide people on the steps to producing a good publication or a good message. One very good, and widely used one, which talks about good communication planning, is Making Health Communication Programs Work, produced by the National Cancer Institute.

What we don't have are translation and interpretation standards, where we provide a roadmap to help organizations follow guidelines to measure quality of both oral and written information that has been translated from English into another language. We heard Dr. Baker say this morning that when translators and interpreters are used, we are reducing health disparities.

But what we don't know is whether these interpreters or translators are being trained and how well they are doing. Why bother? Well, there is plenty of evidence again about the need for easy-to-read information including wording that is culturally sensitive and appropriate. (Rabbi A, 1988) There are several current efforts that should be noted—the Institute of Medicine report *Health Literacy: A Prescription to End Confusion*; the AMA Foundation's *Health Literacy: Help Your Patients Understand* educational kit; the ASK Me 3™ campaign and the *Clear Health Communication Initiative* being led by Pfizer Inc. But what is more important to me is what people are still saying. In my 15 years of experience producing health publications and materials in other languages and most specifically in Spanish, people are still saying this in every single focus group that we do before we create a piece, "Those big words are for lawyers, write the words that we use, the way we talk."

It's clear that we need to address these three issues: that we cannot speak about culture, cultural sensitivity, and cultural competency, without including health literacy in the same context as well as language. These three are linked and we cannot separate them nor can we talk about them separately.

The reasons, of course, include increasing demographic changes, eliminating health disparities, improving quality of services, and improving outcomes, the ultimate goal. And of course, something that we all as human beings need when we are in medical care is to feel we can trust. We need to avoid offensive messages to those we are communicating with, and we need to show personal perspective.

But some of the subtleties are what keep us from being successful at this. Health literacy actually does help, and making easy-to-read materials does help but there are issues of diversity, subgroups within the different cultural groups. I always say we Latinos come in many colors. And other subtleties like whether people are from the countryside or from the city, whether they have been educated in their country or not, whether their socioeconomic status has allowed them to be knowledgeable of certain systems such as the medical system in the United States. To use myself as an example—I came to this country as a professional, even though I didn't speak English, and I felt blind and helpless because I couldn't communicate with my doctor. I could tell when something was wrong and when my son was not being treated well. We were accused of having TB, tuberculosis, because his testing came up positive. We did not have TB; the testing came back positive because all children in our country are vaccinated; of course, the testing will come back positive. I could explain this for myself because I knew the difference. But when people do not have this level of education they do not know what's going on and it's very scary.

There are many, many countries and nationalities represented in a group called Latinos (eg, Puerto Ricans, Mexicans, Cubans, South Americans, Central Americans, Spanish, Brazilian). Many differ in culture. There are many different beliefs and of course, in terms of language, there are many different words used. (Washington Medical Center, Staff Development Workgroup, 2005)

And of course, there are similarities in many cases: the values, the attitudes, health beliefs, religious beliefs, and views of family interaction.

In the case of family interaction, the person who is going to assume the lead role and the responsibility may not be the individual who is being treated; it may be an elder in the family. In my case, in my house, it's not my husband, but trust me, I count on his opinion. I am a very progressive and liberated woman, but I need the support and need the opinion and it's just a fact.

In one case, we asked a patient in our diabetes classes, "So how are you doing, don Mario (Mr. Mario)?" He turned to his daughter, and let his daughter answer. And when we were talking about his medications and his diabetes control, he just let her do the talking. And that is again, a fact of how things may happen in other cultures.

Consider the languages spoken in the United States. The U.S. Census shows Spanish, French, Chinese, German, Tagalog, and Vietnamese, as the most common languages spoken in the United States. And of course, many more depending on geographic area. We have to stay away from the common assumptions, and the common assumption, unfortunately, is that a person who is bilingual is the one responsible for interpreting and translating and making decisions for how we should address or not address the patient.

Unfortunately, not just anyone can actually translate, or review translated documents already done by a professional, or interpret if they have not been trained with a good medical interpreting model. In terms of developing messages, translators need to know about the principles of health literacy and the plain language techniques. Let me describe what is happening at this point.

Because of the CLAS standards and because there is more awareness of civil rights and discrimination, most organizations, institutions, and hospitals are translating their documents into the languages of their patients.

However, they're choosing existing pieces and translating them. And in the case of these pieces, what is the reading level? What do you think?

It's grade 14, college level. On top of that, translations, documents that are being translated are inaccurate, grammatically incorrect; they don't have cultural appeal, as well as they're not easy to read, even though the English version was intended to be easy to read. Here are some examples:

English message:

You and your doctor can keep your blood pressure down.

Translation:

You and your doctor can keep the blood pressure down.

The English version says keep "your" blood pressure down, the Spanish version says "the" blood pressure. It is important here to make sure whose blood pressure it is; in the Spanish message that's lost.

English message:

Three ways to take special care of your breasts.

Translation:

Three ways to take care of your breasts.

"Care" is not the same as "special" care. Just "take care of your breasts." And believe me, I do. I always make sure that I buy the right size bra so that I feel comfortable. So is this what they are talking about? One word sometimes makes a big difference in meaning and understanding.

This is exactly what happens when interpreters and translators are not trained. We need to develop policies and guidelines and plan the process. We need experienced/trained translators and interpreters, trained in easy-to-read, plain language writing and translating techniques. Unfortunately, that is not what is happening. And we need to improve communication especially with the elders. That's the next step.

Allan Noonan: Thank you, Ms. Rosales. We're talking a lot about direct communication between a health care provider and the patient. Let us remember that a lot of health is primary prevention. We have messages throughout the media on personal hygiene, on what to eat, on exercise, on behaviors, on toxins in the

environment. We need to keep all of that in mind as we talk about health literacy that's going to have the greatest possible impact.

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Questions—Panel One

Audience member: My name is Peg Dublin. I work for the Cook County Bureau of Health Services and I appreciate all your comments. There is a lot of emphasis on speaking and writing, but I think we need to learn from the educational field about how people learn. I didn't hear much about that, but there are people who have studied how we learn. There are multiple intelligences; we learn in multiple ways and the best way of learning may be to teach others. We retain 10% by hearing; by hearing and seeing (hearing and reading), 20%. But when we teach others we get up to 90% retention. There's been some discussion about the role of community health workers, so that teaching is more culturally appropriate, but all of us in the health care field need to learn from those in the educational field about how people learn. Most of the things that we're dealing with are chronic conditions that people have to deal with over time. We need to think about other ways of communication. We are doing a lot at County now with group learning and people teaching each other; I think that's the way we need to go. I would like to hear more discussion over the day about other methods of teaching and learning that are effective.

Panelist Rima Rudd: Total support for what you were noting. The Health and Human Services report for Healthy People 2010 as well as the IOM report, both stress the importance of working with the adult education sector, with the education sector, and with librarians.

Panelist Wayne Giles: I also think you made an excellent point. The other thing we need to think about is, “Are there novel ways to teach people about health issues when they think they’re learning about something else?” Some of the REACH communities have taught us (I think this is the REACH community in Chicago) some methods. They’ve got some older folks who want to learn how to use the computer at the YMCA and YWCA. They use diabetes education Web sites to teach folks about how to use the computer so at the same time the people think they’re learning about computer skills, the reality is they’re also learning about diabetes. We need to think about doing some of that work as well.

Audience member: I had a question for Ms. Rosales. You emphasized how difficult it is to train people how to develop these materials. My question is, Can we expect all of these different health care providers across the country to develop these on their own? Is it realistic that we are going to train this huge cadre of people to develop these materials or should there be a major public effort to develop the best written materials and disseminate those free of charge?

Panelist Aracely Rosales: It would really be a big effort. What we are saying in the literacy field is that there are experts in writing and developing materials and there are content experts. One, we need to team up those experts. We need to have the organizations like health institutions decide first of all what is important for them to develop, to have in another language, and what is not. Start with that. Two, simplify in English first. Once it is simplified in English, of course, it’s going to be easier to do it in other languages. And three, standards need to be developed within the organization on the skills of the people doing this task and also monitoring this task. Again, that is not happening. What is happening is relying on one person whom they hire, either in-house or outside, to do the writing or translating without testing their qualifications.

Panelist Rima Rudd: May I add to that briefly? We need to have a climate change. We need to look at materials development as a rigorous effort and apply very rigorous formative evaluation. We’ve known about the mismatch between the documents that we provide for people and people’s ability to read them. The Department of Agriculture in the 1970s brought this to people’s attention. We have well over 600 articles in medical and public health journals attesting to this mismatch. We must apply rigorous evaluations to any materials long before it goes to print. As researchers and as practitioners, we must give due respect to the importance of materials and apply rigor.

Audience member: Eugene Rogers, MD. One of the things I feel very strongly about is that the educational system, not only for patients but also for physicians, has to include quality-of-life questionnaires. That has not been done in the past.

Audience member: My name is Sarah Gregory and I’m with the Centers for Disease Control and Prevention. I am co-chair of the CDC Health Literacy work group. My colleague and I worked with Dr. Noonan to develop the smoking and health Surgeon General consumer piece, What The Surgeon General’s Report Means to You. I was going to speak to several of you individually but I thought I’d take this opportunity to speak to everyone. We are in the process of trying to start a year-long training program for CDC and all the divisions and we were going to invite several of you to come and speak. We are doing one workshop per month, an afternoon presentation/training. We’re hoping to have a kickoff in October 2005. We’re thinking we would perhaps invite Dr. Carmona. If you’re interested in participating in this, please let me know.

Moderator Allan Noonan: This has been a very exciting panel. The people on the panel will be here for the rest of the day, so please talk to them in the hallways. Let me get in one last plug. We haven’t spoken about the education of our health care providers very much. Schools of public health and other health care provider educational institutions should play a major role in addressing this issue.

Panel Two: Patient Safety and Drug Benefit: Reducing the Risk of Medication Errors

Moderator: Justine Handelman

Director of Federal Relations, BlueCross
BlueShield Association

Moderator Justine Handelman: It's a pleasure to be here, and a pleasure to be co-hosting this event with the American Medical Association. We've heard a lot of important things this morning and I know this panel will bring another very important perspective to our discussions and debate today.

This panel is focused on patient safety and the Medicare drug benefit. Specifically, we're going to look at what can we do to reduce medication errors, a big problem today and a big issue we want to tackle. We have an impressive number of panelists here today who will speak about this issue, so with no further ado, I will get things going.

Terry C. Davis, PhD

Professor of Medicine and Pediatrics,
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Terry Davis: I was asked today to talk about a study that Mike Wolf, Ruth Parker, Dave Baker and several of us did about patient comprehension of prescription drug warning labels. (Wolf MS, et al, 2005) This was conceived of on an early morning jog along Lake Michigan when Ruth and I were doing an AMA train-the-trainer session. Patients' understanding of warning labels is a patient safety issue. Medication error is the most common medical mistake. As you've been hearing this morning, 90 million Americans have trouble understanding and acting on health information.

The IOM report taught me that unfamiliar and complex information is the most difficult for any of us to read. If you think about it, who teaches people to read a prescription label? It's a certain kind of code, it's not standard. How do we learn to read that? Pharmacists' and physicians' time is increasingly limited. There are more than 17,000 prescription and over-the-counter drugs.

The average U.S. adult takes about 9 to 12 prescription medications a year. The elderly take 20 to 30 or more a year and they see 8 physicians. So we are ripe for problems here.

When I was doing a review of the literature, I also did interviews with all kinds of pharmacists (eg, pharmacists in chain drug stores, independent drug stores, wholesale pharmaceutical companies, hospital pharmacies). I learned there are 14 different software companies that make warning labels. There is no standardization. Text, icons, color, nothing is standardized. Most are English language only—we've been hearing about language as a problem. Text and icons are apparently not developed with any input from patients, nor are they pilot-tested for understanding. There are few prescription label studies around and most of these only evaluated font size, white space and reading level. Also, it's hard to tell who's in charge. If you want to make a policy shift, who do you go to? The FDA is not in charge of warning labels. Maybe it's state legislatures.

We asked our patients, "What does this label mean to you?" Labels were chosen by pharmacists and physicians, the most common labels, the most important labels. So simple, familiar wording was understood by most patients. The labels were to give them focus, focus on what they need to do. Examples:

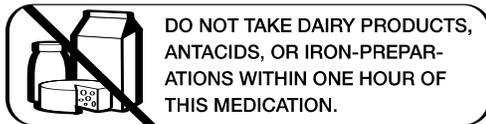


Label: Take with food.

Most of our patients understood this. Note this label: Take with food. Why is food written so big? The simpler the message, the greater the comprehension.



Label: Medication should be taken with plenty of water. Now, what's plenty of water? I'm not sure. Only about half of the patients understood this one.



Label: Do not take dairy products, antacid or iron preparations within one hour of this medication. That's a complex, bulky step. I don't know if people will get through that whole label. Almost none of the patients at my hospital understood this. So difficulty of the reading label predicted comprehension.



This is another icon that I think is hilarious. It's a martini glass. I don't think that would resonate with a lot of the patients in my hospital.

I want to show you examples of patients trying to read labels and warning labels. (Shows video examples)

Patient: It says "Take one capsule."

Davis: So how would you take this?

Patient: You see it's not on there telling you how to take it. It says take it twice daily, but it doesn't say what time to take it.

Davis: Dairy.

Patient: Yeah, dairy.

Davis: Do not take dairy products, antacids ...?

Patient: I don't know.

Davis: How many times do you take these thyroid pills?

Patient: Once a day.

Davis: Okay. You take one of each of these? (holds up two pill bottles—both for thyroid)

Patient: Uh huh.

Davis: Okay, so you take two thyroid pills?

Patient: No, take one...

Davis: And then, are these stickers helpful?

Patient: Don't even look at them.

Davis: You don't even look at them?

Man: What do you take that medicine for?

Patient: I don't know. There are just pills in here and don't even tell me what they are. I just take it.

This is what's it like if you can't read very well and you're trying to read a label or a warning label.

The theme this morning was focus on need to know and need to do. Lessons learned from patients. Break it down. What is it? How do you take it concretely? Why do I take it and what should I expect? And Toni, I use your quote all the time, "Remember what's clear to you, is clear to you."

So in closing, future directions. Consumers must be involved in the development and the testing of text and icons. Labels need to be patient friendly. Use plain language. Focus on need to know and need to do. Guidelines are needed for warning labels, and standardization needs to be considered.

Reference

Wolf MS, Davis TC, Parker RM. Low literacy impairs comprehension of drug warning labels. Presented at the International Conference on Communication in Healthcare, Chicago, Illinois, October 5-8, 2005.

Mary Kelly, RPh

Vice President, General Merchandising Manger for Health, Beauty and Pharmacy at Target, Inc.

Mary Kelly: I'm a pharmacist and Vice President at Target. Joining me today is Minda Gralnek who is in the audience. Minda is Vice President and Creative Director at Target. Minda was the first person at Target to recognize and foresee the importance of our new ClearRx system. Minda and I, pharmacist and designer, are here together today because our ClearRx system is a product of pharmacy experience and a company-wide commitment to great design.

The ClearRx story is exciting for us because it embodies our company goal of leveraging design to solve everyday problems. And it shows that Target's brand promise of "expect more, pay less" is more than just words, it's a commitment we work hard to deliver.

As proud as we are of our new system, we are also honored to be here with you to learn more about better ways to improve health literacy for our Target guests.

First, I'll share an overview of how ClearRx evolved. The story begins with a young designer named Debra Adler, who attempted to tackle this critical problem for her Master of Fine Arts thesis. She identified the need because her grandmother had misread a prescription bottle and mistakenly ingested medicine intended for Debra's grandfather. Incidentally, Debra's grandmother does not have poor eyesight. The bottle containing her medicine looked exactly like her grandfather's bottle. The difference was described on some very small and poorly located printing on the bottle. It wasn't a Target prescription. Debra found that this same mistake could have happened to anyone regardless of their age. Ambitiously, she set out to determine the extent of the problem nationwide. In her research, she found case after case in which people had become ill or even died because of confusing prescription packaging and instructions.

While Debra's initial work may not look entirely like our finished product, her recognition of the problem, her proposed solution and insight as a designer provided the designers and pharmacists at Target with a strong foundation. When Debra presented her idea to Minda, Minda immediately saw the benefit. Then Target quickly inspired the passion of 100 Target team members. In partnership with Debra we went to work on our basic design ideas, and created a new prescription delivery system with a lofty goal of replacing confusion with simplicity, clarity and understanding. We drew on several sources of knowledge and information. We tapped into the many experienced pharmacists who managed our pharmacies nationwide. We conducted focus groups with our guests of all ages, and we worked with regulatory boards across the country. We worked with bottle and label designers and developed new software and extensive training programs for our pharmacy teams. The ClearRx design reflects the culmination of this knowledge and consumer insight.

The first thing you'll notice about ClearRx is that it is built with the patient in mind. The bottle itself is easy to hold and clearly communicates the vital information with simple language and easy to read type. Obviously, we have a little ways to go now that we've heard what you're all talking about today. With the traditional bottle shape, labels wrap around a curve, making them difficult to read. You have to turn the bottle to read the instructions. ClearRx features a flat surface, so Target guests can see all vital information without turning the bottle. Information is also presented in a clear and intuitive hierarchy. The name of the drug is printed, big and bold on the top of the bottle, making it easier to see at a glance. The important information, drug name, dosage and directions are clear, concise and printed in a large text in the primary area of the bottle. Less critical, but necessary information is printed below the primary text area. This includes quantity, expiration date and the prescribing doctor's name. The pharmacy name is less prominent and at the bottom.

Additionally, we developed a concise patient information card, which is securely tucked in the back of the bottle. It summarizes common uses, potential side effects, and what to do in case of a missed dose. It stays with the bottle. In the old system, this information was generally printed on separate sheets of paper. The patient often threw them away. Incidentally, based on regulations, we still print the longer, more detailed information sheets, and we're developing ways to make them more accessible as well.

Color-coded rubber rings, available in six different primary colors, attach securely to the neck of the bottle providing even more clarity. Each person in the household can be assigned a particular color. This provides yet another line of defense against someone mistakenly taking medication intended for someone else. The cap on the new bottle is child-resistant, of course. The larger cap, along with our new wedge shape, makes it easier to grip. You can hold the bottle and turn it in a way that's more ergonomically efficient. Older people were able to do it a lot easier.

With the help of Debra and our designers, we also redesigned warning and instructional icons. We located them all together on the back of the bottle. In the old system, the stickers are often placed anywhere they would fit. In addition, we introduced a spill resistant bottle for liquid medications. Instead of pouring the liquid onto a spoon, the patient or caregiver can insert the prepackaged syringe into the spill resistant bottle and draw a precise amount of medicine.

As a pharmacist, I can look back and recall incremental improvements in our industry, but I believe this isn't just an incremental step. Actually, the bottle and label haven't changed in over 50 years. As you can tell I'm passionate about this subject. However, we were pleased that others agree with our benefits. The U.S. Surgeon General, Dr. Richard Carmona, reviewed our ClearRx system and said, "I would like to congratulate Debra Adler and Target for their leadership in designing a new, more easily understandable prescription bottle. The new design is a simple yet important step in improving health literacy of all Americans." Dr. Carmona's

comments mean a great deal to us. Also, the patients using our new ClearRx system have expressed great satisfaction. We collected a few of the comments and we've heard some rewarding feedback.

One guest said, "This just looks like something Target would do. It's smart, it's safe and I'll never go anywhere else." Another said, "I used to go to two different pharmacies for my kid's prescriptions, so I wouldn't get them mixed up. Now I don't have to." Another said, "I spilled the amoxicillin last week so my son had to go without antibiotic for two days. I'm excited about the new dispensing syringe." Another guest said, "I love the color-coding. I can't believe it doesn't cost more."

We feel good about this last statement. The truth is, the new ClearRx system does cost more, but not for our patients. Target decided to make an investment in research, design, training and testing because we believe it was the right thing to do. Manufacturing the new bottle is more expensive. We are pleased to bring these improvements to our guests without adding additional cost for them. This brings to life the "pay less" side of the Target brand promise. Of course, we also hope it will inspire more guests to choose our pharmacy. As a company, we're excited to help improve health literacy for guests who visit our pharmacies. We also believe we can collaborate with health care professionals, like all of you, to bring ideas and fresh thinking to make health care better. At Target, innovation and design are what our brand is all about. As a health care provider, we are thrilled to apply this to the practice of pharmacy. There is one additional thought I want to share before I'm done. We have not reached a final destination with ClearRx. We know there is plenty of room for improvement on our own design and in other things and we see it as a collaborative process. We welcome the opportunity to hear your views on ClearRx and how you think we can make it better.

Please let us know what we can do as a pharmacy as well as a corporation to help people who take prescription medications. We welcome opportunities to participate in the development of new ideas and new standards that improve the quality of life for our patients across the United States. We certainly appreciate you asking us to come and share the ClearRx story with you. It's humbling to speak to such a distinguished group. I hope our presence here today and our continued refinement of the ClearRx system leads to new relationships, new opportunities and measurable improvements in health literacy.

Bryan A. Liang, MD, PhD, JD

Executive Director, Institute of Health Law Studies, California Western School of Law and Co-Director, San Diego Center for Patient Safety, University of California, San Diego School of Medicine

Bryan A. Liang: Thank you for providing me with this opportunity to talk to you about some of the things we are doing on the ground level with respect to patient safety and patient literacy. I'm here today to frame some of these issues and perhaps look at some models that might help improve health literacy for all patients. As some of you might know, there is a small state called California, and we have a very small thing called an \$8-\$10 billion deficit. There is not much room for new programs with us, so we have to work within our framework and that's what we are trying to do.

First, some statistics. You've heard some of this already but I think it's worth emphasizing. In this country, almost 50 million people don't speak English well or at all in their homes. More than a quarter are Spanish-speaking homes, about a quarter of Asian-Pacific Islander-speaking homes. And I can tell you in my family virtually every single generation above mine does not speak English at home.

More than 10% of the U.S. population has limited English proficiency. This problem is exponentially growing. According to the 2000 U.S. census, fifteen states have more than 100% growth since the last census in limited English proficiency populations. This is clearly not a problem that is going to go away.

A lot of people I talk with say, "More education." But that's not going to work. You've got literally hundreds of people coming into San Diego every day who do not speak English. Education of these people simply isn't feasible.

Asians, a group that we focus on a lot, are the fastest growing population, with a 75% increase from 1990 to 2000. This group is extremely linguistically isolated. In fact, between 26% and up to more than 50% of all Asian-American homes in the United States are linguistically isolated. In other words, they do not speak English or only one person under the age of 14 within that family group—and these are extended families—actually speaks English.

As well, more than 25% of Hispanic homes are linguistically isolated. I can tell you being in a border state with Mexico, it's a tremendous issue. When we see people in an emergency department, roughly one out of two Hispanics do not speak English. So it's a serious problem for us.

Finally, to further identify the problem, consider New York City. More than 50% of the patients who enter health care facilities in New York don't speak English. So, in fact, in New York, guess who's the minority? The people speaking English.

Consider the problem of medication errors and its relation to health and linguistic proficiency. Here, elders and minority groups obviously intersect. We talked about the IOM report, and I would emphasize that although many are affected by medication errors, most of the fatal medication errors in hospitals affect the senior population. I'm defining this group as patients over 65 years of age. They represent over 13% of the population but 40% of the medication use.

Importantly, it should be noted that about half of all seniors exhibit poor functional literacy when it comes to health care information. We talked about the National Adult Literacy Survey (NALS); many are only at NALS literacy Level 1. What does Level 1 mean? You can't enter background information on a Social Security application. You can't find an intersection on a street map, and this is a roughly a 20-block street map. And you can't locate two pieces of information in a sports article. With respect to trying to figure out what's going on in the society around you, you are very limited at NALS Level 1.

Dr. Baker mentioned that 28% of the patients 55 to 64 years of age are functionally at NALS Level 1. This is therefore an unbelievably broad problem.

But let's look at some more detail. Fifteen percent of whites are at NALS Level 1, and yes, that's a huge issue to address. Yet it gets worse. If you are a minority, you are not participating in our society: 26% of American Indian/Alaskan natives are at NALS Level 1, which represents about 12 different minority groups. Thirty-five percent of Asian-Pacific Islanders are at NALS Level 1, which represents about 70 different Asian-Pacific Islander groups in the United States. In California alone, we have almost that number. In San Diego County, we have 38 groups. Further, 41% of African-Americans are functionally at the NALS Level 1, and that obviously includes the over 50 different African-American groups. And 52% of Hispanic-Americans function at NALS Level 1, which includes about 70 groups.

Therefore, if you are a member of a minority group, you are likely not going to be a part of this society who can actually function and fully obtain the benefits you are entitled to. Now, there are a lot of implications and people talked about that already, but I want to point out two things with respect to patient safety.

