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Administration On Aging AoA

Young Lawyers to Help Seniors

The American Bar Association Young Lawyers Division (ABA/YLD) has just embarked upon a one-year national public service project, called "Service to Seniors." Young lawyer sections and committees in state and local bar associations are preparing consumer educational materials and conducting legal clinics on issues such as planning for incapacity, guardianship, consumer fraud, and elder abuse. In addition, some young lawyer groups are providing pro bono legal assistance. Others are participating in non-legal projects, such as delivering meals on wheels, visiting nursing home residents, or helping to develop "elder friendly" court systems. Special focus will be on outreach to homebound elders. "Not only do our efforts as young lawyers touch seniors directly, our efforts impact each person's family. Reaching out to those seniors who do not have the ability to leave their homes or do not have the resources to afford legal services should be a priority in every community," said Jo Ellen McBride, ABA special project coordinator for "Service to Seniors."

"Service to Seniors" is intended to complement existing legal services for older people, such as those funded under the Older Americans Act and the Legal Services Corporation, and those provided by the private bar. The initiative represents an opportunity for state and area agencies on aging and legal assistance and elder rights advocates to collaborate with young lawyer groups, and to develop projects that fill the gaps and meet the legal needs of elders in their communities. Each state bar association has a section or division of young lawyers, and each has been asked by the ABA/YLD to participate in this initiative. Projects have been confirmed in Arizona, Florida, Illinois, Texas, California, Georgia, Washington and Colorado, and are being developed in many other states.

Young lawyers (who are usually under age 36 or licensed as lawyers for less than five years) have been interested in aging issues for some time, and were the force behind the creation of several bar association elder law committees. Indeed, in Georgia, Texas and Utah, elder law committees are still housed within young lawyer sections. In most bar associations, however, the section or committee devoted to the practice of elder law is a separate entity. Some elder law groups may be collaborating with the young lawyers in the "Service to Seniors" project. If not, they are still likely to be involved in some activities designed to benefit older people, such as consumer education, legislative advocacy, or reduced fee or pro bono representation projects.

For more information about the Service to Seniors initiative, or the ABA Young Lawyers Division, contact Ann Fiegen, American Bar Association, 750 North Lake Shore Drive, Chicago, IL 60611, Telephone 312/988-5614, or e-mail fiegen@staff.abanet.org. **The ABA/YLD website, http://www.abanet.org/yld includes links to state and local bar association young lawyer groups.**

The American Bar Association Commission on Legal Problems of the Elderly provides assistance to state and area agencies on aging on a variety of law-related issues, including development of legal assistance and elder rights systems that involve the private bar.

To discuss how the aging network can collaborate with bar association elder law sections and committees, contact: Stephanie Edelstein, ABA Commission on Legal Problems of the Elderly, 740 15th Street, NW, Washington DC 20005, Phone: 202/662-8694; Fax: 202/662-8698, E-mail: sedelstein@staff.abanet.org

- **Go to Top of Page**
- **Go to AoA Press Release Menu**
- **Go to Site Index**
- **Go to What's New**
- **Go to AoA Home Page**

Hypertext by Saadia Greenberg, -- last modified 12/01/98 16:41:53

Administration On Aging

For Immediate Release - Monday, October 19, 1998
Contact: Moya Benoit Thompson (202) 401-4541

Federal Government Kicks off the International Year of Older Persons, 1999

HHS Secretary Donna E. Shalala today launched the Federal government's official acknowledgement of 1999, the International Year of Older Persons. The International Year of Older Persons, with its theme, "Towards a Society for All Ages" was designated by the United Nations General Assembly in 1992 to highlight the challenges and opportunities of a rapidly aging global population. In a message delivered from President Clinton to the United Nations on October 1, 1998 the first official day of the International Year, he said, "Longevity is one of the great achievements of the 20th Century. Thanks to remarkable advances in health care and research, life spans are increasing around the world, and the world's older population is expected to approach 1.2 billion by the year 2025."

Speaking before a gathering of Cabinet representatives, international delegates and senior advocates in Washington, D.C. Secretary Shalala said, "In the Year 2000, older people will outnumber children for the first time in our history.....the good news is that the millennium promises to be a golden age for older people. We've completely changed what it means to "act your age." Among the internationally recognized guests and speakers were Dr. Alexandre Kalache, Chief, World Health Organization Ageing and Health Programm, Geneva, Switzerland and Dr. Rose Dobrof, CoChair of the US Committee to Celebrate the International Year of Older Persons. In addition, a special video message was delivered from United States Senator John Glenn (D-OH) who at age 77 is returning to space on October 29 as a NASA researcher.

Over 30 federal government departments and agencies, coordinated by the Administration on Aging and chaired by Assistant Secretary Jeanette C. Takamura, have joined together to plan government-wide activities throughout 1999 to discuss common issues that will affect aging populations of this country in the next century, and to collect and share best practices among other nations of the world. During the International Year, the Federal Committee is planning several key events including a government-wide conference in June 1999 focusing on the implications of longevity and active aging on federal programs, services and policy areas, as well as developing an aging agenda for the 21st Century. The Federal Committee is also working with public and private sector organizations, including the Brookdale Center on Aging-based U.S. Committee to Celebrate the International Year of Older Persons. Many federal agencies are also planning specific initiatives that will focus on their unique programs that serve an older population. The Department of Transportation, for example, is planning an international conference to examine the myriad of issues related to transportation services and programs for older persons of today as well as the 76 million baby boomers anticipated early in the next century. Many other events are being planned at the Federal, state and local level to highlight the International Year.

Jeanette C. Takamura, assistant secretary for aging and Chair of the Federal Committee said, "It is compelling that we move now to prepare our own nation, as well as our colleagues around the world, for the international demographic shift in aging populations. The United States has a leadership role and responsibility to provide the blueprint for the societal changes that need to take place to prepare the world for this gift of longevity."

For more information about the International Year of Older Persons, please contact Marla Bush,

International Year of Older Persons Coordinator, Administration on Aging, at (202) 619-3996.

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- Go to Top of Page
- Go to AoA Press Release Menu
- Go to text of HHS Sec. Shalala's remarks
- Go to text of USDA Dep. Sec. Rominger's Remarks
- Go to What's New
- Go to top of AoA Home Page
- Go to AoA International Menu
- Go to Site Index

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DEPARTMENT OF HEALTH & HUMAN SERVICES

FOR IMMEDIATE RELEASE (Copy of Health Care Financing Administration Press Release)
Date: October 14, 1998
Contact: HCFA Press Office (202) 690-6145

HEALTHY AGING PROJECT

The United States will have 68 million seniors by the year 2030 -- double today's 34 million. The age groups covering those ages 75 to 85, and over 85 will double, increasing the demand for health care. The number of seniors with chronic diseases is expected to increase by 100 percent over the next several decades.

Chronic disease is the leading cause of death, severe illness and disability in the United States, accounting for three out of four deaths and affecting more than 100 million people. Eighty percent of the senior population have one or more chronic diseases, 50 percent have two or more chronic conditions, and 24 percent have severe chronic conditions that limit their ability to perform one or more activities of daily living.

Impact of chronic illness

Direct medical costs for persons with chronic conditions represent nearly 70 percent of national expenditures on health care. Research indicates that a major portion of the physical decline among the elderly is caused more by the absence of comprehensive health promotion and disease prevention strategies than by aging.

A growing body of medical literature indicates that chronic disease and functional disability can be measurably reduced or postponed through lifestyle changes, and that healthy behaviors are particularly beneficial for the elderly. Exercise--even if started later in life--along with diet, smoking cessation, clinical preventive services, and meaningful activity and socialization, can improve functioning and reduce disease and disability in old age.

Reduction of chronic disability in the elderly should result in lower rates of morbidity and functional disability and should produce considerable savings for Medicare.

The Healthy Aging Project

The Healthy Aging Project will use the best available science to identify what works to promote health and prevent functional decline in older populations, and will apply this information in practical ways to Medicare programs and policies. Many health promotion and disease prevention programs have been shown to reduce risk factors and lower health care costs, but these programs have never been compiled, rigorously evaluated or tested for effectiveness in the Medicare population.

The Healthy Aging Project is the Health Care Financing Administration's first initiative to examine ways to reduce behavioral risk factors in the elderly, which contribute to 70 percent of the physical decline that occurs with aging. The Healthy Aging Project will identify and test interventions to reduce behavioral risk factors in the managed care and fee-for-service settings.

Examples of interventions include: health risk appraisals combined with targeted interventions to reduce risk factors, arthritis self-management programs, smoking cessation strategies, and home-based geriatric

assessments to reduce falls and nursing home admissions.

The Healthy Aging Project will examine whether health promotion interventions have a measurable impact on behavior change, health status, functional status, quality of life, use of services, consumer satisfaction, or cost of care. The project will also identify ways to promote the use of Medicare clinical preventive services, such as flu shots, colorectal cancer screening, and mammograms.

The Healthy Aging Project will provide strategies that beneficiaries, health care professionals, peer review organizations, and communities can use to promote health and delay disease in older populations.

HCFA has awarded a contract to the RAND Corp. of Santa Monica, Calif., to conduct the activities of the Healthy Aging Project. The primary subcontractor is the Connecticut Peer Review Organization.

The Healthy Aging Project was jointly developed by HCFA and the Agency for Health Care Policy and Research, in consultation with the National Institute on Aging, the National Heart, Lung, and Blood Institute, the Administration on Aging, and the Centers for Disease Control and Prevention.

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- **Go to Top of Page**
- **Go to What's New**
- **Go to HCFA Press Releases**
- **Go to AoA Press Release Menu**
- **Go to top of AoA Home Page**

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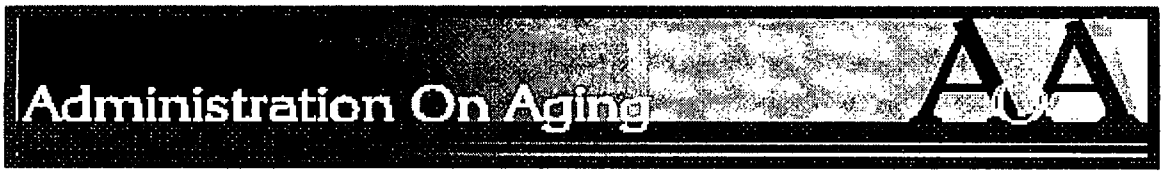


The ADMINISTRATION ON AGING and the OLDER AMERICANS ACT

AGING IN AMERICA

Today, thanks to the strides made in our health care and standard of living, 43 million, or one in six, Americans have celebrated their 60th birthday. Improved health and programs, such as Social Security, Medicare and pension plans, have made it possible for most Americans to enjoy almost 14 years of retirement with a degree of economic security that few older people had at the turn of the century-years that offer the opportunity for leisure activities, second careers, and volunteer service. Nevertheless, many older Americans are at risk of losing their independence, including:

- The 3 million Americans who are 85 or older,
- Those living alone without a caregiver,
- Members of minority groups,
- Older persons with physical or mental impairments,
- Low-income older persons, and
- Those who are abused, neglected, or exploited.

Of the 9 million Americans over age 65 who live alone, two million say they have no one to turn to if they need help. Lack of a caregiver is a serious problem for those older persons who have chronic conditions and limitations on their ability to care for themselves and their homes. Their problems are often compounded by increased medical costs due to poor health and the need for more supportive services.

Unfortunately, those who are most vulnerable are also most likely to live alone and to have limited incomes. Eighty percent of those living alone are women and nearly half of persons aged 85 or older live alone. Older women, the very old, and minority elderly, have, on average, the lowest incomes among the older population which severely limits their ability to purchase the health care, goods, services, and housing options which could help them to remain independent.

THE OLDER AMERICANS ACT AND THE ADMINISTRATION ON AGING

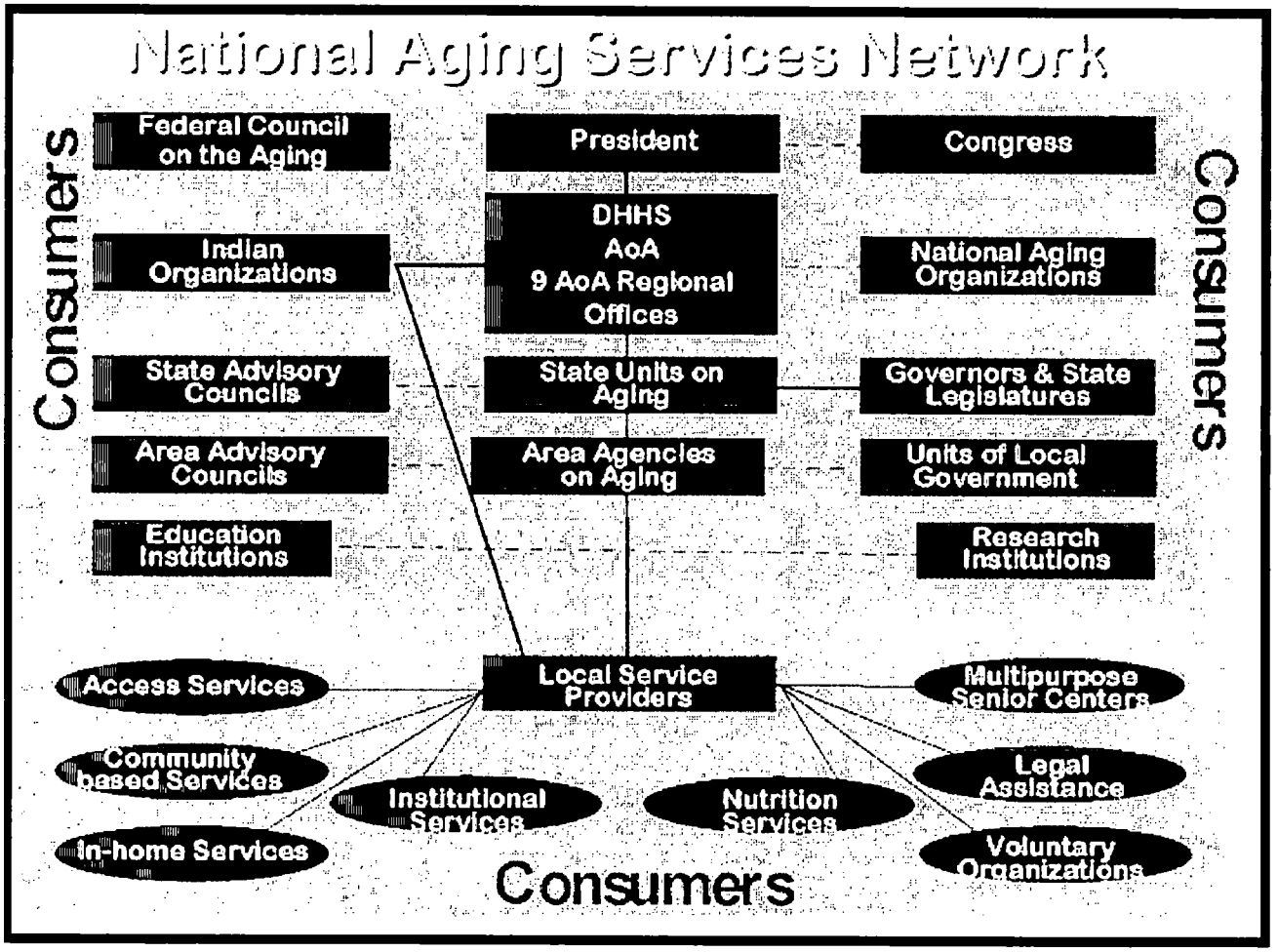
In response to the growing number of older people and their diverse needs, the Older Americans Act of 1965 as Amended calls for a range of programs that offer services and opportunities for older Americans, especially those at risk of losing their independence. The Act established the Administration on Aging (AoA), an agency of the U.S. Department of Health and Human Services, which is headed by the Assistant Secretary for Aging in the Department.

AoA is the Federal focal point and advocate agency for older persons and their concerns. In this role, AoA works to heighten awareness among other Federal agencies, organizations, groups, and the public about the valuable contributions that older Americans make to the Nation and alerts them to the needs of vulnerable older people. Through information and referral and outreach efforts at the community level, AoA seeks to educate older people and their caregivers about the benefits and services available to help them.

AoA works closely with its nationwide network of Regional offices and State and Area Agencies on Aging to plan, coordinate, and develop community-level systems of services that meet the unique needs

of individual older persons and their caregivers. The Administration on Aging collaborates with Federal agencies, national organizations, and representatives of business to ensure that, whenever possible, their programs and resources are targeted to the elderly and coordinated with those of the network on aging.

AoA administers key programs at the Federal level mandated under various titles of the Older Americans Act. These programs help vulnerable older persons to remain in their own homes by providing supportive services. Other programs offer opportunities for older Americans to enhance their health and to be active contributors to their families, communities, and the Nation through employment and volunteer programs.



STATE AND COMMUNITY PROGRAMS

Several Titles of the Act provide for supportive in-home and community-based services. Title III supports a range of services including nutrition, transportation, senior center, health promotion, and homemaker services. Title VII places emphasis on elder rights programs, including the nursing home ombudsman program, legal services, outreach, public benefit and insurance counseling and elder abuse prevention efforts. AoA awards funds for Titles III and VII to the 57 STATE AGENCIES ON AGING (sometimes referred to as State UNITS on Aging) which are located in every State and Territory. Under Title VI, AoA also awards funds to 216 tribes and native organizations to meet the needs of older American Indians, Aleuts, Eskimos, and Hawaiians. The grantees provide services in keeping with the unique cultural heritage of these native Americans.

