

Testimony of

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before the

Special Committee on Aging

United States Senate

May 20, 2003

Thank you very much, Chairman Craig, Senator Breaux, and Members of the Committee for inviting me to testify at this important hearing on innovative services and technologies that can help empower our growing numbers of older Americans. It is especially appropriate during Older Americans Month, 2003 for which our theme is "What We Do Makes a Difference."

Both globally and here in the United States we are witnessing one of society's greatest achievements – an extension of human longevity more dramatic than the preceding 4,500 years. Advancements in medicine, public health, and technology make it increasingly commonplace for people to live 80, 90, 100 or more years. With the first of the baby boom generation reaching age 60 in less than three years, we must update and re-energize old programs and comprehensively develop new ones that can better empower and serve older Americans in their communities and in settings that work best for them. For example, the types of senior centers that were familiar to our parents and grandparents twenty years ago will transform to community and family centers of the future, with more of an appeal across the generations.

I am also pleased to announce that today, the Departments of Labor (DOL) and Health and Human Services (HHS) have transmitted a Report to Congress that examines the future supply of long-term care workers in relation to the aging baby boom generation. Ensuring the adequacy and availability of direct care workers is a critical goal of the Administration, and we have been taking steps to prepare for the increased

demand for direct care workers. HHS has estimated that the demand for direct care workers in long-term care settings will grow from approximately 1.9 million workers in 2000 to somewhere between 5.7 and 6.6 million workers in 2050. This increase, over 200 percent, in demand will be occurring at a time when the supply of workers who have traditionally filled these jobs is expected to increase only slightly. Our report, which I have brought copies of for Members of the Committee, makes recommendations on how to retain existing long-term care workers and attract new pools of workers. It urges continued support of many of the Bush Administration's existing efforts to address the growing demand for long-term care workers. These include:

- Supporting State and local initiatives that increase the recruitment and retention of direct care workers – such as the DOL's Workforce Investment System, Registered Apprenticeship Programs, and HHS' Real Choice System Change Grants, and the National Initiative for Direct Care Workers in Long-Term Care Settings;
- Continuing to support the training and education of long-term care workers through programs such as the One-Stop Career Centers system established under the Workforce Investment Act (WIA), programs for youth and adults funded under the WIA, Pilot Demonstration Programs, H-1C Labor Attestation Programs, the National Panel on Nursing, and HHS' Medicaid Infrastructure Grants, Advanced Education Nursing Program, Nursing Education and Practice Program, Nursing Workforce Diversity, and Nursing Education Loan Repayment and Scholarship Programs;
- Continuing to examine issues of worker compensation, benefits, and safety through programs and projects such as DOL's Occupational Safety and Health

Administration's National Emphasis Program, and HHS' National Clearinghouse of Innovative Provider Practices;

- Supporting ways to find new sources of workers and insure the adequacy of the existing workforce through DOL's Transition Assistance Program, and HHS' Nursing Workforce Diversity Program;
- Continuing to support research that provides more information to policymakers on the quality and availability of the long-term care workforce such as HHS' Regional

Workforce Studies, National Survey of Nurses, Nursing Forecasting Model, Direct Care Workforce Survey, and through the work of DOL's Bureau of Labor Statistics.

One recommendation has specific relevance to the subject of today's hearing. Our Departments have recommended that we need to explore new technologies in recruitment, education and training, record keeping and patient care. Staff at both Departments are actively implementing these and other recommendations.

Now I would like to take a few minutes to give you an overview of how the President, the Department of Health and Human Services, and the Administration on Aging (AoA) are working in partnership with communities and families to support longevity and productive aging. My remarks will focus on three priority initiatives designed to empower older persons and to better support their preferences and needs. These priorities are:

- To make it easier for older people to access an integrated array of health and social supports by re-balancing the long-term care system;
- To help older people stay active and healthy through health promotion and disease prevention activities; and
- To support families' efforts to care for their loved ones at home and in their communities.

### *Rebalancing the Long-Term Care System*

Let me begin with the Administration's initiative aimed at rebalancing the long-

term care system to create real choices in home and community-based care. Currently, 75 percent of public long-term care funding goes to institutional care, while many people prefer to remain at home.