First, a study of physician-patient communication when a family member or untrained staff was used as interpreter for a non-English speaking patient found an average of 31 mistakes per visit—and two-thirds of them had potential

negative sequelae. (Flores G, et al, 2003) Second, minorities have a greater probability of being admitted to the hospital. As you know, patient safety and medical errors are a real problem on the inpatient level. If you get admitted, guess what? You are more likely to be subjected to a medical error, particularly a medication error. It may not kill you, it may just maim you, but being in a hospital creates the risk that a medical error will affect your life. In addition, you are going to be paying more. (Hampers LC, et al, 1999)

Poor/untrained/ad hoc/or lack of translation results in at least:

Average of 31 mistakes per visit and two-thirds have negative clinical sequelae (Flores G, et al, 2003)

Greater probability of being admitted; longer time period in emergency department; charges 39% greater than other patients (Hampers LC, et al, 1999)

Reduced compliance with medications (David RA, et al, 1998)

>10 fold misunderstanding of medication instructions (Andrulis D, et al, 2002)

Poor/untrained/ad hoc/or lack of translation has tremendous implications on quality, safety, and life.

So we've got a big problem here. Empirical data suggest that if you are a minority, if you have low health literacy, you are going to have a problem with errors by providers, and the impact of those errors. Now, what are the kinds of problems that you might have? Miscommunication about medications. Allergy information lost. Mistakes about or in understanding the dose. Mistakes regarding the frequency for use. Mistakes regarding the duration of treatment. Basically, it's everything important. So we need to focus on communications methodology so we can reduce the errors, actually empower the patients to understand the treatment regimen, and save some lives.

Another issue that is tremendously important with respect to health care, and specifically medications, is fraud. Last year, physicians wrote about 3.5 billion prescriptions. That's an unbelievable number of prescriptions and that number is going up about 16% a year. Hence, there is a lot of opportunity for those who want to cheat paying consumers who are looking for cheaper sources.

Who is targeted for fraudulent drug schemes and counterfeits? Seniors and minorities. Why? Well, first because seniors have to take a lot of medications and they are trying to save money because we are the only health system in the world that doesn't have price controls or negotiated discounts, so we are the only ones who have to worry about this particular kind of issue.

Second, minorities who are disproportionately represented among the uninsured are targeted because they are looking for less expensive drugs as well. So, for black marketers and gray marketers who are very capitalistically oriented, these are the groups they prey upon because these groups are the people who are unsophisticated and vulnerable. They're certainly not going to go after the pharmacy benefits managers.

There is a business case, and I hate that term, but there is business case for improving health literacy. Creating appropriate materials and mechanisms for good communications about care is cost beneficial. And by the way, it does save lives as a secondary benefit.

What are the financial benefits? Reduced costs. For the bean counters, bluntly, reduced outpatient and emergency department costs, admissions, diagnostic testing are a result of improved health literacy. Of course, part and parcel of this is the reduction in medical errors or their potential harm.

Of course, the big benefit is patient empowerment. With improved health literacy and understanding, patients will be part of the therapeutic process; they will be partners in their delivery of care. And therefore, you are going to get therapeutic compliance. You are actually going to improve the care by going through this process.

Now, importantly, from a different point of view, improving health literacy is cost-beneficial because it reduces risks of liability.

Miscommunications due to limited English proficiency have been tried in the courts, believe it or not. Lack of informed consent can result in damages up to the seven figure level. Breach of duty to instruct and monitor patients has also resulted in liability, even for public health clinics. Miscommunication could also result in provider liability such as negligence and medical malpractice.

Further, issues with medication labeling and counterfeit sales and fraud include pharmaceutical company liability and supplier and pharmacy suits for counterfeits. This is a huge issue, and it doesn't just affect the older people in the community, it affects all members of society, all the stakeholders in the medication process, which may broaden the potential risks of litigation without attention to it.

So what do we have to do? First, let's define patient rights. Every patient has a right to understand their medications, the effects, and their role in treatment. They have a right to have that information explained to them in a way they can understand. Again, this is part of the therapeutic process. Every patient has a right to safe and effective medicine.

Patient Rights

Every patient has a right to understand the medications, their effects, and their role in treatment.

Every patient has a right to have medication and medicine information explained to him/her in a manner he/she can comprehend.

Every patient has a right to be assured of safe, effective medicines.

What are the potential solutions? I mentioned that we're looking at models that exist, public models alone, public-private partnerships, or public and private partnerships underwritten by for-profit companies. As a baseline, we need materials created at the sixth-grade reading level or below. How do we accomplish this?

First, we should note that we cannot use telephone translation services or family members. Although there are arguments for both, neither can be used as a facility's primary translation method. These alternatives are in direct violation of the Office for Civil Rights assessment of Title VI rights, so we have to work on that level. (Glasser BL, et al, 2000).

We could have state-based committees on appropriate medicine use that are translated for public beneficiaries. Why is this a good possible alternative? Because there are, in fact, federal matching funds available for Medicaid program translation services. We may be able to take advantage of such available funding for this very important service, and hence it is worth exploring.

In addition, we have clearinghouse programs for reduced cost drugs. These programs are using consortiums of state non-profits like ourselves and pharmaceutical companies who are helping us. Now, we use this reduced cost medication program to also enroll people in Medi-Cal or give them information about Medi-Cal, and about Healthy Families, another state program. We have 15 different languages that are represented on the state level. So this is possibly a very important model for us to think about using and expanding. There are also national programs, not-for-profit clearinghouse programs for reduced cost medications, and other clearinghouse programs underwritten by pharmaceutical companies. And again, many different languages are available—up to 150—to the caller through a single 1-800 number.

As another possible solution we could involve the FDA, perhaps the same kind of committee structure like the FDA's Center for Drug Evaluation and Research (CDER), which evaluates clinical efficacy. We could get medication use information first translated, assessed, determined by professionals and then put it out for pilot-testing, rather than trying to fix the problem after the drug is placed into the market with no patient assessment. Other kinds of federal-private partnerships are also possible and right now we are looking into that.

Importantly, we cannot forget that patients are the last barrier to harm, particularly with respect to being exploited by those who peddle fake or tainted medicines. Educational efforts for providers and patients with information on appropriate sources of drugs and potential financial abuse may be a solution. Critically, providers have to be educated; an index of suspicion for fake or tainted drugs, and asking about it, is currently not a standard assessment taught in our health professional schools. This, and training in health literacy in our professional schools should be a priority.

Easy tools should be provided to help patients and providers, particularly to be informed about the issue of real medicines and the potential for fakes. The AMA is working on a simple tool placed on a card to help providers be sensitive to patient safety issues associated with health literacy. We need to make it easy for patients and providers to communicate to minimize risk of harm due to error or miscommunications.

We also want everyone to be empowered to protect themselves against unscrupulous medicine sellers. Part of that patient effort has got to be grass roots, and in fact the Partnership for Safe Medicine (<http://www.safemedicines.org>), which I'm part of and to which my organization belongs, has developed something called the SAFE DRUG checklist. The checklist uses the aviation model; people get cards, which are easy to understand and easy to carry, to review their reactions and medications each time they take them. We've distributed about 1200 of these cards to people in the elderly and minority communities. We've also created a similar provider card, and have distributed that to about 200 nurses. And right now we are working with the International Council of Nurses, which represents 12 million nurses, to try to do that same thing around the world. This is a possible way of dealing with vulnerable patients being scammed by fake, tainted, and counterfeit medicines.

Finally, I want to note that in this room, we are the minority elite. We understand in general what's happening to us in the health care system. We have to eliminate that elitism, so everyone gets the benefit of the great health care delivery system we have in this country.

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David L. Clark, RPh, MBA

Vice President, Pharmacy Services,
The Regence Group

David Clark: Today, we're hearing about things that can be done at the patient level to help care. I want to talk also about things that can be done before medications get to the patients to decrease medication errors. We know that patient medication safety is not a new issue; it's an old issue.

We know that frequently medications have been withdrawn from the market. We saw what happened with COX II inhibitors recently. There was also a new medication for treating multiple sclerosis TYSABRI® that was highly touted and subsequently withdrawn. Now, the FDA is doing several things to change that including premarketing risk assessment, development and use of risk minimization action plans and good pharmacovigilance practices. But more can still be done.

With medication safety, there is a serious impact from new medications. Of course, medications

add value; I don't want to take away from that. As a pharmacist, I've seen first-hand what new medications can do to clinically benefit patients. But as medications come out, they're highly advertised. From 2001 to 2003, retail drug spending went up over \$30 billion, and new medications accounted for 25% of the total retail spending. We also see a lot going on with consumer advertising. Last year, almost \$3.9 billion was spent on direct-to-consumer advertising. That's about one-sixth of the total advertising budget. That does impact utilization and can add to confusion.

There is not a direct correlation of the volume of television advertising and the number of prescriptions being written for patients, but clearly there could be. (Milliman USA; Kaiser Family Foundation) It's interesting to note that even though we may not have good patient information in medications as you go through different magazines, through television channels devoted to different cultures, those sources are still highly frequented by advertisements for medications.

Also, we know that as people age, they use more medications. (RxHealth Value Congressional Briefing, 2001) Part of this has to do with new medications coming out but it also has to do with our ability to provide treatment for new areas. Now, as you relate this to advertising, I want to re-emphasize that direct-to-consumer advertising is a big issue. VIOXX, which was pulled from the market in 2004—they spent roughly the same amount advertising that single product as Dell did for advertising their whole computer line. They spent more on that than was spent by PepsiCo advertising Pepsi. So there's a lot of spin on various medications.

Of the new medications coming out, only a limited number add a significant benefit to the clinical treatment of patients. In a study that looked at new medication evaluation from 1989 to 2000 (National Institute for Healthcare Management (NICHM) Foundation, 2002), only 11% of the drugs were classified by the FDA as priority new molecular entities. In other words, the FDA felt that most of the other medications were not priority; they could take their time

reviewing them because they did not add any significant benefit. When this was repeated by another group for the years 2001 to 2003, it went from 15% to 11%, so the actual number of priority new molecular entities, again medications that added significant value to the clinical treatment of patients, was limited to about 11%. (Presentation, Academy of Managed Care Pharmacy, October 2004)

To simplify it by looking at product value: in all new medications released, less than one fourth actually added anything in being more effective to treat patients. Only one out of 20 added anything in safety. Some helped lower costs, or improved consistency. We've seen there are a lot of opportunities, a lot of directions that we can work on, and perhaps restricting advertising for new medications is something that we could look at.

One thing we need to understand more is how these medications work in the elderly or in different racial or ethnic populations. The studies on the elderly are very limited and rarely do they include patients on multiple medications. As a rule, we see most of our patients who are elderly taking anywhere from 3 to 1 different medications. Clinical studies are not designed to understand how these medications will impact those patient populations. So we need the ability to get more studies to do that, but we also need improved systems to monitor the safety of medications after they're approved. The FDA will frequently require what are called conditional trials. They may say "We need to have you come back and answer these questions." Most of those are never responded to. We need to improve the system to monitor safety trials when medications are approved conditionally. We need perhaps a significant financial penalty if they don't do it.

We can improve communications with patients to improve medication safety. I've broken it into two different directions of focus.

Focus One, those things that can be done before information goes to the consumer. The first is restricting advertising and also support for more evidence-based studies. The second is use databases like the Centers for Medicare & Medicaid Services' (CMS) to identify preventable, adverse drug events. Now health plans are doing

some of this today. Fortunately, with the new Medicare law, CMS is going to create a database. Health plans or providers are required to supply data to them monthly. So we can monitor preventable adverse drug effects using the CMS database, much as we've been doing with health plan databases. A study published in 2003 showed that out of every 20 patient years treated in the elderly, there was one adverse drug event. And more than 25% of these were preventable with data we have today. So there are a lot of things occurring that could be prevented.

We could also do more to monitor for drug-drug interactions. We need to do more to monitor post-marketing. What actually happens with the medications? Hopefully, with the CMS database we'll be able to do that. Several health plans have been trying to coordinate with the FDA on that but that has not been well received to date.

Focus 1— Improve information before it gets to the consumer

- Restrict advertising for new medications unless extensive international safety data is available
- Support or commission more evidence-based studies
 - studies in the elderly, involving patients taking multiple medications
 - improve system to monitor safety trials when medications are approved conditionally; significant financial penalties if not completed
- Use CMS database and other databases for analysis and reporting:
 - preventable adverse drug events (ADEs)
 - drug-drug interactions, and
 - to monitor for high risk medications
- Conduct postmarketing surveillance
 - Reporting available by age and to the public
 - Use CMS or insurer databases

Focus Two is on consumer education. First of all, educate consumers. We need to engage the consumer. Professionals routinely ask, “Do you have any questions?” Many patients have no idea what questions to ask. Professionals need to be asking, “Why are you taking this medication? How long will you take the medication? When do you take the medication?” Those questions will help the professional understand the patient’s level of understanding.

We also need educational campaigns on what questions to ask. It’s important for patients to know that they need to ask those same types of questions, “How long do I need to take this? When do I stop? What should I do if I forget to take a dose?” Patients don’t know that because there is significant confusion. We believe that if the patient had a wallet card they could carry with the questions, as well as a card that listed all the medications they take, whether prescription or over-the-counter or herbal, that would be very beneficial to the health care provider.

There aren’t very many educational pieces out there that tell the consumer what the real information is on different medications. Within several plans, including our own, we produce consumer-friendly pieces and we are trying to target them to a very easy to understand education level. We are starting to look at how we can put them into multiple languages. Others are doing some things—Consumers Union is doing a lot of work on this and AARP is looking at it as well. The main issues are that they are needed in multiple languages. They need to be targeted at lower reading abilities, as was evidenced by the label studies, and then patients need to have the ability to call someone if they don’t understand.

We also need to provide interactive modules about drug interactions and high-risk medication. Frequently, when patients have questions about the medication, they don’t know where to go. Tools are made available to professionals but not to consumers. We need to make tools available to the consumer and for those who aren’t able to do it online, we need to also make it available through telephone or other types of media for education.

Focus 2 – Consumer Education

- Need to engage consumers and professionals—the professional can ask the consumer:
 - How will you be taking this medication?
 - How long will you be taking this medication?
 - What do you do if...?
- Educational campaign for consumers on which questions to ask—a 3”x5” wallet card can hold the 4 or 5 most important questions a consumer should ask the professional:
 - How long will I need to take this?
 - Will this affect other medications I take?
 - What should I do if I forget to take a dose?
 - What should I do with leftover pills?
- Consumer friendly components—need multiple languages, lower reading levels, ability to call someone with questions, eg,
 - Regence Rx Consumer Rx
 - Consumers Union
 - AARP
- Provide interactive modules on drug interactions and high risk medications, making information available to the public
- Provide multi-lingual telephone support in addition to interactive modules

We get involved sending physicians lists of patients on medications that could cause problems. It does change behavior there. Getting involved with consumers in community education centers, helping them understand what questions to ask and what things they don’t want to be doing has been very beneficial.

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Questions—Panel Two

Audience member: A number of groups, the Institute for Safe Medical Practices among them, have advocated that physicians include even the organ system or the disease for which the medicine is prescribed. It helps the pharmacist decide what the prescription is for, but it also helps the patient. Labels are not as big a problem for an individual who is only taking amoxicillin for an infection. But you have elderly patients with multiple diseases. To expect an elderly patient to understand the brand name or the generic name of the drug they are taking for their high blood pressure and the brand name or generic name of the medicine they are taking for their heart and so forth, is unlikely. They are not going to be able to make that kind of connection. However, if there is something included on the label that “This is the medicine for your blood pressure, this is the medicine for your diabetes, this is the medicine for your lungs”, the patient may be able to keep clear among these five different bottles that they are taking.

I would ask Terry Davis, in terms of Target, how do you handle the problem of a patient who has been taking a brand name medication over a period of time and is now getting a generic? Do you put a generic name on it or do you link the generic name back to what the brand name was? The patient may be confused because the pills will look different and the name is different.

Panelist Terry Davis: My friend Ruth Parker went to a Target pharmacist and asked, “How do you think this is working?” Things were working well, but to your point, patients wanted prescriptions color-coded by the disease so these yellow ones are for my hypertension, and these blue ones are for something else. That can’t be done now because we’ve got the family deal going (color-coded rubber rings on bottle). But that was a patient recommendation.

I think it is a huge problem. If only physicians could show patients how to take the medicine. Part of it is “show me, show me, show me.” And then if you look by the color and that changes by the generic, that is a huge problem. The other point that I want to make is that it’s not just getting the reading level down. It’s making it make sense and fit for how the patient conceptualizes things.

Panelist Mary Kelly: The problem is you can’t fit all the things you might want on the label itself, so that’s why the designers developed that little card with the top three questions asked from patients. And the first one was, “What is it? What’s it for?” So that’s what we put on there. It has common uses. It has the drug name and the generic name and then the common uses, so it might say, “This is for blood pressure” or “This is for XYZ.” That’s where we find a lot of questions coming from patients, “Well, I don’t have high blood pressure, you know.” So then we’re able to engage in a conversation with the patient. Next question from patients was the instructions and what to do with a missed dose, so those were the things that we put on that little card. The big sheet has a million more pieces of information but those are the things that we put on the card.

Again, we are hoping to talk with our patients and understand, “Well, does this work? Is there something else that would have made more sense?”

Panelist David Clark: You brought up another point and that has to do with what the physician’s writing when ordering the prescription. Many of us have worked for years to try to get physicians to include the diagnosis and what the patient is taking it for, and we have met a lot of resistance. There’s hope with e-prescribing, if and when that is fully adopted, and we know there’s work to encourage that. It will enable us to have more information. It’s been a major problem, and historically it’s been dealt with by more of the medication sheets which try to list everything, and the patient has no idea what the heck is going on.

Panelist Bryan Liang: We do have e-prescribing, and we do have electronic medical records so when we give a prescription to a patient, we generally have the option of putting the diagnosis in. The other issue is we have taken some lessons from the European Union, because they have so many languages and so many different contexts for drug dispensing. They have a uniform color-coding system. You can drive from Belgium to the Netherlands over to Germany and if you have a kid who has a certain kind of cough syrup you will always be able to identify the doses correctly as long as you’ve gotten the right color code from the original pharmacy. You can

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compare that to the other countries. So there are other ways of doing it, but I think it's a multifactorial problem. One of the problems is, physicians aren't doing it. The second thing is the handwriting and the prescribing issue. And finally, it is a complex system that is, right now, quite broken.

Audience member: My name is Arvind Goyal. My day job is practicing family medicine, geriatrics and preventive medicine in Rolling Meadows, Illinois. Welcome to all of you who are not from Chicago. My evening job includes being President of the Association of Public Health Physicians and also a member of the Commission to End Health Care Disparities.

One of the basic things that stands out in my mind thus far for action, number one, is that we develop a health disparities health information and advance directives and Medicare information course, a health literacy 101 course, for consumers, for patients, and seniors. And parallel we also develop a health competency 101 course, handwriting course and all those things you want physicians and providers to do which should be mandated in medical schools, nursing schools, and pharmacy schools. For my part I would take that suggestion to the school that I teach in, which is the Chicago Medical School. The 101 course for the consumers, I think you need some incentives for people to participate. Since we are talking about the aging population, it may be reasonable to put some incentives into the Medicare program at their initial enrollment and possibly in each subsequent year. If consumers take the course, sign a one-page evaluation or complete it and also sign a health advance directive, then maybe they get a 10% discount on their Medicare premiums.

I have a hunch that the people who are not proficient in English should be encouraged also to have a bilingual family member who speaks English with them if possible at all health encounters, including when patients are admitted to the hospital.

Panelist Bryan Liang: I think incentives are great. I actually graduated from the University of Chicago, so I know money helps. We have absolutely no problem when we go to community centers and we say, "Do you guys want us to teach you

something about how to read, so you get safer meds?" It's always standing room only. I think people want this information, they want to be empowered. They want to be able to participate. So although money's great, I think we can start this effort without that. We've gone to community centers and nursing home facilities—when we ask if we can come in to provide some information, we are the social event of the month. We have had so much benefit from those opportunities. It's wonderful, they welcome us so warmly. Everyone is dressed up, which means I have to get dressed up. I think that's the way to approach it.

With respect to the family members, I agree you need an advocate but in terms of translation we have the Civil Rights Act and the Executive Order mandates. (<http://www.lep.gov>) So we cannot rely on family members as our primary source of translation, we have to use another method. I'm all for trying to change the ruling on that but right now we can't; we're stuck with the rule as is until there is an organized effort to alter it.

Audience member: I work as a social worker for 600 low-income seniors in the Chicagoland area. Additionally, I was designated by Congresswoman Judy Biggert to serve as a delegate in Washington, DC, in December 2005 at the White House Conference on Aging. So I come here with huge interest to learn from all of you. What I've heard is very interesting and I've certainly learned a lot.

My interest falls into the practical nature of what will help seniors. We're talking mostly about the general population which as we age is going to be beneficial for seniors when they get to that point. The seniors I see trust their doctors, they trust their pharmacists. They're not looking necessarily to be educated on their diseases as much as they want to know if you tell them to take a medication, they are going to take it. Medication error for them happens in their apartment, in their homes. So what I would suggest is the labeling we're talking about this morning, one thing that we know with seniors, of course, is that they suffer from other things such as cognitive deficiency. Also, we have not heard much about macular degeneration. Some of the

things that seniors struggle with, of course, they simply cannot see the medication. Additionally, arthritis, we talked a little about that this morning with the Target representative. Those are all practical suggestions, where are we going to put the funding for those types of things?

Additionally, Title VI policy. If it is the reality that a person needs a translator or a family member to accompany them but it violates policy, is that not where we should recommend to Congress that policy be changed? That's the reality. Seniors need assistance. Additionally, I would recommend that pharmacies provide medication delivery. So many do not offer that and seniors' transportation issues are real. They don't have access to the pharmacies all the time. They're relying on family members who don't always have time... they're working full time. We as a generation taking care of the seniors are also working full time and have families.

I might also recommend that pharmacies offer a service that fills medication reminder systems for seniors who cannot fill them, seniors who cannot see the boxes. And perhaps something that will help people who have hearing loss, which we know is something that affects seniors. Something that is going to alert them with a loud tone to take their medications. I know that's a lot to suggest because of the multiple medications seniors are on. Are we going to have a different tone for two times a day and another for four times a day? I realize the logistics are a problem, but you are the experts in the field and we look to you. As a social worker, I look to you to help seniors with these practical issues that affect them every day. Thank you all for your attention and good luck. I'm looking forward to all of your suggestions in Washington and I appreciate everything you shared today.

Audience member: Neal Winston, Medical Director for Preventive Services Cook County Public Health. Just a quick comment and a question. One of the things that happened this morning when I woke up is that 35 million people in this country were at or below the poverty level and 44 million people in this country were without health insurance. One of the challenges that Dr. Davis brought up was the need for educating

our patients on how to take the medications they are prescribed. As an emergency specialist I see a person, maybe one of those 44 million, in an acute care situation and I know they may not follow up with another health provider after they've seen me. My concern is how that education occurs in that setting. I don't know if there's any real answer right now but that certainly is a strong concern I've had over the past several years.

I usually like to do some prep before I come to a meeting like this so last night I watched the HBO Chris Rock special and that was preparation because he was talking about paradigm shifts. Now that's not exactly the phrase he used. He used slightly more colorful language ... but he talked about the dependency of our culture, the paradigm shift that we've had, that was based on the pharmaceutical ads that you see on TV. First of all, you couldn't realize what riding a horse or running through a field with a balloon in your hand has to do with taking prescribed drugs of any kind. And he was concerned because he saw all these ads and he couldn't figure out which one applied to him. So he said he finally heard an ad that said, "If you go to sleep at night and you wake up in the morning" He said, "Oh, that's my drug." I know if we all took macro- or micro-economics courses, we could all realize how the pharmaceutical industry wants to recoup its R&D money and blah, blah, blah, but how do we break this paradigm shift in our general public who love these pharmaceutical ads and actually, even in the emergency setting, ask for a specific medication?

Panelist David Clark: A number of issues have been raised by the last two people at the microphone. One thing I'll say on the medications. Bryan Liang mentioned we're the only country that doesn't take care of all of their patients with some type of health care coverage. We're also the only civilized nation that allows direct-to-consumer advertising on prescription drugs. And that does drive a lot of utilization. In our own plans we noticed a significant increase in requests for COX II inhibitors but based on the data that were available 3 or 4 years ago, we identified a cardiovascular risk and we worked aggressively

with physicians in our markets to decrease that utilization. So last year when the changes started to occur it wasn't a big issue in the population we insure because we had already decreased utilization. But it was a major effort to undo the perceived need created by billions of dollars of advertising when frequently people may not have needed a medication at all, and secondly, if they did need one there might have been one already on the market that was just as effective or had a better safety record. So that is a major issue. It is interesting how well the pharmaceutical industry has done on the advertising to hit almost everybody—like you said, “If you go to bed at night and you wake up in the morning.” But the work hasn't been done to give the consumer information so consumers understand what they should be asking for.