Program funding is allocated to each State Agency on Aging, based on the number of older persons in the State, to plan, develop, and coordinate systems of supportive in-home and community-based services. Most States are divided into Planning and Service Areas (PSAs) so that programs can be effectively developed and targeted to meet the unique needs of the elderly residing in that area.

Nationwide some 660 AREA AGENCIES ON AGING (AAA) receive funds from their respective State Agencies on Aging to plan, develop, coordinate and arrange for services in each PSA. In rural areas, an AAA may serve the needs of elderly people living in a number of counties, while other AAA's may serve the elderly living in a single city.

AAA's contract with public or private groups to provide services. There are some 27,000 service provider agencies nationwide. In some cases, the AAA may act as the service provider, if no local contractor is available. Supportive services fall under several categories, including.

- Access Services-such as information and referral, outreach, case management, escort and transportation;
- In-Home Services-which include chore, homemaker, personal care, home-delivered meals, and home repair and rehabilitation,
- Community Services-including senior center, congregate meal, day care, nursing home ombudsman, elder abuse prevention, legal, employment counseling and referral, health promotion, and fitness programs.
- Caregiver Services-such as respite, counseling, and education programs.

Older persons, their caregivers, or anyone concerned about the welfare of an older person can contact their Area Agency on Aging for information and referral to services and benefits in their community. AAAs are usually listed in the Yellow Pages under the city or county government headings. A nationwide toll free hotline also provides information about assistance for older individuals anywhere in the Nation. The number is: 1 800 677- 1116. When calling, please provide the older persons's address as well as their zip code number.

RESEARCH, DEMONSTRATION TRAINING AND RESOURCE CENTER PROGRAMS

In addition to service programs, the Administration on Aging, under Title IV of the Act, awards funds to support research, demonstration, and training programs. Research projects collect information about the status and needs of various subgroups of elderly which is used to plan services and opportunities that will assist them. Demonstration projects test new program initiatives that better serve the elderly, especially those who are vulnerable.

Some successful demonstration projects have laid the groundwork for ongoing nationwide programs under the Older Americans Act. Examples include the national Nutrition Program for the Elderly which provides congregate and home-delivered meals to older people; the nationwide network of Area Agencies on Aging; and the elder abuse prevention program.

Under Title IV, AoA also has provided funds to educational institutions to develop curricula and training programs for professionals and paraprofessionals in the field of aging. Programs, for example, has provided training to paraprofessionals in legal counseling and to homemaker-home health aides who provide supportive services to the frail elderly. Other programs trained members of minority groups in leadership, management and direct service provider roles to enhance the delivery of services to elderly minority individuals.

In the recent past, AoA has awarded funds under Title IV of the Act to support National Resource Centers for Long Term Care. These centers conduct research, disseminate information and provide training and technical assistance to improve national, State and local systems for providing home and community based long term care. Emphasis is on ethical issues and case management, the increasing diversity of America's elderly, improving community infrastructures to better meet the needs of long-term care consumers, and improving the availability of long-term care services for the rural elderly.

AGING IN THE FUTURE

In the future, America's older population will grow and change rapidly. By the year 2030, those 60 and older will more than double to 85 million, while those 85+ will triple to 8 million. At the same time, the

number of minority elderly will increase far more rapidly than the general population. While the number of older white Americans will increase by 97 percent, elderly black Americans will increase by 265 percent, and Hispanic Americans by 530 percent. The minority elderly tend to have shorter life expectancies and more serious health problems at younger ages than do white Americans. They are also sometimes less able to advocate for themselves because of cultural, language, or educational barriers. As a group, they, like older women, have limited incomes due to histories of work that offered low wages and few pension benefits.

While a great deal of progress has been made in establishing community-based service systems, many communities do not yet have the range of programs needed, and some report that they have waiting lists for services. Meeting the needs of older Americans goes far beyond the efforts of government. It requires the talents and commitment of active older people and a range of groups and organizations. AoA is working to expand the involvement of agencies and organizations representing government, business, labor, and the voluntary, religious, and civic communities that have not worked with the elderly. By encouraging groups to adopt an agenda and assist their local affiliates in developing a variety of approaches that help vulnerable older persons, AoA seeks to increase the array of services and the number of at-risk elderly who can be helped in each community.

The aging of America presents many challenges, but it also offers many opportunities. Older Americans represent a great reservoir of talent, experience, and knowledge which can and is being used to better their communities and the Nation. AoA is working to tap the rich resource of older Americans. Through intergenerational programming, older persons are serving in preschool, school, and after school programs as tutors, mentors, role models, and surrogate grandparents. They are assisting families by working with Head Start children and their parents, as counselors to troubled youth, and by providing respite care for handicapped children. AoA's Older Americans Act Eldercare Volunteer Corps uses the talents of a half million volunteers, many of them older persons, to assist in service programs supported under the Act. These volunteers work at the community level to enhance the independence of the elderly.

Through these and the many other programs supported by AoA, the mandate of the Older Americans Act-to ensure the dignity and independence of older Americans in their own homes and the opportunity to contribute to their communities and our Nations coming closer to being fully realized for present and future generations.

Go to Top of Page • Go to Previous Menu • Go to top of AoA Home Page

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Hypertext conversion by Saadia Greenberg, *last updated November 4, 1997*

Administration On Aging AoA

U.S. ADMINISTRATION ON AGING: ACCOMPLISHMENTS 1993 - 1996

INTRODUCTION

In order to better prepare for the nation's unprecedented doubling of its older population over the next 35 years, President Clinton and Secretary Shalala elevated the position of Commissioner on Aging to the level of Assistant Secretary for Aging (ASA) to serve as the lead advocate for older individuals within the Department of Health and Human Services, across the Cabinet, and across the country.

The ASA also oversees the U.S. Administration on Aging (AoA) which works in partnership with a network of 57 State Units on Aging, 661 Area Agencies on Aging, 228 Native American, Alaskan, and Hawaiian tribal organizations representing 300 tribes, 5,000 senior centers and more than 27,000 local service providers to assist older persons to remain independent in their homes and communities.

As such, the roles of the first ASA have included:

- providing a necessary link between the concerns of the elderly and other groups and organizations;
- maintaining oversight, evaluation, and accountability for AoA's programs and activities;
- furnishing technical assistance and consultation to States and localities;
- forging a more unified and effective cooperation between government agencies in serving older persons and their families;
- developing policies and setting priorities;
- stimulating more effective use of existing resources;
- preparing, publishing and disseminating educational materials;
- working to expand and improve the delivery of home- and community-based long-term care;
- addressing the problem of malnutrition among the elderly;
- improving the quality of life for America's older women; and
- helping to prepare younger age groups for their aging.

This document highlights some of the key accomplishments of the Administration on Aging during the period 1993 - 1996 under the first Assistant Secretary for Aging, Dr. Fernando M. Torres-Gil. It incorporates the continued commitment to aging issues by the Acting Assistant Secretary for Aging, Dr. Robyn I. Stone.

These activities, events and research products are a direct result of the partnership that exists between the AoA and the aging community. They reflect the dedication provided by staff, governing boards,

advisory councils and volunteers who work tirelessly across the country in states and local communities on behalf of older Americans. We at the AoA commend and thank all of them for their work and their commitment to meeting the needs of older people.

• Improving Services for Seniors and Their Families

PRESERVING AND STRENGTHENING THE OLDER AMERICANS ACT

In consultation with key partners in the aging network, AoA produced a reauthorization proposal for the Older Americans Act designed to strengthen its services and maintain the integrity of its successful programs and titles, while improving local flexibility, protecting the most vulnerable, and preparing for a growing and diverse aging population.

PROTECTING ELDERS' RIGHTS

- Sponsored Bi-Regional Elder Rights Protection meetings to explore the potential of Older Americans Act Title VII (Vulnerable Elder Rights Protection Activities) in enabling states to assist elders in securing the rights and benefits to which they are entitled. These meetings served to develop ways to resolve problems affecting large numbers of vulnerable older persons, and many states have continued the approaches and coalitions which were initiated.
- Established the National Ombudsman Reporting System (NORS) to obtain detailed ombudsman complaint and program information in an effort to design policy and serve as a baseline against which to measure program outcomes in future years.
- Sponsored a symposium on coordinating long-term care ombudsman and adult protective services programs. Findings and recommendations of the symposium have provided guidance to elder rights advocates in areas including functions and administration of Adult Protective Services and ombudsman programs by the same agency.
- Convened a special task force to develop outcomes measures for the work of ombudsmen which have been compiled into a paper entitled, "An Approach to Measuring the Outcomes of the Long-Term Care Ombudsman Program" issued to States and other interested parties.
- Continued support for the Congressionally-mandated National Long-Term Care Ombudsman Resource Center to provide technical assistance and training activities for state long-term care ombudsmen in nursing homes and board and care facilities.

PREVENTING CRIME & VIOLENCE

- Established a Crime/Violence Prevention Initiative which focuses on the prevention of crimes and violence against older persons.
- Continued support for the Congressionally-mandated National Center on Elder Abuse to serve the information knowledge and skills development, and knowledge building needs of organizations, individuals, and professionals working within and outside the nation's elder abuse/neglect prevention network.
- Collaborated with the HHS Administration for Children, Youth and Families to conduct a National Elder Abuse Incidence Study designed to examine the incidence of elder abuse, neglect, and financial exploitation. The three-year study will also identify the characteristics of victims of domestic elder abuse as well as those of the perpetrators.
- Entered into an interagency agreement with the Department of Justice to address the public safety and security needs of older Americans. Activities include promoting the formation of local and state TRIAD programs (efforts to increase cooperation between law enforcement and aging and social services providers to reduce criminal victimization).
- Established projects to link, at the state and local levels, domestic violence and aging networks to develop model programs for the protection of older women against domestic violence.

CRACKING DOWN ON HEALTH CARE FRAUD

- Worked in partnership with the Office of the Inspector General and the Health Care Financing Administration in carrying out "Operation Restore Trust" -- a Presidential initiative to detect and punish fraud and abuse in the Medicare and Medicaid programs.
- The pilot program is operating in five states including New York, Florida, Illinois, Texas, and California with proposed expansion to all fifty states.
- In its first year, the program has produced $42.3 million in restitutions, fines, settlements and recovery of overpayments.

INCREASING VISIBILITY OF NUTRITION AS KEY HEALTH COMPONENT

- Established the Nutrition/Malnutrition Initiative to more effectively respond to the documented needs of older persons and to heighten public awareness of the critical role nutrition plays in the health status of older persons.
- Completed an independent Congressionally-mandated evaluation of the Elderly Nutrition Program (ENP) under Titles III and VI of the Older Americans Act. The study determined the effectiveness of the ENP in meeting the nutritional needs of older persons as well as in addressing unmet needs. It is the first national evaluation of the OAA nutrition programs since 1983, and the first-ever to evaluate Title VI nutrition programs. Key findings include:
  - the ENP provides an average of 1 million meals per day to older Americans;
  - in FY94, 127 million meals were served to 2.3 million people at congregate sites, and more than 113 million home-delivered meals were provided to 877,000 homebound elderly persons;
  - Federal ENP dollars are highly leveraged with money from other sources including state, local and private funds, donations and participant contributions; and
  - Older Americans Act funding accounts for 37% of congregate costs, and 23% of home-delivered costs.
- Established the National Policy and Resource Center on Nutrition and Aging which focuses on providing information dissemination, training and technical assistance, and knowledge-building and policy analysis. The Center's activities include:
  - creating an elderly nutrition homepage;
  - developing a home and community-based care nutrition manual;
  - providing telephone assistance to programs and practitioners; and
  - developing a series of background and policy papers, nutrition studies, surveys and manuals.
- Established the National Nutrition Advisory Council which provided policy and implementation recommendations pertaining to the role of nutrition and home and community-based long-term care, as well as Older Americans Act nutrition program standards and guidelines, training, best practices, and results-oriented management.
- Hosted the first national meeting of state nutritionists in 20 years, resulting in the development of an on-going training and technical assistance plan designed to meet the needs of each region and states within the region.

IMPLEMENTING EXPEDITED ASSISTANCE FOR DISASTERS

- Established a mechanism for distributing funds under the Older Americans Act to assist older persons in their homes and local communities within 48 hours of Presidentially declared disasters. Through this expedited process, states have been able to immediately target special assistance to older persons where it is needed, including providing case management, relocation into temporary housing, identifying losses, filing timely claims, and facilitating chore services, home repairs, meals, day care, and transportation.
- Signed a Statement of Understanding with the American Red Cross to make the delivery of relief efforts to elderly victims of disasters more efficient through cooperative efforts, including training, data collection, emergency meal distribution and transition of services.
- Produced a training video in both English and Spanish which addresses the impact of disasters on the elderly.

IMPROVING CUSTOMER SERVICE

- Developed the first-ever strategic plan for the AoA which articulated the mission as well as goals and objectives for the agency and the aging network.
- Jointly issued with HHS Secretary Donna E. Shalala a customer service plan for the Administration on Aging. The plan contains nine customer service standards for AoA employees in delivering services to older persons and their families, to State and Area Agencies on Aging, tribal organizations, as well as other agencies, organizations and grantees.
- Expanded the use of these standards by establishing a comprehensive AoA Homepage on the Internet which provides data and information on a variety of matters of concern to older consumers and their families. (http://WWW.AoA.DHHS.Gov)
- Established a monthly newsletter, "AoA Update," for distribution to the Aging Network, agency employees and other interested individuals to keep them apprised of agency activities/initiatives on a regular basis.
- Convened a National Symposium on Performance-Based Management which brought together representatives of the aging network to address data and technology requirements for the future.

Enhancing the Capacity of the Network

ESTABLISHING A NATIONAL AGING DATA BASE INFORMATION & RESOURCE CENTER (NAIC)

- Established a Congressionally mandated National Aging Information Center to provide convenient access to a wide range of resources for those interested in aging issues and information. The Center serves policymakers and Congress, the aging network, educators, researchers, practitioners and the public, and is the repository of documents and the final report of the 1995 White House Conference on Aging.

WORKING TO EXPAND HOME- AND COMMUNITY-BASED LONG-TERM CARE

- Established a long-term care agenda aimed at the development of consumer-driven home and community-based systems of care for older persons who need services.
- Funded four long-term care resource centers in various parts of the country to conduct applied and policy- oriented research; to disseminate information; and to provide training and technical assistance. Some of the products include:
    - developing consumer information, guidebooks, policy papers, manuals, and research briefs on such diverse topics as expanding consumer choices, addressing the needs of persons with disabilities, overcoming barriers to long-term care assistance in rural areas, examining managed care and frail elders, highlighting home and community-based care best practices, evaluating housing for rural and African American elders, analyzing assisted living alternatives, reducing the cost of institutional care, improving transportation for the elderly, and others.
- Convened a national "Health Care University" to educate and inform the aging network about issues in health care delivery and reform efforts including the Health Security Act; AoA's Long-Term Care Agenda; as well as to provide findings of a state-by-state profile of selected data on various systems providing home and community-based care.
- Convened Phase II of the Health Care University, a conference on managed care which brought together 750 representatives of the aging network to better understand the concept of managed care for the elderly and individuals with disabilities and its relationship to Medicare, Medicaid and the OAA. The conference also provided an opportunity to examine ways to assure consumer protection and offer advocacy to those in managed care.
- Established the National Long-Term Care Mentoring Program which assists States to develop more extensive programs in home and community-based care, analyzes State long-term care systems, profiles model home and community-based programs, and provides a corps of "mentors" with a wide range of expertise.
- Continued support for the Neighborhood Senior Care Program to demonstrate innovative neighborhood-based efforts which encourage health professionals and community volunteers to

provide home and community-based services.
- Established a working partnership with the Department of Housing and Urban Development (HUD) to enhance the availability and accessibility of services for the elderly and persons with disabilities who reside in Federally assisted housing facilities. Collaborated with HUD in presenting "Best Practice" awards to the top-rated housing facilities demonstrating successful coordination between the aging network and government- assisted housing facilities.

ESTABLISHING LINKAGES BETWEEN AGING AND DISABILITY COMMUNITIES

- Joined as a participant in the National Coalition on Disability and Aging. The Coalition, comprised of twenty-eight national aging and disability organizations, seeks to focus national attention on the common concerns of aging and disability constituencies.
- Worked to enhance collaboration between the disability and aging communities particularly with respect to home and community-based services:
- Funded projects to provide information and technical assistance on consumer directed services; building model partnerships between communities; fostering involvement of home and community-based consumers in systems development; and coordinating with agencies that serve persons with developmental disabilities.
- Provided joint funding with the Office of the Assistant Secretary for Planning and Evaluation for the National Institute on Consumer-Directed Home and Community-Based Care Systems to foster increased opportunities for consumer choice and direction in systems and services for adults with disabilities.
- Renewed an informal partnership with the National Easter Seal Society designed to call greater attention to the needs of individuals who suffer from post-polio syndrome, the long-term impact of which mirrors an accelerated aging process.