If we are to support and expand our network of caring communities to enhance the long-term independence of aging baby boomers, our system of care should be designed to provide all Americans with the following opportunities:

- Affordable choices and options that promote people's independence and dignity and their preference to remain at home.
- Consumer control and meaningful involvement in the design and delivery of the programs and services that affect their lives.
- Information that empowers people to make informed decisions.
- Easy access to a full range of health, long-term care and environmental supports.
- Support for family caregivers – our most important partners in caring for older Americans.
- Assurances that people are getting the highest quality of care available.

In his 2004 budget request for CMS, the President has proposed a \$1.75 billion program over five years to encourage states to transition people from nursing homes or other long-term care institutions to the community. Under this proposal, the “Money Follows the Person” Rebalancing Initiative, Federal funds would provide financial incentives for States to develop and implement strategies to re-balance their long-term care systems in a way that is responsive to consumer needs and preferences. The

centerpiece of the program is a focus on individuals who are unnecessarily in long-term care institutions when their preferences and needs would be better met in a community setting.

The President's FY 2004 budget would also fund State systems change projects and demonstration programs that promote home and community-based care alternatives, including those designed to provide respite care services. These, and other re-balancing initiatives represent an historic turning point in Federal long-term care policy.

In concert, we are launching several initiatives this year to support the establishment of a more balanced, consumer-oriented system of care.

- Within the next several weeks, the Administration on Aging and the Centers for Medicare and Medicaid Services (CMS) will jointly issue a competitive grants announcement to support the efforts of States to empower consumers by developing "one stop-shop entry points" to long-term care, called resource centers. This program will make it easier for consumers to learn about and access existing care options, including alternatives to institutional care.
- We will also issue a grant announcement to support the work of our area agencies on aging and community service providers to develop evidence-based models that help to prevent and/or reduce the risk of chronic conditions among the elderly.
- We will be working with the CMS, the Substance Abuse and Mental Health Services Administration, the Centers for Disease Control and Prevention, the Agency for Healthcare Research and Quality, and other agencies on a technical assistance program that will help States learn about the most promising practices in state efforts

to-date at rebalancing long-term care.

Working in partnership with States and area agencies on aging, local community service providers, and thousands of dedicated volunteers and advocates for almost 40 years, the Older Americans Act has helped to establish a strong foundation for providing more home and community-based care. Today, Older Americans Act programs serve more than 7 million older adults annually -- 3 million of whom have intensive care needs.

We need to continue to work to provide greater access to home and community-based systems of care.

### ***Health Promotion/Disease Prevention***

The Administration is leading a focused initiative on Health Promotion and Disease Prevention activities for persons of all ages. Just yesterday you heard testimony from Dr. James Marks of the Centers for Disease Control and Prevention in which he indicated that we must be more aggressive in addressing the prevention of disease and disability among older Americans.

The statistics related to this topic are alarming – three out of five American adults are overweight or obese. The costs are distressing – an estimated \$117 billion is lost to our economy each year due to this epidemic. The problem is growing – since 1990, the

prevalence of obesity has increased by 50 percent. And the effects are deadly serious – sedentary lifestyles and inadequate diets account for 14 percent of all deaths in the United States.

Scientific evidence reveals that we can significantly reduce at least five major chronic conditions – diabetes, heart disease, cancer, depression, and arthritis – through increased physical activity and improved nutrition. These benefits can be seen among persons of all ages.

A far-reaching prevention strategy was launched earlier this month by HHS Secretary Tommy Thompson. The \$15 million “Steps to a HealthierUS” initiative, which advances President Bush’s HealthierUS goal of helping Americans live better, longer, and healthier lives, will support innovative community-based programs that demonstrate approaches to reduce the prevalence and impact of diabetes, asthma, and obesity. The President’s fiscal year 2004 budget proposal would substantially increase the investment in this initiative to a total of \$125 million. As Secretary Thompson said in announcing this initiative, “The communities awarded these grants will help lead the country in changing our healthcare model from one that only treats the sick to one that successfully promotes better health.”

The Administration on Aging is a partner in this effort, fostering greater collaboration between aging network providers at the State and local level with public health departments and community health centers. We are also sponsoring a “USA on the Move: Steps to Healthy Aging” program, focused on empowering older individuals to eat

better and to move more. By late summer, we will produce a *Guide to Eating Better and Moving More*. This guide will be designed to help communities establish walking programs for older individuals. It will be available in print and on our web site, and include materials for program managers, as well as for consumers.