Panelist Bryan Liang: About DTC, the direct-to-consumer advertising. If you talk to many of the pharmaceutical companies, at least some don't like it. The major problem is that if they don't do it, the competitor is going to do it and so it just snowballs. In fact, there was a pharmaceutical council meeting that agreed that this is a bad thing and they need to talk to the FDA about it and create some guidelines at least. That's the first thing.

The second thing, with respect to the emergency department patient who comes into acute care, how do you explain and teach to them? We have done this in San Diego. Some facilities work to have a partnership with the community clinics and coordinate their efforts with the community clinic. When patients come to the emergency department, they get their needed acute care and then are moved to the community clinic, so there is no violation of federal law, the Emergency Medical Treatment Act & Labor Act. That partnership has helped to get patients preventive care as well as continuity of care. But you need buy-in and money to do it. It's been an expensive process but overall, it's saved money.

Panel Three: Incentives to Improve Quality through Patient Centered Primary Care

Moderator: Margaret Gadon, MD, MPH
Director of Disparities Initiative, Medicine & Public Health American Medical Association

Margaret Gadon: I'd like start by thanking both Dr. Aparicio and Dr. Schwartzberg for inviting me to be on this planning committee. It's been a great honor.

This session is going to differ slightly from the other sessions in that we are going to offer you some strategies to improve quality through patient-centered care. Why don't we start by defining exactly what we mean by quality and by patient-centered care?

Quality is a word that has been used extensively in the health care field in the past 15 years in an effort to have consistency of care, care which causes no harm and which is capable of improvement measures. There can be a process of care or an outcome of care whose quality we are measuring.

And patient-centered care is an attempt to bring in people's psychosocial elements. Their cultures, their values, their language, their educational level, their person, into the visit itself, so that the care is aimed at an individual level and permits the patient to get involved in the care and follow the recommendations of their health care provider.

We have four presentations today. Two are directly related to seniors in that they are talking about the Medicare initiatives, which aim at improving quality for everyone, especially improving the gap in disparities which currently exists as delineated earlier by Dr. Baker. One presentation shows how physicians can be incentivized and trained to improve quality in culturally diverse populations. And our first presentation will describe two programs—one for diabetes and one for congestive heart failure. In these programs, even with a small investment in training patients in methods of self-care for their illnesses and a modicum of support and outreach from the physician's office, disparities and the gap between poor quality and good quality care can be addressed.

Darren A. DeWalt, MD, MPH
Assistant Professor of Medicine, University of North Carolina

Darren DeWalt: It's an honor that the planning committee invited me to talk about improving quality through what I'm calling "planned primary care." I will walk you through the programs that we've developed at UNC to give you a snapshot of what we are trying to do.

My hypothesis through this, and this came up earlier in Dr. Baker's talk and in Dr. Giles' talk as well, is that systematically improving the quality of care can reduce literacy related and other types of health disparities. To illustrate this, I'll discuss two programs we've developed and then I'll close by discussing some information about the costs of developing and implementing those programs.

I'll refer to these programs as planned care. We have remodeled our systems of providing care for chronic illness. The new model includes multi-disciplinary teams of pharmacists, physicians, social workers, nurses. We've incorporated defined follow-up procedures, treatment algorithms based on best available evidence, information systems for tracking patients and lastly, patient education for self-care. We are going to try to help the patients learn to be better self managers.

We've developed these planned care programs for patients with heart failure and diabetes because they are common chronic illnesses among adults, require effective self-care, involve complicated medical regimens, lead to potentially serious complications, and they are expensive. In point of fact, 13% of Medicare enrollees have heart failure and that 13% of enrollees accounts for 37% of Medicare expenditures, so this is a big part of what we are spending our health care dollars on.

First, I'll review briefly the heart failure program. The Living with Heart Failure program is a self-management training program that includes a one-hour individualized education session, with an accompanying educational booklet written below the sixth-grade level, and scheduled

follow-up phone calls to reinforce that education over time. As part of the program, we handed out a digital scale, gave easy access to our care team, and helped with barriers like scheduling transportation to the clinic. And a note about our program: we made no effort to adjust or change medication based on clinical guidelines. This is all about helping patients become better self-managers.

We tested this program in a clinical trial of the planned care approach versus usual care. Patients in planned care had a reduction in the incidence of hospitalization; in fact, patients in the planned care program had 40% fewer hospitalizations than those in usual care. We did a subgroup analysis of patients with inadequate literacy, those who scored in the inadequate range which is somewhere around a fourth-grade level or below. And those patients had a 50% reduction on their rate of hospitalization.

Next, I'll describe the diabetes program. Similar to the heart failure program, we put together a group of activities that seemed beneficial for promoting high-quality care. That included a registry for tracking the patients, organized patient education for self-management, and some care coordination to help patients navigate the system—where do they go to get their pharmacy benefits, forms filled out, etc. We scheduled telephone follow-ups, used treatment and monitoring algorithms and we addressed the barriers to transportation and communication again. I'll talk about a couple of these in more detail.

Our educational strategies employed ongoing patient-centered learning, as we refer to it, as opposed to the kind of traditional one-time session. We found in both of these programs that patients learn over time; it's not a one-time thing. They leave knowing what to do and all of the activities they need to carry out. We also tried to develop a therapeutic alliance with the patient by collaborative goal-setting and incorporated the teach-back method to confirm patient understanding. This gets back to the idea of having patients teach, and just the act of having them teach back to the doctor, we think has some effect in helping them retain information.

Patient Education Strategies

- Ongoing patient-centered learning
- Therapeutic alliance with the patient
- Teach-back method
- Repetition/reinforcement
- Survival skills

Our care coordinators called the patients at least once a month in this diabetes program. They reviewed self-care skills and helped to navigate the health care system by filling out forms or making phone calls on behalf of the patient and making sure they got to the subspecialty clinic appointments. Another important aspect of our program was the use of treatment algorithms to overcome what's called clinical inertia or the failure to advance medical therapies in light of evidence that that needs to happen. Clinical pharmacist practitioners use algorithms that were approved by our physician staff to increase medications for glycemic control, blood pressure and cholesterol. We also incorporated automatic lab ordering of lab tests that needed to be monitored over time and scheduled earlier follow-up for patients if they were not reaching goals.

Like the heart failure program, we tested the diabetes program with a randomized clinical trial. (Rothman RL, et al, 2004) We found that patients in the planned care group had much more improvement in their glycemic control compared to those in the usual care group. And this difference of about one percentage point in hemoglobin A1C is extremely clinically significant and is about the same benefit that you get when you start a new anti-diabetes medication.

To explain one other piece of background. Both sets of patients got a one-time education session. Then the control group flipped into usual care, while the intervention group got the intervention I described. Now, see what happened when we performed the analysis according to literacy status. Here you see the results of patients in the higher literacy group, those who read at a higher than sixth-grade level. In the high literacy group there was still a benefit, but it was more modest

than in the study overall. And if you look at patients with very low literacy, those reading below the sixth-grade level, the difference between the usual care group and the planned care group was substantial. Here we're seeing a greater benefit among the most vulnerable. In this case the vulnerability that we measured was literacy. As you recall from David Baker's slide earlier this morning, they looked at vulnerability in terms of race in dialysis care and how there are greater improvements for the most vulnerable.

In this planned care program we not only addressed glycemic control but you'll notice patients have improvements in their blood pressure, use of aspirin and cholesterol levels. These improvements account for a large reduction in cardiovascular risk for diabetes.

In this diabetes study, we closely followed the time spent by our staff in caring for patients. All activities related to the care of the patients were coded in five-minute increments. If a phone call was two minutes, it got a five-minute increment; if you were on for 20 minutes, it got four increments. By costing out the time spent on planned care versus usual care we found that program costs were \$37 per patient per month. For this cost, we improved A1C by almost one point, improved systolic blood pressure by almost 10 mm of mercury and improved aspirin use over 40%. Notably, we did not see significant change in the use of clinical services or adverse events beyond the care coordination and the style of treatment I mentioned earlier.

Labor Inputs and Costs

For program costs of ~\$37 per patient per month, we:

- Improved A1C by almost 1% point
- Improved systolic BP by almost 10mmHg
- Improved aspirin use by over 40%
- Did not see any significant change in use of clinic services or adverse events

Just for comparison, a commonly used diabetes medication at moderate doses costs about \$37 per month, and that's a generic formulation. Many insulin prescriptions are about \$60 a month;

thiazolidinediones, a very popular diabetes medication covered by health plans, are in the range of \$80 to \$150 a month. It's not a perfectly straightforward comparison but it gives you an idea of where we are spending our health care dollars and the benefits we are getting. Each of those diabetes medications focuses mainly on glycemic control and doesn't address all these other areas as well.

So how do you pay for planned care? Current financing systems, both Medicare and private insurers are not well designed for chronic care and prevention, particularly within the doctor's office. It is possible to bill for many but not all of the program activities that I've outlined here. We have found locally that payers are very interested in the results of our program and want to explore creative ways to get us to take care of their patients. And to incentivize planned care approaches, I suspect that payers will need very creative strategies to support systems of care rather than individual services. Additionally, creative pay-for-performance programs may incentivize practices and systems to adopt more planned care approaches.

In summary, planned care is an effective tool for improving health outcomes and can reduce literacy-related barriers in disparities. Planned care interventions require a team approach but current reimbursement strategies do not adequately incentivize for such models of care.

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Mary "Toni" Flowers, RN, BA

MPRO-Michigan's Quality Improvement Organization

Toni Flowers: Thank you to the planning committee for inviting me to participate and to talk about the work that was done in Michigan. I want to focus on the strategy we used to get results and the top down approach that we used to engage health systems to reduce health disparities.

The Centers for Medicare & Medicaid Services, which pays our bills and pays me, thank you, gave us the directive to identify the underserved

populations that had the greatest disparities; in Michigan, it was African-Americans. The directive then was to obtain a qualitative understanding of the causes of health disparities. We wanted to get that in writing because that was the first time we heard the word “qualitative” and we were so excited about it, to get a good understanding from our beneficiaries as to why they felt health disparities existed. And further, to design an intervention to address the specific identified causes within each state and to demonstrate a measurable reduction in the disparity rates.

We identified African-Americans as our target population. Diabetes was our health topic and reducing the disparity in lipid profile was the quality indicator. We were directed to reduce health disparities among the 25% of Michigan’s African-American Medicare beneficiaries with diabetes and to increase the frequency with which providers follow the quality indicators for diabetes management.

When we talk about health disparities within quality improvement organizations, we’re talking about the differences between doctors choosing to follow the quality indicators. I haven’t heard that discussed today—that health disparities are often the result of a choice, that someone is making a decision to make a difference. We focused, narrowed in on the decision that was being made. The ETHOS project (ETHOS is a Greek word that means all the elements that make a culture) was a two-pronged design.

The first intervention group was beneficiaries; our intervention was focused on increasing the health literacy levels of the beneficiaries. We noted in our developmental work, and I’m sure it’s true in many of the northern U.S. states, that many of the seniors we’re dealing with migrated from the South to the North looking for jobs, for example, in the auto industry in Detroit. Many of them left a rural segregated experience with the possibility of very low educational achievements and moved to the northern states looking for jobs in many of the industries. We identified what we called a “double yoke” of health disparities, two different health disparities that our African-American beneficiaries were experiencing. It refers to a duality: rural and urban and mixing

modern medicine with traditional curative methods. We’ve had to address that. There is a white paper that will be coming up probably next year. My great aunt, who is 80 years old (but she’ll tell you she’s 79), gives us a lot of our best material on what we mean by the “double yoke.” She keeps her medicine in the kitchen because it’s the cleanest place in the house. She has four shelves; on the top two shelves, she has all of her prescription drugs. On the second two shelves she has her garlic, her ginger, her vinegar, all those home remedies and traditional methods that her grandmother taught her to cure herself. Now we’re finding some of those same medications coming in nice, tight packages with names like Garlique®. But what she does is she takes her prescription medication for her blood pressure with a vinegar chaser. I found out that a lot of the providers in our state had no idea that many of their patients were using home remedies in conjunction with their prescription drugs.

We were also increasing provider awareness of health literacy and increasing their degree of cultural competency. To do that in our development, we looked at the profile of providers in our state as well as the residents. Ninety-two percent of all the physicians in the state are Caucasian or Asian-Pacific Islanders. For our African-American Medicare beneficiaries, that meant that most of the doctors who are caring for them either don’t look like them or may not sound like them and certainly may not have an appreciation for their culture. These are the other representations of ethnicity that we were looking at; that helped us solidify the need for cultural competence training.

We developed a training program for physicians with four different presentations to help them understand historical perspectives of health disparities for African-Americans and some very specific things they need to know about topics such as touch, space, respect and ultimately understanding how culture impacts health.

Adult literacy numbers in Detroit are about the same as nationally and that also supported our need for health literacy intervention. We were very fortunate to be a recipient of an AMA Foundation Health Literacy Grant to do health literacy training for providers in our state.

We did focus groups with physicians in our state, primarily looking at cross-cultural relationships. We focused on Eastern Indian, which is the subgroup of the Asian-Pacific Islander category that had the most doctors in our state, along with Caucasian doctors. These are the things they told us that we recognized as challenges. They already thought they were culturally competent, which is very surprising to us. They did not perceive a difference between the term cultural diversity and cultural competency, which kind of disproves the first point. And they possessed a very limited awareness of the topic of health literacy. They also thought that they had no time to incorporate any new strategy into their visits with their patients. They only have 12 minutes and half of that is spent in the waiting room. They were more interested in getting an increase in compensation for their present work, which we totally understood with the issues of reimbursement. But the issue was that they really were not interested in learning anything new or doing anything new because they thought they were doing the best work they possibly could do. And we didn't argue with that. We recognized that knocking on doctors' doors and saying, "We have this wonderful program that we feel will benefit you in being able to provide a higher quality of service to your beneficiaries," was not the way for us to have a successful intervention. We also didn't have the kind of manpower that would facilitate that kind of work. So we had to develop a strategy that was going to give us the most "bang for our buck."

In addition to being a nurse and anthropologist, I have a background in marketing so I had to figure out how can we market this program so that people are going to embrace it at a high enough level to make an impact all the way down to what happens in the examination room?

What we did was to approach the three largest health systems in Wayne County and those were in Detroit, although our intervention was in three different counties. Wayne County was where most of our beneficiaries resided and also the place where we had the most tremendous results. We created the business case—I'm sorry Bryan, I know you don't like that term—but we created a business case for health disparities that sold it to them because we recognize that

hospitals are not altruistic, they're businesses and they're trying to stop the bleeding financially and also trying to make a profit. So we helped them to understand some of the issues that occur with their underserved populations—that there is certainly an over-utilization of emergency departments as sources of primary care; high volumes of no shows; decrease in reimbursements; high health litigation costs (Michigan is a very, very high health litigation state); and high expenditures related to secondary and tertiary complications of chronic illnesses, particularly diabetes.

Health System Challenges

- Over-utilization of emergency departments as sources of primary care
- High volumes of no shows
- Decrease in reimbursements
- High health care litigation costs
- High expenditures related to secondary and tertiary complications of chronic illnesses

We helped them understand that they needed to focus on why their emergency departments had such high expenditures. Among other things, we had to tell them that they need to make their emergency room like "Cheers," it needs to be a place where "everybody knows your name," where people feel respected and cared for when they get there. They had to recognize that a primary care office is the very last place that a patient is going to go to get care because they are going to try every other possible remedy and treatment and that's why they end up in the emergency room.

Our business case focused on quality improvement, risk reduction, cost efficiency, and patient safety. We used positive peer pressure, which worked well because once we got one of the three biggest health systems in Detroit on board, we used that; you know, "It would be a shame for you to get left out. And this other health system is really going gangbusters on it, and we know that you are

competitors.” So that marketing came into play there. We got two of them on board, then we finally got the last one on “You will be totally left out, and what a shame that all those patients will understand how wonderful these other two health systems are and they will, maybe not, will kind of frown upon you.” So they jumped on board quickly. We showed them the benefits of participation. We provided free CME training for providers. We developed an awards program called the Pillar Award of Excellence for Addressing Health Disparities. We provided great press coverage for them. And we had this history-making collaboration because these three health systems had never collaborated before. We gave them very positive affiliations with national, state and local champions. We engaged one of Michigan’s U.S. Senators, we had our first and only state surgeon general, we had local champions, and we had the President of the AMA Foundation who came to the press conference in our governor’s office. We assisted the systems to showcase their commitment to the work to reduce health disparities within their communities and the award was gorgeous, by the way. The results were: the establishment of partnerships with these large health systems and providing training (within a two-year period) to 1,000 providers on the topic of health literacy and cultural competency. Finally, we demonstrated a 60.1% reduction in the disparity rate of lipid profiles. This is the place where you spontaneously applaud!

The Results

- Established partnerships with the three largest health systems in Wayne County
- Trained approximately 1000 providers on the topics of health literacy and cultural competency
- Demonstrated a 60.1 percent reduction in disparity rate (lipid profile) among African – American beneficiaries

That was really phenomenal. From the baseline to re-measurement; we achieved a 60.1%

reduction. This is a reduction because the doctors were not providing these lipid profile tests for African-Americans at the same rate as they were for Caucasians. This raised awareness so they began to follow the quality indicators.

Robert S. Mirsky, MD

Medical Director, BlueCross BlueShield of Florida

Robert Mirsky: It’s truly an honor to be here and to have been invited, especially in light of the truly humbling group of presenters that have preceded me. It becomes increasingly difficult to give a presentation in light of what’s gone before, so I’ve scribbled tons of notes and I’m going to try to bounce between the prompter, my notes and the screen and certainly to engage you as well.

The topic I’m going to cover today is the BlueCross BlueShield of Florida Recognizing Physician ExcellenceSM program. It is a physician pay-for-performance program that was rolled out recently in Florida. I’m going to give a brief overview of the program itself to provide some context for the tool that we have imbedded in that program called Quality Interactions, which is designed to enhance the cultural competency, what we’re calling the cultural excellence, of the providers in Florida.

This is our approach to working collaboratively with physicians in the pay-for-performance program to help all of us achieve the goals that we need to in terms of increased satisfaction and increased quality with outcomes by giving the physicians the tools they need instead of asking them to figure it out. One of those tools is certainly helping them to be more culturally effective.

The physician excellence program was designed in 2004 to recognize and reward, so it’s not just about the money, it’s about recognition, as well, of physicians who are committed to providing quality care and excellent service. It’s important to emphasize that we are upfront, looking for that commitment. It’s a voluntary program. We identified 4,000 or so high-volume primary care physicians and asked them to voluntarily enroll. We met with the physicians in their communities to describe the program and get their proactive buy-in to participating in the program. The program supports the BlueCross BlueShield of

Florida mission to advance the health and well-being of Florida citizens.

I want to describe the Phase One physicians, the primary care physicians, that you'd recognize as the usual suspects, internal medicine, family practice, geriatrics, pediatrics and primary OB-GYN, because we are looking at not only disease state quality indicators but also preventive care, particularly around women's health issues such as breast cancer and cervical cancer screening. Physicians in the program are already high-volume, high-performing providers in our network. They need to be so in order to measure them in a robust manner. And as I mentioned, despite the fact that it's a voluntary program, 70% of the 4,000 physicians we identified who met the eligibility criteria enrolled, which is unheard of, particularly for a first-year pay-for-performance program, or any quality improvement program. We have about 2,700 physicians in the program in the first year, and they have rendered services to about a third of our members in the prior year. So we get a big impact out of working with primary care physicians.

The program objectives are: 1) to improve the delivery of care that affects the outcomes related to preventive services, preventive care and chronic conditions, and 2) to increase physician satisfaction. We're trying to differentiate ourselves in our marketplace by building preferred relationships with providers and physicians in our network and giving them the tools and resources that they need to improve satisfaction and quality. And also 3) to improve the consumers' experience with the delivery system; that is, with physicians and other providers and to help those individuals contain their medical costs. Additionally, we are trying 4) to improve administrative efficiency in the delivery of health care, and 5) to foster the use of health information technology. We are starting with our e-medicine capability, which is an Internet-based interactive tool that allows patients to communicate with physicians in their offices in an asynchronous manner for certain administrative functions such as scheduling an appointment, getting normal test results, even prescribing. It also includes an actual e-visit that we pay for where the patient can stay at home or on the job and can engage their physician in the

e-visit and get advice and even an e-prescription when the visit is completed.

The last objective is 6) to enhance the cultural excellence of our physicians, which is a lead-in to our Quality Interactions. Again, this is a tool that we're going to put at their disposal to help them succeed in this program. The tools are designed to enhance their success in a pay-for-performance program as we measure patient satisfaction, including the patient's perception of the cultural competency of their physician. But also and ultimately the quality of care patients receive and the outcomes of that care.

So what is Quality Interactions? Well, first a little background. I know that you've heard most of these statistics already, but studies show that by improving communication with patients from diverse backgrounds, physicians will help patients stay with and develop an agreed-to treatment plan. The time to act is now and that is why we are here. Demographics indicate that by 2050, 50% of Americans will be part of an ethnic or racial minority, and that is accelerated in the state of Florida. Programs like Quality Interactions demonstrate our commitment to improving member quality of care and service.

An overview of the Quality Interactions tool: it's an interactive e-learning course, designed to improve the delivery of quality care to culturally diverse patient populations. It does this through the use of actual patient vignettes, so the physician will interact on an Internet-based tool with these vignettes and they will progress through them and learn lessons as they go through. They can scroll down and get information, important facts about certain cultural groups that are included in the vignettes. The goal of the program is to point out the blind spots that physicians have in dealing with any type of patient who comes in with cultural viewpoints that may be different from theirs.

The program was developed by leaders in the fields of cross-cultural health care and it's used by leading medical schools; it does provide a CME and CEU credit for physicians and nurses. The program helps physicians identify cross-cultural issues, conduct a culturally competent history and medical exam, address language barriers, work effectively with family members and interpreters, identify the impact of cultural issues on medical

decision making and effectively explain the patient's diagnosis and management options to positively impact outcomes. But to get back to the business case, I think it has been well-stated before that there's definitely a business case, whether it's risk management or being more effective in your practice, for participating and using a tool like this. Taking it another step further, a tool like this will help physicians score higher in our pay-for-performance program, thereby getting a greater pay out. It certainly helps to connect the dots better and is consistent with the IOM recommendations about pay-for-performance.

While the initial program is that two-credit CME online program, we realize we need to continue to inoculate physicians over time so that their skills don't deteriorate; therefore, the program continues beyond the completion of the base course. The participants will have access to one hour refresher courses every six months. There are quarterly newsletters they will receive throughout the program. Here it's set for a year, but we hope to continue this program over a number of years. There are literature and policy updates and more fact-based updates for them.

It is offered to our Recognizing Physician ExcellenceSM physicians at no cost. And as I said, not only is our pay-for-performance program voluntary but initially, so is taking the course. As was already stated, many physicians feel they may or may not have a problem in this arena. We have worked with focus groups of physicians and there is certainly recognition from the physicians that they don't see this as a problem. Wherever they are throughout the state, regardless of their ethnic background or the populations they serve, they tend to not acknowledge that they have this blind spot.

Importantly, the online course can be completed on a physician's schedule. They can start it, stop it at their convenience, and ultimately can complete the course with the two CME credits.

Again, the first phase is voluntary based upon self-selection. The program will continue to be voluntary but as we have data on physician performance in our pay-for-performance program we will be able to point out where they may not have scored quite so well in the satisfaction portion of the program. It's a 19-question survey;

three of the questions are based upon the patient's perception of the physician's cultural competency, but certainly that spills over to the perception of the physician in general. So if we note that they are having patient satisfaction issues in terms of their scoring, we may recommend that they take the course. We hope that over time as the communication improves, as patient satisfaction improves, as the treatment plans are established and followed that the actual clinical quality indicators and outcomes will improve over time thereby driving their score to a higher level.

BlueCross BlueShield of Florida clinical staff will be required to take the program as well. All of our medical directors and our clinical nurses, particularly those who do case management, disease management, where they are interacting with the public and patients and members will be first on the list, but we hope to deploy it for all of our clinical quality staff and ultimately to other stakeholders within BlueCross BlueShield Florida.

We are also beginning to work with various factions of organized medicine. We've been in discussions with the Florida Academy of Family Physicians about co-promoting this tool to the Florida community and family physician members. We are engaging leadership in our medical schools and residency training programs to promulgate this program in addition to whatever curriculum they have. In addition to that, we are going into the community and meeting directly with physicians in town hall meetings and with large groups. We have developed a 15-minute CD-ROM that describes the program in great detail.