DOCUMENTING VALUE OF AGING NETWORK IN HUMAN TERMS

- Developed the National Aging Program Information System (NAPIS), a comprehensive and coordinated information and reporting system designed to provide data primarily on clients, services and costs of the programs provided to the elderly under the Older Americans Act. The system is an important step in enhancing the capacities of the aging network at all levels to utilize the data in support of policy development, program enhancement, and advocacy.

Planning for the Future

HELPING TO PLAN AND IMPLEMENT THE 1995 WHITE HOUSE CONFERENCE ON AGING

- Provided leadership in planning, coordinating, highlighting, promoting, and working to implement resolutions adopted at the 1995 White House Conference on Aging, convened May 2-5, 1995. This bi-partisan effort included more than 1000 regional, state and local grass roots events, as well as over 2000 delegates. The conference focused on a host of issues designed to lead the nation into the 21st Century including health care, caregiving, income security, housing, diversity and the role of organizations not traditionally involved in aging.
- Participated in numerous pre- and post-WHCoA conference events focusing on nutrition, disability and aging, older women, income security, transportation, housing, and other issues of importance to older persons and their families.

PREPARING FOR THE NEEDS OF A GROWING AGING POPULATION

- Established an Initiative on Redefining Retirement designed to lay the foundation for changing behaviors, attitudes and choices for planning and improving our quality of life. The Initiative seeks to educate and motivate baby boomers to make thoughtful choices now so that they will be more likely to be financially secure, productive, healthy and socially involved in their later years.

- Initiated the National Planning Objectives Project:
  - Brought together for the first time various leaders of the public and private sector to explore and initiate a process for setting national planning objectives for an aging society.
- Established mechanisms for policy dialogue at the national, state and local level:
  - Funded the National Academy on Aging to serve as a resource for objective information on broad policy issues including the Older Americans Act, Medicare, Medicaid and Social Security.
  - Provided funding for an initiative designed and implemented by the Council of Governors' Policy Advisors to provide an understanding of the implications of an aging population for state policymaking.
- Established Partnerships with Other Federal Agencies:
  - Entered into a Memorandum of Understanding with the Social Security Administration to engage in collaborative activities to better inform middle- aged and younger groups about planning for a longer life span and for retirement security.
  - Promoted the Department of Labor's Retirement Savings Education Campaign to encourage savings.
- Established Partnerships With the Private Sector
  - Co-sponsored a publication produced by the Metropolitan Life Insurance Company which provides tips on how to enjoy one's retirement.

Addressing Diversity

IMPROVING SERVICE DELIVERY TO HISPANIC ELDERS

- Co-chaired the HHS Working Group on Hispanic Issues which worked to improve the delivery of services to Hispanic customers. The working group prepared a final report and recommendations for the Secretary on strategies for improving services to Hispanic Americans.
- Through the Eldercare Locator, a nationwide Congressionally mandated information and referral service funded by AoA, assistance is being made available in Spanish and the Locator is beginning an outreach campaign to inform the Hispanic community about this important service. A Spanish language brochure and advertisements have been developed.

RAISING DIVERSITY ISSUES RELATED TO WELFARE REFORM

- Participated in the intra-departmental process pertaining to welfare reform, providing information on issues related to older immigrants, persons with disabilities, and other vulnerable subpopulations of elderly Americans.

WORKING TO IMPROVE THE QUALITY OF LIFE FOR OLDER WOMEN

- Established an Initiative on Older Women designed to improve the quality of life for America's older women by raising the nation's awareness of their contributions and by developing an action agenda for addressing their needs.
- Participated with the Pension Welfare Benefits Administration in launching the "Pensions Not Posies Campaign" -- a public education effort developed by the Pension Policy Consortium (Older Women's League, Pension Rights Center and National Senior Citizens Law Center) to inform women about the importance of pensions and future planning.
- In 1995, convened a "Celebration of Older Women" to educate women and other organizations not traditionally involved in aging issues about the contributions women make to their families and communities as well as the importance of this rapidly growing segment of our older population.
- Established the National Policy and Resource Center on Women and Aging to provide a National focal point for coordinating efforts to educate older women at a grassroots/local level about issues of concern including income security, health, housing and caregiving. Key activities of the Center include:
  - A National Conference on Women and Aging convened in conjunction with the Office of

Women's Health in the Department of Health and Human Services. This post-White House Conference on Aging event brought together representatives of national women's organizations and national aging organizations to address women's concerns about aging.
    - A monthly newsletter which focuses on critical issues impacting older women including Social Security and managed care. Also publishes numerous pamphlets and reports on topics of interest to women including hormone replacement therapy, caregiving, housing, health care and economic security.
- In conjunction with the Pension Rights Center, convened a roundtable discussion entitled "Grass Roots Innovations for Older Women's Employment." The forum highlighted innovative mechanisms at the state and local level for assisting women to overcome barriers to employment in areas of job training, caregiving and pensions.
- Participated in inter/intra-agency working groups, including HHS Secretary Shalala's work group to prepare for the 39th session of the UN Commission on the Status of Women; the Beijing Task Force which focuses on implementation of recommendations that came out of the 4th World Conference on Women; and the National Action Plan on Breast Cancer Federal Coordinating Committee.
- Worked with the Department of Health and Human Services, the Office of Public Liaison at the White House, and the Office of the First Lady in a campaign to promote the availability of Medicare coverage for and use of mammography screenings by older women.

Expanding International Partnerships

ESTABLISHING COOPERATIVE EFFORTS WITH MEXICO

- Worked to establish stronger partnerships between Mexico and the United States in preparing for the growing numbers of older persons in both countries and to elevate aging matters as a priority issue.

PROVIDING INTERNATIONAL TRAINING AND TECHNICAL ASSISTANCE

- Signed a memorandum of understanding between AoA and Sister Cities International which joins aging professionals and volunteers in the U.S. with their counterparts in other countries to provide technical assistance in meeting the needs of an aging population.

Go to Top of Page Go to What's New Menu Go to top of AoA Home Page

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Developed by Brian Lutz, Administration on Aging
Hypertext by Saadia Greenberg, December 17, 1996

Medicaid Waivers

A. What are Medicaid Waivers?

1. In general, there are two types of Medicaid waivers that can be provided within HCFA: "program" waivers and "research and demonstration" waivers.

2. In contrast to research waivers, which can be quite broad in scope and permit experimentation in many areas, program waivers are usually limited in scope. In the Medicaid program, there are two types of program waivers:

a. home- and community-based service (HCBS) waivers, and

b. freedom of choice (FOC) waivers.

B. Home- and Community-Based Waivers

1. Medicaid home- and community-based service (HCBS) waivers afford States the flexibility to develop and implement creative alternatives to placing Medicaid-eligible individuals in medical facilities such as nursing homes. The HCBS waiver program recognizes that many individuals at risk of being placed in a medical facility can be cared for in their homes and communities, preserving their independence and ties to family and friends at a cost no higher than that of institutional care.

2. Under section 1915 (c) of the Social Security Act (the Act), States may request waivers of certain Federal requirements which impede the development of Medicaid-financed community-based treatment alternatives. The requirements that may be waived are in section 1902 of the Act and deal with statewideness, comparability of services, community income and resource rules, and rules that require States to provide services to all persons in the State who are eligible on an equal basis.

3. The Act specifically lists seven services which may be provided in HCBS waiver programs: case management, homemaker services, home health aide services, personal care services, adult day health, habilitation, and respite care. Other services, requested by the State because they are needed by waiver participants to avoid being placed in a medical facility (such as transportation, in-home support services, meal services, special communication services, minor home modifications, and adult day care) may also be provided, subject to HCFA approval. The law further permits day treatment or other partial hospitalization services, psychosocial rehabilitation services, and clinic services (whether or not furnished in a facility) for individuals with chronic mental illness.

4. States have the flexibility to design each waiver program and select the mix of waiver services that best meets the needs of the population they wish to serve. HCBS waiver service may be provided statewide or may be limited to specific geographic subdivisions.

5. States can make home- and community-based services available to individuals who would otherwise qualify for Medicaid only if they were residents of a medical facility. Federal regulations permit HCBS waiver programs to serve the elderly and disabled, the physically disabled, the developmentally disabled, or the mentally retarded or mentally ill. States may target 1915(c) waiver programs to individuals with a specific illness or condition, suchas technology-dependent children or individuals with AIDS.

6. To receive approval to implement HCBS waiver programs, State Medicaid agencies must assure HCFA that, on average, the cost of providing home- and community-based services will not exceed the cost of care for the identical population in an institution. The Medicaid agency must also document that there are safeguards in place to protect the health and welfare of beneficiaries.

7. HCBS waiver programs are initially approved for 3 years and may be renewed at 5- year intervals.

8. HCFA's first home- and community-based waiver program was established in 1981. There are currently over 200 HCBS waiver programs in effect, serving more than 250,000 people as cost effective and humane alternatives to confinement in a medical facility. All States except Arizona have at least one such program. Arizona is a technical exception, though, because it runs the equivalent of an HCBS waiver program under section 1115 demonstration waiver authority.

9. HCBS waiver programs are currently the responsibility of the Medicaid Bureau's Office of Long-Term Care Services within HCFA.

C. Freedom of Choice Waivers

1. Freedom of choice (FOC) waivers are authorized under section 1915(b) of the Act. Through this section, HCFA may give States the authority to waive certain provisions of section 1902 of the Act including:

a. beneficiaries' right to select their own Medicaid providers,

b. comparability of services, and

c. the requirement to make any service provided available statewide.

2. Freedom of choice--or 1915(b)--waivers allow States to place beneficiaries in primary care case management programs (PCCMs), which are run on a "managed" fee-for-service basis using a gatekeeper concept, or in a prepaid capitated arrangement. The latter type of arrangement can involve mandatory enrollment in health maintenance organizations (HMOs), health insuring organizations (HIOs), or prepaid health plans (PHPs).

3. At present, freedom of choice waivers are approved for 2-year periods and may be renewed at 2-year intervals.

4. The purpose of freedom of choice waivers is to improve beneficiary access to care through enrollment in a guaranteed provider network which operates in a cost efficient manner. Such waivers also facilitate the monitoring of beneficiary quality of care. They frequently place beneficiaries in delivery systems in which there is greater emphasis on health education and preventive medicine.

5. Enrollment in both FOC waiver programs and voluntary managed care programs has greatly increased in recent years. As of June 30, 1995, approximately one-third of all Medicaid beneficiaries were being served by managed care programs of various types (including demonstration programs,see below).

6. Not all managed care programs require FOC waivers. Programs in which beneficiaries may choose between fee-for-service and some form of managed care or which do not otherwise restrict a client's choice of providers do not require 1915(b) waivers.

7. FOC waiver programs must ensure that Medicaid beneficiaries have a choice of at least two or more providers.

8. FOC waiver programs are currently the responsibility of the Medicaid Managed Care Team within HCFA's Office of Managed Care (OMC).

D. Research and Demonstration Waivers

1. Under section 1115 of the Act, States can deviate from a great many standard Medicaid requirements in order to test new ideas of policy merit. In return for greater flexibility, such States must commit to a policy experiment that can be formally evaluated.

2. Section 1115 waivers, also called "research and demonstration" waivers, are being used increasingly by States to enact a broad variety of initiatives. Approved waiver programs range from small-scale pilot

projects testing new benefits or financing mechanisms to major restructurings of State Medicaid programs. States are also using 1115 waivers for welfare reform projects.

3. Demonstration waiver authority can normally be granted for up to 5 years at a time. Such authority permits States to try out a far greater range of policies than would otherwise be permissible in ordinary freedom of choice waiver programs. Under 1115 demonstrations, for example, States may:

-- require beneficiaries to stay enrolled in the same managed care plan for longer periods of time in their mandatory Medicaid managed care programs and contract with a greater variety of managed care entities,

-- cover new services,

-- offer different service packages or different combinations of services in different parts of the State,

-- test new reimbursement methods, and

-- change Medicaid eligibility criteria in order to offer coverage to new or expanded groups.

4. States may not use 1115 demonstration waivers to waive all Medicaid policies or program requirements, however. Among the requirements that HCFA will not or cannot legally allow to be waived are:

-- services for pregnant women and children,

-- copayment and other cost sharing requirements for current categorically needy eligibles,

-- Federal matching Medicaid (FMAP) rates

-- requirements for maintaining appropriate levels of access to and quality of care, along with QA monitoring responsibilities,

-- current HCFA contract approval authority, and

-- applicable requirements of the Employee Retirement and Income Security Act (ERISA).

In addition, 1115 demonstrations must demonstrate that they are budget neutral. This means that such programs cannot cost more over their duration than the Medicaid program would have spent in the absence of the demonstration.

5. HCFA's Office of Research and Demonstrations (ORD) is responsible for section 1115 waiver programs. Until recently most of these have not been large-scale demonstrations in the sense of involving entire State Medicaid programs. Since 1993, however, with the new emphasis on State flexibility, a rapid growth in the number of major demonstrations has occurred; and a great deal of potentially fruitful Medicaid program restructuing is being tested in this manner.

6. ORD works closely with the Medicaid Bureau, Office of Managed Care, and HCFA's Regional Offices in reviewing, implementing, and monitoring state wide health reform demonstrations.

Contacts:

For program information regarding the status of all 1115 State waivers or pending 1115 State waivers, please contact Gloria Smiddy at (410) 786-7723 or E-mail, gsmiddy@hcfa.gov.

For information regarding home and community-based waivers (1915(c)), please contact Mary Jean Duckett at (410) 786-3294 or E-mail, mduckett@hcfa.gov.

For information regarding freedom of choice waivers (1915(b)), please contact Anna Meyers at (410)

786-5364 or E-mail, ameyers@hcfa.gov.


Return to Medicaid Professional/Technical Page

Last updated July 22, 1997

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Profile:

46 year old Caucasian male is caring for his parents at home. The Caregiver's mother is 78 years old and was diagnosed with Alzheimer's disease in 1992. Currently, mother requires total assistance in all her care, such as bathing, dressing, feeding, etc. She is bedbound, incontinent of bowel and bladder (she uses a catheter and Depends), and cannot speak or communicate. The only movement she can make is with her eyelids and she is nonresponsive to touch in all areas. The caregiver turns the patient every few hours to prevent bedsores.

The caregiver's father is 85 years old and suffered a stroke in 1992, one month after his wife was diagnosed with Alzheimer's disease. Father requires constant supervision due to his confusion and short term memory loss. Father's condition has declined recently, he has fallen, and he also being evaluated for a heart condition. Father needs assistance with dressing, bathing, and is incontinent of bladder, especially at night.

Del Oro Caregiver Resource Center has been working with this caregiver since 1992 to provide assistance with his difficult situation. Del Oro provides monthly respite care (since 1993) to caregiver for both his mother and father. Del Oro has provided ongoing emotional support and family consultation services to this caregiver. The caregiver copes with his stress through his art (paintings and sculpture) which is inspired by his caregiving. Recently he had an exhibit of his art locally and has another show planned soon.

*Del Oro CRC recommends this caregiver as a speaker.

NO. Medical

Caregiver:
Care Recipients: P6/(b)(6)

[001a]

Deborah

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Profile:

71 year old Caucasian male has been caring for his 66 year old wife with Multiple Sclerosis at home. Wife was diagnosed with MS in 1960 and needs assistance with bathing, dressing, grooming, and is incontinent of both bowel and bladder. Patient is unable to walk, uses a wheelchair, and needs complete assistance to transfer. The patient mainly stays in bed due to weakness in her body and pain in her back. Caregiver originally contacted Del Oro Caregiver Resource Center in 1992 after his wife broke her hip, and he hurt his back when lifting her. Del Oro CRC has provided ongoing emotional support and family consultation services to this caregiver. Del Oro has also provided monthly respite services for the past 6 years for in home care services to allow the caregiver some time off in his caregiving role. The respite services provided by Del Oro have allowed the caregiver to continue teaching kayaking and being outdoors as this reduces his stress. Caregiver receives support from his daughter, though it is limited. The patient is able to communicate and states that her strong Christian faith helps her cope with this difficult situation. Both the patient and caregiver will attend the forum on Monday at the Senior Center.

Caregiver:
Care Recipient: P6/(b)(6) [0016]

Sarah

PROFILE:

This caregiver is a 57 year old Caucasian male who is caring for his 58 year old wife who was diagnosed with Alzheimers Disease in 1993. This caregiver continues to work full-time in order to provide for his wife's care. He is also caring for his 95 year old father on the weekends. Currently his wife needs direction and/or physical assistance with all her Activities of Daily Functioning such as bathing, dressing and grooming. The patient has exhibited increased tearfulness and irritability as well. She attends the Triple "R" program three times a week. Del Oro Caregiver Resource Center has provided emotional support, family consultation services and ongoing respite for the patient to attend the Social Day Center. Del Oro Caregiver Resource Center has also provided information and referral services to the caregiver as he hired private in-home help to assist with personal care as needed. His wife will be at the Triple "R" daycare program on Monday. He is a soft-spoken, thoughtful and articulate man. He is an example of someone who is juggling a number of different roles successfully.

CAREGIVER: James Burns
CARE RECIPIENT: Ruth Burns

Sarah

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PROFILE:

This caregiver is a 54 year old Caucasian female who is caring for her 57 year old spouse who suffered anoxic brain injury in 1994 after going into cardiac arrest. This caregiver continues to work part-time as well as care for her husband. Today the patient needs assistance with bathing, dressing and grooming. The patient has aphasia, memory loss and has experienced hallucinations in the past. The patient now attends the Triple "R" program five times a week and will be at the center on Monday. This caregiver has been able to benefit from Del Oro's respite care which assists with covering some of the cost of his attendance at the daycare program. She has also benefitted from ongoing emotional support and family consultation from Del Oro Care giver Resource Center. She reports one of her challenges to be that the patient presents high-functioning, but actually has significant brain injury. This caregiver attends a Care giver Support Group to help her cope with the stress. She is energetic, positive and articulate and would feel comfortable speaking publicly.