In addition, as part of our health promotion activities, step counters are being used as a pilot demonstration at nutrition projects throughout the country to inspire older individuals to walk more. Program goals center around the number of steps participants take per day, and are customized for each individual based on age, functional ability, cultural preferences, or health status.

### ***Support for Family Caregivers***

The key to ensuring that older Americans can continue to remain at home is the support they receive from family caregivers. More than 23 million Americans are providing compassionate assistance to a family member, neighbor or friend.

Approximately 30 percent of the current workforce has some responsibility caring for a relative. This rate is expected to increase to 54 percent by 2008.

If we were to pay for the care provided by these relatives and friends to their loved ones, a recent study estimates that it would cost \$257 billion per year. This is more than the amount spent on formal home care and nursing home care combined.

At listening sessions in communities throughout the country, one of the recurring messages I hear time and time again is the considerable physical demands, emotional distress, and losses caregivers experience. Whether it is the 51 year-old son who, as the sole caregiver for his blind mother, spends his workday worrying how she is doing, or the 80 year-old woman who is struggling to bathe, feed, and care for her 102 year-old mother, or the grandmother who lives on a working farm in Idaho and is struggling to take care of her grandchildren – the message is the same – just give me a little help – a little hope – a little relief, and I can take care of my loved one in my home.

Staying in the home is what the caregiver and those who need caregiving, overwhelmingly prefer. Yet caregivers face serious difficulties. According to national data the Administration on Aging collected about individuals who provide caregiver support to elderly individuals served by the Older Americans Act:

- One out of four (24 percent) report difficulty providing care because of their own physical limitation.
- Nearly two out of five (37 percent) are also providing care for someone else.
- More than six in ten (65 percent) take care of someone who is at least 75 years old.

Other recent research indicates that caregivers suffer a mortality rate 63 percent higher than that of non-caregivers.

## *The National Family Caregiver Support Program*

It is for these reasons that, in community after community throughout the country, caregivers tell me that the National Family Caregiver Support Program is the best program the government provides. Many people have thanked me for the program with tears in their eyes.

Findings from AoA's national data about caregivers who received assistance under the National Family Caregiver Support Program reveal that:

- 88 percent report that Older Americans Act services help them provide care longer than they would have been able to without the services.
- 72 percent report that the services help a lot in their efforts to provide care.
- 95 percent are very or somewhat satisfied with the Older Americans Act services provided to the elderly person they serve.

Let me share just a few of the stories of the tens of thousands of caregivers the program supports.

A disabled individual is caring for his wife who is diagnosed with Alzheimer's disease. He does not want his wife to go to a nursing home, but he is unable to help her with her personal care and the fact that she needs 24 hour care. By receiving help from the caregiver program in Arkansas, he has been able to take his spouse to adult day care

five days a week for four hours per day. He has also hired a woman who bathes his wife and helps her get up and get ready to go to the adult day care center. With this assistance, the husband now has time to receive his own therapy and complete his personal business without worrying about his wife.

An elderly Kentucky grandmother has sole caregiving responsibilities for her eleven year-old grandson. She had twice put off needed outpatient surgery because she knew she would be unable to temporarily care for her grandson. After hearing about the National Family Caregiver Support Program, she was able to arrange housekeeping and chore assistance, as well as temporary personal care assistance for her own needs following the surgery.

In Alaska, a 47 year-old son who is responsible for running a food shipping business struggled with being the sole caregiver for his 78 year-old mother who is legally blind, has diabetes and arthritis. His mother's chronic conditions made her prone to falls and she was not able to prepare her meals or control her strict diet. The Alaska caregiver program provided the necessary assistance for arranging a Senior Companion to provide respite services and assist with meals during the week. What had been a caregiving crisis is now a stabilized situation.

A woman in North Carolina is the sole caregiver for her father, who is wheelchair bound. The daughter was carrying her father up and down the steps each time she had to take him out of the house. A volunteer from a local church referred her to the National

Family Caregiver Support Program, where she received assistance installing a wheelchair ramp for her home.

Focus groups and community listening sessions inform us that safety is a major concern of caregivers, and that safety in the bathroom and while transporting the person they are caring for are the two greatest areas of concern. Assistive technology through the National Family Caregiver Support Program is playing an important role in addressing these concerns. Non-skid surfaces, grab bars, and other safety features are being installed in bathrooms. Videos have been made to instruct caregivers on the best and safest techniques for getting disabled individuals in and out of vehicles. Caregiver program funds are also being used in places like Monmouth County, New Jersey to connect frail elders and their caregivers with nurses through a system that allows older persons to be electronically monitored in between visits to the doctor's office.