Physicians access this tool through their scorecard from Recognizing Physician ExcellenceSM. Once they are on the Web site, and they look at how they are scored, what the indicators are, they will be prompted in a number of screens to log on and take the course. When they are engaged in the Recognizing Physician ExcellenceSM program, and they are looking for tools to improve their scores, they can learn a little bit about the Quality Interactions background, including the folks who developed the program. They get into the menu of options; a couple of highlights here. There is a cultural competency Q&A that points out some key facts, like the

ones we learned here today, that will help set the stage and whet the appetite of the physician to learn more. There is also a pre-test and a post-test, where the physician will be asked to answer a series of questions and at the end take a post-test. The scores dramatically improve whenever this happens and the physicians then qualify for their CME credit.

The real heart of the tool is the patient cases; right now we have three vignettes that are being used. There are numerous other vignettes in various stages of development. In fact, there is a senior citizen vignette that we are trying to push out the door. That's particularly important in Florida. But you can see from these that we have a vignette of a 55-year-old Hispanic woman with hypertension and hypercholesterolemia; we have a vignette of a 58-year-old African-American woman with non-insulin dependent diabetes, and a vignette of a 68-year-old man with abdominal pain and weight loss who was admitted to the hospital. In this particular case, a family member comes as an interpreter and a lot of the issues around interpreters arise. Again, there are facts imbedded in there but it's more about gaining experience and comfort in dealing with the cases. Each of these vignettes highlights certain things about these ethnic groups but does not limit the learning in how to deal with these specific ethnic groups. There will be facts in there but the goal of the program is to give the physician some real-time experience of how these interactions will go.

In looking at one patient, you can see there are numerous screens, up to 10, that go through the interactions with this patient, beginning with her background and then the physician will be asked to interact with her. The program asks you questions, how it's going and it shows them how they're doing on a Dow Jones Industrial Average kind of tool on the bottom of the screen. So if they are asking lots of inappropriate, time-consuming questions that aren't getting at what she's here for and aren't moving the case along, their performance will dip down, and as they go through the program and learn how to interact with her, hopefully they will begin to move into the positive column. There's some real-time feedback there. The clock on the screen is designed to show the physician that it takes

no more time; in fact it may take less time, to do a culturally appropriate interview, physical exam and discussion with a patient. Physicians are very concerned that doing this is just going to consume all of their time when in fact that has not been the case. They will be able to pick up where they left off. They will be able to review the case and look at transcripts and if they do want particular facts about those patients or their ethnic subgroup, they will be able to go in here and get lots of information but again that's not the focus of the program.

Moderator Margaret Gadon: I highly recommend that program. There are several other programs available for cultural competence training with physicians. The BlueCross BlueShield of Florida program Dr. Mirsky described and another one offered by the Office of Minority Health (<http://www.omhrc.gov>) are interactive. The Office of Minority Health program is free of charge and can be accessed through the Internet. I would also like to point out the use of e-learning by consumers which Dr. Mirsky talked about. This is one of the techniques that we are going to look at as a method of reducing health disparities in health literacy. The government is actively looking at that right now.

Linda Magno
Director, Medicare Demonstrations Program
Group, Centers for Medicare & Medicaid
Services

Linda Magno: I, too, am honored to be here and very pleased to have the opportunity to participate in this mini-conference on health literacy and disparities. I feel that I've benefited far more than I have to offer back.

But I do appreciate the opportunity to tell you a bit about Medicare's demonstration program and specifically about a couple of our demonstrations. Unlike Robert Mirsky, I didn't scribble notes all over my presentation. I thought about abandoning it all together and talking about some of what I've heard but I've decided I'm going to stay with the presentation and give you information about two of our very important demonstrations. I'm going to move through that very quickly so that I can talk about some of what is on the drawing boards, as well.

I always find it useful to talk about what a Medicare demonstration program is. Its purpose is to test the development and implementation of Medicare policy changes prior to implementing those changes on a national basis. I feel like I run a research and development laboratory; I'm having as much fun as I ever have working. It's one of the most exciting parts of the Centers for Medicare & Medicaid Services because it is doing cutting edge work. We get to learn about what's at the forefront, what's under development by the private sector, how can we apply some of those things to Medicare in our slow (by everyone else's standards) bureaucratic, clunky kind of way. But we are out there and we get to see some of these things first and try to figure out ways to adapt them to the Medicare program. As was said, most of what we deal with is payment alternatives and new benefits, sometimes organizational changes, organizational systems such as testing new models in care. For example, Medicare HMOs came out of the demonstrations program. Our goals are to find out whether this change works for the Medicare program and the Medicare population and if so what refinements are needed before we go live nationwide.

We have certain authority for demonstrations if they're not specifically mandated by Congress as many of our demonstrations are. That authority deals with whether or not the changes in payment or benefits or reimbursement rates or coverage, increase efficiency and reduce cost, so we do have a significant constraint on what we can do. We find there are a number of great ideas that would help us spend more money but we usually do a pretty good job of that on our own in the Medicare program without any help. Our goal and a real constraint in designing demonstrations is to structure them so they can be budget neutral or produce savings. Or at least better quality at no greater cost.

The two demonstrations I wanted to talk about are our Physician Group Practice demonstrations, which is the first Medicare pay-for-performance project for physicians. One project is in large practices (200 or more physicians); the second is in smaller practices. We have one for hospitals, as well, the Premier Hospital Quality Incentive Demonstration, but I'm not going to talk about that today. I want to focus on primary care,

which is of critical importance as the population ages and as the Medicare program is increasingly dealing with a population that is confounded by the complexities we've heard about today in dealing with chronic illness. Beneficiaries who are routinely dealing with multiple conditions, multiple medications, and confusion. I've heard a lot this morning about literacy and translation and family members. I read an article not too long ago about the Patient Navigator Act, talking about the importance of that for people of low income, of low means, of low health literacy, and I thought "Everybody needs that." I need it, when I'm dealing with the health care system. A year ago a friend of mine who is a pediatric oncologist felt she needed exactly the same sort of services out of the health care system. She was taking care of her father and the system was not responsive to her needs as a family member to help him deal with his end of life issues. The issues were compounded rather than aided by the health care system; the system was simply resistant to sharing information with family members. So when we talk about translation we're not talking about language translation only, we're talking about translating scientific language into language that the rest of us can understand. It can be very important at critical times in health and illness.

The Physician Group Practice demonstration was designed to encourage the coordination of Medicare Part A and Part B services. Even within Medicare we create additional fragmentation on top of an already fragmented health care system in this country. The way we finance the two parts of the program, inpatient and physician and other ambulatory services.

It was also designed to reward physicians for improving quality and outcomes and to promote efficiency by rewarding organizations for investing in some of the administrative structures and processes that could improve their own efficiency.

We provide fee-for-service payments and performance payments. The performance payments are derived from savings generated by practice efficiencies and improved patient care management. Basically, the goal is to improve primary care by these large physician group practices so that they are putting in place some of the proactive activities and outreach that

we've heard talked about, very much like the planned care approach that was talked about. And to put in place some of those things to help patients manage their own care and avoid acute exacerbation of chronic conditions and there by avoid emergency visits and unnecessary hospitalizations for their conditions. Good primary care can make a big difference in the use of very expensive hospitalization services. In this demonstration we will have the ability to share savings by reducing hospitalizations; we can share savings from that part of the program with physician groups that are engaged in this. These physician groups will receive these performance-based payments both on the mere fact they've had the generated savings by reduced utilization of things like hospitalization and emergency room visits, but also partly and increasingly over the life of the demonstration, on the basis of their quality performance with respect to a number of quality measures and preventive services.

The demonstration is intended to be budget neutral. Because it's based on a shared savings model we have no concern that it won't be budget neutral.

I'm not going to go into details on the specifics of the performance payment. There is a great deal of information on our Web site about the specifics of this demonstration but basically, we will be looking at the group's expenditure growth on a per capita basis over time and comparing it to growth in their local communities for the non-demonstration areas, and deriving an estimate of savings on that basis. On this slide, the yellow bars represent the growing percentage; the groups themselves will get up to 80% of any savings generated over the first 2%, which the Medicare program retains. After that, they get up to 80% of the savings, a growing proportion of that is related to their performance on a number of quality measures. The remainder of the 80% is simply based on them having generated savings. And the maximum annual savings is targeted at 5% for total Medicare spending for their populations.

The particulars of the model in terms of assigning or attributing patients to the large practices—the group has to provide the plurality of ambulatory

visits. We'll be using actual claims experience, and as I said comparison, and there is a three-year performance period with no annual rebasing. Once they achieve that 2% savings then everything else on top of that is shared with the program. It's not 2% every year. We are looking at a number of process and outcome measures related to congestive heart failure, coronary artery disease, diabetes mellitus, hypertension and cancer screening. Practices will submit data on various measures (eg, eye exam, foot exam, blood pressure screening, lipid profile, influenza vaccination, breast cancer screening) over the life of the demonstration. We have an abstraction tool for them to pull the data from medical records. We'll populate the tool with what we can from claims to minimize the amount of work they have to do in advance and then they'll report the additional measures, some of which are not claims-based, like the actual lab values and so on.

They will be scored on each of these measures; their overall score will allow us to measure year over year improvement and how they relate to benchmarks that were established in negotiations with the practice sites. There are a number of beneficiary protections in this to ensure that the practices don't achieve savings merely by stinting on care or refusing to send people to the emergency department or the hospital when that's where they belong. Because an increasing part of the performance payment is based on the quality measures, we believe that will certainly set down an incentive for them to achieve those goals over time. In addition, this is a non-enrollment model so beneficiaries are free to get care anywhere they choose to get care. They are not locked in either before or over the course of the demonstration. We will also look at who the applicable population is year by year over the life of the demonstration as people move in and out of practices or as they die or as they move out of geographic areas altogether.

Beneficiaries will be notified by signage in the practices that this demonstration is going on and does not change the way physicians are being paid in part. The groups themselves were selected based on their own leadership commitment and commitment to quality assurance and quality

improvement programs and to improving and managing the care of their population. And finally, there will be an independent evaluation that goes on.

The site characteristics in terms of some of the things they will be adopting (eg, case management, increased access through nurse call lines, primary care physicians and geriatricians, enhanced patient monitoring through electronic medical records, disease registries, the use of evidence-based guidelines and expansion of managed care infrastructure and processes to Medicare fee-for-service population) again reflect some of the kinds of things already talked about, in terms of the planned care model or the chronic care model attributed to Ed Wagner. There are some other models out there as well and these sites will be adopting some of them, disease management and case management strategies. One has employed a disease management organization to work with the physician practice to provide some of the infrastructure and some of the outreach and nurse call lines. Some of them will directly provide the increased access through their own nurse call lines, primary care physicians and use of geriatricians. They are expected to enhance patient monitoring by having electronic medical records, providing disease registries, reminders, etc.

The second demonstration is an attempt to do some of these same types of things with smaller practices because the first demonstration I talked about was limited to practices of 200 or more physicians. Well, that's not the way most care, and certainly not the way most primary care, in this country is furnished. So this demonstration is aimed at smaller practices but it's been mandated by the Medicare Modernization Act. Its goal is to improve quality and coordination of care for chronically ill Medicare beneficiaries in the fee-for-service program and to promote the adoption and use of information technology that deals with things like electronic health records, registries, reminders and decision support by these practices. The same kinds of things will allow them to engage in some of the outreach and population management for their population.

We will be providing additional payments to physicians who adopt and use health information technology and achieve quality benchmarks for chronically ill beneficiaries with diabetes, heart failure and coronary artery disease, including a prevention module.

We are developing the infrastructure for collecting data over time for electronic health records though we know that is not where they are going to start, that electronic health records are a longer term goal, but we'll look at assessing the use of health information technology and the functionalities of health information technology in these practices over the course of the demonstration. And whether or not the additional incentive payments to the practices encourage broader diffusion.

The demonstration will start, we hope, in fall 2005 in about 800 practices in four states in which the quality improvement organizations (QIOs) have already been doing work under their scope of work. As Toni Flowers mentioned, they're going to be moving into their eighth contract cycle. But four states were pilot states for doctors' office quality information technology projects. In those, the QIOs help the practices redesign and begin to make some of the changes in the way care is structured and practices are structured to incorporate the use of health information technology. The technical assistance to the physicians' practices will continue to be available by the QIOs.

The program itself is modeled after the Bridges to Excellence program, which many of you may have heard about. GE, Verizon, and other private sector employers are participating. We may try to partner over time with some of the Bridges sites where we are co-located.

Again the quality measures will focus on diabetes, heart failure, coronary artery disease and prevention. There is a great deal of information about our demonstrations on our Web site, <http://www.cms.hhs.gov/researchers/demos>. We have more than 20 live projects.

We have another demonstration that we will be soliciting proposals on very shortly that was again mandated by the Medicare Modernization Act called the Medicare Health Care Quality

Demonstration program. It is an attempt to begin to get more broadly at system redesign. It was said earlier that some of the kinds of things we're talking about here today probably require focus on systems rather than on individual practices. The Medicare program is dealing with more than 40 million beneficiaries and while we've heard about some wonderful projects, and we hear about them all the time, trying to get the entire world to shift, small practice by small practice, in increments that affect maybe 500 beneficiaries here and there is long way from changing how care is delivered to 40 million beneficiaries. This demonstration will invite organizations, large physician groups or integrated delivery systems or regional coalitions, to put together efforts to redesign the health care delivery system to focus on achieving the six aims proven by the IOM in its Crossing The Quality Chasm report; namely, care should be safe, effective, patient-centered, timely, efficient and equitable. I think it will give us some opportunity to begin to focus on things that look at how better to engage patients, that begin to address these issues of health literacy and disparities in a way that our demonstrations have not necessarily done in the past.

Questions—Panel Three

Audience member: Joseph Murphy, practicing physician, representing the AMA. Just from feedback from patients over 30-plus years in primary solo care in geriatric medicine, one of their biggest complaints is understanding Medicare forms and commercial insurance forms. So I think that could be put on the agenda, as well, not just what the physicians and the pharmacists have to do. The forms are a pain in you-know-where. The only thing they understand on the forms is where it says, "Payment denied." Everyone can understand that. It's always in big block letters.

This question is for Dr. Mirsky, regarding the profiling on your system. It is very elaborate and I'm glad that you have the Florida Academy of Family Physicians involved in it but I wanted to know, are the elements involved there due to claims, based on claims? What are some of the elements that you use on measuring the physicians and what role did the practicing physicians have in the evolution of these elements for performance measurements? I would appreciate knowing that.

Panelist Robert Mirsky: Currently, the elements are administrative data-driven except for the patient satisfaction survey, which the patient will access on-line or on the telephone to answer. Their input will be captured on a physician-specific basis. At this time the administrative data includes claims and pharmacy data and will evolve to include lab data and ultimately data from the electronic health record. But however far electronic health record adoption has not gone, it's even worse in Florida. The adoption rate is 1% or 2%. It's extremely onerous for physicians and for us to try to integrate that data. That being said, we are currently in talks with Bridges to Excellence on how to bring some of their chart data elements into our program without co-mingling the data. So we'll look at the physician office link, which demonstrates their adoption of health information technology and other tools and infrastructure, and ultimately look at their clinical modules. As we go along, especially for those specialties down the road like orthopedics and others where the administrative data-driven metrics aren't quite there, the program will evolve. We have engaged physicians on a variety of levels, whether it's organized medicine like the Florida Academy of Family Physicians or physicians at the practice level at the town hall meeting level. We have a physician advisory panel that has leaders from 40 different practices across the state. They are intimately involved in the development and continued refinement and support of the program as we go along.

Audience member: Neil Winston. I'll give my disclaimer, too, like Dr. Murphy. I'm the first African-American President of the Chicago Medical Society, past President and so was Dr. Murphy. Dr. Schneider, also a past president, is here in the audience.

I've been practicing in inner city Chicago and Gary, Indiana, for several years. This question is for Linda Magno. As I am sure you know, there was an extraordinary amount of discussion about pay-for-performance at the recent AMA House of Delegates meeting and there was also a significant amount of discussion in our AMA Minority Affairs Caucus Consortium. I want to ask a very straightforward question. In the evaluation tools that you have for the success of pay-for-performance among, not only groups, but

also the smaller clusters of physician providers, are you going to be actively measuring any disparities that may possibly be created in pay-for-performance for those of us who practice in the kind of communities where health disparities and health literacy are major issues?

Panelist Linda Magno: We are certainly aware of the concerns about the possible side effects or possible unintended consequences of pay-for-performance with respect to its impact on provider willingness to treat patients who may be perceived as difficult or as more severely ill and therefore more likely to not look as good on performance measures.

I can't speak to the particulars of the evaluations but I'm sure those issues will be taken into account given the increased amount of attention and concern being focused on it by the physician community. Clearly, there is interest in not rewarding behavior that's worsening the issue of disparities even as we are trying to improve the basis on which we recognize the excellence in providing medical care.

Panelist Terry Davis: This is another unintended consequence of pay-for-performance. Darren DeWalt and I are doing focus groups of internists and patients all over the country looking at self-management of diabetes. In focus groups of middle class, upper middle class practices in Louisiana, physicians are seriously considering firing patients. The physicians put it on the table, "pay-for-performance." We were talking about diabetes specifically and patients who are not getting their A1C under control. I said, "Well, what is your strategy now?" and this eight-man practice in an upper middle class section said, "We're considering just writing them letters and terminating them." So that's an unintended consequence for these mostly white middle class folks.

Wrap-up

CDR Mercedes J. Benitez-McCrary, USPHS
Commander, United States Public Health
Service

CDR Mercedes Benitez-McCrary: There is so much to say. I was producing lots of notes but my friend Rima Rudd said, “Don’t do that.” What you do is take back the information you have, do wonderful things with it, write lots of letters and then let’s see if we can see some change sooner than we could have imagined.

Panel One was charged with a very interesting objective. We looked at improved communication methods. We were very much involved in who would be on this panel; I tell you, I’m just so impressed. Everybody was just wonderful.

We’re going to have to look at environmental changes in the health care arena as well as the method of communication. For those of you who are not aware, as a speech and language pathologist, this has been my mantra for years. We have to look at how we approach a patient on an individual basis versus a continuum of care basis. If we are going to improve outcomes, then we are going to have to make our treatment individualized. I don’t care if you have 12 minutes, you are to do the best you can with those 12 minutes. And we are going to have to look at environmental changes and that includes direct attention to the material you use. Is it effective? Are you evaluating the effectiveness of your material and thereby producing some quality measures that you can use to enhance the care given to other patients in other places?

In Panel Two, we looked at patient safety and how that is linked to communication. I was particularly interested in restraints, no one mentioned that. That’s a big issue at Medicare now, patient restraints. And someone spoke about activities of daily living and lack of consistent referrals. So we’re looking at safety and whether safety is involved in the entire referral process for continuing care or is it just in the communication part. We are going to look at reducing disparity and improving literacy along both avenues simultaneously.

And of course, as always, we should keep all our efforts consistent with the patients’ needs. Again, individualized care.

Panel Three was very interesting as well; all the panelists spoke very clearly of the different partnerships that are developing. I personally can see changes since the Medicare Modernization Act of 2003. Not only were we asked to do this, we were told we have to do this. So we have to look back at our bureaucratic legislative process and realize that we do indeed have a great deal of power that perhaps we are not using to the maximum, and we can orchestrate change. Here we have seen a classic example where the White House Conference on Aging was proceeding with many, many conferences and we were still able to orchestrate something as wonderful as this mini-conference.

At the same time, we must stay focused to the mission and to our service, because that’s why we’re here. We must remember that service means good care, quality care for our patients, as well as prevention and education of what they should stop, avoid, and not do, keeping in mind that America is always open-armed to all races and colors. That’s not going to change. What we’re saying is we have to change how we provide our services. And above all, we must do no harm.

Joanne Schwartzberg: You’ve been a wonderful audience. I think people will probably think of more questions. If you would like to write them on index cards, we will look at them and try to include them in the materials we send to the White House Conference. I’ve had several requests, people saying, “I would like to continue with these conversations” or “May I have the e-mail addresses of some of the presenters?” If you are interested, there is a sign-up sheet as you leave. Just put your name and e-mail address and we will send you more information about how to reach people. And so with that, thank you very, very much for coming.

Post-Event Summary and Recommendations

Ensuring all patients understand health care information

Patients have the right to understand health care information that is necessary for them to safely care for themselves, and to choose among available alternatives. Health care providers have a duty to provide information in simple, clear, and plain language and to make sure patients have understood the information before ending the conversation.

Currently, the health care system in the United States demands full participation of patients in their own care. While health professionals determine what care is needed, it is up to the patients to provide most of their own care. The instructions for such care are often complex, poorly written, and use unfamiliar concepts appropriate for medical textbooks and not easily understood by patients. While the average American reads at the eighth grade level, medical information is usually written at the college level. This puts 50% of the adult population at risk for misunderstandings, medical errors, excess hospitalizations and poorer health outcomes. Research has found that patients with limited literacy skills are twice as likely to be hospitalized and stay in the hospital longer. The excess annual costs to the health care system have been estimated to range from \$50-\$73 billion.

This situation is most serious for the elderly, many of whom have to cope with problems such as loss of vision and hearing, loss of family support and social isolation, fatigue, pain, chronic illness and cognitive decline, in addition to the multiple instructions for care of multiple illnesses and medications. Seniors, aged 65 years and older, account for 40% of all medication use and the average 65-year-old has nearly 31 prescriptions filled per year. All medications have the potential of causing harm as well as benefit; the incidence of adverse medication events increases with the number of medications. Medication errors are the most common medical mistakes—some as a result of misread or misunderstood prescription labels—causing up to 7,000 deaths each year and costing the health

care system nearly \$73 billion annually.

Improving communications on medications can improve care, reduce errors, and save lives.

The decline in social support compounded by chronic illness also makes this population increasingly vulnerable to fraud.

The unrealistic expectations of health care providers that brief oral instructions and lengthy written materials will be sufficient to educate their patients in carrying out unknown and complex self-care tasks pose serious (and unnecessary) safety risks. Low literacy skills affect not only a patient's ability to safely and successfully navigate the many layers within the health care system, but even their ability to gain access to the health care system at all.

While a majority of the 90 million Americans who have inadequate literacy skills are native-born, white, and educated in American schools, there are increasing numbers of recent immigrants who need to access the health care system before they become proficient in English. They face almost insurmountable challenges in receiving health care from providers who cannot communicate with them. One recent study found that when family members or untrained interpreters are used to assist with communication, an average of 31 translation errors per visit are made.

Repeated research studies have found that both these populations—those with inadequate literacy and those with limited English proficiency—experience unexpectedly poor health outcomes, excess hospitalizations, longer lengths of stay in hospital and emergency rooms, and higher costs of care.

Proposed Solutions

- Training in communication strategies (to include giving clear instructions and assessing patient understanding) should be implemented for all health care staff (professional and administrative) to ensure that all patients can accurately summarize the information they need in their own words and demonstrate how the information can be applied in their daily life.
- Public health messages and community outreach should use simple, clear, plain language.
 - Messages should be field-tested with consumers for accuracy and understandability.
 - Special attention should be paid to multicultural media such as radio, local newspapers, community and faith-based organizations.
 - Health literacy efforts should work with social service agencies, libraries, adult education and local literacy programs.
- Third party payors (Medicare, Medicare + Choice, VA, DoD, Tricare, etc.) should make all health information they provide available in simple, clear, plain language (field-tested by consumers with limited literacy and limited English proficiency).
- Payment should be provided for the necessary one-on-one patient education, as well as other services, to ensure patients understand information provided to them and are able to safely care for themselves. (Other services may include: interpreters, group education sessions, telephone education follow-up, home health care, disease management or chronic care coordination/management programs.)
- Simplify and standardize written and oral communications to improve patient understanding, to improve patient safety and to reduce medication misuse.
 - All U.S. prescription drug labels should be standardized. Congress should establish a public-private expert panel to develop the uniform format (similar to nutrition labels) which should be validated by consumer focus groups (including consumers with limited literacy and limited English proficiency). Accurate translations in multiple languages should be available for all retail pharmacies to use as needed. Side-by-side translations should be available.
 - Standardize basic patient medication information leaflets. Pharmaceutical companies should submit simple, accurate information for consumers about the drug at the time that the Food and Drug Administration is considering approval (this is the procedure in Europe). The patient leaflets should be translated under supervision of the pharmaceutical companies and reviewed by an FDA panel that includes practicing physicians, to ensure the accuracy, fair balance and clinical appropriateness of the information. Consumer focus groups should validate the leaflets for the ease of understanding the information.
 - Congress should establish a public/private expert panel to develop a basic standard set of questions about any medication and educate consumers to ask these questions of their physicians, nurses and pharmacists. These standard questions should be validated by consumer focus groups including

consumers with limited literacy and limited English proficiency. Public health messages and patient education programs should disseminate the information. Educate health professionals through their professional associations and institutions to respond clearly to these basic safe medication questions.