*Del Oro highly recommends this caregiver.

CAREGIVER: P6/(b)(6) [0010]
CARE RECIPIENT: P6/(b)(6)

Sarah

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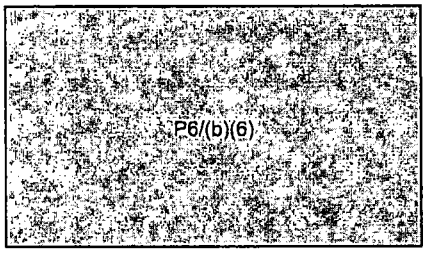
b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

PROFILE:

This caregiver is 38 year old Hispanic woman who is caring for her 68 year old father who was diagnosed with Parkinson's Disease and Dementia in March of 1993. The caregiver currently lives with her spouse, their two children ages 10 and 6, and her father. She cares full-time for her father as well as her own children. This caregiver's father has multiple unstable medical needs as well. P6/(b)(6) . Currently the patient requires assistance with all Activities of Daily Living such as bathing, dressing and grooming. He is currently receives nutrition through a feeding tube and has had multiple hospitalizations in the last year. This caregiver has been a Del Oro Caregiver Resource Center client since 1995 and has benefitted from in-home respite, on-going family consultation and emotional support. This caregiver has a strong support system in her spouse and extended family. She remains committed in caring for her father at home until the end of his life. She has sought individual as well as couple's counseling to cope with the ongoing stress of her multiple roles. Some of this counseling has been provided by a Del Oro Caregiver Resource Center Family Consultant. She is an example of a Sandwich Generation caregiver (caring for both parent and children).

[old]



CAREGIVER: Barbara Cepeda-Adams
CARE RECIPIENT: Jesus Cepeda

turn for the worse in September.

Del

4

- backing from lifting
- left job

Deborah

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001e. profile	re: names (partial) (1 page)	n.d.	P6/b(6)

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Long Term Care [Folder 6]

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RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

P1 National Security Classified Information [(a)(1) of the PRA]
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RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

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PROFILE:

This caregiver is 64 year old Hispanic female who is caring for her 98 year old mother who was diagnosed in 1997 with Dementia. She recently moved her mother here from the Midwest. She is caring for her mother full-time. This caregiver is an only child so she does not have additional sibling support. Currently the patient needs assistance with bathing, dressing and toileting. She also needs cueing to complete additional personal care tasks. The caregiver reports her mother is having increasing difficulty expressing herself. The patient attends the Triple "R" program three times a week. The caregiver will be utilizing Del Oro's legal consultation services. She also benefits from ongoing emotional support and family consultation services from her Family Consultant at Del Oro Caregiver Resource Center. Her mother will be at the day center on Monday. This caregiver is open and expressive and has a strong understanding of her mother's needs.

CAREGIVER: P6/(b)(6) [Cole]
CARE RECIPIENT: P6/(b)(6)

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001f. fax	David Baker to Sarah Bianci re: phone number (partial) (1 page)	12/30/1998	P6/b(6)

COLLECTION:
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Devorah Adler
OA/Box Number: 20469

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Fax Transmission

Del Oro Caregiver Resource Center
5713A Marconi Avenue
Carmichael, CA 95608
916-971-0893/ Fax 971-9446

To: Sarah Bianci

Fax #: 202-456-5557

From: David Baker

Pages (including cover sheet): 11

December 30, 1998

Sarah,

The following are the profiles that we have selected for the event. We were uncertain whether you were going to call all of the profiles sent to you or only the three that you select. Because of this uncertainty and issues of confidentiality, we did not enclose the caregiver's phone numbers. However, we will provide them to you as soon as you make your final selection. If there are any questions or problems, please feel free to contact me at home as early as need be at P6/(b)(6) or at Del Oro after 7AM Pacific Time.

[001f]

Sincerely,

David Baker
Gerontologist
Community Resource Specialist

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Profile:

41 year old Caucasian son is providing care for his 72 year old mother who has been diagnosed with Parkinson's Disease for about nine years. The caregiver has been caring for his mother in his home for less than one year after relocating her from another state. The caregiver has always been supportive of his mother and her care in other capacities. The caregiver's mother requires assistance with dressing and bathing, and is incontinent and requires supervision when ambulating due to an unsteady gait. The caregiver's mother is easily confused and will often repeat herself. The caregiver is in the process of a re-evaluation by a physician to determine if she has Alzheimer's Disease as well as Parkinson's Disease. The caregiver also is trying to support his spouse who is caring for her father who is ill. The caregiver works full-time with respite assistance provided by Del Oro Caregiver Resource Center. The caregiver has also used the legal consultation provided by Del Oro to make sure his mother's affairs are in order. Del Oro has provided on-going emotional support and family consultation services to the caregiver as well as education about Parkinson's Disease and caregiving issues at a local conference.

CAREGIVER: P6/(b)(6) [illegible]
CARE RECIPIENT: P6/(b)(6)

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PROFILE:

This caregiver is a 60-year-old Australian female who is caring for her 90-year-old mother who was diagnosed with Dementia in 1996. When first contacting Del Oro Caregiver Resource Center in January 1998, the caregiver had recently relocated her mother to her home, was experiencing marital problems, and was diagnosed with breast cancer and needed surgery. The caregiver's mother needs assistance with bathing, showering, dressing, preparing meals, taking medication, using the telephone, mobility, as well as containment of wandering. Del Oro Caregiver Resource Center provided the caregiver with family consultation, legal/financial consultation, and emergency respite services due to her emotional stress and physical health issues. Del Oro Caregiver Resource Center is providing the caregiver with monthly respite services. Caregiver must return to work due to financial difficulties.

Caregiver: P6/(b)(6) [001h]

Care Recipient: P6/(b)(6)

January 3, 1999

REMARKS ON A NEW INITIATIVE TO ADDRESS GROWING LONG-TERM CARE NEEDS AND SUPPORT FAMILY CAREGIVERS

DATE:	January 4, 1999
TIME:	10:30 am to 11:00 am (Pre-brief)
	11:00 am to 11:15 am (Meet and Greet)
	11:15 am to 12:10 pm (Event)
LOCATION:	Oval Office (Pre-brief)
	Blue Room (Meet and Greet)
	Grand Foyer (Event)
FROM:	Bruce Reed / Chris Jennings

I. PURPOSE

You are unveiling a new long-term care initiative to support Americans with long-term care needs and the millions of family members who care for them.

II. BACKGROUND

Overview. You will unveil a new, four-pronged initiative that takes important steps to address the complex needs of long-term care recipients and their family members through:

- **Supporting families with long term care needs through a historic $1000 tax credit.** This initiative, for the first time, acknowledges and supports the millions of family members who care for and house their ill or disabled relatives through a $1,000 tax credit. This new tax credit supports the diverse needs of families by compensating a wide range of formal or informal long-term care for people of all ages with three or more limitations in activities of daily living (ADL) -- such as adult day care, respite care reduced hours at work. This proposal, which supports rather than supplants family caregiving, would help about 2 million Americans, including 1.2 million older Americans, over 500,000 non-elderly adults, and approximately 250,000 children. It costs $5.5 billion over five years and phases out beginning at $110,000 for couples and $75,000 for unmarried taxpayers.

- **Creating an unprecedented National Family Caregiver Support Program.** Recent studies have found that services like respite care can relieve caregiver stress and delay nursing home entry, and that support for families of Alzheimer's disease patients can delay institutionalization for as long as a year. This new nationwide program would support families who care for elderly relatives with chronic illnesses or disabilities by enabling states to create "one-stop-shops" that provide: quality respite care or adult day care services; critical information about community based long-term services that best meet a family's needs; and counseling and support, such as teaching model approaches

for caregivers that are coping with new responsibilities and offering training for complex care needs, such as feeding tubes. This $125 million program would serve approximately 250,000 families nationwide.

- **Launching a national campaign to educate Medicare beneficiaries about the programs' long-term care shortcomings and how best to evaluate long-term care options.** Nearly 60 percent of Medicare beneficiaries are unaware that Medicare does not cover most long term care, and many do not know what long-term care services would best meet their needs. This $10 million nationwide campaign would provide all 39 million Medicare beneficiaries with critical information about long-term care options including: what long-term care Medicare does and does not cover; how to find out about Medicaid long-term care coverage; what to look for in a quality private long term care policy; and how to access information about home and community based care services that best fit beneficiaries need.

- **Having the Federal government serve as a model employer by offering quality private long-term care insurance to Federal employees.** You also called on Congress to pass a new proposal that allows the federal government as the nation's largest employer to use its market leverage and set a national example by offering quality private long-term care insurance to all federal employees, retirees, and their families. This proposal will provide employers a nationwide model for offering quality long-term care insurance. OPM anticipates that approximately 300,000 Federal employees would participate in this program.

Role of the Vice President and Mrs. Gore. The Vice President and Mrs. Gore are participating in this event from the Triple "R" Adult Day Care Program, an adult day care program serving approximately 30 families in the Sacramento area. ~~This program is similar to~~ the family caregiving resource programs that the Administration is launching nationwide today. The Vice President and Mrs. Gore, who will meet with a number of families with long-term care needs during your remarks, will join you via satellite at 11:40 to discuss the experiences of these families.

Program Participants.

Patricia Darlak, who will introduce you at the event, is a Maryland resident who has recently assumed the responsibility of caring for her 83 year old mother. Mrs. Darlak is a special education teacher in Maryland. Her mother was diagnosed with Alzheimer's almost 2 years ago and has been living with the Darlaks for four months. She currently requires assistance with bathing, dressing, eating, and toileting. Mrs. Darlak had a great deal of difficulty finding information on how to obtain respite and adult day care services for her mother, and still has been unable to find a regular source of respite care. Presently, she drives home during her lunch break in order to check on her mother. She is very worried about the financial burden that caring for her mother creates, especially since she and her husband are still responsible for their two children, who are in college in Florida. The Darlaks would be eligible for the proposed tax credit

and would benefit from the respite care, adult day care, and information and referral services provided by the proposed National Family Caregivers Support Program.

When they join you via satellite, the Vice President and Mrs. Gore will tell you about the following caregivers:

Barbara Cepeda-Adams is a 39 year old Hispanic woman who has cared for her father since 1994, when his Parkinson's disease made it impossible for him to continue to live by himself. Ms. Cepeda-Adams stopped working full time shortly after her father moved in with her and was forced to stop working altogether last January in order to care for him properly. Her father, Jesus Cepeda, currently requires assistance with bathing, dressing, eating, and toileting. He is incontinent and is unable to move around the house without assistance. Since Ms. Cepeda-Adams is no longer working, her husband has been the sole financial support for both her father and their two children, aged 6 and 10. Although Mr. Cepeda has a limited income, it does not come close to covering the expenses associated with his care. The Cepeda-Adams family has greatly benefited from the services provided by California's model statewide family caregiving resource program, and would be eligible for the new proposed tax credit.

James Burns has been caring for his wife Ruth since 1993, when she was diagnosed with Alzheimer's disease. He continues to work full time in order to provide for his wife's care. Currently, Ms. Burns requires assistance with bathing, eating, dressing, and toileting. She is unable to move around the house without assistance. Mr. Burns receives respite care services and has enrolled his wife in the adult day care program administered by Triple "R".

III. PARTICIPANTS

Briefing Participants
You
The First Lady
Secretary Shalala
Secretary Rubin
Janice LaChance
Bruce Reed
Gene Sperling
Chris Jennings

Program Participants (Washington, DC)
You
The First Lady
Secretary Shalala
Secretary Rubin
Janice LaChance
Patricia Darlak

Program Participants (Sacramento, CA)
The Vice President
Mrs. Gore
Barbara Cepeda-Adams
James Burns

IV. PRESS PLAN

Information about the new initiative has been advanced to all major national papers for Monday. In addition, Secretaries Rubin and Shalala, together with Director LaChance, will brief members of the press at the beginning of Joe Lockhart's daily briefing.

V. SEQUENCE OF EVENTS

-- **You** will ~~be briefed on how~~ the event will unfold.

-- **You** and the First Lady, together with Secretary Rubin, Secretary Shalala, and Director LaChance, will ~~spend 15 minutes in the Blue Room~~ meeting with Patricia Darlak.

-- **You** and the First Lady, together with Secretary Rubin, Secretary Shalala, Director LaChance and Patricia Darlak, are announced into the Grand Foyer.

-- The First Lady delivers remarks and introduces Patricia Darlak.

-- Patricia Darlak delivers brief remarks and introduces **you**.

-- **You** deliver remarks.

-- The First Lady introduces the Vice President and Mrs. Gore via satellite.

-- **You** proceed to your seat.

-- The Vice President and Mrs. Gore deliver remarks. (**You** will ~~have the option to~~ ask follow-up questions; please see attached Q&A.)

-- Upon conclusion of the discussion, the Vice President makes concluding remarks and bids farewell.

-- **You** deliver concluding remarks and depart.

VI. REMARKS

Your remarks have been prepared by speechwriting.

VII. ATTACHMENTS

-- Background on the California program
-- Questions and Answers

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
002. email	Devorah Adler to Jeanne Lambrew re: conference call lines (partial) (1 page)	12/31/1998	P6/b(6)

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Devorah Adler
OA/Box Number: 20469

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Devorah R. Adler
12/31/98 12:27:27 PM

Record Type: Record

To: Jeanne Lambrew/OPD/EOP

cc:
Subject: conference call lines

Jeanne -

here is the conference call information. I tried to get different access codes but could not -- sorry.

Devorah

---

3 pm - 4:30
call in line 456 6755 / 456 6766
access code 8888
8 lines

5 pm to 6
call in line 456 6777 / 456 6799 / 456 6766
access code 8888
15 lines

Maria Ibanez

P6/(b)(6) [002]

P6/(b)(6) Laura

Mike H.

National Family Caregiver Support Program

Authorizing Legislation: Section 341 of the Older Americans Act (OAA) of 1965, as amended (expired)

FY 1998 Enacted	FY 1999 President's Budget	FY 1999 House Action	FY 2000 Request
N/A	N/A	N/A	$150,000,000

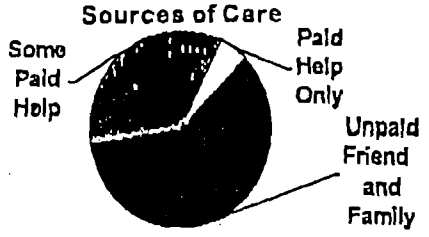
Unpaid families are the major providers of long term care (LTC) in this country. According to the 1994 National Long Term Care Survey, there are 7 million informal caregivers, i.e, spouses, adult children, other relatives, and friends, helping disabled older persons live in the community. These caregivers assist 95% of the older persons needing help. They are the sole source of assistance for almost two-thirds of these older persons.

Rationale for the Request

There are 7 million informal caregivers helping disabled older persons live in the community. This informal care, if provided by home care aides, would cost $45-75 billion per year.

Help for caregivers is needed now more than ever due to changing aspects of our society such as increased population longevity and changing family patterns which are placing greater pressure on caregivers. Lengthening life spans mean that the population age 85 and over has grown and will continue to grow faster than any other population cohort, e.g. From 1996 to 2010, this population will increase by 50 percent. With advanced age comes an increase in chronic disease leading to significantly higher disability levels and therefore greater need for assistance.

While the U.S. population is aging, the structure of the American family is rapidly changing: more women are employed in the workforce thus making it more difficult for them to be available as caregivers; family mobility has increased thus geographically separating older family members from younger ones; and family size has decreased resulting in fewer adult



children being available to serve as caregivers. Thus, caregiving responsibilities will increasingly be shared by fewer family members.

Research has shown that providing care to older persons exacts a heavy emotional, physical, and financial toll.

caregiving to older persons can exact a heavy emotional, physical, and financial toll.

- Half of all caregivers of older persons are over the age of 65, and thus are vulnerable to a decline in their own health. In fact, one third of caregivers of older persons describe their own health as fair to poor;
- Because primary caregivers are emotionally strained, they have a high rate of depression. Numerous studies show that caregivers are significantly more depressed than age-matched controls in the general population;
- Almost one third of caregivers are employed full-time, and most of these caregivers have experienced conflicts that require them to rearrange their work schedules, work fewer hours or take an unpaid leave of absence.

Research also indicates that informal caregiving supports have a significant impact on the status of caregivers as well as on delaying the need for nursing home services. For example, a recent NIH study found that the provision of adult day care not only reduces caregiver stress but delays institutionalization of the care recipient as well. Another recent study indicates that counseling and support for caregivers of individuals with Alzheimer's disease can permit the care recipient to stay at home an additional year before being admitted to a nursing home.

The provision of adult day care reduces caregiver stress and delays/prevents institutionalization of the care recipient

To date, public financing has been directed to support formal services for older people. It has not provided an organized response to help maintain and sustain the efforts of caregivers.