Since the enactment of the caregiver program, States and localities have demonstrated a great deal of creativity in forming new local partnerships, improving access to a wide range of services, conducting outreach to special populations, and providing flexible services that can respond to the unique needs of consumers.

The data further indicate that over 3.8 million caregivers have been empowered with information about caregiver programs and services through the National Family Caregiver Support Program. There are indications that States also have made significant strides in addressing the needs of individuals with a variety of services. These data

indicate that States provided access assistance to approximately 436,000 caregivers, which significantly exceeds the agency targets to serve 250,000 caregivers. Significant numbers of caregivers have also been reached with intensive, direct services. The data also indicate that States served almost 180,000 caregivers with counseling and training services; provided respite to over 70,000 caregivers; and provided supplemental services designed to complement other care to over 50,000 caregivers.

The caregiver program is creating a new way of doing business in the aging network by focusing on caregivers, not care recipients. It is promoting creativity at the State and local level, while allowing consumers to have choices. As States have implemented this new program the national data gathered begins to reveal the following innovative activities:

- Building a new infrastructure for the support of caregivers and developing partnerships with the business community, faith-based organizations, rural health systems, and universities.
- Developing a single point of entry for caregiver access and promoting consumer directed services.
- Conducting consumer listening sessions to address priorities in the development of flexible service standards and new models of service delivery.
- Administering, piloting, and testing consumer-directed strategies by putting families first.
- Tailoring special messages, information, and program promotion strategies to

reach special populations, including the rural, grandparents, low-income individuals, minorities, the hearing impaired, and limited English-speaking caregivers.

Similar advancements for members of Indian Tribes are also being made under the Native American Caregiver Support Program. The building blocks of a caregiver support infrastructure are being created that are heightening awareness and establishing culturally appropriate access to services. All of the programs are administering public awareness campaigns; nearly all of the programs (92 percent) are providing respite services; approximately two-thirds (64 percent) are providing support groups or individual counseling; and over half (58 percent) are providing caregiver training.

We plan to release the complete report of our findings and data at a national summit entitled, "Creating Caring Communities" in September. The purpose of this summit will be to bring together aging, health, and long-term care providers and practitioners from across the country to strengthen the capacity of State and community services networks to:

- Promote policy and program changes at the State and local level that would make the long-term care system more balanced and responsive to the needs and preferences of older people and their family caregivers;
- Develop and operate innovative programs at the State and local level that will help older people to remain at home and support family caregivers; and
- Promote strategies and tools at the State and local level to prevent chronic

diseases and eliminate risk factors that cause them.

In advance of this effort, I am announcing at this hearing the release of a new public service campaign called, "Who Cares for the Caregivers?" This campaign is designed to inform caregivers that assistance is available in their communities, and how to access them. Today I am sending the television and radio Public Service Announcements in English and Spanish to radio and TV stations throughout the country. I would like to let you be the first to preview these 30-second spots following my testimony.

### ***Conclusion***

In short, the best way for us to comprehensively prepare for the aging of the baby boom population is to create incentives for all sectors of our society to actively be involved. That is what the Administration is undertaking, through the many activities I have just described, as well as others.

An important component of this effort will be the national network on aging, which is well-positioned to successfully shape and address our future by building caring communities, and by expanding and providing community-based services. These assets include:

- A deeply ingrained focus on the consumer that's inherent in our ethic of care.
- Our commitment to early intervention, and the social model of care.

- A national network that is grounded in the community and capable of delivering an extensive array of low-cost services.
- A proven track record in leveraging other resources on behalf of the people we serve.
- A history of working under capped funding and managing defined budget.
- The capacity to reach out to and serve private-pay consumers, as well as consumers who are low-income, culturally diverse and isolated.

These assets are the building blocks we will use to thrive in the changing health and long-term care environment.

We cannot afford to maintain the status quo. We need to continue to work together to create systems of care in home and community-based care settings as well as in institutional settings that can best meet the needs of older Americans.

We must work together to develop a comprehensive approach to health and long-term care that focuses on the community and truly reflects the needs and preferences of older Americans. We know what we do through the Older Americans Act makes a difference! We must work in partnership to make sure that EVERY community is a caring community.

Thank you very much. I would be pleased to answer any questions you may have.