- The Centers for Medicare & Medicaid Services (CMS), as it begins to implement the new Medicare prescription drug program, should track the utilization of prescription drugs, the potential for adverse events, the source of purchase of the drug, the frequency of drug substitutions/changes, the results of appeals processes, the availability and accuracy of patient education materials (in multiple languages), and the utilization of pharmacy counseling practices to improve patient understanding. This research should be available to health care providers to improve safe prescribing practices and lead to better health outcomes.
- The number of minority students going into the health professions should be increased through public/private partnerships of government, grants, and outreach to these communities.
- Training and certification programs for interpreters should be developed. These health professionals should be recognized as an essential part of the health care team, and payment should be provided for their services.
- The Centers for Medicare & Medicaid Services and the Agency for Healthcare Research and Quality should support research to identify and evaluate successful practices that ensure patient understanding and eliminate health disparities.
- All health care providers and third party payors should commit themselves to improving health outcomes, ensuring patient understanding, and eliminating health disparities; all federal agencies regulating and studying the health care system should also so commit themselves and agree to report annually on the progress their agencies and programs are making to achieve this goal.

Appendix A: Biographical Information

Alejandro Aparicio, MD, FACP

Dr. Aparicio is a Board Certified General Internist and holds a Certificate of Added Qualifications in Geriatrics. He is a Fellow of the American College of Physicians and also a Certified Medical Director of Long Term Care Facilities. He has served as President of the Illinois Geriatrics Society and is the current Vice President of the Illinois Medical Directors Association. For approximately 20 years he practiced on the north side of Chicago and was affiliated with Advocate Illinois Masonic Medical Center, where he was the Director of Medical Education and Associate Medical Director. For 10 years he was Vice President for Medical Affairs at Ballard Health Care in Des Plaines, Illinois, a Joint Commission Accredited Long Term and Subacute Care facility. He is also a Clinical Assistant Professor of Medicine at the University of Illinois at Chicago College of Medicine.

On September 1, 2004, he became the Director, Division of Continuing Physician Professional Development at the American Medical Association. His previous involvement with CME included five years as chairman of the Illinois State Medical Society Committee on CME Accreditation as well as serving on several local, regional and national organizations' CME committees. Dr. Aparicio is a member of the Society for Academic CME and the Alliance for CME where he also serves in the Clearinghouse Task Force and the State and Regional Organizations Committee. He is a Past President of the Illinois Alliance for CME.

In 2004 he was appointed to the Policy Committee of the 2005 White House Conference on Aging. He also co-chairs its Health Subcommittee.

David W. Baker, MD, MPH

Dr. David W. Baker is Associate Professor of Medicine and Chief of the Division Chief of General Internal Medicine at the Feinberg

School of Medicine at Northwestern University in Chicago. He is also co-director of the Institute for Healthcare Studies and acting director of the Center for Healthcare Equity. Dr. Baker's research activities have focused on health care delivery for underserved populations and improving quality of care for chronic medical conditions. He was one of the Principal Investigators for the Literacy in Health Care Study, the first major study examining how often patients are unable to accurately read pill bottles, appointment slips, and the other written materials they encounter when they come to see a doctor. He was also the Principal Investigator for a large study of literacy, health status, and use of health care services that included over 3000 Medicare managed care enrollees in four cities in the United States. He was one of the developers of the Test of Functional Health Literacy in Adults, and he has published over 25 articles on the measurement of health literacy and the consequences of inadequate health literacy.

CDR Mercedes J. Benitez-McCrary, USPHS

Commander Mercedes J. Benitez-McCrary has twenty-nine years of experience in the health care field inclusive of direct patient care, policy and academia. CDR Benitez-McCrary is a member of the U.S. Public Health Service Regular Corp, the seventh branch of the military. Recent career highlights include being selected the first junior (LCDR) officer to serve as Special Assistant to the Office of the Surgeon General in 2003-2004 for 17th Surgeon General of the United States, VADM Richard H. Carmona MD, MPH. This tour was completed with exceptional reviews and the Surgeon General's Certificate of Appreciation. Currently, CDR Benitez-McCrary is stationed at the Centers for Medicare & Medicaid Services (CMS), Office of Clinical Standards and Quality, as a Senior Health Policy Analyst. Additional career highlights include former faculty at Howard University College of Medicine and part of the executive administration of The University of Medicine and Dentistry

of New Jersey (UMDNJ) as Chief of Staff to the President. Some of her past research projects include the development of intervention protocols for the elderly, bilingual/bicultural, cancer and traumatically head-injured populations. Protocols were designed to reduce health disparities among various socioeconomic populations with different modes of communication, thereby improving health literacy. CDR Benitez-McCrary has published articles in peer reviewed and professional journals as well as written a chapter in medical textbook for surgical residents of otolaryngology. She continues to serve on military USPHS appointment boards, scholarship boards and NIH research funding boards. The CDR obtained an undergraduate degree from New York University/The George Washington University and holds a graduate degree from The George Washington University in speech & language pathology. She is board certified in clinical speech language pathology in Maryland and Virginia. Her areas of interest are health disparities, health literacy, head trauma (head injury), geriatric medicine, domestic health prevention, global health strategies and restorative medicine. As part of her continuing commitment to service, CDR Benitez-McCrary served as president of the Commissioned Officers Association (COA) and as the Baltimore branch president and co-founder.

David L. Clark, RPh, MBA

David L. Clark, RPh, MBA, is Vice President, Pharmacy Services, for The Regence Group, in Portland, Oregon, with health plans in Oregon, Washington, Utah and Idaho, serving 3 million subscribers. The Regence Group also provides pharmacy benefit management support nationally through its RegenceRx subsidiary.

His responsibilities include overseeing all pharmacy-related services including formulary activities, P&T Committees, product reviews, clinical services, contracting, and benefit design.

Prior to joining The Regence Group, he was Director of Pharmacy Services for Intermountain Health Care in Salt Lake City, Utah, an integrated health care system with hospitals, clinics, surgery centers, and a mixed-model managed care company.

He received both his pharmacy degree and his MBA from the University of Utah in Salt Lake City.

His pharmacy experience includes pharmacy benefit management as well as practice in hospital, managed care, clinical, and retail settings. He has been an active participant in disease management groups and previously filled an administrative role with one of the country's largest group purchasing organizations for several years.

He has spoken at national and regional conferences on topics related to health care delivery and pharmacy, including patient safety, pharmacy benefit management, evidence-based product evaluation, diabetes, cardiovascular disease, disease state management, managed care, Medicare, health care system integration, and developing relationships between health care providers and the pharmaceutical industry.

He is an active member of the Academy of Managed Care Pharmacy. He also taught pharmacology for a college of nursing for more than six years. He is on the Board of Directors for the Northwest Affiliate of the American Heart Association in Portland, Oregon, a member of the Executive Committee of the National Council of Physician Executives for the BlueCross BlueShield Association, and was previously selected by HHS Secretary Thompson to serve on the State Pharmaceutical Assistance Transition Commission.

Toni Cordell

Toni Cordell is a native of San Francisco, California where she graduated from high school reading at the fifth-grade level. Ms. Cordell became involved in literacy after being tutored by a Laubach Literacy volunteer in 1989. Now she is nationally recognized in literacy circles because Toni roller-skated across the United States in 1990 to raise awareness about the issue. The sole purpose of that event was to draw mass media attention to the solvable problem of illiteracy.

One of the achievements Ms. Cordell is most proud of is the film production company she formed in the 1970s. This company made it

possible for her to travel to India, Africa and Central American filming documentaries. In India she was thrilled to meet Mother Teresa.

Ms. Cordell continues to believe that life long education is one of the major keys to personal growth and success. She hopes that there is still time for her to earn a college degree.

One can say that Toni Cordell's life story is one "of stumbling blocks being turned into stepping stones" as she has become a national patient advocate for health literacy. She has faced numerous challenges because of her poor education. It is not a surprise to her that her challenges with literacy created problems dealing with the medical system.

By the way, she now reads about one book per week.

Terry C. Davis, PhD

A pioneer in the field of health literacy, Terry C. Davis, PhD, is Professor of Medicine and Pediatrics at Louisiana State University (LSU) Health Sciences Center in Shreveport, Louisiana, where she also heads the Behavioral Science Unit of the Feist-Weiller Cancer Center. Among her faculty responsibilities, Dr. Davis directs the Doctor/Patient Communication course for medical students and internal medicine residents. For the past 20 years, she has led an interdisciplinary team investigating the impact of patient literacy on health and healthcare.

Dr. Davis was awarded the Louisiana Public Health Association's Founders Award for Significant Achievement in Public Health Research. In 2003, she was asked to chair Louisiana's statewide Health Literacy Task Force, the first legislatively mandated health literacy group in the nation.

Dr. Davis, who holds her PhD in clinical psychology from the Fielding Institute, has published more than seventy articles and book chapters related to health literacy, health communication and preventive medicine. Patient and provider education products developed by Dr. Davis and her team are being distributed by HRSA, the American Academy of Pediatrics, the American College of Obstetricians and

Gynecologists and the American Academy of Family Physicians. Current research projects funded by the American College of Physicians Foundation include working with investigators at the University of North Carolina and the University of California at San Francisco to develop a diabetes self-management toolkit for patients with limited literacy.

Active in health literacy on the national level, Dr. Davis has served on the National Cancer Institute's Work Group on Cancer and Literacy, the Health Literacy Advisory Board for the American Medical Association Foundation, and as an independent agent of the Institute of Medicine's Committee on Health Literacy. Currently she is chair of the American College of Physicians Foundation's Patient-Centered Health Literacy Advisory Board, serves on the master faculty of the AMA's Train-the-Trainer Health Literacy Curriculum, and as a member of the Healthy People 2010, Health Literacy/Health Communication Section.

Darren A. DeWalt, MD, MPH

Darren A. DeWalt, MD, MPH, is assistant professor in the Division of General Internal Medicine at the University of North Carolina at Chapel Hill. He is board certified in pediatrics and in internal medicine.

Dr. DeWalt actively researches interventions for low-literacy patients with congestive heart failure and diabetes. He recently received the Pfizer Health Literacy Scholar Award to investigate mediators of the relationship between literacy and health outcomes. Dr. DeWalt is also a member of the RTI-UNC Evidence-Based Practice Center scientific team, which performed a systematic review of the impact of literacy on health outcomes for the Agency for Healthcare Research and Quality. He is currently a member of the Health Literacy Advisory Board for the American College of Physicians Foundation.

Dr. DeWalt is a former Robert Wood Johnson Clinical Scholar at the University of North Carolina at Chapel Hill. He completed his residency in internal medicine and pediatrics at the University of North Carolina at Chapel Hill where he also served as chief resident in internal

medicine. He received his medical degree from the Vanderbilt University School of Medicine.

Mary “Toni” Flowers, RN, BA

Ms. Flowers is the Director of Health Disparities & Cultural Competency at MPRO-Michigan’s Quality Improvement Organization. In this role she oversees the projects and initiatives that seek to reduce health disparities among underserved populations and seek to provide insight and understanding regarding diverse work settings. Ms. Flowers has nearly 20 years of health care experience and previously served as the Project Manager responsible for MPRO’s Enhancing Traditional Health Outreach Strategies (ETHOS) Diabetes Project. This project called for the development and implementation of cultural competency and health literacy training programs to health providers throughout the state of Michigan.

She has presented to audiences both nationally and internationally. She has testified and lobbied before national legislators and is a strong health policy and patient advocate. Toni is a licensed minister and has traveled for fourteen years as a medical missionary and cultural specialist, working in countries throughout Africa, South America, and the West Indies. Currently, Ms. Flowers provides cultural competency and cultural diversity training to organizations across the United States.

She is a registered nurse and received her bachelor’s degree in liberal arts (anthropology) from Wayne State University. She is a former research fellow for the National Institutes of Mental Health and now serves as the Community Liaison for the Center for Urban and African American Health. She received cultural competency training from the National Multicultural Institute in Washington, DC, and health literacy training from the American Medical Association Foundation in Chicago, Illinois.

Margaret Gadon, MD, MPH

Margaret Gadon, MD, MPH, directs the initiative on Health Disparities at the American Medical Association where she has worked since October 2004. Prior to that she worked as a community health physician and directed the Community Medicine program for medicine-pediatric residents at Baystate Medical Center in Springfield, MA, served as a medical director of a migrant health worker program and worked as a public health physician for the New York State Department of Health. In addition to issues of health equity, she is interested in the integration of medicine and public health at the level of training, interdisciplinary medical education and international community health. In addition to her health policy work, she teaches in the patient, physician and society course at Northwestern University School of Medicine. Dr. Gadon received her medical degree from Albert Einstein College of Medicine and her public health degree from Johns Hopkins University.

Wayne H. Giles, MD, MS

Wayne H. Giles, MD, MS, joined the Centers for Disease Control and Prevention in July 1992. He is currently the Acting Division Director for the Division of Adult and Community Health, National Center for Chronic Disease Prevention and Health Promotion. He holds a BA (biology) from Washington University, a MS (epidemiology) from the University of Maryland, and a MD from Washington University and has completed residencies in both internal medicine (University of Alabama at Birmingham) and preventive medicine (University of Maryland).

His past work experience has included studies examining the prevalence of hypertension in Africa, clinical trials evaluating the effectiveness of cholesterol-lowering agents, and studies examining racial differences in the incidence of stroke. Dr. Giles currently oversees programmatic and research activities in cardiovascular diseases, arthritis, aging, health care utilization, and racial and ethnic disparities in health within the Division of Adult and Community Health at CDC. He has over 100 publications in peer

reviewed journals and has authored several book chapters. Ongoing research includes the surveillance of cardiovascular disease, secondary prevention activities related to cardiovascular disease, racial and socioeconomic determinants of end-stage renal disease, and the evaluation of genetic and environmental risk factors for cardiovascular disease.

He has been the recipient of numerous awards including Distinguished Researcher Award by the International Society on Hypertension in Blacks and the Jeffrey P. Koplan Award by the Centers for Disease Control and Prevention.

Justine Handelman

Justine Handelman, Director of Federal Relations for the BlueCross BlueShield Association (BCBSA), has over thirteen years experience in providing strategic analysis, policy development, and federal representation services for clients on legislative and regulatory issues pertaining to health care and Medicare. She joined the BlueCross BlueShield Association in April 2001. Ms. Handelman works on a range of federal issues of importance to Blue Plans, including insurance reforms, health information technology, and Medicare issues, specifically as they pertain to Medicare contractors.

Prior to joining BCBSA, Ms. Handelman was the Director of the Health Care Practice Group in the Government Relations Division of Smith, Bucklin & Associates, Inc. In this capacity, she was responsible for the day-to-day government relations activities for several non-profit professional medical specialty societies and health care organizations.

Prior to joining the Smith, Bucklin team, Ms. Handelman served as a Senior Legislative Associate of MARC Associates, Inc. providing strategic analysis, policy development and federal representation services for clients on legislative and regulatory matters pertaining to health care, education, telecommunications, and technology infrastructure.

Ms. Handelman has provided in-depth comparative analyses of the evolving private and federal health care systems. She has broad

experience in arranging and coordinating health presentations on reforms to federal and private health care and insurance systems on issues ranging from quality of care and access for beneficiaries, to provider reimbursement, quality assurance and utilization review, and graduate medical education. She has worked with Congressional members and staff to model successful, innovative health and education programs in authorization legislation and to increase appropriations for specific initiatives.

Ms. Handelman has assisted in developing and organizing grassroots programs focused on Medicare/Medicaid and health insurance reforms and provided updates and analysis on federal health developments through written reports and articles for several publications.

Ms. Handelman received her Bachelor of Arts degree in political science from the Catholic University of America.

Mary Kelly, RPh

Mary Kelly is a Registered Pharmacist and the Vice President, General Merchandising Manager for Health, Beauty and Pharmacy at Target. Mary joined Target in 1991 as Regional Pharmacy Manager. She was promoted to her current position in 2001. Kelly's current responsibilities include overseeing the operations of more than 1,000 Target pharmacies, purchasing and merchandising of all prescription and over the counter products, as well as the beauty and other health categories at Target.

Before joining Target, she worked for Revco Drug Stores and Eli Lilly and Company. Mary has been actively involved with pharmacy and beauty industry organizations, and served on the advisory boards for several U.S. colleges of pharmacy. She has been recognized as a leader by the Ohio State University College of Pharmacy and served as chairperson of the Pharmacy Operations Committee for the National Association of Chain Drug Stores.

Mary is a graduate of the Ohio State University College of Pharmacy.

Allan Korn, MD, FACP

Allan Korn, MD, is Senior Vice President and Chief Medical Officer of the BlueCross BlueShield Association (BCBSA), a national federation of 40 independent, locally operated BlueCross BlueShield companies.

The Blue System is the nation's largest insurer and managed healthcare provider, collectively providing coverage for more than 92 million people – nearly one-in-three of all Americans. The Blue System also is the largest single processor of Medicare claims in the nation, and holds the world's largest privately underwritten health insurance contract — the 4 million-member Federal Employee Program (FEP), for which Dr. Korn serves as Medical Director.

Dr. Korn oversees the Technology Evaluation Center (TEC), an independent, applied health service research organization that uses an evidence-based methodology for the assessment of clinical technologies. He also represents BCBSA with governmental agencies, regulatory bodies and accrediting entities, and oversees the National Council of Physician Executives made up of senior BCBS Plan physicians who advise BCBSA.

Before joining BCBSA, Dr. Korn served as Vice President and Chief Medical Officer for BlueCross BlueShield of Illinois. From 1994 until 1996, Dr. Korn was Senior Vice President, Medical Affairs for Premier Health Alliance, where he provided strategic direction and product development for risk adjusted IP and OP clinical data systems. Earlier, he served as a Principal for William M. Mercer, Inc. and as Vice President, Medical Affairs for Healthcare Compare/Affordable Healthcare Network. From 1976 until 1986, he was an internist at St. Mary's Medical Center in Evansville, Indiana.

Dr. Korn received his Bachelor of Science and Medical Degree from Tufts University. He completed his internship and internal medicine residency at Chicago Wesley Memorial Hospital and at the Mayo Clinic.

Dr. Korn is certified by the American Board of Internal Medicine and is a Fellow of the American College of Physicians/American

Society of Internal Medicine. He is a member of the American Medical Association, the Illinois State Medical Society, the Society of Chief Medical Officers, the Institute of Medicine Research Roundtable and the American College of Medical Quality.

Bryan A. Liang, MD, PhD, JD

Bryan A. Liang, MD, PhD, JD, is co-director, San Diego Center for Patient Safety and Adjunct Associate Professor of Anesthesiology, UCSD School of Medicine and Executive Director and Professor of Law, Institute of Health Law Studies, California Western School of Law. He received his BS from MIT, PhD in health policy from the University of Chicago, MD from the Columbia University College of Physicians & Surgeons and JD from Harvard Law School.

Dr. Liang has a longstanding interest in minority and underserved populations, access, language and health literacy, and quality and safety in health care. His PhD dissertation analyzed the population of Medicaid managed care programs and the characteristics associated with service to underserved populations, decades before managed care programs were considered for these groups. His work has also encompassed activism to advance health care delivery to Asian-Americans and other underserved groups with English as a second language through participation on the Board of Directors of the Southwest Center for Asian-Pacific American Law, the Community Health Improvement Partners Steering Committee, the AMA Patient Safety Health Literacy Advisory Panel, the Healthy San Diego Consumer and Professional Advisory Committee, and San Diego School Health Innovations Project Steering Committee. He was chosen to speak at the invitation-only conference on Implementing a Partnership to Empower Minority and Underserved Patients at the Office of Minority Health Conference, Promoting Trust and Trustworthiness: Strengthening the Informed Consent Process to Address Racial & Ethnic Disparities, sponsored by the U.S. Department of Health and Human Services. His other community service work includes regular presentations on patient rights in the health

care system to the Community Law School, a grassroots organization promoting senior citizen and community knowledge of important legal principles, and working with the senior population on the San Diego Elder Abuse Council, which acts to inform and protect seniors from physical and financial abuse as well as providing education on health care rights and information. He also works to educate seniors on drug policy issues such as the provisions of the Medicare Modernization Act as well as creating checklists and methods for elderly empowerment to protect themselves against fake, tainted, and counterfeit drugs. He was the keynote speaker of the American Bar Association Senior Lawyer's Council annual meeting on this latter topic.

Finally, he acts as a volunteer Commander Pilot for Angel Flight, which provides needy patients and their families free private aircraft transportation to distant medical care facilities. Dr. Liang is a first generation U.S. citizen.

Linda Magno

Linda Magno is director of the Medicare Demonstrations Group in the Centers for Medicare & Medicaid Services Office of Research, Development and Information. She and her staff are responsible for developing, implementing and managing Medicare demonstrations of new models of health care delivery for the nation's 40 million elderly and disabled Medicare beneficiaries. Over the life of the program, Medicare demonstrations have tested the impacts, feasibility and desirability of new benefits, new payment methodologies, and new delivery system alternatives including hospice, prospective payment for hospitals, and Medicare HMOs and preferred provider organizations before they were incorporated into the Medicare program on a permanent basis. The Demonstrations Group currently manages more than 20 active projects, including CMS's first pay-for-performance demonstrations for physicians and hospitals, as well as a number of case management and disease management demonstrations.

Prior to her current position, Ms. Magno served as managing director for policy development and director of regulatory affairs at the American Hospital Association in Washington, DC. She started her career at the CMS's predecessor agency, the Health Care Financing Administration. In her last several years at HCFA, she was responsible for implementing and refining the prospective payment system for hospitals.

Ms. Magno has a master's degree in public affairs from Princeton University and a bachelor's degree in political science from the University of California at Berkeley.

Michael D. Maves, MD, MBA

Michael D. Maves, MD, MBA, serves as executive vice president and chief executive officer for the nation's largest physicians group, the American Medical Association.

Dr. Maves has extensive medical and association management experience. Prior to joining the AMA, he served as executive vice president of the American Academy of Otolaryngology – Head and Neck Surgery, Inc. (AAO-HNS) from 1994-1999. Under his leadership, AAO-HNS increased visibility in Washington for the 12,000-member physician group, establishing the association's first political action committee.

Previously, he headed the Consumer Healthcare Products Association (CHPA) in Washington, D.C. At CHPA, a 120-year-old trade organization representing more than 200 U.S. manufacturers and distributors of nonprescription (over-the-counter) medicines, Dr. Maves improved both the group's operational efficiency and financial reserves.

An active participant in organized medicine throughout his professional career, Dr. Maves has served as a specialty society representative and alternate delegate to the AMA House of Delegates as well as a governor of the American College of Surgeons. At the local level, he has served as a member of the board of the St. Louis Metropolitan Medical Society, a Councilor of the St. Louis Surgical Society, and a delegate to the Missouri State Medical Association.

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FINAL REPORT APPENDIX

Dr. Maves was a member of the initial AMA Resource-Based Relative Value Scale Update Committee and has testified before Congress, the Centers for Medicare & Medicaid Services and the Food and Drug Administration. In addition, he is a consultant to the Clinical Center at the National Institutes of Health in Bethesda, MD. He currently co-chairs the medical/surgical panel of the CMS Medicare Coverage Advisory Committee and serves on its executive committee.

A clinically trained and board-certified otolaryngologist, Dr. Maves has distinguished himself in academic circles as well. He served as professor and chairman, Department of Otolaryngology – Head and Neck Surgery at Saint Louis University College of Medicine from 1988-1994. He has also held faculty appointments at the University of Iowa Hospitals and Clinics (1984-1988) and Indiana University School of Medicine (1981-1984). Presently, he is adjunct professor at the Saint Louis University School of Medicine.

Dr. Maves is the author of nearly 100 peer-reviewed medical journal articles and book chapters, and has lectured extensively on such topics as head-and-neck surgery, medical practice and medical economics.

Raised in Ohio, Dr. Maves received his undergraduate degree from the University of Toledo and his medical degree from the Ohio State University. He received his MBA from the University of Iowa College of Business Administration. Dr. Maves is a former captain in the U.S. Army Medical Corps and served in Europe.

Robert S. Mirsky, MD

Medical Director for the Southwestern region of BlueCross BlueShield of Florida, Dr. Mirsky leads the company's statewide pay-for-performance program to recognize physician excellence. He also co-chairs the BlueCross BlueShield Association Pay-for-Performance Workgroup.

Dr. Mirsky joined BCBS of Florida in January 2001 after serving as the Chief Medical Officer for Tenet Network Management, a division of Tenet Florida HealthSystems, in Ft. Lauderdale.

Dr. Mirsky is board certified in family practice, a Fellow of the American Academy of Family Physicians, and a member of the Florida Academy of Family Physicians, where he serves on the Quality Practice Management Committee. He holds a Master of Medical Management degree from Tulane University, School of Public Health and Tropical Medicine.

Allan S. Noonan, MD, MPH

Dr. Noonan was recently appointed as director of the Public Health Program at Morgan State University, Baltimore, Maryland. Until January 2005, he served as a Senior Advisor in the Office of the Surgeon General of the U.S. Public Health Service coordinating the production of all Surgeon Generals' reports and calls to action.