Purpose and Method of Operations:

The Administration on Aging (AoA) proposes to establish a **National Family Caregiver Support Program** to help families sustain their caregiving roles. The program, proposed for funding at $150,000,000 in FY 2000, will establish a multifaceted support system in each state for family caregivers. All states will be expected to put in place five basic system components:

- Information about resources that will help them in their caregiver roles;
- Assistance to families in locating services from a variety of private and voluntary agencies;
- Caregiver counseling, training and peer support to help them better cope with the emotional and physical stress of dealing with the disabling effects of a family member's chronic condition;
- Respite care provided in one's home, an adult day care center or over a weekend in a nursing home or residential setting such as an assisted living facility; and
- Limited supplemental services to fill a service gap that cannot be filled in any other manner.

Information for Caregivers

Assistance locating services

Caregiver counseling

Respite care

Limited supplemental services

The National Family Caregiver Support Program will include three interelated elements:

- A formula grant program through which a basic family caregivers support system will be established in each state.
- Competitive innovation grants though which states will develop new approaches to specialized caregiving issues such as promoting employer caregiver support that can be adopted by the private sector and through demonstrations and applied research, the results of which will be translated into practice through incorporation into the formula grant program.
- AoA collaboration with sister agencies in the Department, e.g. ASPE, CDC and HCFA, to enhance public health education efforts directed toward caregivers, conduct research, and provide technical assistance.

AoA has actively supported the development of home and community based systems of LTC throughout the country. This has included funding national research and demonstrations in family caregiving, respite care, and adult day care. As a partner in the Department's LTC initiative, AoA will take this experience and that of other agencies to develop appropriate caregiver support systems in each state.

AoA is submitting legislative language to amend Title III of the Older Americans Act (OAA) to establish the National Family Caregiver Support Program.

Further discussion is found in the Annual Performance Plan.

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P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [a)(5) of the PRA]
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C. Closed in accordance with restrictions contained in donor's deed of gift.
PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).
RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

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b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
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Presidential Records Act - [44 U.S.C. 2204(a)]

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Profile:

62 year old Caucasian female is caring for her 62 year old husband who was diagnosed with Huntington's Disease about two years ago. The caregiver's spouse requires assistance with dressing, bathing, and ambulating. The caregiver's spouse does exhibit some psychological behavior due to his diagnosis, such as sobbing, screaming, and crying daily. The caregiver works full-time and manages her spouse's care with the help of monthly respite provided by Del Oro Caregiver Resource Center. The caregiver has grown children who are also trying to cope with their father's illness. The caregiver is planning to utilize a legal consultation through Del Oro to assist her with long term care planning. The caregiver also has received emotional support through family consultation services and attended educational programs sponsored by Del Oro Caregiver Resource Center. This caregiver has also taken on the role of advocate and educator regarding caregiving and Huntington's Disease issues within the community. She recently participated in a family panel at a Huntington's Disease conference and shared her personal experience.

CAREGIVER: P6/(b)(6) [004]
CARE RECIPIENT: P6/(b)(6)

WORKING?

* Del Oro highly recommends this caregiver

Deborah

FOR ADDITIONAL INFORMATION CONTACT:

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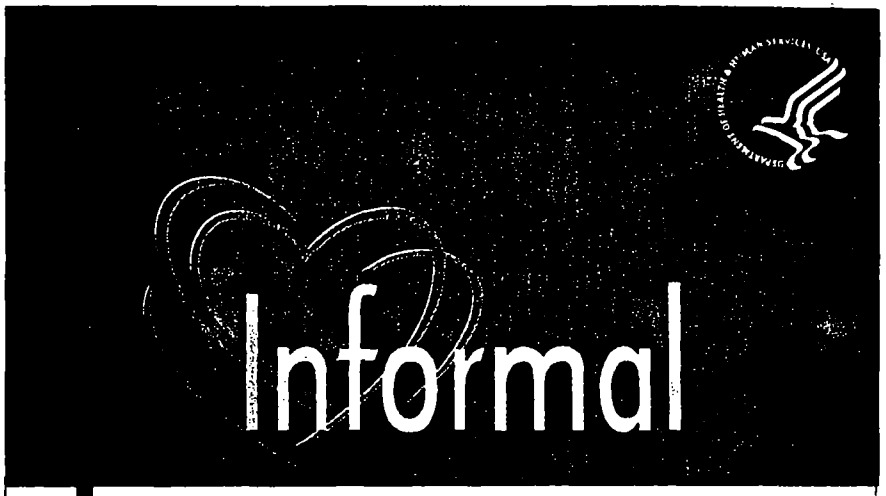


Informal Caregiving

COMPASSION IN ACTION

The Assistant Secretary for Planning and Evaluation
The Administration on Aging

Informal Caregiving

COMPASSION IN ACTION

AN INTRODUCTORY MESSAGE FROM

Bob Williams (Deputy Assistant Secretary/Disability, Aging, and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation)

Jeannette Takamura (Assistant Secretary for Aging)

This booklet, developed by the U.S. Department of Health and Human Services (DHHS) is about informal caregiving--unpaid care given voluntarily to ill or disabled persons by their families and friends. Informal caregiving by families and friends is the backbone of America's long term care system. According to recent surveys sponsored by DHHS, 52 million of our fellow Americans are informal caregivers. These caregivers provide help to individuals of all ages. They are the lifeline for aging parents. They provide loving care to spouses who can no longer care for themselves. With determination, and sometimes considerable sacrifice, they raise children with even the most severe disabilities at home. Increasingly, we see parents continuing to care for their sons and daughters with disabilities well into old age.

In our society, informal caregivers often go unnoticed except by those who depend on their care. The recipients of informal caregiving understand how important their caregivers' efforts are to their personal well-being. We would like the leaders of all segments of society--including policymakers, educators, the clergy and the media--to acknowledge and celebrate informal caregiving as one of the notable strengths of our Nation's families and communities. Nowhere are these strengths more evident than in the vital role that families and communities continue to play in providing informal care to family, friends, and neighbors who because of illness or disability need help with the routine activities of daily life.

Most of us think of "health care" as services provided by medical professionals (e.g., physicians and nurses) in hospitals, doctor's offices, and nursing homes. However, for individuals whose medical conditions or injuries have resulted in chronic illness or disability, the foundation of health care is access to help with daily living tasks, such as eating, bathing, leaving their homes to go to the doctor or to church. In most instances, this type of assistance can be provided by family members, friends, and neighbors because it involves helping others perform ordinary everyday activities.

In our view, we can draw two important lessons from the descriptive data presented in this booklet. The first lesson is that the contributions of informal caregivers are irreplaceable. We could not, as individuals or as a society, afford to pay the costs of replacing all informal caregivers with paid personnel. The second lesson is that we cannot take informal caregiving for granted. Providing informal care--particularly to an individual who requires a great deal of assistance on a daily basis--involves a substantial amount of time, dedication, and perseverance. Individuals who take on the role of "informal caregiver" will almost certainly be required to forfeit many hours of what might otherwise have been their leisure time. If employed, informal caregivers will likely face conflicts between their work and caregiving responsibilities. We also know that most informal caregivers gain personal satisfaction from helping family members, friends, and neighbors. Oftentimes this is what enables those who also experience considerable stress and burden to persevere.

In the years to come, it will become increasingly important to formulate policies that support and sustain informal caregiving. These policies must recognize that families and communities cannot always meet the needs of their ill and disabled members by themselves. Moreover, individual caregivers can not be expected or required to do so much that their own health and well being is placed in jeopardy. A great deal of debate may need to go into determining what are reasonable expectations for informal caregivers and how much is "too much." In order to accommodate the needs of informal caregivers, society may also need to adjust expectations in other areas of life, such as in the workplace. Some "family-friendly" policies have been put in place, such as the 1993 Family and Medical Leave Act, but much more thought and effort needs to be given to developing additional ways of enabling--but also, when necessary, providing relief to--informal caregivers.

PART I: INFORMAL CAREGIVING TO FAMILY AND FRIENDS ACROSS THE LIFE COURSE

INTRODUCTION

Individuals of all ages with disabilities depend on informal care provided by their families and friends to carry out many of the routine activities of daily life. Part I of this booklet presents information from the National Surveys of Families and Households. These surveys include data on the characteristics and extent of caregiving provided to all people with disabilities including young children, working age adults, and older people.

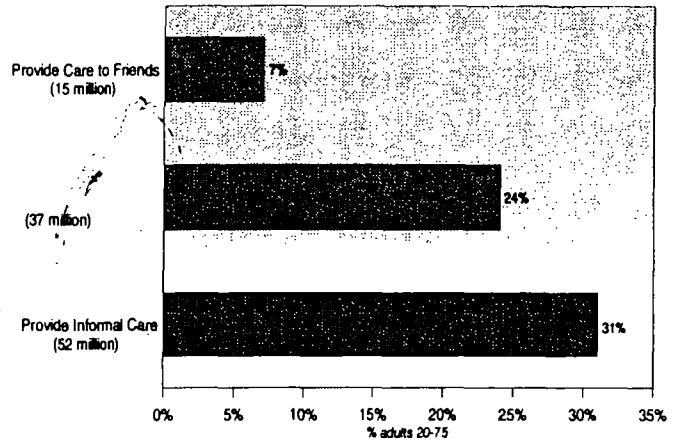
OVERVIEW

One in three Americans voluntarily provide unpaid informal care each year to one or more ill or disabled family members or friends.

- 52 million Americans (31 percent of the adult population age 20 to 75) provide "informal care" to a family member or friend who is ill or disabled. About 37 million of these caregivers provide help to family members and about 15 million provide help to friends.
- 8 percent of these caregivers reported providing help over the last year to more than one care recipient.

FIGURE 1

Adults 20-75 Providing Informal Care



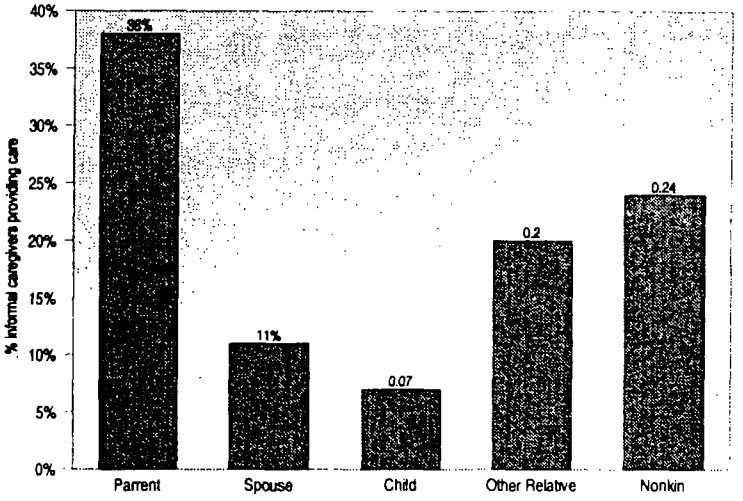
Source: National Survey of Families and Households

People at all stages of life give and receive informal care.

- The most common informal caregiving relationship is that of an adult child assisting an elderly parent. Thirty eight percent of informal caregiving is provided by children to aging parents.
- Eleven percent of informal caregiving is provided by spouses, most often to their elderly wives or husbands.
- Seven percent of informal care is provided to significantly disabled children, most often to adult disabled children by middle-aged parents.
- Finally, about 20 percent of informal care is provided to other relatives such as grandparents, siblings, aunts, and uncles, and about 24 percent is provided to friends and neighbors.

FIGURE 2

Recipients of Informal Care



Source: National Survey of Families and Households

One in five Americans are providing informal care to an ill or disabled family member at any point in time, reflecting the long-term nature of much informal care.

- Nearly 40 percent of individuals who reported providing informal care to an ill or disabled family member in the 1987 National Survey of Families and Households (NSFH) also reported providing informal care in the 1992 survey.

Caregiving responsibilities are assumed by adults of all ages but are most common in middle age.

- The average age of all informal caregivers is 43 years old. Spouses caring for their disabled husband or wife are somewhat older, with an average age of 55 years. Parents who care for an ill or disabled child have an average age of 46 years. The average age of those who assist other relatives is about 41.

- Adults in their forties and early fifties are twice as likely to provide informal care as adults in their twenties or seventies. Thirteen percent of Americans in their early twenties and 14 percent of adults aged 70 and older provide informal care, compared with 30 percent of Americans in the age group 40 to 54.
- Among Americans from their mid-twenties to their seventies, parents are the most frequent recipients of care. However, the likelihood of caring for an ill or disabled child is also greatest in middle age.
- Younger caregivers are more likely to care for other family members such as grandparents, aunts, and uncles. Caregiving to other relatives declines through middle age as other familial responsibilities take hold, but increases in the late fifties and early sixties. Over the age of 60, women frequently report providing care to a sibling.

Both men and women provide informal care. However, up to age 70, women are more likely to be caregivers and to provide more hours of care, to provide more care over longer periods, and to care for more than one person.

- Across all age groups, 27 percent of women as compared with 21 percent of men provide informal care over the course of a year.
- On average, women provide about 50 percent more hours of informal care per week to their care recipients than their male counterparts.
- Women are twice as likely as men to provide informal care to ill or disabled children. This is partly the result of traditional gender expectations for child care but also

because of the increase in households headed by single mothers.

- Mothers also provide about three times more informal care to children with disabilities who do not live in the same household. However, fathers provide informal care over slightly longer periods--averaging about 19 weeks over the course of a year compared with 15 weeks for mothers.
- The number of hours of informal care provided by men across the life course is relatively low--ranging from about 5 hours per week among men aged 60 to 64 to 11 hours per week among men in their late forties. The exception to this pattern are men in their late sixties who provide about 15 hours of help per week to their disabled wives.
- Nearly two-fifths of the women who reported providing informal care in 1987 also reported providing informal care in 1992--whereas only one-third of the men who were informal caregivers in 1987 also reported providing care in 1992.

Both black and white Americans are equally likely to provide informal care. However, black women are more likely to be caregivers than white women.

- Across the life course, black women are more likely to provide care to disabled relatives other than immediate family members than are white women. Additionally, the likelihood of parental caregiving to children with disabilities starts earlier in the life course for black women.
- White women are more likely to provide care to a disabled spouse, probably because of differences in marriage patterns between black and white women. White women

are most likely to care for an ill or disabled child as young adults or in early middle age. Caregiving for a child is more prevalent in late middle-age among black women. Six percent of black women in their fifties reported caring for an ill or disabled child.

- Parental caregiving for disabled children peaks for both blacks and whites in middle age. In addition, at similar ages, 8 percent of black men provide care to an ill or disabled parent and 15 percent of white men provide such care.

Caregiving also varies by marital status.

- Married caregivers are most likely to be assisting their aging parents while never-married caregivers are more likely to be giving informal care to disabled relatives outside the immediate family. Widowed, divorced, and separated caregivers are more likely to provide care to friends and neighbors.

Caregivers generally tend to be as healthy--and sometimes healthier--as the general population or non-caregivers their age.

- Three-quarters of all caregivers report that they are in "excellent or good health," while about 18 percent report they are in "fair health," and only 6 percent report that they are in "poor health."

- Spouse caregivers are twice as likely to report being in "poor or fair" health than the caregivers of parents, children or other relatives. This can be explained by the older average age of spouse caregivers.

- Conversely, caregivers to other kin are more apt to report "good or excellent" health, probably because they are younger, on average, than other caregivers.

- Daughters providing care to their ill or disabled parents are more likely to report being in "good or excellent" health than the average population; however, sons who provide such care report being no more or less healthy than the average.

The majority of informal caregivers are also employed.

- Nearly 64 percent of all informal caregivers report being employed during the previous twelve months. About 65 percent of caregivers who provided care to more than one person over the last year also reported being employed.

- The percentage of employed women caregivers closely mirrors the average percent of non-caregiving women in the work force. Working women caregivers are only slightly more likely to be working part-time (i.e., less than 35 hours per week) than are employed women in general. In 1992, 31 percent of non-caregiving women worked part-time and 41 percent of caregiving women worked part-time.

- Male caregivers are as likely to be in the labor force as other men who do not provide informal care. For men, caregiving did not affect their likelihood of working part-time.

- Working women employed full time generally provide as much care as women working part-time. On average, in 1992, full and part-time employed women provided 11 and 12 hours, respectively, of informal care per week.

- Of "career caregivers" (those who reported providing informal care both in 1987 and 1992), nearly 65 percent were employed in both years. The majority (88 percent) of career caregivers worked 35 hours or more per week in 1992.

SUMMARY

Providing informal care to ill or disabled family and friends is a normative experience. Most Americans will be informal caregivers at some point during their lives and many will provide informal care at various ages to multiple care recipients.

(DATA SOURCES: The statistics reported above are from the 1987 and 1992 National Surveys of Families and Households. These surveys were designed and conducted by the University of Wisconsin, Center for Demography and Ecology, Madison, Wisconsin (Principal Investigators: James Sweet and Larry Bumpass). Funding for the surveys was provided by the National Institute for Child Health and Human Development and the National Institute on Aging, U.S. Department of Health and Human Services. Data analyses were performed by Janice I. Farkas, Research Associate, Department of Sociology, Duke University, and Christine L. Himes, Senior Research Associate and Assistant Professor of Sociology, Center for Policy Research, Maxwell School, Syracuse University, under contract to the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services.

PART II: IN-DEPTH FOCUS ON INFORMAL ELDERCARE

The most typical informal caregiving in the U.S. involves the provision of assistance to elderly persons who, because of chronic illness and/or disability, need help with everyday activities. The information in Part II of the booklet will takes a closer look at characteristics of caregiving for older people with functional disabilities.[1] The information provided below is drawn from the National Long Term Care Surveys. It is different from the information contained in Part I because it focuses exclusively on elderly recipients of care and their primary caregivers.

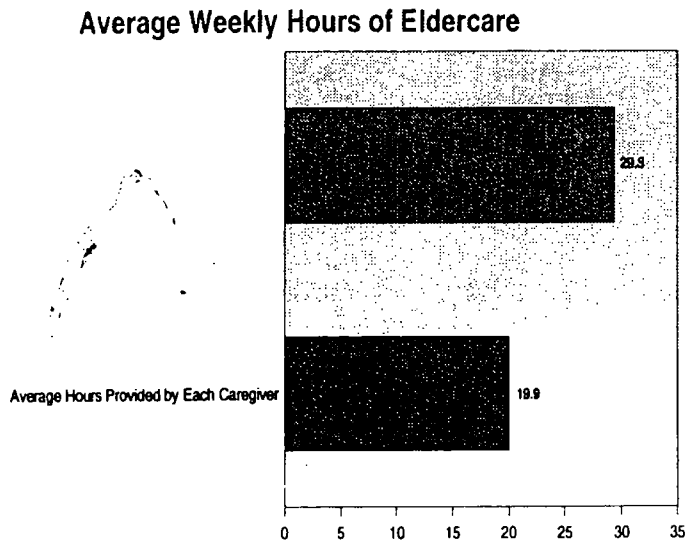
OVERVIEW

Over 7 million Americans provide 120 million hours of informal care to approximately 4.2 million functionally disabled elders each and every week. If the work of these caregivers had to be replaced by paid home care, the cost would run from $45 billion to $94 billion dollars a year.

- The majority of caregivers of disabled elders are assisting family members.
- The average number of informal caregivers per disabled elder is 1.7 and each caregiver provides an average of almost 20 hours of unpaid help each week.
- Each disabled elder receives an average of 29 hours of help from informal caregivers each week.

[1] Functional disability is defined as an inability to perform, without human and/or mechanical assistance, one or more of six basic Activities of Daily Living (ADLs) including bathing, dressing, moving around indoors, transferring from bed to chair, using the toilet, or eating, and/or one or more of nine Instrumental Activities of Daily Living (IADLs) including light housekeeping, meal preparation, grocery shopping, laundry, taking medications, managing money, telephoning, outdoor mobility, and transportation.

FIGURE 3



Source: 1994 national Long-Term Care Survey

Most older people with functional disabilities live in the community rather than in nursing homes.

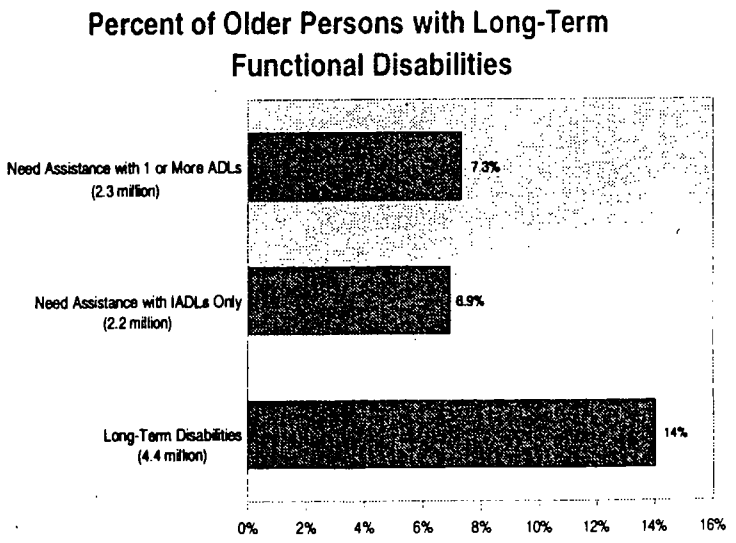
- Less than one-quarter of the elderly with functional disabilities--about 1.4 million people--live in nursing homes at any point in time, while 4.2 million live in their own homes and communities.
- Research suggests that informal care plays a significant role in preventing or delaying the need of a disabled elder to go into a nursing home. In fact, 1.6 million elders with severe long-term disabilities (defined as having 3 or more ADL dependencies or severe cognitive impairment) are able to live in the community in their own or relatives' homes. There are 1.4 million elders who live in nursing homes.

A Portrait Of Elders Living In The Community In Need Of Long Term Care

Of the 31.4 million Americans aged 65 and older living in the community, about 4.4 million (14 percent) have long-term functional disabilities. These disabled elders require on-going help from others for an extended period (3 or more months) to perform one or more ADL or IADL tasks.

- About 2.3 million elders need help with one or more ADL tasks such as eating, bathing or dressing.
- About 2.2 million elders need help with only IADL tasks, such as cooking, shopping or going outside of their house.
- Almost one million elders are severely cognitively impaired because they have Alzheimer's disease or another form of dementia.

FIGURE 4



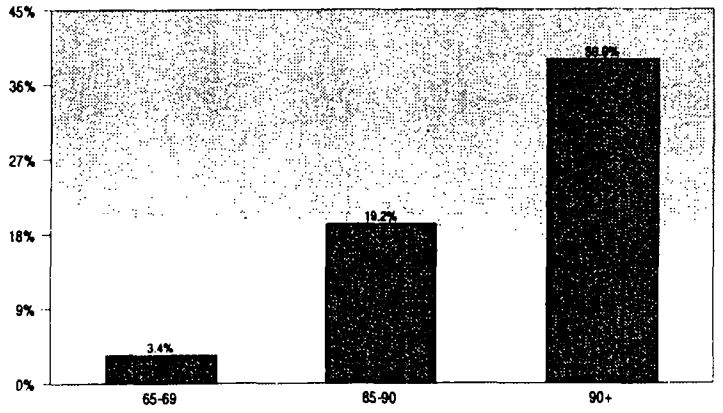
Source: 1994 national Long-Term Care Survey

Functional disability increases at older ages and is more common among elderly women than men.

- Among individuals aged 65-69, only 3.4 percent have an on-going need for help with an ADL activity. Among those aged 85 to 90, this percentage rises to a little over 19 percent, and by age 90 almost 40 percent of elders are limited in their ability to perfom ADL activities.
- Long-term functional disability is also more common among older women than older men. For example, in the 65 to 69 age group only about 2.5 percent of men have an ADL limitation while 4 percent of women do. Among elders age 90 or older, only about one-quarter of men need help to perform an ADL task while over 44 percent of women need such assistance.

FIGURE 5

ADL Disability by Age



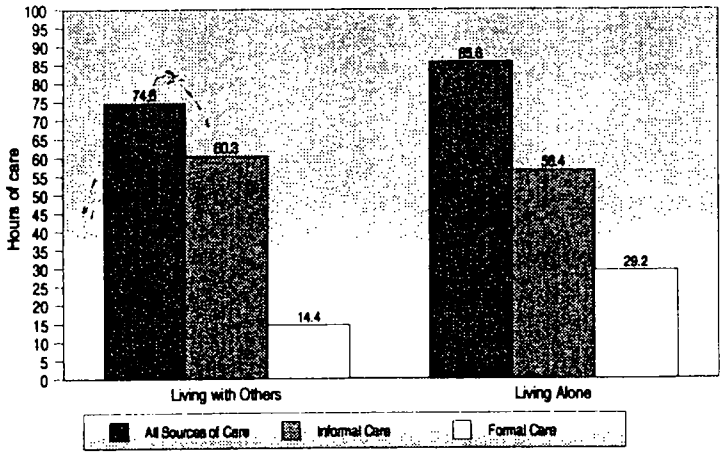
Source: 1994 national Long-Term Care Survey

Informal care is the main source of help for the majority of disabled elders living in the community.

- The majority of elders with functional disabilities continue to reside in the community rather than in nursing homes, even at higher levels of disability.
- The overwhelming majority (about 96 percent) receive at least some assistance from informal caregivers and about two-thirds rely exclusively on informal caregiving.
- As disability increases, elders receive more and more informal care. Eighty-six percent of elders at greatest risk of nursing home placement (those with 3 or more ADL disabilities) live with others and receive about 60 hours of informal care per week, supplemented by a little over 14 hours of assistance from paid helpers.
- The small proportion (4 percent) of disabled elders who live alone and experience high levels of disability receive more paid care (56 hours per week) than informal care (about 29 hours per week).

FIGURE 6

Care Received by Elders At Risk for Nursing Home Placement by Living Arrangement

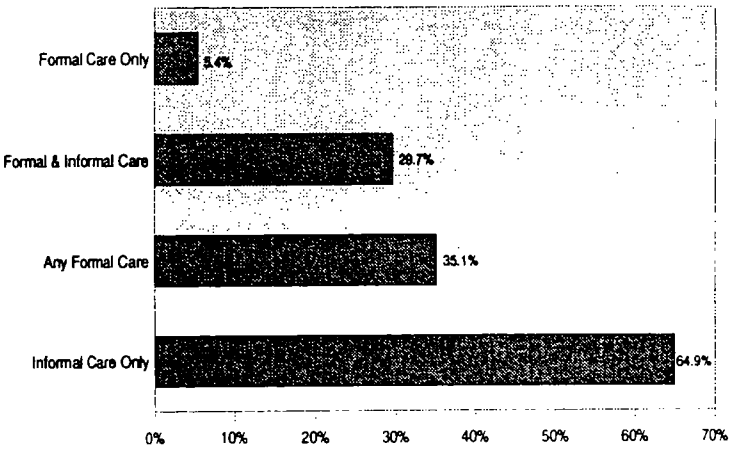


Source: 1994 national Long-Term Care Survey

THE ROLE OF FORMAL PAID HOME CARE

FIGURE 7

Use of Informal and Formal Care by Community-Dwelling Elders with Chronic Disabilities



Source: 1994 national Long-Term Care Survey

Formal paid home care is the exception, not the rule, for the great majority of functionally disabled elders.

- Slightly over one-third (35.1 percent) of disabled elders with long term care needs use any formal home care--and only 5.4 percent rely entirely on paid helpers.
- The use of paid home care is much greater among elders with moderate to severe levels of disability (that is, those requiring assistance with one or more ADL task). Roughly half of the most severely disabled elders (those who are considered at high risk of nursing home placement because they have 3 or more ADLs) use some paid home care.

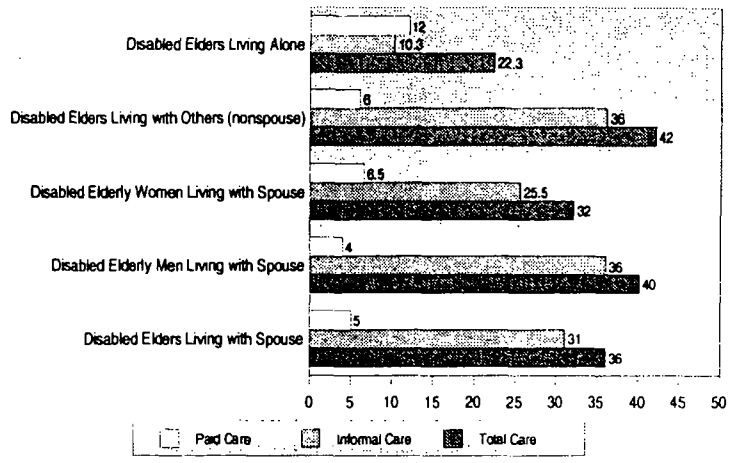
- Disabled elders who live with their spouses are least likely to rely on formal help, receiving on average about 5 hours of assistance from paid caregivers each week in comparison to the 36 hours of help they receive each week from informal caregivers. Disabled elderly men cared for by their wives use the least amount of paid care, averaging about 4 hours a week from formal home care providers in comparison to about 40 hours received informally.
- On the other hand, disabled elderly women who live with their husbands receive somewhat less informal help (about 32 hours per week) from their husbands and more help from paid caregivers (about 6.5 hours per week).
- The use of paid home care, although it still constitutes a relatively small proportion of all home care, has been slowly increasing from the early 1980s to the mid-1990s. In 1982, only 25 percent of elders with long-term care needs used any formal home care. By 1992, over 35 percent used paid care.

On average, disabled elders who live alone are less severely disabled than those who live with others. Even though disabled elders who live alone receive fewer total weekly hours of assistance from all sources, they receive more hours of paid help per week than those who live with others.

- Disabled elders who live with other relatives or with friends receive an average of 42 hours of care per week, of which 6 hours are from paid helpers.
- Disabled elders who live alone receive an average of 22 hours of care, of which 12 hours are from paid helpers.

FIGURE 8

Hours of Assistance Received Per Week By Type of Assistance, Care Recipient, and Living Arrangement



Source: 1994 national Long-Term Care Survey

WHO PAYS FOR HOME CARE

- Almost half of disabled elders who use formal home care pay for it themselves or their families pay for it out of pocket.
- Medicare is the most common third party payer. In 1994, slightly under one-third (31 percent) of disabled elders with long-term care needs used Medicare home health services at some point during the year. To qualify for Medicare home health coverage, beneficiaries must require skilled nursing or therapy services.

- Other payers include Medicaid, the Social Services Block Grant, Title III of the Older Americans Act, and the Veteran's Administration. Private long-term care insurance currently finances only very small amounts of home care--but may develop into a more significant funding source over the next twenty years.

In sum: Because the care that severely disabled elders require is very labor intensive, the evidence strongly suggests that most elders with 3 or more ADL disabilities are able to avoid nursing home admission and continue residing in the community because they do not live alone and are able to obtain most of the help they require on an unpaid basis, from family, friends, and neighbors.

Primary Informal Caregiver Characteristics

Experts on eldercare typically refer to the person who regularly provides the most assistance as the "primary" informal caregiver. Most disabled elders have a primary informal caregiver who provides the bulk of their care and obtains and coordinates additional help from other paid and unpaid "secondary" caregivers.

- Almost three-quarters of primary informal caregivers are women.
- The average age of primary caregivers is over 60 years old. Half are 65 or older and slightly over one-third are between the ages of 45 and 64.

- Over two-thirds (68 percent) of primary caregivers live in the same household with the disabled elders for whom they provide care and a majority of primary caregivers are spouses (40 percent) or adult children (36 percent). The prevalence of spouse caregiving is higher among elders with moderate to severe levels of disability.

In sum, disabled elders rely primarily on their spouses if they have spouses healthy enough to provide assistance. Adult (mostly middle-aged) children are the next most frequent source of informal eldercare--and constitute the main source of assistance for disabled elders who are widowed. Other relatives and friends are most often secondary helpers, stepping into the role of primary caregiver only when spouses or adult children are not available.

Employment And Caregiving

- While the great majority of primary informal caregivers are not employed because they are beyond retirement age, almost one-third (31 percent) do work. About two-thirds of those who are employed work full-time (35 or more hours per week). Employed primary caregivers work an average of about 40 hours per week.
- Employed caregivers personally provide fewer weekly hours of assistance than non-employed caregivers but they still make a substantial weekly time commitment to informal caregiving (18 hours per week, on average).

- Employed primary caregivers are less likely than non-employed primary caregivers to be sole caregivers; they are able to maintain their primary caregiving role even to elders with high levels of disability (3 to 5 ADLs), by obtaining supplemental assistance from other family members, paid caregivers, or a combination of help from both these sources.

- Even with supplemental help, employed primary caregivers contribute personally between 32 and 39 hours per week of informal care to their disabled elders with 3, 4, or 5 ADL dependencies.

CAREGIVING--THE GREAT BALANCING ACT

Caregiving can create some conflict for caregivers who have to balance work and caregiving responsibilities or who have health problems of their own.

- Primary caregivers are of disabled elders typically in late middle-age or even older, and as a result, a significant minority have health problems of their own. About one-third (31 percent) describe their own health as fair to poor.

- Two-thirds of working caregivers report experiencing conflicts between work and caregiving that caused them to rearrange their work schedules, work fewer hours than they otherwise would have, or take an unpaid leave of absence from work.

- Although most employed caregivers work full-time (35 or more hours per week), a significant minority of employed women who are primary caregivers cut back on their hours of work in order to provide eldercare. Close to half of part-time employed female primary caregivers report working less because of eldercare responsibilities. A smaller percentage of full-time employed female primary caregivers (16 percent) say that caregiving causes them to work fewer hours than they otherwise would.

- Nevertheless, the great majority of caregivers believe that their caregiving experience is rewarding to them.

SUMMARY

Most disabled elders with long-term disabilities rely primarily on informal care, predominantly from family members, to provide them with the functional assistance they require. When elders are severely disabled, it is most often the availability of informal care from relatives and friends, who provide substantial hours of assistance on a weekly basis, that makes it possible for them to avoid nursing home placement.

(DATA SOURCES: The statistics reported in Part II on informal eldercare in the community are from the 1982 and 1994 National Long-Term Care Surveys and the Informal Caregiver Supplement to the 1989 National Long-Term Care Survey. These surveys have been designed and conducted by the Duke University Center for Demographic Studies (Principal Investigator: Kenneth G. Manton). Funding for these surveys was provided by agencies of the U.S. Department of Health and Human Services, principally the National Institute on Aging. Data analyses were carried out by Pamela Doty, of the Office of the Assistant Secretary for Planning and Evaluation (OASPE), U.S. DHHS and Mary Elizabeth Jackson, of the MEDSTAT Group, Cambridge, MA., under contract to OASPE.)