Dr. Noonan has been a proactive public health professional for more than thirty years. He has worked as a developer and implementer of public health programs at the local, state, and national levels in this country. Early in his career, he also participated in educating about smallpox in West Africa. He worked in epidemiology, maternal and child health, public health administration, and the training of health professionals—always mindful of strategies to improve the health status of the underserved. He was the Secretary of Health for the state of Pennsylvania; the Regional Health Administrator and Assistant Surgeon General responsible for the public health service programs in six Midwestern states; and the Director of the Department of Health in the District of Columbia. Throughout his career, Dr. Noonan has played key roles in efforts to eliminate racial and ethnic disparities in health outcomes.

Aracely Rosales

Aracely Rosales is known locally and nationally for her extensive efforts to bring accessible information and education to diverse communities. Ms. Rosales is the president of Plain Language and Culture, Inc. (PLC). Formerly the director of the Latino Health Project of the Health Promotion Council, she has extensive experience writing and designing bilingual educational materials, scripts, social marketing and media

messages. She conducts presentations on cross-cultural communications and on how to develop easy-to-read multilingual translations, materials and programs. In addition, she trains multilingual medical interpreters and translators. Her company conducts needs assessments and focus groups with a diverse range of consumers. She is the author, reviewer and advisor of many bilingual publications which have been distributed nationally. She is a co-author of the Latino Diabetes Recommendations Report for the CDC. She has served on many national advisory committees and is currently serving on the National Coalition for Healthcare Translation Standards for Kaiser Permanente and on the Robert Wood Johnson Foundation National Advisory Committee Diabetes Initiative. She has received, among many other commendations, the National Robert Wood Johnson Community Health Leadership award and the Pennsylvania Against All Odds award for her health communications and community-based chronic disease management programs. Aracely Rosales is from Guatemala.

Rima E. Rudd, MSPH, ScD

Rima Rudd is senior lecturer on society, human development, and health at the Harvard School of Public Health. Her work centers on health communication and on the design and evaluation of public health community-based programs. She teaches graduate courses in program design and evaluation, innovative strategies in health education, and health literacy. Her research is currently focused on literacy related disparities and literacy related barriers to health programs, services, and care.

Dr. Rudd is a research fellow of the National Center for the Study of Adult Learning and Literacy and serves as Principal Investigator for the Health and Adult Literacy and Learning (HALL). She is Principal Investigator for a study of health literacy among adults in Canada and the United States, working with Statistics Canada and the Educational Testing Services. She is also Principal Investigator for the NIAMS Literacy in Arthritis Management: a Randomized Controlled Trial of a Novel Patient Education

Intervention with the Robert B. Brigham Arthritis and Musculoskeletal Diseases Clinical Research Center and the co-Principal Investigator for the NIH study of Pathways Linking Education to Health.

Dr. Rudd directs several practice initiatives. She designed the New York City Health Literacy Initiative, working in close partnership with the Literacy Assistance Center and the Mayor's Office. She is working with several cities and states for the development of health literacy initiatives and in support of partnerships between adult education educators and health professionals and adult education programs and health and hospital institutions.

Dr. Rudd wrote several reports that are helping to shape the agenda in health literacy research and practice including the health literacy action plan for the Healthy People 2010, reported in the Health and Human Services book *Communicating Health: Priorities and Strategies for Progress* (2003) and the Educational Testing Services report, *Literacy and Health in America* (2004). Finally, she served on two National Academies of Sciences committees and contributed to the final reports of the Institute of Medicine Committee on Health Literacy, *Health Literacy: a Prescription to End Confusion* (2004) and the National Research Council Committee on Measuring Literacy: *Performance Levels in Adult Literacy*.

Joanne G. Schwartzberg, MD

Dr. Schwartzberg is Director of Aging and Community Health at the American Medical Association and Senior Science Advisor on Health Literacy at the American Medical Association Foundation. She received her BA from Harvard and MD from Northwestern and is a clinical assistant professor of preventive medicine and community health at the University of Illinois at Chicago College of Medicine. Dr. Schwartzberg is a past-president of the Institute of Medicine of Chicago, the Illinois Geriatrics Society, and the American Academy of Home Care Physicians.

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FINAL REPORT APPENDIX

In 1988 she received the Physician of the Year Award from the National Association for Home Care. In 1992 she received the Physician of the Year Award from the American Academy of Home Care Physicians. In 1995 she served as co-chair of the Illinois Delegation to the White House Conference on Aging, Caucus on Health and Social Services. She also served as AMA liaison to the National Patient Safety Foundation's Partnership for Safe Medication Use – Educating and Empowering the Health Consumer.

She is the 2001 recipient of the Henry P. Russe, MD, Citation for Exemplary Compassion in Healthcare awarded by the Institute of Medicine of Chicago and the Rush-Presbyterian-St Luke's Medical Center.

Appendix B: Mini-Conference on Health Literacy and Health Disparities Planning Committee

Joanne Schwartzberg, MD, Chairperson
Director of Aging and Community Health,
Medicine and Public Health
American Medical Association

Mercedes Benitez-McCrary, MA CCC-SLP
CDR, United States Public Health Service
Commander/Public Health Policy Analyst
Centers for Medicare & Medicaid Services
Office of Clinical Standards & Quality/CSG

Gloria Cavanaugh
President & CEO
American Society on Aging

Kaytura Felix-Aaron, MD
Chief, Clinical Quality Data Branch
Division of Clinical Quality
Bureau of Primary Health Care

Margaret Gadon, MD, MPH
Director of Disparities Initiative,
Medicine & Public Health
American Medical Association

Justine Handelman
Director, Federal Relations
BlueCross BlueShield Association

Allan Korn MD, FACP
Senior Vice President
Chief Medical Officer
BlueCross BlueShield Association

Allan Noonan, MD, MPH
Former Public Health Commissioner
Director, Public Health Program
Morgan State University

Ruth Parker, MD
Professor of Medicine
Emory University School of Medicine

Winston Price, MD, FAAP
President
National Medical Association

Aracely Rosales, BS
President, Plain Language and Culture, Inc.
Division of Rosales Communications

Appendix C: Selected Readings and Resources Health Literacy and Health Care Disparities

Health Literacy

Institute of Medicine of the National Academies.

- Health Literacy: A Prescription to End Confusion, April 2004.
<http://www.nap.edu/catalog/10883.html>
- Crossing the Quality Chasm: A New Health System for the 21st Century, 2001.
<http://www.iom.edu/report.asp?id=5432>
- Who Will Keep the Public Healthy: Educating Public Health Professionals for the 21st Century, 2002.
<http://www.iom.edu/report.asp?id=4307>

Literacy and Health Outcomes.

Evidence Report/Technology Assessment Number 87. January 2004. Agency for Healthcare Research and Quality, Rockville, MD.
<http://www.ahrq.gov/clinic/epcsums/litsum.htm>

Understanding health literacy: implications for medicine and public health.

Schwartzberg JG, VanGeest JB, Wang CC, eds. AMA Press, 2005. 250p.

Health Literacy: Help Your Patients Understand

American Medical Foundation Educational Kit
<http://www.ama-assn.org/ama/pub/category/9913.html>

Healthy People 2010

Healthy People 2010 is a statement of national health objectives designed to identify the most significant preventable threats to health and to establish national goals to reduce these threats.
<http://www.healthypeople.gov/>

Office of Minority Health (OMH)

OMH was established in 1985 by the U.S. Department of Health and Human Services (HHS). It advises the Secretary and the Office of Public Health and Science on public health program activities affecting American Indians and Alaska Natives, Asian Americans, Blacks/African-Americans, Hispanics/Latinos, Native Hawaiians, and other Pacific Islanders.

- OMH, The Center for Linguistic and Cultural Competence in Health Care
<http://www.omhrc.gov/cultural/>
- OMH, CLAS (Culturally and Linguistically Appropriate Services) standards
<http://www.omhrc.gov/cultural/>

Readability Analysis of Consumer Health Materials

in *Consumer Health, An Online Manual*. 2000. National Network of Libraries of Medicine, South Central Region
<http://nmlm.gov/scr/conhlth/read.htm>

Harvard School of Public Health, Health Literacy Studies and National Center for the Study of Adult Learning and Literacy (NCSALL)

Health Literacy Studies (HLS) is located in the Department of Society, Human Development and Health at the Harvard School of Public Health. HLS is a research program of the National Center for the Study of Adult Learning and Literacy (NCSALL) engaged in a variety of activities, studies, and explorations linking health and literacy. The work is based in public health, health care settings, and adult education programs with strong links to public health and medical institutions, adult education programs, as well as to state departments of public health and education. The site is designed for professionals in health and education who are interested in health literacy.
<http://www.hsph.harvard.edu/healthliteracy/>

Plain Language and Culture, Inc.

Philadelphia, PA <http://www.plculture.org>
<http://www.clearlanguagegroup.com>

National Institute for Literacy

The Health & Literacy Special Collection
 The Health & Literacy site is for teachers, students, health educators, or anyone interested in teaching health to people with limited literacy skills. <http://www.worlded.org/us/health/lincs/>

MEDLINEPlus: How to Write Easy to Read Health Materials

Guide to creating easy-to-read materials with links to readability software programs, other guidelines and bibliographies. <http://www.nlm.nih.gov/medlineplus/etr.html>

Centers for Disease Control and Prevention Simply Put

Simply Put is the CDC's guide to putting information in readable, plain language with tips for print materials, such as brochures and fact sheets, for use by any audience. http://www.cdc.gov/communication/resources/resource_idea.htm

National Cancer Institute

Clear & Simple: Developing Effective Print Materials for Low-Literate Readers
 This guide outlines a process for developing publications for people with limited-literacy skills. The process was derived from communications, health education, and literacy research and practice. <http://www.cancer.gov/cancerinformation/clearandsimple>

The Council of State Governments

Health Literacy Links & Research
<http://csg.org/CSG/Policy/health/health+literacy/health+literacy+links.htm>

Partnership for Safe Medicine

<http://www.safemedicines.org>

The Institute for Safe Medication Practices (ISMP)

<http://www.ismp.org/>

Health Care Disparities

U.S. Department of Health and Human Services

The Initiative to Eliminate Racial and Ethnic Disparities in Health
<http://www.omhrc.gov/healthdisparities/index.htm>

Institute of Medicine of the National Academies

Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care, 2002.
<http://www.iom.edu/report.asp?id=4475>

Commission to End Health Care Disparities
 American Medical Association, in conjunction with the National Medical Association and the National Hispanic Medical Association
<http://www.ama-assn.org/ama/pub/category/12809.html>

Agency for Healthcare Research and Quality
National Healthcare Disparities Report: Summary. February 2004.
<http://www.ahrq.gov/qual/nhdr03/nhdrsum03.htm>

Center for Health Equity Research and Promotion (CHERP)

Veterans' Administration National HSR&D Center of Excellence in Health Services Research
<http://www.cherp.research.med.va.gov/index.php>

Racial and Ethnic Health Disparities: Schools of Public Health Respond as Engaged Institutions

The Kellogg Foundation 75th Anniversary Seminar, February 2005. Links include a Proceedings Report and a Premise Paper.
<http://75.wkcf.org/EventsDetail.aspx?ID=1>

Health Research and Educational Trust (HRET) Disparities Toolkit.

A Toolkit for Collecting Race, Ethnicity, and Primary Language Information from Patients
 The toolkit is designed to help hospitals, health systems, community health centers, health plans, and other potential users in understanding the importance of accurate data collection, assessing organizational capacity to do so, and implementing a framework designed specifically for obtaining information from patients/enrollees about their race, ethnicity, and primary (preferred) language efficiently, effectively, and respectfully.
<http://www.hretdisparities.org/hretdisparities/index.jsp>

Association of Schools of Public Health (ASPH)

An initiative to provide information about the health disparities research activities of member schools and diversity-related issues in public health and to provide important information that will help in diversifying schools' faculty and student body, since these are necessary steps toward advancing schools' capacity to eliminate U.S. health disparities.

<http://www.asph.org/diversity/>



Mini-Conference

Disability & Aging



*Disability & Aging: Seeking Solutions to Improve Health, Productivity,
and Community Living*

A Mini-Conference of the 2005 White House Conference on Aging

July 21 & 22, 2005

Crystal City Marriott at Reagan National Airport
Arlington, Virginia

Final Report and Recommendations



Disability & Aging Mini-Conference

Executive Summary of Recommendations Developed by the White House Conference on Aging Mini-Conference on Disability & Aging

1. *Social Engagement and Productivity*

Congress should enact legislation to provide incentives to create public and private partnerships to remove barriers so that employers can hire and retain older workers with and without disabilities. This will:

- Enable more older workers to gain entry and remain in the workplace
- Increase accommodations **of all kinds** as one ages in the workforce

2. *Healthy Long-Term Living*

Adopt and fully fund a system that will ensure that people aging *with* and aging *into* disabilities in mid- to later-life have access to competently trained health care providers and can choose from a full-range of timely and appropriate, culturally-sensitive, and consumer-directed home- and community-based health services and supports that meet individual needs.

3. *Economic Security: Planning and Choice*

For both persons who are aging *with* and *into* disability, expand options to participate in the economy and improve the overall standard of living of people aging with disabilities.

4. *Assistive and Universally Designed Technologies and Environments*

Bring the goal of an “accessible nation” within our reach by expanding the availability and utilization of assistive and universally designed technologies and environmental interventions.

5. *Positive Messaging*

Conduct a national positive messaging campaign to reduce the negative attitudes about disabilities and to build appreciation for individual choice and self-direction throughout the lifespan.



Background, Challenges, Recommendations, & Strategies Developed for Presentation to the WHCoA Policy Committee

Title of Event: *Disability & Aging: Seeking Solutions to Improve Health, Productivity, and Community Living* – A Mini-Conference of the 2005 White House Conference on Aging

Date of Event: July 21-22, 2005

Location of Event: Arlington, Virginia

Number of Persons Attending: 200

Sponsoring Organizations:

AARP

Aetna

America's Health Insurance Plans

American Association of People with Disabilities

MetLife Disability

National Council on Independent Living

Paralyzed Veterans of America

U.S. Department of Education, Office of Special Education and Rehabilitative Services

U.S. Department of Health and Human Services, Office on Disability

U.S. Department of Labor, Office of Disability Employment Policy

U.S. Department of Veterans Affairs

UnumProvident Corporation

Contact Names: Winthrop Cashdollar, Margaret L. Campbell, Ph.D.

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Background: While disability can arise at any age, the likelihood of acquiring a disability increases as a person ages. With America's baby-boom generation approaching retirement age, our nation must pay greater attention to the social, economic, physical, and mental well-being of middle-aged and older adults who are living with long-term disabilities, acquired at birth, in childhood or young-adulthood, as well as to those who are aging into disability for the first time in later life. Health care policies that emphasize institutional over community-based care are out of sync with the new demographic possibilities of "aging in place" and "living well with a disability," and have led to more than a million adults with unmet needs for assistance with basic daily activities such as bathing, eating, toileting, dressing, preparing meals, and getting around in the community. This institutional bias, combined with lack of access to affordable assistive technologies, also places adults aging *with* and aging *into* disability at increased risk of developing secondary health conditions, defined as preventable physical, mental, and social



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disorders resulting directly or indirectly from an initial disabling condition, that diminished their quality of life and limit their opportunities to work and participate in community and family life.

Now is the time for America to take the steps necessary to fix the problems with our outdated systems of health care, income supports, and community programs by promoting greater coordination of services and emphasizing home- and community-based care over institutional care. Laws such as the 1990 Americans with Disabilities Act (ADA) have given us a new way to adjust our community infrastructures so that they are more welcoming of all people with disabilities across the age span. The President's 2001 New Freedom Initiative (NFI) also calls for actions to promote community living for persons of all ages with disabilities by increasing access to assistive and universally designed technologies and environmental accommodations, improving employment and educational opportunities, and expanding opportunities for full participation in community life. The nation should make our technologies more accessible and our communities more livable for residents with disabilities, and promote better integrated community-based health care systems that facilitate healthy, productive aging. In doing so, America can improve the lives of millions of older adults and persons with disabilities and benefit from their contributions to the workforce, their communities, and their families and friends for decades to come.

The high-priority recommendations contained in this report are forward-looking, reasonably ambitious, actionable, and represent the consensus of participants across five broad themes:

- Social Engagement and Productivity
- Healthy Long-Term Living
- Economic Security, Planning, and Choice
- Technology, Universal Design, and Environments
- Positive Messaging

Social Engagement and Productivity

While the risk of disability increases with age, disability and aging are not synonymous. Further, disability is not an illness. What connects aging and disability is common interest in productivity, self-determination, and social engagement and the strong desire to avoid dependence, economic insecurity, and diminished opportunities for work and self-expression. Contrary to frequently held negative stereotypes, both productivity and social engagement are real possibilities for individuals who are:

- **Aging with disability** — Individuals who have been born with or acquired a physical, sensory, cognitive, or behavioral disability and now are entering their 50s and 60s and experience changes in work capacity and community participation.



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- **Aging into disability** — Individuals who have been relatively free of injury, illness, or impairment but who, as they enter into their 50s, 60s, or 70s experience chronic disease and disabilities that affect work capacity and participation in community and family life.

Challenges:

The challenges to productive aging and continued social engagement are embedded in: (1) the lack of public and private collaboration providing incentives for individuals to continue working with an impairment; (2) the lack of incentives for employers to maintain a flexible and adaptable workplace; and (3) the need to strengthen incentives for U.S. health care providers to offer health care services, including prevention, screening, diagnosis and treatment, that are both accessible and affordable, and focused on preventing the onset and mitigating the impact of chronic disease and disability on work capacity and mobility.

Recommendation:

Congress should enact legislation to provide incentives to create public and private partnerships to remove barriers so that employers can hire and retain older workers with and without disabilities. This will:

- Enable more older workers to gain entry and remain in the workplace
- Increase accommodations of all kinds as one ages in the workforce

Strategies:

1. Enact legislation to provide incentives and remove barriers for employers in hiring and retaining older workers with and without disabilities.
2. Establish a coherent research agenda to address the full range of critical work disability issues related to aging, including improved measurement, identification of risk factors, evaluation of public and private sector initiatives, and testing of innovative strategies to increase the hiring and retention of older workers, with or without disabilities.
3. Promote funding to support increased worksite accommodations as one ages in the workforce.
4. Promote funding for affordable and accessible mass transit and ensure that new housing and communities include plans for connection to mass transit.



Healthy Long-Term Living

Everyone of any age in the United States is at risk of disability. The chance of acquiring a disability is predicted by a broad array of factors including age, health history, socioeconomic status, and education. This risk increases with age: Every person age 65 and over is likely to have at least one disability. The critical issue is not the presence of a disability, but the extent to which an individual's health and wellness are affected by that disability, directly or indirectly. The relationship between health and wellness and all other aspects of life for persons aging *with* and aging *into* disability necessitates:

- Increased attention to the availability of integrated health services and providers respectful and knowledgeable of individual needs and capacities, and
- Health promotion and wellness services accessible to persons with all types of disabilities.

Challenges:

The American health care system is not sufficiently prepared to meet the community-based health care needs of the expanding population who are aging *with* or aging *into* disability. The lack of a seamless system of health care services and appropriately trained health care providers (including geriatricians, geriatric pharmacists, and rehabilitation specialists), who understand the special health care needs of middle-aged and older adults with disabilities, all too often results in serious medical conditions and premature deaths due to incorrect diagnoses, inappropriate drug therapy, and inadequate management of secondary conditions resulting from a disability that could have been prevented. By providing early prevention and wellness services along with a seamless system of health services that ensures access to needed health care, the special needs of older adults with disabilities can be addressed effectively. Consistent with the goals of the 2005 "Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities," if we "pay now" rather than "pay more later," the result can be a more effective, efficient system of health care that helps individuals with disabilities reside in the community, prevents clinically unnecessary hospitalizations and nursing home placements, and eliminates excessive health care costs.

Recommendation:

Adopt and fully fund a system that will ensure that people aging *with* and aging *into* disabilities in mid- to later-life have access to competently trained health care providers and can choose from a full-range of timely and appropriate, culturally-sensitive, and consumer-directed home- and community-based health services and supports that meet individual needs.

Strategies:

1. Support public and private funding for timely and coordinated health screenings, evaluations, and services to prevent decline, improve function, and eliminate or reduce the risks of secondary conditions associated with specific disabilities and chronic conditions.



2. Mandate and support interdisciplinary research across relevant Federal agencies on the health effects of aging with disability (whether physical, cognitive, sensory, behavioral, or in combination) and the role of environmental and lifestyle factors in promoting healthy long-term living.
3. Support the inclusion of disability-specific and gerontology-oriented educational curricula in formal training programs for medical students, physicians, and other providers of health care services and supports, and adapt this information for use in the training of informal care providers.

Economic Security: Planning and Choice

In the context of a rapidly maturing society faced with an economy that is evolving from an agricultural/manufacturing base to a 21st century global knowledge service-based economy, we want to preserve the economic security of all American across the lifespan. As such, we want to encourage lifelong development of transferable skills and incentives that will enable all Americans to participate in the economy according to the extent of their abilities and choices with appropriate supports and accommodations.

Challenges:

Adults living with disabilities very often face economic insecurity due to limitations on employment options; difficulty or impossibility of saving and investing; limitations of public programs; and added expenses that can accompany disability. Adults aging into disability can see their economic security disrupted by departure from the workforce earlier than planned; by diminished ability to save for retirement; and by additional expenses of a disabling illness or injury. Current practices in the private sector and programs in the public sector do not sufficiently support employment for those living with or aging into disability. Nor do private and public practices and programs adequately guarantee economic security to those living with disability or facing the onset of disability.

Recommendation:

For both persons who are aging *with* and *into* disability, expand options to participate in the economy and improve the overall standard of living of people aging with disabilities.

Strategies:

1. Preserve the overall solvency of the Social Security Trust Fund and enhance the income protection provided through the Social Security retirement, disability, and survivor programs.



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2. Reform existing public and private income supports and public and private long-term service and support programs to:
 - a) Incorporate incentives and remove disincentives to:
 - Save;
 - Earn;
 - Learn;
 - Plan;
 - Participate in community life; and
 - b) Improve the standard of living of people with disabilities across the lifespan.
3. Support public and private programs, such as tax credits for lifelong learning and educational programs that encourage American citizens and employers to plan ahead and take steps to preserve lifelong economic security—including steps to safeguard against the financial risk of disability.
4. Integrate into public and private disability programs an early intervention orientation that will support people who choose to remain in the workforce as they age and as they experience impairments associated with aging.
5. Establish a payroll deduction throughout the person’s work life that will enable the individual to access and finance long-term care services when needed.

Assistive and Universally Designed Technologies and Environments

At some point during a lifetime, most people will need assistive or universally designed technologies and environmental accommodations to support health, productivity and community living. This is particularly true for the large number of Americans who are aging *with* and aging *into* disability in mid- to later life. To meet this need, we envision a nation in which all technology, products, services, systems and physical environments are accessible to, usable by, and actually used by the approximately 50 million adults living with disabilities. Creating an accessible nation is central to fulfilling the promise of the President’s New Freedom Initiative. Creating an accessible nation also will provide significant, measurable economic benefits to businesses and the American public through access to larger markets, to more diverse talent, and to the productive potential of all in our society.



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Challenges:

Despite recent progress, the vision of an accessible nation has yet to be realized. Significant barriers remain that prevent assistive technologies (AT) and universally designed (UD) technologies and environments from being developed, deployed, and used by people with disabilities across the lifespan and by their families, caregivers, employers, and communities, including:

- Insufficient coordination of and investment in research and development;
- Inadequate education and training of researchers, engineers, and other professionals;
- Lack of support for prototype development, poor market data on needs for AT and UD, costs and questions of reimbursement which hinder commercialization;
- Legislative barriers and lack of coordination among public and private programs; and
- Lack of awareness among consumers, providers, policymakers and businesses regarding the availability and benefits of AT and UD.

Recommendation:

Bring the goal of an “accessible nation” within our reach by expanding the availability and utilization of assistive and universally designed technologies and environmental interventions.

Strategies:

1. Establish a national accessibility and visitability tax credit for Americans to adapt their home environments to promote independent living and aging in place.
2. Direct increased Federal research and development investments toward accessible, assistive, and universally designed technologies and environmental interventions that will support independence, productivity, and community living for people aging with disabilities and older adults.
3. Expand market-driven, Federal procurement strategies beyond Electronic and Information Technology (e.g., Section 508 of the Rehabilitation Act) to promote increased availability and utilization of accessible, universally designed technologies that are effective in reducing other barriers to full participation in work and community life.
4. Amend the Older Americans Act to mandate the development and delivery of trans-generational accessible, assistive, and universally designed technologies and environmental interventions that support healthy and productive living in a safe and least restrictive environment.
5. Support the establishment of a national “consumer report” of users’ experiences with accessible products.



Positive Messaging

Despite the aging of society and the changing reality of disability, America's view of people who are aging and those who have disabilities is still based, to a large degree, on negative representations. These representations are reinforced throughout all media types and outlets and through the use of language that supports perceptions of peculiarity, incompetence, frailty, and helplessness, and affects every aspect of public, private, and community life. A coordinated, broad-spectrum effort to improve Americans' perceptions of disability and aging is needed to reduce negative attitudes toward disability and aging.

Challenges:

The primary challenge of a positive messaging campaign on disability and aging is the need for it to reach every aspect of American society with cost-effective, focused messages targeted to various constituencies. The Federal government is situated to facilitate this task successfully in partnership with states, localities, and the private sector. A successful positive messaging campaign can create opportunities to develop communities in which everyone can live, work, and participate fully, consistent with individual choice and direction, free of labeling, stigma, or discrimination.

Recommendation:

Conduct a national positive messaging campaign to reduce the negative attitudes about disabilities and build to appreciation for individual choice and self-direction throughout the lifespan.

Strategies:

1. Develop comprehensive, cost-effective, and cross-government plans for targeting key audiences with messages that promote full participation of aging Americans including those with disabilities.
2. Assess how government programs use partnerships, grants, procurements, and other mechanisms in reinforcing consistent messages.
3. Institute a commission to examine relevant programs and recommend ways that they could improve access to information and decision-making support to strengthen the ability of disabled and older Americans to self-direct services and supports.



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Appendix: Disability Statistics Fact Sheet

Prepared for 2005 White House Conference on Aging
Mini Conference on Disability –
Disability & Aging: Seeking Solutions to Improve Health, Productivity and Community Living

July 21 & 22, 2005
Crystal City Marriott at Reagan National Airport
1999 Jefferson Davis Highway
Arlington, Virginia 22202

(References provided below)

Prevalence of Disability

The Census Bureau defines a person with a disability as someone who has difficulty in performing functional tasks or daily living activities or meets other criteria, such as a learning or developmental disability. People are considered to have a severe disability if they are completely unable to perform one or more of these tasks or activities, need personal assistance or have one of the severe conditions described in the report. The following statistics are from the panel of the Survey of Income and Program Participation (SIPP) that started in 1996 and are intended by the Census Bureau to broadly represent persons who fit the definition of the Americans with Disabilities Act. 1

- According to the US Census Bureau's 1997 Survey of Income and Program Participation (SIPP), which provides the latest data available using a broad measure of disability, there were 52.6 million persons with a disability living in the community (ages 5 and older). Additionally, about 2 million people live in nursing homes and other long-term care facilities. Thus, bringing the total prevalence to the oft-cited 54 million Americans with disabilities.
- In 1997, nearly 1 in 5 Americans said they had some level of disability, while 1 in 8 -- 33 million -- reported they had a severe disability, according to the U.S. Census Bureau.
- The likelihood of having a disability increased with age.
 - o For those 45 to 54 years old, 22.6 percent had some form of disability, 13.9 percent had a severe disability, and 3.6 percent needed personal assistance.
 - o For those 65 to 69 years old, the comparable estimates were 44.9 percent, 30.7 percent, and 8.1 percent.
 - o For the oldest age group, 80 years old and over, the estimates were 73.6 percent, 57.6 percent, and 34.9 percent.



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- Other highlights:
 - The poverty rate among the population 25-to-64 years old with no disability was 8 percent, compared with 10 percent for people with a nonsevere disability and 28 percent for people with a severe disability.
 - In 1997, 9.7 million people age 16 to 64 had a disability that prevented them from working and another 7.2 million were limited as to the kind or amount of work they could do.

Number of Americans Aging *with* Long-Term Disabilities

- For the first time in history, many individuals with significant disabilities, like their non-disabled counterparts before them, are surviving long enough to experience the rewards and challenges of "aging." 2, 3
- However, determining the size of this emerging segment of the disabled population has been difficult due to lack of appropriate survey questions that ask about age of onset and duration of primary disability. 4
- The only analyses available to date are from the 1990 U.S. Census and suggest that there may be as many as 25,000,000 Americans who are aging with various types of early-onset and long-term disabilities. 5

Prevalence of Secondary Conditions among People with Disabilities

- People living with long-term with disabilities are at increased risk for "secondary conditions," defined as preventable physical, mental, and social disorders resulting directly or indirectly from an initial disabling condition.⁶ The Centers for Disease Control and Prevention in their Healthy People 2010 Report targeted prevention of secondary conditions as a major component of health promotion for people with disabilities. 6
- In a recent article Kinne, Patrick and Lochner report on the first effort to collect (self-report) population data on population prevalence and impact of 16 common secondary conditions.⁸ Prior to this article, what has been known about the prevalence of secondary conditions stems primarily from clinical studies of patients and convenience samples. 7
- According to data from 2075 respondents to the disability supplement of the 2001 Washington State Risk Factor Surveillance Survey, 87 percent of respondents with disabilities reported at least one secondary condition compared to only 49 percent of respondents without disabilities. People with disabilities also reported more conditions than did those without limitations, with an average of 4.02 vs. 1.28 conditions per respondent ($p < .0001$). 8



- For the 8 most prevalent conditions (pain, weight problems, fatigue, difficulty getting into the community, falls and injuries, sleep problems, muscle spasms, bowel and bladder problems) having a disability was the strongest predictor of the presence of the condition compared to age, gender, education, income and health status. Age and health status contributed more to having anxiety, depression, social isolation, and asthma than did disability, but disability remained a significant factor. 8

Needs and Costs of Personal Assistance and Community-Based Services

The following statistics were compiled by the NIDRR-funded Rehabilitation Research and Training Center on Personal Assistance Services (RRTC on PAS) at the University of California, San Francisco based on tabulations of public use data from the Census Bureau's American Community Survey (ACS) for 2003, which contains information on over 1 million residents of randomly selected U.S. households

(http://www.pascenter.org/state_based_stats/state_statistics_2003.php?state=us).

- Over 13 million adults (6.2 million aged 65 and older) living in the home and community receive an average of 31 hours of week of personal assistance services with activities of daily living. 9
- Only 16 percent of total care is paid care. The economic value of informal personal care is estimated to be over \$200 billion per year (for all adults). 9
- About 1 million adults have unmet needs for help with two or more activities of daily living for about 17 hours per week. Those individuals with unmet needs for help are significantly more like to have adverse consequences including discomfort, weight loss, dehydration, falls, burns, and dissatisfaction with help received. 10
- The US spent an estimated \$151 billion on long term care in 2003. Of this total, 73 percent was spent on institutional care. 11
- Medicaid is the major payer of long term care in the US, paying for 40 of total long term care expenditures. 12
- In 2004, Medicaid spent \$89 billion on long-term care and of this, 64 percent is spent on institutional services and 36 percent on home and community based services. Of the total Medicaid spending, 32 percent was for long term care in 2004. 12
- Medicaid home and community based waivers, personal care, and home health care are the major sources for providing personal care to the aged and disabled. These programs provided care to over 2 million participants and spent over \$25 billion in expenditures in 2002. There is waiver interstate variation in the amount and types of services provided. The total number of people on waiting lists of HCBS is 206,427 in 2004. The aged and disabled represent 53% of those on waiting lists. 13
- Using the latest expenditures data, it would cost an estimated \$4 billion in new funds to provide Medicaid community based attendant services and support (MiCASSA) to individuals with unmet need in the US. 14



Disability & Aging MinConference

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Mini-Conference

*Preparing for the Boom:
The Access and Development of
Health and Financial Information
Across the Lifespan*

2005 Mini-White House Conference on Aging

Preparing for the Boom: The Access and Development of Health and Financial Information Across the Lifespan

September 27, 2005

The New York Athletic Club, New York, NY

POST EVENT SUMMARY REPORT

Title of Conference:

Preparing for the Boom: The Access and Development of Health and Financial Information Across the Lifespan

Number of Persons Attending:

115

Sponsoring Organizations:

ZivaContinuum, Financial Planning Association, American Bar Association-Senior Lawyers Division

Welcome Speaker:

Michael Berne, Chief Executive Officer, ZivaContinuum

Moderator:

Robert Blancato, President, Matz, Blancato & Associates

WHCoA Speaker:

The Honorable Dorcas R. Hardy, Chairman of WHCoA Policy Committee

Expert Panel Speakers:

Tracy Callahan, Chief Operating Officer, ZivaGuide
Topic: Emerging Issues: The Access of Healthcare Information

Ellen Eichelbaum, Corporate Gerontologist, The Speakeasy Group
Topic: Opportunity and Role of Corporate America

Monsignor Charles Fahey, Fordham University
Topic: Identifying and Meeting the Holistic Needs of the Aging

Dr. Rubin Cooper, F.A.A.P., F.A.C.C., Weill-Cornell Medical College
Topic: Utilization of Technology to Educate and Inform

Walter Burke, Esq., ABA, Senior Lawyers Division
Topic: The Informed Decision

Jerry Schwartz, CFP, Financial Planning Association
Topic: Changing Expectations and Emerging Trends

Robert Abrams, Chairman & President, ZivaContinuum
Topic: Innovative Technology to Improve the Quality of Life of Aging Americans:
The Role of the Public and Private Sector

Priority Issue:

Maximizing Access to Healthcare and Financial Information

Goal of the Conference:

To encourage associations and corporations, private and public, to engage in discussions to promote awareness to Americans and guide them through the healthcare and financial planning necessary during their lifespan.

Background:

America has entered an unprecedented information age. As Americans age, information is a vital component of planning across the lifespan. This is especially true with respect to assisting individuals and families to make informed choices and decisions about financial planning for their later years to accommodate changing circumstances and health care needs.

Barriers:

There continue to be gaps and barriers that inhibit all Americans from taking advantage of information which can assist them in healthcare and financial planning. These obstacles include the ongoing digital divide in our nation and the inability of individuals to navigate through the wealth of information that is available through multiple sources.

Expert Panel Discussion:

It was the consensus of the expert panel that Americans must be able to access the important and critical information they will need to make informed decisions. Additionally, the panel expressed a sense of urgency in getting this information to the forefront of each individual.

Attendee Participation/Comments:

The attendees agreed that corporations and associations, public and private, should take the lead in helping to educate and guide Americans through the maze of information to lead them to the right choices for themselves and their loved ones. Additionally, it was publicly noted that it will be necessary to translate all emerging issues into the native language of individuals with limited English language skills in order to provide them with equal access to the same information.

Proposed Solutions:

Encourage more public-private partnerships dedicated to improving access and utilization of all forms of information to assist individuals and families to plan throughout the lifespan in financial and health matters.

Encourage Congress to examine the extent of gaps and barriers that exist which serve to deny some Americans from having all necessary tools to assist in planning along the lifespan and propose appropriate legislative remedies.

Provide incentives for new innovative information development initiatives which achieve universal dissemination through centralized or one-stop information centers.

Initiate a national public service campaign with public-private support tied to the start of each school year to encourage Americans to review and update their plans for their future, especially financial and healthcare planning.



**Independent Agenda
Aging Events**

Independent Aging Agenda Events

Independent aging agenda events were designed to provide input to the Policy Committee of the 2005 White House Conference on Aging. These events were neither sponsored nor endorsed by the White House nor in any way represented the policies, positions, or opinions of the 2005 White House Conference on Aging or the Federal government, but helped the Policy Committee to identify issues of concern and interest to people across the country.

2004

- 9/29/04 – 10/01/04 **2004 National Adult Protective Services Association 15th Annual Conference**
Portland, MA
- 9/30/04 **Westchester County Department of Senior Programs and Services Pre-White House Conference Mini-Series Event**
Westchester, NY
- 10/12/04 **Senior Summit of South County**
San Clemente, CA
- 10/16/04 **WomanSage First Annual Conference**
Orange, CA
- 10/17/04 – 10/20/04 **Joint Conference of the Southeastern Association of Area Agencies on Aging and the North Carolina Conference on Aging**
Research Triangle Park, NC
- 10/20/04 **Westchester County Department of Senior Programs and Services SPEAK-UP (Student Participants Embrace Aging Issues of Key Concern)**
Tarrytown, NY
- 10/27/04 **Innovations in Civic Participation Forum cosponsored by AARP and the National Council on the Aging (with support from the Corporation for National and Community Service and the Administration on Aging)**
Washington, DC
- 11/05/04 **Maryland Department of Aging Governor's Conference on Vital Aging**
College Park, MD
- 11/9/04 **Navajo Area Agency on Aging Tuba City Senior Centers Forum**
Navajo Mountain, UT
- 11/10/04 **Partnerships for Aging Annual Conference**
Kansas City, MO
- 11/17/04 **Navajo Area Agency on Aging Crownpoint Senior Centers Forum**
Crownpoint, NM
- 11/18/04 **Georgia Aging and Development Disabilities**
Athens, GA

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11/18/04	Navajo Area Agency on Aging Fort Defiance Senior Centers Forum Tohatchi, NM
11/19/04	Connecticut Commission on Aging and Elderly Services Division WHCoA Kickoff Event Waterbury, CT
11/19/04	Navajo Area Agency on Aging Chinle Senior Centers Forum Chinle, AZ
11/30/04	Navajo Area Agency on Aging Shiprock Senior Centers Forum Teec Nos Pos, AZ
12/7/04	2004 Indiana Governor's Conference on Aging Indianapolis, IN
12/8/04	Illinois Governor's Conference on Aging Chicago, IL
12/8/04	The National Council on the Aging National Summit to Develop an Action Plan to Reduce Falls in Older Adults Washington, D.C.
12/15/04	Hawaii County Office of Aging Focus Group Session for Community Participants Hilo, HI
12/17/04	Agency on Elderly Affairs Focus Group for Advisory Committee Members Lihue, HI
12/21/04	Hawaii County on Aging Focus Group Pahala, HI
2005	
1/6/05	Georgia Division of Aging Services WHCoA Event Atlanta, GA
1/6/05	Task Force on Issues Affecting Women As They Age, Chicago Bar Association/Women's Bar Association of Illinois Chicago, IL
1/11/05	Elderly Affairs Division, City and County of Honolulu Focus Group for Community Participants Honolulu, HI
1/21/05	Maui County Office on Aging WHCoA Event Maui, HI
1/27/05	Council of Senior Centers and Services of NYC Conference 2005 New York, NY

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- 1/27/05 – 9/29/05 **North Central-Flint Hills Area Agency on Aging**
One event in each county covered by North Central-Flint Hills Area Agency on Aging
KS
- 2/2/05 – 2/3/05 **Maine Gerontological Society Conference**
South Portland, MA
- 2/3/05 **The Chicago Bar Association/Women’s Bar Association of Illinois**
Chicago, IL
- 2/3/05 **National Academy on An Aging Society Civic and Social Engagement Series Event**
Orlando, FL
- 2/8/05 **Bronx Regional Interagency Council on Aging Conference “Who Are You Calling Old? Serving the Baby Boomers in 2015”**
Bronx, NY
- 2/15/05 **National Academy on An Aging Society Civic and Social Engagement Series Event**
St. Louis, MO
- 2/24/05 – 2/25/05 **Alaska Commission on Aging “The Future of Aging in Alaska: Planning for the 2005 White House Conference on Aging”**
Juneau, AK
- 2/25/05 **National Academy on An Aging Society Civic and Social Engagement Series Event**
Phoenix, AZ
- 2/26/05 – 3/1/05 **Council on Social Work Education’s National Center for Gerontological Social Work Education Conference**
New York, NY
- 2/26/05 – 3/1/05 **National Silver Haired Congress Annual Legislative Session**
Alexandria, VA
- 2/28/05 **Suburban Area Agency on Aging “Make Medicare Work” Medicare Summit**
Chicago, IL
- 2/28/05 **National Academy on An Aging Society Civic and Social Engagement Series Event**
Boston, MA
- 2/28/05 **Westchester County Department of Senior Programs and Services Pre-WHCoA Event “Shaping National Aging Policy: The Issues Take Stage”**
White Plains, NY
- 2/28/05 – 3/2/05 **Centers for Medicare and Medicaid Services Conference “New Freedom Initiative: Building Sustainable Systems for Independence”**
Baltimore, MD

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- 3/2/05 **Westchester County Department of Senior Programs and Services
Pre-WHCoA Mini-Series Event (How Elder Abuse Affects Women as
Caregivers and Victims)**
New Rochelle, NY
- 3/3/05 **Geriatric Mental Health Foundation Conference cosponsored by the Older Adult
San Diego, CA**
- 3/3/05 **Upper Savannah Council of Governments/Area Agency on Aging
Pre-WHCoA event**
Greenwood, SC
- 3/3/05 **Task Force on Issues Affecting Women as They Age of the Chicago Bar
Association/Women's Bar Association of Illinois**
Chicago, IL
- 3/3/05 – 3/4/05 **Program on Aging and Health Promotion School of Rural Public Health Texas
A&M University Health Science Center**
Washington, DC
- 3/7/05 **California Commission on Aging/California Department of Transportation**
Sacramento, CA
- 3/8/05 **California Commission on Aging**
Sacramento, CA
- 3/9/05 **Consortium of New York Geriatric Education Centers Conference On “Elder
Mistreatment: What Every Health Care Professional Should Know”**
New York, NY
- 3/9/05 **California Commission on Aging WHCoA Solutions Forum**
Sacramento, CA
- 3/10/05 **2005 What's Next? Boomer Business Summit**
Philadelphia, PA
- 3/10/05 **Buckeye Hills Area Agency on Aging Town Hall Meeting**
McConnelsville, OH
- 3/10/05 **“The Changing Face of Mobility: Getting Around Elder-Friendly
Communities”**
Philadelphia, PA
- 3/12/05 **National Committee for the Prevention of Elder Abuse
Abuse Mini-Conference**
Philadelphia, PA
- 3/12/05 **American Foundation for the Blind Event**
Boston, MA
- 3/14/05 **Missouri's 2nd Show Me Summit on Aging and Health “Challenges of Aging”**
Branson, MO

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- 3/14/05 **Central Midlands Area Agency on Aging Conference on Aging**
Columbia, SC
- 3/14/05 **Trident Area Agency on Aging, ElderLink, Inc. Event**
Charleston, SC
- 3/15/05 **Arizona Aging and Adult Administration Public Hearing On “Elder Rights and Protection”**
Phoenix, AZ
- 3/17/05 **Catawaba Area Agency on Aging**
Rock Hill, SC
- 3/17/05 **Massachusetts Executive Office of Elder Affairs And Massachusetts Meals on Wheels Association Nutrition Event**
Boston, MA
- 3/18/05 **East Central Illinois Area Agency on Aging**
Decatur, IL
- 3/18/05 **The Center for Community Solutions Pre-WHCoA Event**
Cleveland, OH
- 3/18/05 – 03/19/05 **Shenandoah University in Collaboration with the Loudon County Area Agency On Aging Symposium on Aging “Independence: Strategies for Maintaining Control.”**
Dulles, VA
- 3/21/05 **Midland Area Agency on Aging, Inc/Kaskaskia Community College**
- 3/21/05 **Lowcountry Council of Governments, Area Agency on Aging Forum with Lt. Governor’s Office**
Bluffton, SC
- 3/22/05 **Lower Savannah Area Agency on Aging and Orangeburg County Council on Aging Forum**
Orangeburg, SC
- 3/22/05 **Vantage Point Community Forum**
Florence, SC
- 3/23/05 **Lower Savannah Area Agency on Aging and the H. Odell Weeks Activity Center Aging Forum**
Aiken, SC
- 3/23/05 – 3/25/05 **20th Annual Oklahoma Minority Aging Conference**
Tulsa, OK
- 3/29/05 **Westchester County Department of Senior Programs and Services Pre-WHCoA Mini-Series Event (Housing Options Caucus)**
Moriches, NY

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- 3/29/05 **Westchester County Department of Senior Programs and Services Housing Options and Services Outstation to Seniors Caucuses “There’s No Place Like Home”**
Pleasantville, NY
- 3/29/05 **Nassau County Department of Senior Citizen Affairs
“We Are Super-Sized: Big and Getting Bigger”**
Albertson, NY
- 3/30/05 **Mississippi Department of Human Services Division of Aging and Adult Services
Annual Mississippi Association of Planning Development Districts Conference**
Biloxi, MS
- 3/31/05 **Vermilion County States Attorneys Office and the Community Research
Resource Information and Services for Seniors (CRIS) pre-WHCoA event**
Danville, IL
- 3/31/05 **Minnesota River Area Agency on Aging Regional Forum**
Willmar, MN
- 4/01/05 **Puerto Rico Office of the Ombudsman for the Elderly Island-Wide
Pre-WHCoA event**
Cayey, PR
- 4/01/05 **Texas White House Conference on Aging Capitol Symposium**
Austin, TX
- 4/03/05 **East Central Illinois Area Agency on Aging Forum on Nutrition,
Wellness and Aging**
Charleston and Vincennes, IL
- 4/4/05 **DOROT, City Meals-on-Wheels of the New York City Department for the Aging
Symposium “Let’s Put Friendly Visiting on the Map”**
New York, NY
- 4/4/05 **Minnesota River Area Agency on Aging Regional Forum**
Mankato, MN
- 4/6/05 **Minnesota River Area Agency on Aging Regional Forum**
Montevideo, MN
- 4/7/05 **National Hospice and Palliative Care Organization Policy Forum**
Washington, D.C.
- 4/7/05 **New England Regional Elder Nutrition Programs Conference**
Portsmouth, NH
- 4/7/05 **Task Force on Issues Affecting Women as They Age of the Chicago Bar
Association/Women’s Bar Association of Illinois**
Chicago, IL
- 4/7/05 **Minnesota River Area Agency on Aging Regional Forum**
Marshall, MN

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- 4/7/05 – 4/8/05 **American Association for Active Lifestyles and Fitness Workshop “Travel on the Healthy Living Highway”**
West Lafayette, IN
- 4/8/05 **Friendship Retirement Community Resident’s Center**
Roanoke, VA
- 4/8/05 – 4/9/05 **South Dakota Division of Adult Services and Aging Annual Caregiver Conference**
Pierre, SD
- 4/9/05 **Sarasota County Openly Plans for Excellence (SCOPE) Event “Aging: The Possibilities”**
Sarasota, FL
- 4/9/05 **Northwest Aging Association Senior Lifestyle Expo and Listening Session**
Spencer, IA
- 4/11/05 **Arkansas Healthy Aging Coalition Public Forum “What Policies Do We Need to Be Able to Stay in Our Own Homes As We Age?”**
Little Rock, AR
- 4/11/05 **Gerontology Institute, University of Massachusetts Boston “Questions and Answers on Social Security Reform: What the Public Wants to Know”**
Boston, MA
- 4/14/05 **Buckeye Hills Area Agency on Aging Town Hall Meeting**
Middleport, OH
- 4/14/05 **DOT, AARP and MIT AGELAB event on Safe Mobility of Older Persons and Transportation**
Boston, MA
- 4/14/05 **North Carolina Association on Aging Forum for Local Providers**
Wrightsville Beach, NC
- 4/15/05 **Wurzweiler School of Social Work, Yeshiva University**
New York, NY
- 4/15/05 **Osterhout & McKinney 4th Annual Conference on Aging**
Fort Myers, FL
- 4/18/05 **BWICA Educational Fund, Inc. Independent Aging Agenda Event**
Brooklyn, NY
- 4/18/05 **Wisconsin Governor’s Conference**
Oshkosh, WI
- 4/20/05 **City of St. Petersburg (Elder Care Advocacy of Florida)**
St. Petersburg, FL
- 4/20/05 **Upper Coastal Plain Area Agency on Aging Regional Event**
Rocky Mount, NC

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- 4/20/05 **National Hospice and Palliative Care Organization**
“Caring Connections Seminar”
Atlanta, GA
- 4/20/05 **New York City Chapter – Alzheimer’s Association Annual Early Stage**
Alzheimer’s Conference “Sharing the Journey: Forging Relationships that
Ease the Way”
New York, NY
- 4/21/05 **Brooklyn-wide Educational Fund, Inc. Forum for Brooklyn Senior Citizens**
Brooklyn, NY
- 4/21/05 **Georgia Division of Aging Services Event**
Augusta, GA
- 4/21/05 **Illinois Coalition on Mental Health and Aging 5th Annual Mental Health and**
Aging Conference
Schaumburg, IL
- 4/21/05 **Michigan Public Forum on Economics of Aging**
Grand Rapids, MI
- 4/21/05 – 4/22/05 **Alaska Commission on Aging Public Forum**
Anchorage, AK
- 4/22/05 **United Neighborhood Houses of New York “Aging In the Shadows: A Public**
Forum on Senior Isolation in New York City”
New York, NY
- 4/25/05 **Minnesota Board on Aging Symposium “Challenges to Health and Long**
Term Care”
St. Paul, MN
- 4/25/05 – 4/27/05 **South Carolina White House Conference on Aging**
Myrtle Beach, SC
- 4/26/05 **Michigan Public Forum on Communities**
Troy, MI
- 4/27/05 **Jamaica Service Program for Older Adults, Inc.**
Jamaica, NY
- 4/27/05 **Queens Interagency Council on Aging, Inc. and Queensboro Council**
for Social Welfare Conference on “Our Community: Providing for the Seniors
of the Future”
Queens, NY
- 4/27/05 **Inter Tribal Council of Arizona, Inc. 17th Annual Arizona Indian Council on**
Aging Conference
Tucson, AZ
- 4/27/05 **Good Samaritan Hospital Senior Appreciation Education and Health Fair**
West Islip, NY