PART III: ADDITIONAL SOURCES OF INFORMATION ABOUT CAREGIVING AND ASSISTANCE AVAILABLE TO INFORMAL CAREGIVERS

THE ELDERCARE LOCATOR

1-800-677-1116

The Locator provides information about community assistance for seniors in communities across the United States. The toll-free number is a public service sponsored by the U.S. Administration on Aging. An informative brochure describing the Eldercare Locator service is available free by contacting:

The National Aging Information Center
330 Independence Avenue, S.W.
Washington, DC 20201
(202) 619-7501

U.S. ADMINISTRATION ON AGING

The Administration on Aging (AOA) is the focal point for services to seniors in the U.S. Department of Health and Human Services. Through a nationwide network of State and Area Agencies on Aging and Tribal Organizations, AoA plans, develops, and supports comprehensive in-home and community services including information and referral services, job and volunteer opportunities, senior center and day care center programs, transportation, a nationwide congregate and home delivered meals program, and homemaker and home health aide services as well as legal services, nursing home ombudsmen services, and counseling programs to assist them if they are abused, neglected or exploited.

330 Independence Avenue, SW
Washington, DC 20201
(202) 619-0724

Internet: http:// www.aoa.dhhs.gov/elderpage.html

Office of Disability, Aging, and Long-Term Care Policy, ASPE, HHS

The Office of Disability, Aging, and Long-Term Care Policy, under the Assistant Secretary for Planning and Evaluation, conducts policy research on informal caregiving for the U.S. Department of Health and Human Services. For a list of recent research publications on informal caregiving, contact:

DALTCP/ASPE/DHHS
Room 424E, H.H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201
(202) 690-6443

E-mail: daltcp2@osaspe.dhhs.gov
Internet: http://aspe.os.dhhs.gov/daltcp/home.htm

National Institute on Aging

The National Institute on Aging conducts biomedical and social and behavior research on aging. The Public Information Office at the National Institute on Aging produces science-based educational materials on a wide range of topics related to health and aging. Topics cover specific diseases and health conditions, treatments, and research. The materials are for use by the general public, patients and family members, health professionals, voluntary and community organizations, and the media.

Public Information Office
National Institute on Aging

Building 31, Room 5C27
31 Center Drive, MSC 2292,
Bethesda, MD 20892-2292.

(301) 496-1752

E-mail: niainfo@access.digex.net
Internet: http://www.nih.gov/nia/

The Resource Directory for Older People

The Resource Directory for Older People is available on the AoA website (http://www.aoa.dhhs.gov) and is also available in hard copy. It is intended to serve a wide audience including older people and their families, health and legal professionals, social service providers, librarians, researchers, and others with an interest in the field of aging. The directory contains names, addresses, phone numbers, and fax numbers of organizations which provide information and other resources on matters relevant to the needs of older persons. The Directory is a joint project of the Administration on Aging and the National Institute on Aging.

A hard copy of the Directory is available for $11.00 from:

Superintendent of Documents
P.O. Box 371954
Pittsburgh, PA 15250-7954
Publication Number - 0106200145-6

(202) 512-1800

The National Respite Locator Service

1-800-773-5433

The National Respite Locator Service helps parents, caregivers, and professionals caring for children with disabilities or chronic illness, terminal illness, or children at risk for neglect and abuse to find respite services in their state and local area. This service is funded by the U.S. Department of Health and Human Services, Administration for Children and Families, Administration on Children, Youth and Families, Children's Bureau under contract with the North Carolina Department of Human Resources, Division of Mental Health/Developmental Disabilities/ Substance Abuse Services, Child and Family Services Branch of Mental Health Programs, Raleigh, North Carolina.

ARCH National Resource Center
Chapel Hill Training-Outreach Project
800 Eastowne Drive, Suite 105
Chapel Hill, NC 27514

1-800-773-5433

Internet: http://www.chtop.com/locator.htm

National Family Caregivers Association

The National Family Caregivers Association, a caregiver membership organization, provides services in the areas of information and education; support and validation; public awareness and advocacy for caregivers.

10605 Concord St., Suite 501
Kensington, MD 20895-2504

1-800-896-3650

E-mail: info@nfcacares.org
Internet: http://www.nfcacares.org/home/html

National Alliance for Caregiving

The National Alliance for Caregiving, a partnership of several aging organizations, conducts research, develops national projects, and works to increase public awareness of the issues of family caregiving for older Americans.

4720 Montgomery Lane
Suite 662
Bethesda, MD 20814

(301) 718-8444

Family Voices

Family Voices is a national advocacy organization and clearinghouse for information and education concerning the health care of children with special health needs. Family Voices has a volunteer coordinator in every State; 10 regional coordinators; and a small staff working in several locations around the country. Families share their expertise and experiences with State and national policymakers, the media, health professionals, and other families.

Family Voices National Office
P.O. Box 769
Algodones, New Mexico 87001

(505) 867-2368

E-mail: famvoi@usa.net
Internet: http://www.familyvoices.org

The Arc (formerly the Association for Retarded Citizens)

The Arc, a national organization on mental retardation, works to secure for all people with mental retardation the opportunity to choose and realize their goals of where and how they learn, live, work, and play. Through its national, State, and local offices, the Arc provides education, research, advocacy, and the support of families, friends, and community.

The Arc of the United States
500 East Border Street, Suite 300
Arlington, Texas 76010

(817) 261-6003

E-mail: arc@metronet.com.
Internet: http://www.thearc.org

National Associations

For information and assistance resources for persons with particular diseases and conditions, the national associations provide a great deal of information and guides to supportive services, e.g., the Alzheimer's Disease and Related Disorders Association, the American Cancer Society, the American Diabetes Association, United Cerebral Palsy Associations, etc. Many of the associations also have local offices.

WHITE HOUSE STAFFING MEMORANDUM

Date: 12/30/98 ACTION / CONCURRENCE / COMMENT DUE BY: 4:30 p.m. TODAY

Subject: LONG-TERM CARE REMARKS

	ACTION	FYI		ACTION	FYI
VICE PRESIDENT	☑	☐	NASH	☐	☐
PODESTA	☑	☐	REED	☑	☐
ECHAVESTE	☑	☐	RUFF	☐	☐
LEW	☑	☐	SMITH	☐	☐
BEGALA	☑	☐	SOSNIK	☑	☐
BERGER	☐	☐	SPERLING	☑	☐
BLUMENTHAL	☐	☐	STEIN	☐	☐
FRAMPTON	☐	☐	STERN	☐	☐
IBARRA	☐	☐	STREETT	☐	☐
KLAIN	☑	☐	TRAMONTANO	☑	☐
LANE	☐	☐	VERVEER	☑	☐
LEWIS	☑	☐	WALDMAN	☑	☐
LINDSEY	☐	☐	YELLEN	☐	☐
LOCKHART	☐	☑	JENNINGS	☑	☐
MARSHALL	☑	☐	ORSZAG	☑	☐
MOORE	☑	☐	_____	☐	☐
			_____	☐	☐

REMARKS:

COMMENTS TO JEFF SHESOL

RESPONSE:

Staff Secretary's Office
Ext. 62702

Draft 12/30/98 12:00pm
Jeff Shesol

'98 DEC 30 PM12:14

PRESIDENT WILLIAM J. CLINTON
REMARKS ON LONG-TERM CARE
THE WHITE HOUSE
January 4, 1999

Acknowledgments: the First Lady; the VP (via satellite from California); Secs. Rubin and Shalala; Janice LaChance, OPM; person TBD

Another new year is upon us -- a time for celebration, and, perhaps, a time to feel a little bit older. If we do, we are not alone. America may be young in spirit; our nation may have all the energy and intensity and ambition of youth; but our people are aging. On the verge of the new century, we are undergoing a profound, seismic demographic shift. Today I want to talk about the ways we are going to meet the challenges of this new America.

Simply put: The baby boom will soon become the senior boom. And, like the baby boom did in decades past, the senior boom will change the face of America. During the next 30 years, 76 million baby boomers will join -- and greatly expand -- the ranks of the retired. The number of elderly Americans will double by 2030. By the middle of the next century, the average American will live to 82, six years longer than today.

Longer lives will also be stronger, healthier lives, thanks to medical science. Already, older Americans are redefining retirement. They are proving that, rather than an ending, it can be a new beginning: a time to learn new ideas, start a new business, travel to new and distant lands.

Still, aging is inevitable; and so are the infirmities of age. Nearly half the people over 85 -- one of the fastest-growing segments of the American population -- need help with everyday tasks. Eating. Dressing. Going to the doctor. We cannot expect all or even most older Americans to fend for themselves. We cannot expect it and we would never wish it. Nor would we, in every case, send an aging relative to a nursing home. Millions require the kind of care only a nursing home can provide, but millions more choose to remain at home, close to family and friends.

Indeed, the elderly and disabled are staying at home in record numbers, cared for by those who care the very most. Today, more than 22 million households are caring for elderly relatives and even neighbors. It is, more and more, a common choice, but it is rarely an easy one. Since long-term care at home is rarely covered by private insurance or Medicare, out-of-pocket expenses can be high. So, too, are the professional costs. Caregivers who hold jobs outside the home -- and that is a vast majority -- may have to take unpaid leave or work fewer hours to fulfill all their responsibilities. Caregiving is, in countless ways, vital, meaningful work; but it can also be stressful work.

The Vice President just told you what we've been doing to ease the burdens on families:

by improving nursing homes, strengthening Medicare, and making Medicaid more flexible. But America, in the 21st Century, will be a nation of caregivers; so there is more work to be done.

Today, I am announcing a bold initiative to give care to the caregivers -- to help Americans provide for aging and ailing loved ones. The size of the senior boom demands it. The length of our lives makes it more important than ever. And so does the sacrifice of American families -- 22 million households putting the well-being of relatives or neighbors above their own.

To improve long-term care in America, to give it the priority and support these families deserve, there are four things we must do. First, I am proposing a long-term care tax credit -- up to $1,000 for people with long-term care needs or for the families that shelter them. It is far better to devote this money to help keep the elderly and disabled at home than to spend the same amount to have them live away from home. Our parents worked and saved and sacrificed to care for us in our youth. Adult children are working and saving and sacrificing to care for their parents in old age. It is the cycle of life -- a vital and sacred compact among generations -- and one we should recognize and reward as a nation. This targeted tax cut, paid for in our balanced budget, would help offset the direct costs of long-term care -- home health visits, adult day care -- as well as the indirect costs, like the unpaid leave some caregivers take from work. The care they provide is invaluable; but we can show we value it very much indeed.

Second, we should create a Family Caregiver Support Program -- a new national network to support Americans who care for the chronically ill or disabled. In decades past, families could do little for ailing relatives but give them shelter and love. Today, due to advances in science, caregivers tend to everything from dialysis to depression, and prepare everything from intravenous meals to the paperwork that is, it seems, an inescapable part of modern medicine. This initiative enables states to create "one-stop shops" -- providing critical information, caregiver counseling, and respite and adult day care services to families that need them. They want to provide the best possible care; we want do everything in our power to help them.

That is why, third, we must educate Medicare beneficiaries about long-term care options. This is an efficient way to answer people's essential questions: What are my choices? What should I look for in a private long-term care insurance policy? By launching a national educational campaign, we can help ensure that people in need get the answers -- and the quality care -- they deserve.

Fourth, I am proposing that we offer private long-term care insurance to federal employees. The federal government can, in this way, use its power as the nation's largest employer to set a national example -- promoting high-quality and affordable care to hundreds of thousands of workers.

There is no single solution to the challenges of caregiving. But together, these initiatives represent a powerful force for positive change. To fulfill our fundamental obligation to

America's elderly and disabled, we, too, must act together -- as members of both parties, of two branches of government, putting progress above partisanship for the sake of our people. That means giving care to the caregivers by taking these important steps. It also means strengthening Medicare, and, as I have said many times in the past year, it means saving Social Security for the 21st Century -- for Social Security, too, is a sacred trust between generations. We now have a remarkable opportunity to strengthen it for the future; we must make the most of it.

The senior boom is one of the central challenges of the coming century. If we face these challenges together and make them our top priorities, if we make the efforts I have described today, then we can prove what no generation in history has had the opportunity to prove -- that the infirmities of age need not be the indignities of age. Thank you.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

OFFICE OF THE ASSISTANT SECRETARY FOR LEGISLATION

FROM: Andrea S. Levario

Room 410H/2, HHH Building
200 Independence Ave., SW
Washington, D.C. 20201

PHONE: (202) 690-7538
FAX: (202) 690-8425

For Rich Tarplin

DATE: 12/30/98

TO: DeNora

OFFICE:

ROOM:

PHONE: 456-5560

FAX: 456-5557

TOTAL PAGES (INCLUDING COVER): 2

REMARKS:

Congressional Invites for White House Long-Term Care Event

Senate	House
Grassley	Waxman
Breaux	Dingell
Kennedy	Brown, Sherrod
Frist	Stark
Gramm	Thomas
Roth	Bilirakis
Moynihan	McDermott
Rockefeller	Johnson, N
Kohl	Bliley
Specter	Smith, Chris
Jeffords	Towns
Snowe	
Dodd	

Elderly Care To Anchor Clinton Plan

By Jacob M. Schlesinger
And Laurie McGinley
Staff Reporters of The Wall Street Journal

WASHINGTON—President Clinton is planning to launch a modest campaign to help families defray the high costs of long-term care for elderly and disabled family members—care that generally gets limited coverage by private and government plans.

The centerpiece of the effort, which could be announced as soon as Monday, will likely be a proposed tax credit of as much as $750 for each family. Under recent versions of the proposals shown to advocacy groups, about two million families—20% of all Americans currently believed to be paying for long-term care—would be eligible for the program, which could cost the government between $5 billion and $6 billion during the next five years.

In addition to the tax credit, Mr. Clinton is expected to propose in his budget for the fiscal year ending Sept. 30, 2000, other initiatives to address the issue. Those could include new funds to organizations that provide information about long-term care. People familiar with the plans said details of the package still were being discussed and would likely be completed over the weekend.

"By acknowledging the role of caregivers, this is important," said Stephen McConnell, a senior vice president at the Alzheimer's Association, an organization supporting research, treatment and support for people suffering from the disease. "There isn't any coverage for long-term care in Medicare—the only help that people can get is if they become impoverished and go on Medicaid." Private insurance plans also offer only modest coverage.

Still, Mr. McConnell and other advocacy groups said the expected Clinton plan, if approved by Congress, would provide mainly symbolic aid. The average annual cost for caring for someone with Alzheimer's, for example, is more than $45,000. "You don't really address the problem by giving people a small tax credit," Mr. McConnell said. "You have to be careful about overstating what we're doing to address the problem."

Besides, low-income families also likely won't be able to claim the break; only those people who earn enough money to pay income taxes are expected to qualify for the credit. The proposal, in its current form, sets a fairly strict definition of disability that must be met before the family can earn the credit.

The long-term-care initiative is symbolic of Mr. Clinton's fiscal 2000 budget as a whole, to be unveiled bit by bit over the three weeks leading up to the Jan. 19 State of the Union address. The White House is eager to show that it still is trying to address the social issues that Mr. Clinton has long championed, despite his lame-duck status and the diversion of the Senate trial for perjury and obstruction of justice.

But money in the budget is tight. Mr. Clinton has pledged to preserve the surplus until he has shored up Social Security, and also has promised big defense spending increases during the next few years. So he and his aides will try to draw as much attention as possible to proposals that spend as little money as possible.

In addition to the long-term care initiative, Mr. Clinton is expected to propose steps to expand Medicare. He is likely to propose a plan he unsuccessfully advocated last year that would let certain people between the ages of 55 and 65 buy into the government health-insurance program. He also is expected to repropose another program that would encourage Medicare patients with cancer to participate in clinical trials for new therapies. He also is considering cutting the amount of money Medicare beneficiaries have to pay for preventive benefits such as diabetes management.

The Clinton administration also wants to boost federal funds for states to inspect food plants that are supposed to be investigated by the Food and Drug Administration, a former government official said. The FDA's food-safety budget is so lean that inspectors currently visit some plants just once every 10 years. But food-safety advocates already are complaining about the anticipated move, saying it will be impossible for plants across the country to be held to one uniform standard.

Besides health, the White House budget is expected to seek new funds for a wide range of programs, from aiding urban development to beefing up local police forces, to preserving public lands.

—Rochelle Sharpe contributed to this article.

Susan Page

Alissa Rubin

Withdrawal/Redaction Marker
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
005. schedule	Schedule for the President re: phone number (partial) (1 page)	01/04/1999	P6/b(6)

COLLECTION:
Clinton Presidential Records
Domestic Policy Council
Devorah Adler
OA/Box Number: 20469

FOLDER TITLE:
Long Term Care [Folder 6]

2012-0463-S
rc779

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [a)(5) of the PRA]
P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.
PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).
RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

b(1) National security classified information [(b)(1) of the FOIA]
b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

Schedule of the President
for
Monday, January 4, 1999

Final Schedule

SCHEDULING DIRECTOR:	STEPHANIE STREETT
	HOME: P6/(b)(6) [605]
	OFFICE: 202-456-2823
	WHCA PAGER: 4824
PRESS DESK:	ANNE EDWARDS
	HOME: P6/(b)(6)
	OFFICE: 202-456-2921
	WHCA PAGER: 4208
EVENT COORDINATOR:	LAURA SCHWARTZ
	HOME: P6/(b)(6)
	OFFICE: 202-456-5655
	WHCA PAGER: 4293
WEATHER:	WASHINGTON, D.C.
	Cloudy with wintry mix turning to rain by noon. Driving conditions should improve in the afternoon. Winds northwest at 10 to 15 knots. Low 25 to 30. High 35 to 40.