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- 4/27/05 **Michigan Public Forum on Health and Aging**
Detroit, MI
- 4/28/05 **Alabama Department of Senior Services Event**
Montgomery, AL
- 4/28/05 **Nassau County Department of Senior Citizens “Are the Cape and Tights a Little Too Tight?” Caregiver Event**
Albertson, NY
- 4/29/05 **Towson University Gerontology Program’s Community Forum**
Towson, MD
- 4/29/05 **Wisconsin Association of Aging Unit Directors Event**
Stevens Point, WI
- 4/29/05 **National Citizens Coalition for Nursing Home Reform Event “Giving Voice to Quality: A Consumer Dialogue on Facility-Based Long-Term Care.”**
Washington, DC
- 4/29/05 **Connecticut Coalition on Aging, Inc. Long Term Care Event**
Meriden, CT
- 5/2/05 **Cleveland State University Annual Anna V. Brown Community Forum**
Cleveland, OH
- 5/3/05 **2005 Kansas Mental Health and Aging Summit, “Visions for Kansas: Adults at the Crossroads.”**
Topeka, KS
- 5/3/05 **City of Temple Terrace/O.K. Lightfoot Center pre-WHCoA event**
Temple Terrace, FL
- 5/4/05 **Oklahoma Conference on Aging Senior Day**
Midwest City, OK
- 5/4/05 **Michigan Public Forum on Communities**
Saginaw, MI
- 5/4/05 **Washington Alliance for Healthy Aging/Washington State Department of Health 3rd Annual Healthy Aging Summit**
Tukwila, WA
- 5/5/05 **Massachusetts Intergenerational Network Event on Intergenerational Volunteerism**
Boston, MA
- 5/6/05 **Boston Partnership for Older Adults “What Does It Take to Keep an Elder At Home”**
Roxbury Crossing, MA
- 5/6/05 **Minnesota Board on Aging Hearing on Social Security Reform**
St. Paul, MN

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5/6/05	Brooklyn-Wide Educational Fund, Inc Brooklyn, NY
5/6/05	Older Ohioans Nutrition Network Event on Senior Nutrition Columbus, OH
5/6/05	BWICA Educational Fund, Inc. Independent Aging Agenda Event Brooklyn, NY
5/9/05	City of Alexandria Office of Aging and Adult Services and the Virginia Commission on Aging Awards for 2005 Event on Successful Aging in Retirement Alexandria, VA
5/9/05 – 5/11/05	District Four Health Services “Aligning Faith and Health: Strength Through Collaboration” Barnesville, GA
5/9/05	National Indian Council on Aging New Mexico Indian Tribes Event Albuquerque, NM
5/9/05	Area Agency on Aging of Southwestern Illinois and Southern Illinois University Solutions Event Edwardsville, IL
5/10/05	Michigan Public Forum on Caregiving St. Ignace, MI
5/10/05	Chicago Department on the Aging Annual City Wide Senior Conference Chicago, IL
5/10/05	North Central Flint Hills Area Agency on Aging Event Junction City, KS
5/11/05	National Hispanic Council on Aging Latino Elderly Policy Symposium Washington, D.C.
5/11/05	Riverside County Office on Aging Health and Wellness Conference Riverside, CA
5/11/05 – 5/12/05	31st Annual Governor’s Conference on Aging Tamuning, GU
5/11/05 – 5/13/05	West Virginia Bureau of Senior Services Annual Senior Conference Jackson’s Mill, WV
5/11/05	North Central Flint Hills Area Agency on Aging Event Salina, KS
5/12/05	Buckeye Hills Area Agency on Aging Town Hall Meeting Caldwell, OH
5/12/05	Georgia Department of Human Resources Dialogue on Health Care and Spiritual Influence Lake Lanier, GA

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- 5/12/05 **Coalition of Wisconsin Aging Groups Event during their 28th Annual Convention**
Madison, WI
- 5/12/05 **Nebraska State Unit on Aging Regional Event**
Norfolk, NE
- 5/12/05 **Knoxville-Knox County Community Action Committee Office on Aging Event**
Knoxville, TN
- 5/12/05 **Marin County Commission on Aging Healthy Aging Symposium**
San Rafael, CA
- 5/12/05 **Pennsylvania Department of Aging “Creativity and Aging” Event**
Philadelphia, PA
- 5/13/05 **Nassau County Department of Senior Citizen Affairs Older Americans Month Celebration**
Uniondale, NY
- 5/14/05 **Prince George’s Chapter of Delta Sigma Theta Sorority Community Forum on Social Security**
Largo, MD
- 5/16/05 – 5/17/05 **Iowa Governor’s Conference on Aging**
Des Moines, IA
- 5/17/05 **Area Office on Aging of Northwestern Ohio, Inc. Regional Forum**
Maumee, OH
- 5/17/05 **Nebraska State Unit on Aging Regional Event**
Ogallala, NE
- 5/18/05 **Wyoming Governor’s Summit on Aging**
Cheyenne, WY
- 5/18/05 **North Carolina Governor’s Advisory Council on Aging Forum**
Raleigh, NC
- 5/18/05 **University Area Development Center**
Tampa, FL
- 5/19/05 **Alameda County Public Health Department**
Alameda County, CA
- 5/19/05 **The Jewish Home and Hospital Lifecare System Pre-WHCoA Event “Ethics and Aging in Long Term Care”**
Westchester, NY
- 5/19/05 **Lifestream Services, Ball State University and the Indiana Bureau of Aging and In-Home Services Conference “Celebrate Active Aging”**
Muncie, IN

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- 5/19/05 **Hawkeye Valley Area Agency on Aging, in partnership with the Iowa Consortium For Applied Gerontology at the U. of Northern Iowa “Aging Workforce and Caregivers” Conference**
Cedar Falls, IA
- 5/19/05 **Southwest Region/Pennsylvania Council on Aging Public Forum**
Latrobe, PA
- 5/19/05 – 5/22/05 **National Space Society International Space Development Conference**
Washington, DC
- 5/19/05 **Montana Governor’s Conference on Aging**
Helena, MT
- 5/20/05 **Westchester County Department of Senior Programs and Services Employment and Financial Security Caucus**
Valhalla, NY
- 5/20/05 **North Central Flint Hills Area Agency on Aging Event**
Manhattan, KS
- 5/20/05 **Puerto Rican/Hispanic Elderly, Inc. Minority Aging Defense Conference on Aging**
New York, NY
- 5/21/05 **Rhode Island Listening Session for Seniors and Rising Seniors**
Portsmouth, RI
- 5/23/05 – 5/24/05 **National Conference on Transportation for America’s Elders Sponsored by the Community Transportation Association of America, Inc.**
St. Louis, MO
- 5/23/05 – 5/25/05 **Senior Connections — The Capital Area Agency on Aging, Richmond Area Metropolitan Planning Organization, and United Way of Greater Richmond and Petersburg meetings on Public Transportation**
Richmond, VA
- 5/24/05 **Montgomery County Office of Aging and Adult Services Boomer* ANG Project’s Visioning Conference**
Blue Bell, PA
- 5/24/05 – 5/25/05 **Center on Ethnic and Minority Aging, Inc. Conference “Consumer Choice... Consumer Voice”**
Philadelphia, PA
- 5/24/05 **Task Force on Issues Affecting Women as They Age of the Chicago Bar Association/Women’s Bar Association of Illinois Fourth Part of Educational Series for Women**
Chicago, IL
- 5/24/05 **Nebraska State Unit on Aging Regional Event**
Lincoln, NE

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- 5/24/05 **North Central Flint Hills Area Agency on Aging Event**
Emporia, KS
- 5/24/05 **Round Table Discussion on Latino Senior Issues**
Chicago, IL
- 5/25/05 **Northeastern Illinois Area Agency on Aging Event**
Joliet, IL
- 5/25/05 **Salt Lake County Aging Services Symposium**
Salt Lake City, UT
- 5/25/05 **Morgan State University, Gerontology Program Department of Social Work
4th Annual Conference**
Baltimore, MD
- 5/25/05 **Southeastern Minnesota Area Agency on Aging Event**
Rochester, MN
- 5/25/05 – 5/26/05 **Resources for Senior Living in partnership with the Alzheimer’s Association
Western Carolina Chapter, the Charlotte-Mecklenburg Council on Aging, and
the Mecklenburg Status of Seniors Initiative**
Charlotte, NC
- 5/25/05 – 5/26/05 **Bucks County Summit on Aging**
Newtown, PA
- 5/25/05 – 5/26/05 **New York City Department for the Aging Conference on Health, Mental health
and Aging**
New York, NY
- 5/24/05 – 5/27/05 **West Virginia University Center on Aging Mountain State Geriatric
Education Center**
Morgantown, WV
- 5/25/05 **Fountain Club’s Third Annual Well-Being Symposium**
Alexandria, VA
- 2/25/05 **2005 Delaware Governor’s Conference on Aging**
Dover, DE
- 5/26/05 **New Hampshire Speaks (part of NH State Conference on Aging) Forum**
Manchester, NH
- 5/26/05 **Land of Sky Regional Council Area Agency on Aging Senior Friendly
Communities Event**
Asheville, NC
- 5/26/05 **Cleveland Public Library Forum on Library Services to Older Adults**
Cleveland, OH
- 5/27/05 **Social Security: Now and for the Future**
Aurora, IL

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- 5/28/05 **“North Carolina Speaks to the 05 White House Conference on Aging”**
Raleigh, NC
- 6/1/05 – 6/2/05 **Central Illinois Agency on Aging, Inc. Peoria Summit “Aging in Place,
An Ideal Community”**
Peoria, IL
- 6/2/05 **Pennsylvania Department of Aging Cultural Diversity Advisory
Committee Meeting**
Harrisburg, PA
- 6/2/05 **Center for Health and Aging, University of La Verne Symposium**
La Verne, CA
- 6/2/05 **Lower Rio Grande Valley Area Agency on Aging, South Texas Area Agency on
Aging And Middle Rio Grande Area Agency on Aging Event**
McAllen, TX
- 6/2/05 **Central Minnesota Council on Aging Event**
St. Cloud, MN
- 6/3/05 **Great Lakes Native Americans Elder Association Event**
Oneida, WI
- 6/3/05 **VA Maryland Health Care System, Perry Point Division, MD**
Washington, DC
- 6/4/05 **Bridge Builders Senior and Disability Services Conference**
Kansas City, MO
- 6/5/05 **Somerbrook, The Martin and Edith Stein Assisted Living Residence Event**
Somerset, NJ
- 6/6/05 **Massachusetts Executive Office of Elder Affairs Conference “The Aging of
Massachusetts: Inherent Challenges and Opportunities”**
Boston, MA
- 6/6/05 **Cuyahoga County Department of Senior and Adult Services Event “Aging
Affects Everyone: Tell Your Story”**
Cleveland, OH
- 6/7/05 **Bexar Area Agency on Aging Issues Forum**
San Antonio, TX
- 6/8/05 **U.S. Department of Veterans Affairs Office of Geriatrics and Extended
Care Session**
Boston, MA
- 6/8/05 **Colonie Senior Network Meeting/Forum**
Colonie, NY
- 6/9/05 **Bronx VAMC Geriatric Research, Education and Clinical Center “5th Annual
Emerging Issues in Aging: Improving Quality of Life”**
Bronx, NY

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- 6/10/05 **Citizens for Elderly Services Combined Regional Event (Lifetime Resources, IN; N. KY Area Development District and COA of SW Ohio)**
Erlanger, KY
- 6/10/05 **Southwestern Pennsylvania Partnership for Aging Joint Meeting with the National Senior Games Local Organizing Committee**
Pittsburgh, PA
- 6/10/05 **Area Agency on Aging District 7 Ohio “Health Care and Retirement in Southern Ohio: What Does the Future Hold”**
Sardinia, OH
- 6/10/05 **New York State Office on Aging/NYS AAA Association Regional Event**
Canandaigua, NY
- 6/11/05 **Westchester County Department of Senior Programs and Services “Tearing Down Health and Health Care Disparities by Building Alliances”**
Mount Vernon, NY
- 6/12/05 **Town of Clifton Park, New York Town Hall Meeting**
Clifton Park, NY
- 6/14/05 **Orleans and Genesee County Office for Aging Roundtable for Senior Citizens and Baby Boomers**
Batavia, NY
- 6/14/05 **Purchase Area Development District Area Agency on Aging**
Paducah, KY
- 6/15/05 **Area Agency on Aging 10B, District XI Area Agency on Aging And the Western Reserve Area Agency on Aging “Aging in America: Personal Responsibility and the Role of Government”**
Akron, OH
- 6/15/05 **Baltimore City Commission on Aging and Retirement Education Public Hearing**
Baltimore, MD
- 6/15/05 **New Jersey Foundation for Aging Event**
Jamesburg, NJ
- 6/16/05 **West Central Florida Area Agency on Aging “Our Community: Invest in Aging Now and in the Future”**
Tampa, FL
- 6/16/05 **Self-Help Community Services/New School University IRP “Successful Aging: Mind/Body” Event**
New York, NY
- 6/16/05 **Baltimore County Department of Aging Event**
Towson, MD

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- 6/16/05 **Buckeye Hills Area Agency on Aging Town Hall Meeting**
Nelsonville, OH
- 6/17/05 **New Hampshire's Coalition on Substance Abuse/Mental Health and Aging Conference**
Plymouth, NH
- 6/17/05 **New York City Department for the Aging Resolutions Summit**
New York, NY
- 6/17/05 **Area Agency on Aging District 7 Ohio "Health Care and Retirement in Southern Ohio: What Does the Future Hold"**
Ironton, OH
- 6/17/05 **National Respite Coalition — Lifespan Respite Summit**
Washington, DC
- 6/18/05 **Marymount University Physical Therapy Department: "A Physical Therapy and Health Care Management Event: Preventing Frailty"**
Arlington, VA
- 6/20/05 **West Central Florida Area Agency on Aging "Our Community: Invest in Aging Now and In the Future"**
Wauchula, FL
- 6/21/05 **Laurel Gardens of Woodbridge in partnership with the Institute For Learning in Retirement and the Adult Education Department of Amity Regional High School Event**
Woodbridge, CT
- 6/21/05 **New York State Office on Aging/NYS AAA Association Regional Event**
Poughkeepsie, NY
- 6/22/05 **Ohio District 5 Area Agency on Aging Event**
Mansfield, OH
- 6/22/05 **Middlesex County Department on Aging/New Jersey Foundation on Aging event "Planning Along the Lifespan"**
Middlesex, NJ
- 6/22/05 **South Dakota Division of Adult Services and Aging 05 Public Health Conference**
Pierre, SD
- 6/22/05 **Volunteers of America "Coordinating Housing and Health Care: Considerations for the Baby Boom Generation"**
Washington, DC
- 6/22/05 **The Center for American Nurses Workplace of the Future Conference**
Washington, DC
- 6/23/05 **Nebraska Statewide Aging Event**
Kearney, NE

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- 6/23/05 **Area Agency on Aging, PSA 2 (Ohio) “Senior Centers Prepare for Aging Baby Boomers: Challenges and Solutions”**
Vandalia, OH
- 6/23/05 **Indiana Mental Health and Aging Coalition 2nd Annual State Conference**
Indianapolis, IN
- 6/23/05 **Laurel Gardens of Trumbull in Partnership with Elderhostel Institute Network and the Lifetime Learners Institute at Norwalk Community College Event**
Trumbull, CT
- 6/24/05 **American Library Association Forum “Libraries, Lifelong Learning, Information and Older Adults”**
Chicago, IL
- 6/24/05 **Jefferson Area Board for Aging Event “The Rubik’s Cube of Long Term Care: Putting the Puzzle Together”**
Charlottesville, VA
- 6/24/05 **Kentucky Association for Gerontology/KY AARP/KY Association For Area Agencies on Aging Forums**
Louisville, KY
- 6/24/05 **Washington State Council of Senior Citizens Event**
Cheney, WA
- 6/24/05 **New York City Department for the Aging’s Alzheimer’s and Caregiving Center Event**
New York, NY
- 6/24/05 **Area Agency on Aging District 7 Ohio “Health Care and Retirement in Southern Ohio: What Does the Future Hold”**
Piketon, OH
- 6/24/05 **American Family Therapy Academy Event “Later Life Families: Preparing for the Elder Boom”**
Washington, DC
- 6/28/05 **“Quality at End-of-Life Summit” Hosted by PA Dept. Hosted by the PA Department of Aging**
Harrisburg, PA
- 6/28/05 **University of Kentucky Sanders-Brown Center on Aging 22nd Annual Summer Series on Aging**
Lexington, KY
- 6/28/05 **Nassau County Dept of Senior Citizen Affairs “You and Your Home: A Collaborative Transition”**
Albertson, NY
- 6/28/05 **New York State Office on Aging/NYS AAA Association Regional Event**
Binghamton, NY

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- 6/29/05 **West Central Florida Area Agency on Aging “Our Community: Invest in Aging Now and In the Future”**
Bradenton, FL
- 6/29/05 **Kentucky River Area Development District Open Forum Session**
Hazard, KY
- 6/30/05 **The North Central Area Agency on Aging Event Entitled “Imagine, Identify and Implement: Planning for the Long Term Care of our Elders and the Support of their Caregivers”**
Hartford, CT
- 6/30/05 **University of the Sciences in Philadelphia Health Policy Institute Event**
Philadelphia, PA
- 7/6/05 **Illinois Department on Aging Event**
Springfield, IL
- 7/7/05 **New York State Office on Aging/NYS AAA Association Regional Event**
Suffolk County, NY
- 7/7/05 **Central Ohio Area Agency on Aging, “Caregiving Into the Future”**
Columbus, OH
- 7/13/05 **New York State Office on Aging/NYS AAA Association Regional Event**
Troy, NY
- 7/14/05 **Georgia Division of Aging Services Event**
Atlanta, GA
- 7/14/05 **Buckeye Hills Area Agency on Aging Town Hall Meeting**
Marietta, OH
- 7/15/05 **Continuum of Care Consultants Event**
Vienna, VA
- 7/15/05 – 9/15/05 **SeniorNet Online Forum**
- 7/17/05 – 7/28/05 **“Young At Art” Juried Art Show for Artists 55 and Over**
Alexandria, VA
- 7/19/05 **Americans for Better Care of the Dying Revitalized National Mortality Followback Survey**
Washington, DC
- 7/19/05 **Chicago Task Force on LGBT Aging Event**
Chicago, IL
- 7/20/05 **Land of the Dancing Sky AAA Event**
Fargo, ND
- 7/22/05 **CLESE Forum on the Contributions and Concerns of Limited English Speaking Elderly**
Chicago, IL

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- 7/25/05 **Area Agency on Aging, Region 9 Event**
Byesville, OH
- 7/26/05 **Disabled American Veterans Event**
Developed from: Veterans in our Communities
Washington, DC
- 7/26/05 **New York State Office on Aging/NYS AAA Association Regional Event**
Plattsburgh, NY
- 7/28/05 **“Washington County Longevity Forum: The Aging Dilemma in a Rapidly Changing Environment”**
Hagerstown, MD
- 8/01/05 **Senior Forum of Santa Clara County, Department of Aging and Adult Services, Financial Abuse Specialist Team**
San Jose, CA
- 8/4/05 **Metropolitan AME Church Event**
Washington, DC
- 8/12/05 **Maryland Department on Aging Event**
Annapolis, MD
- 8/12/05 **Annual Mississippi Department of Mental Health, Division of Alzheimer’s and Other Dementia Conference**
Philadelphia, MS
- 8/16/05 **The Village at Kensington Place in partnership with Rushford Center, Inc. Event**
Meriden, CT
- 8/17/05 **Lake County Council on Aging and Lake County Senior Advisory Council Event**
Kirtland, OH
- 8/18/05 **Laurel Gardens of Milford Event**
Milford, CT
- 8/19/05 **Psychology and Public Policy Event Sponsored by the American Psychological Association**
Washington, DC
- 8/22/05 **The Village at Mariner’s Point in partnership with Visiting Nurse Association Services and the Strong House Event**
East Haven, CT
- 8/24/05 **The Village at Brookfield Common Event**
Brookfield, CT
- 8/24/05 **“On the Road to the 05 WHCoA: Conversations with America” Session at 2005 Florida Conference on Aging**
Orlando, FL
- 8/24/05 **District 1 Council on Aging State of Louisiana Event**
Harahan, LA

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- 8/25/05 – 8/26/05 **Alzheimer’s Association of Greater Cincinnati 17th Summer Symposium
“Palliative Care, from Beginning to End”**
Erlanger, KY
- 9/01/05 **Meals on Wheels Association of America Forum**
Richmond, VA
- 9/01/05 **Health and Social Services Consortium, Inc. HESSCO Elder Services Event**
Sharon, MA
- 9/7/05 **Caddo Council on Aging Event**
Shreveport, LA
- 9/8/05 **Cooperative Development Foundation Event**
Washington, DC
- 9/8/05 **The Jewish Home and Hospital Lifecare System Fourth International
Palliative Care Conference**
New York, NY
- 9/9/05 **Caddo Area Agency on Aging Event**
Shreveport, LA
- 9/9/05 **Governor’s Office of Elderly Affairs & Southern University Law Center Event**
Baton Rouge, LA
- 9/9/05 **Fair Park Senior Center Event**
Crossville, TN
- 9/9/05 – 9/11/05 **“Where will all the Boomers go? Baby Boomer Weekend” — Burnham Brook Event**
Battle Creek, MI
- 9/13/05 – 9/17/05 **Generations United 13th Biennial International Conference**
Washington, D.C.
- 9/16/05 **Greater Southern Brooklyn Health Coalition Event**
Brooklyn, NY
- 9/16/05 **University of Texas School of Nursing Center on Aging at Houston And Harris
County Area Agency on Aging Conference**
Houston, TX
- 9/17/05 – 9/19/05 **International Conference on Family Violence**
San Diego, CA
- 9/18/05 **RockinR’s Community Social Dance for Baby Boomers/Seniors**
Boise, ID
- 9/18/05 **Gay and Lesbian Community Services Center of Orange County Event**
Garden Grove, CA
- 9/21/05 **Area Agencies on Aging, State Bar of Texas and the Texas Chapter of the
National Academy of Elder Law Attorneys event**
San Antonio, TX

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- 9/21/05 **Maine Bureau of Elder and Adult Services Forum on Healthy Aging**
Augusta, ME
- 9/23/05 **The New York Academy of Medicine, Section on Social Work Event**
New York, NY
- 9/23/05 **Westchester County Conference on Aging – “The Future of Aging Is Now: Lead, Empower and Advocate for Effective Policies (LEAP)”**
Rye, NY
- 9/23-24/05 **Senior Wellness Alliance “Baby Boomers and Beyond...A Conference on Active Aging”**
Austin, TX
- 9/26/05 **Milwaukee County Department on Aging/Milwaukee Commission on Aging Conference “The Plight of Older Adult Refugees and Immigrants”**
Milwaukee, WI
- 9/27/05 **International Council on Active Aging Event**
Washington, DC
- 9/27/05 **Illuminating Engineering Society of North America Event**
Washington, DC
- 9/28/05 **Services and Advocacy for Gay/Lesbian/Bisexual/Transgender Event**
New York, NY
- 9/29/05 **“Summit on the Aging Workforce”**
Waterbury, CT
- 9/30/05 **National Hispanic Council on Aging Roundtable on the Latino Elderly Population**
Washington, DC
- 9/30/05 **Bay Area Coalition for LGBT Elder Advocacy Event**
San Francisco, CA
- 10/7/05 **NY State Office of Children and Family Services Event**
Saratoga Springs, NY
- 10/13/05 – 10/15/05 **University of Illinois at Urbana-Champaign “Walking for Health Conference”**
Urbana, IL
- 10/19/05 – 10/23/05 **State Society on Aging of New York 33rd Annual Meeting “Aging Today and Tomorrow: The Community of New York State”**
Verona, NY
- 10/20/05 **AARP Global Aging Program International Forum on Long Term Care: Delivering Quality Care With a Global Workforce**
Washington, DC
- 10/20-21/05 **ITNAmerica Event**
Freeport, ME