Schedule of the President
for
Monday, January 4, 1999
Final Schedule

9:30 am-		**MEETING**
9:45 am		OVAL OFFICE
		Staff Contact: John Podesta
9:45 am-		**BRIEFING**
10:00 am		OVAL OFFICE
		Staff Contact: Samuel Berger
10:00 am-		**BRIEFING**
10:15 am		OVAL OFFICE
		Staff Contact: Samuel Berger
10:20 am-		**MEETING**
10:30 am		OVAL OFFICE
		Staff Contact: Stephanie Streett
10:30 am-		**BRIEFING**
11:00 am		OVAL OFFICE
		Staff Contact: Bruce Reed
11:05 am		**THE PRESIDENT** and the First Lady proceed to Blue Room
11:10 am-		**MEET AND GREET**
11:15 am		BLUE ROOM
		Staff Contact: Bruce Reed, Capricia Marshall

Background on California Resource Centers

With its network of eleven Caregiver Resource Centers across the state, California has a model system for providing long-term care assistance to families and caregivers of brain-impaired adults. These resource center serve over 10,000 family members and friends who care for loved ones suffering from Alzheimer's disease, stroke, Parkinson's disease, multiple sclerosis, traumatic brain injury, and other adult-onset, brain impairing diseases. The Centers' primary functions include providing information, education, long-term planning, legal/financial consultations, training, support groups and respite care (e.g. in-home respite care, adult day services, or weekend respite camps).

Some of the specific services and programs include 1) workshops for caregivers and family members on topics such as stress management, legal and financial issues, diagnosis, and treatment; 2) subsidies for in-home care, day care, short term or weekend care and transportation to assist caregivers in caring for brain-impaired adults at home; 3) consultations with trained professionals through home visits, telephone and office visits to assess problems, needs and care options or with attorneys on estate and financial planning; 4) short-term counseling programs for caregivers; and 5) monthly support meetings for caregivers to share their experiences and frustrations to ease the stress of caregiving. Furthermore, beyond providing services to its residents, the state has also used these Resource Centers to survey various aspects of long-term care, including the quality and accessibility of services provided.

For FY99, there was $4 million increase in the budget for respite care programs that will allow California to reduce the waiting lists of families in need of respite care and add clinical specialists and other support staff at each of the 11 Caregiver Resource Centers.

Background on Triple "R" Program

Triple "R" Program was conceptualized by the Del Oro Caregiver Resource Center, one of eleven resource centers statewide, and is currently sponsored by the City of Sacramento. It is an adult day care program serving 30 families in the Sacramento area. This social companionship and recreation program for older adults with memory loss is five days a week, 7:30 a.m. to 5:30 p.m. at the E. M. Hart Senior Center. Like other adult day centers associated with a California Resource Center, its main goals are to provide significant alleviation of caregivers stress through volunteer respite services; to improve the quality of life of the participants; reduce the overall costs of more traditional respite services by utilizing the volunteer group model; and provide a workable model for future development of similar programs in similar community-based settings, such as senior centers.

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BACKGROUND: PRESIDENT CLINTON'S LONG-TERM CARE INITIATIVE
DRAFT, EMBARGOED, NOT FOR DISTRIBUTION OR ATTRIBUTION January 4, 1999

Americans of all ages, particularly the elderly and their families, fear developing a need for intense, ongoing long-term care. Unlike acute care, long-term care is rarely paid for by private insurance and Medicare, and is more likely to require out-of-pocket expenditures. It also takes a huge financial and emotional toll on family and friends who provide most of this care. Because of its complexity, however, no single policy can "solve" this problem. Thus, the President is proposing a multi-faceted initiative to provide immediate assistance with long-term care & help prepare for what will surely be one of the great challenges as the baby boom generation ages.

GROWING NEED FOR LONG-TERM CARE

- **Who needs long-term care.** People with chronic illness or disability not only need doctor, hospital and other acute care services -- they also need a wide range of services to manage their health conditions and perform basic activities of daily living. For example, people with strokes may be bed-bound due to paralysis and need help with eating, moving and changing their feeding tubes. Diabetics or people with congestive heart failure may require frequent injections, medication and doctor visits. People with Alzheimer's disease often need constant monitoring and changes to their physical environment to allow them to live at home safely. Long-term care encompasses these and other services. It is probably the most complicated area of health care, since it varies based on a person's specific condition and limitations as well as access to care from institutions, health providers, families and friends.

  About 5 million Americans of all ages have significant limitations (cannot perform 3 or more activities of daily living without assistance) because of illness or disability and thus require long-term care. Nearly 2 million of these people live in nursing homes; the remainder live in the community and benefit from irreplaceable and uncompensated caregiving from countless relatives and friends. In addition, millions more Americans have chronic illnesses or disabilities that are less limiting but still require long-term care.

  More than two-thirds of people with long-term care needs are elderly -- nearly half of all people age 85 and older need assistance with everyday activities. Older women are more likely to need long-term care than men; three-fourths of nursing home residents are women.

- **The aging of America will create a greater need for long-term care.** The sheer increase in number of elderly in the next century means more chronic illnesses. The number of people age 65 years or older will double by 2030 (from 34.3 to 69.4 million), so that one in five Americans will be elderly. The number of people 85 years or older will grow even faster (from 4.0 to 8.4 million). By 2050, the number of older, disabled people could double.

- **Not just a challenge for the elderly**. About 2 million people with substantial long-term care needs are younger than age 65. The rate of disability has been rising among children. In part, this reflects a little-noticed effect of the success in helping premature, sick, or disabled newborns. Their increased survival through infancy has led to a need for long-term care as they grow up. Also, many adults have long-term care needs due to lifelong health conditions (e.g., cerebral palsy) or conditions developed as adults (e.g., multiple sclerosis).

LONG-TERM CARE SYSTEM

- **Medicare was not designed to cover long-term care.** Long-term care costs account for nearly half (44 percent) of all uncovered, out-of-pocket health expenditures for Medicare beneficiaries. When it was created in 1965, Medicare was modeled after a typical private insurance policy and thus did not include long-term care coverage.

  Unfortunately, nearly 60 percent of all Medicare beneficiaries -- and two-thirds of people under age 65 -- do not realize that Medicare does not pay for long-term nursing home care. This means that the majority of Americans are unprepared for the financial and emotional challenges of paying for and/or providing long-term care.

- **Medicaid is already the major payer of long-term care, but historically has focused on nursing homes**. Medicaid is the largest payer of long-term care in the nation. It covers two-thirds of nursing home residents -- many of whom become eligible for this income-related program because long-term care costs impoverish them. Nursing home costs average almost $50,000 per year. About 80 percent of Medicaid long-term care costs are for nursing homes.

  The remaining 20 percent of costs are for home and community-base long-term care services. The share of Medicaid long-term care spending going toward home and community-based services has more than doubled in the last 10 years. Ten years from now, Medicaid spending on these services is projected to equal spending on nursing homes. The President has encouraged the shift away from Medicaid's "institutional bias" by approving over 300 waivers for local home and community-based care programs and proposing to repeal the need for such waivers. Notwithstanding these advances, not all Medicaid beneficiaries with long-term care needs have community-based options, and many people with long-term care needs don't qualify for Medicaid at all.

- **Private insurance is relatively new, untested, and covers very few people**. Only about 4 million Americans -- 1.5 percent of all Americans -- have private long-term care insurance. In part, this reflects the newness of the coverage, the inconsistency of benefits across policies, variable regulation, and low demand. Given their cost, even if every baby boomer who could afford private insurance purchased it, less than one-third of long-term care costs would be paid for by private insurance in 2030.

- **Families and friend provide most long-term care.** Informal caregiving is a part of family life for many Americans. About 70 percent of caregivers report it being a positive experience. Only about one-third of the 5 million people with substantial long-term care needs lives in a nursing home -- virtually all of the 3 million community-based people with similar needs rely on one or more relatives or friends for help. The millions of caregivers that provide nearly full-time assistance for these people with severe needs are part of a larger group of Americans that help people with less intense long-term care needs.

However, the costs of such caregiving -- in time, money, and physical and emotional strain -- can be large. Two-thirds of working caregivers report experiencing conflicts that cause them to rearrange their work schedules, work fewer hours, or take an unpaid leave of absence from work. Most of the primary caregivers for the elderly are elderly themselves. Their average age is 60 years old, and half are older than 65. About one third describe their own health as "fair to poor." This presents problems since informal caregiving often requires physical work like heavy lifting, frequent bedding changes, dressing and bathing. These stresses tend to be more severe for families of people with Alzheimer's disease. Such caregivers tend to experience greater time demands, family conflict, strain, mental and physical problems, and financial hardship.

LONG-TERM CARE INITIATIVE

The challenges of providing and financing long-term care are clearly large and multi-dimensional. No single policy can provide the answer. As such, the President proposes a four-pronged initiative to improve long-term care (described in detail in subsequent pages):

- **Direct financial support through a new tax credit for people with long-term care needs or their family caregivers.** This credit helps pay for the formal and informal costs associated with care for people with significant long-term care needs.

- **Direct service support through a new Family Caregivers Program** that provides information, education, counseling, and respite services directly to families that care for elderly, ill or disabled relatives.

- **Education for Medicare beneficiaries about long-term care issues and options.** Since most people who develop long-term care needs are Medicare beneficiaries, Medicare can be used to provide information on the limitations of its coverage, alternative sources of long-term care services and financing, and how best to choose the most appropriate options.

- **High-quality, affordable private long-term care insurance for Federal employees.** The Federal government would develop a model program to offer high quality, private long-term care insurance policies to its employees, retirees and eligible family members. By offering this coverage, the Federal government will both guide public policy by example and act responsibly as the largest employer in the nation.

TAX CREDIT FOR PEOPLE WITH LONG-TERM CARE NEEDS OR THEIR CAREGIVERS

Eligible people with long-term care needs or their caregivers would receive a $1,000 tax credit beginning in 2000. This would help about 2 million people, at a cost of $5.5 billion for 2000-04.

- **Goal**: This policy offsets some of the paid and unpaid long-term care costs incurred by people with chronic illness or the families with whom they live. A large proportion of long-term care costs are not covered by insurance, and studies suggest that the value of informal, unpaid long-term care provided by families is worth billions of dollars.

- **Amount of the credit**: The credit is $1,000. It phases out for higher income tax payers (taxpayer with modified adjusted gross income exceeding $110,000 for couples, $75,000 for unmarried taxpayers, and $55,000 if the taxpayer is married but filing a separate return; same phase-out as the child tax credit). This credit cannot exceed the total amount of tax liability except, however, it may be refundable for taxpayers with 3 or more dependents.

  The flat $1,000 credit would be given on the basis of a certified need for long-term care rather than expenses for long-term care. This means that families and people with chronic illness or disability do not have to collect and submit receipts for paid home health or respite care. It also recognizes the costs associated with informal, family caregiving. For example, a wife whose husband has had a stroke would not have a receipt for her reduced hours at work, time spent bathing and feeding her husband and other real costs associated with care.

- **Eligibility**: Three types of people could receive this tax credit: (1) taxpayers with long-term care needs; (2) taxpayers whose spouses have long-term care needs; and (3) taxpayers with dependents with long-term care needs.

- **"Person with long-term care needs"**: For this credit, this includes:

  - People with 3 or more limitations in activities of daily living (ADL) (bathing, dressing, eating, toileting, transferring and continence management) who cannot perform these activities without substantial assistance from another individual due to a condition lasting for longer than 6 months, as certified by a licensed doctor in the previous 12 months.

  - People with severe cognitive impairments who require substantial supervision to be protected from threats to their health and safety due to this condition and have difficulty with one or more ADLs or one of four major instrumental ADLs.

  - Children ages 2 through 6 who have difficulty with 2 out of 3 ADLs (eating, transferring and mobility) or are under the age of 2 and require skilled caregiver in the parents' absence or specific durable medical equipment (e.g., a respirator) for over 6 months. Within one year, HHS and Treasury will report on whether these eligibility rules are appropriate and how to improve them if necessary.

- **"Caregivers"**: Families would be eligible for the credit as caregivers if their relatives with long-term care needs can be claimed as dependents. Under current law, a "dependent" is generally an individual who does not pay taxes, is related to the taxpayer, receives more than half of his or her support from the taxpayer, and has gross income less than $2,750. For purposes of this credit, this definition would be expanded significantly in two ways. First, individuals with long-term care needs would not have to meet the support test if they live with a taxpayer who is a close relative for at least half the year (the entire year in the case of a distant relative and other persons). Second, the limit on gross income would be raised to the sum of the exemption amount, the standard deduction, and the additional deduction for the elderly and blind (to $8,100 for single elderly person; in general, Social Security benefits are excluded from gross income for moderate to low-income individuals). Most people with income above this limit would file taxes and receive the long-term care credit themselves

  Broadening the definition of dependency for the purposes of this credit is a major change that allows many more families that house and care for relatives to receive the credit. It does so by allowing caregiving relatives of individuals with long-term care needs to claim the credit when those individuals themselves have insufficient income to pay taxes.

- **Who benefits**: About 2 million people would benefit from this credit: about 1.2 million elderly, about 500,000 nonelderly adults, and about 250,000 children. About three-fourths of people receiving the credit are expected to be spouses or family caregivers of these people with long-term care needs.

- **Cost:** About $5.5 billion over the five-year budget window.

TAX CREDIT FOR PEOPLE WITH LONG-TERM CARE NEEDS: Examples Assuming 1999 Levels					
Elderly Single Person		**Elderly Married Couple (1)**		**Caregiver of Elderly Person (2)**	
INCOME					
Social Security (3)	9,420	Social Security (4)	16,086	Senior's Soc Security (3)	9,420
Pensions	13,765	Pensions	14,370	Son's Income	46,000
Interest Income	1,000	Interest Income	1,500		
Total Money Income	***24,185***	***Total Money Income***	***31,956***	***Total Money Income***	***55,420***
Adj. Gross Income	**14,765**	**Adj. Gross Income**	**15,870**	**Adj. Gross Income**	**46,000**
TAX LIABILITY					
Exemption	-2,750	Exemption	-5,500	Exemption	-8,250
Standard Deduction	-4,300	Standard Deduction	-7,200	Standard Deduction	-7,200
Elderly Deduction	-1,050	Elderly Deduction	-1,700	Elderly Deduction	
Taxable Income	***6,665***	***Taxable Income***	***1,470***	***Taxable Income***	***30,550***
Current Law Tax Liability	**1,000**	**Current Law Tax Liability**	**221**	**Current Law Tax Liability**	**4,583**
				Current Law Child Tax Credit	-500
Proposed LTC Credit	**-1,000**	**Proposed LTC Credit**	**-1,000**	**Proposed LTC Credit**	**-1,000**
Proposed Law Tax Liability	**0**	**Proposed Law Tax Liability**	**0**	**Proposed Law Tax Liability**	**3,083**

Dept of the Treasury; Office of Tax Analysis. (1) Only one individual needs long-term care; both are older than 65. (2) Single elderly person moves in with son, his wife & teenage son; total income (including grandfather's) roughly equals the median income for a family of 4. (3) Weighted average of benefits paid to retired workers, and widows and widowers, in 1996 adjusted for inflation. (4) Average benefits paid to retired workers and their wives in 1996 adjusted for inflation.

NEW FAMILY CAREGIVER SUPPORT PROGRAM

A new National Family Caregivers Support Program would support families who provide long-term care to elderly relatives with chronic illnesses or disabilities through state and local area agencies on aging. This $125 million program would help approximately 250,000 families.

- **Goal**: This policy provides support for families who care for relatives with chronic illness in hope of easing the emotional, physical and financial strain of caregiving. Recent studies have found that services like respite care can relieve caregiver stress and delay nursing home entry, and that counseling and support for families of Alzheimer's disease patients can delay institutionalization for as long as a year.

- **Eligibility**: Families -- especially low-income families -- who provide care to elderly relatives with limitations in activities of daily living would be eligible for services.

- **Services provided**: Funding would be used to help families that take care of elderly relatives with significant long-term care needs. This assistance would include:

  - Connecting families with information on caregiver resources and local services (e.g., detailed information on the condition affecting their relative; names and numbers of local home care and respite services);

  - Providing counseling, training and peer support to teach families how to face the challenges of caregiving (e.g., how to bath people who have had strokes; what exercises work best for people with severe arthritis; how to cook meals for people with diabetes; how to manage the stress of caregiving);

  - Providing and paying for respite care (e.g., attendants so that the caregiver can shop or leave the house for other reasons, adult day care centers, and temporary care in an assisted living facility or nursing home). For people providing intense long-term care, these services provide necessary, temporary relief from caregiving responsibilities, allowing them to restore balance to their lives that strengthens their ability to continue to provide assistance. Most of the funding of this program would pay for respite services.

  Additionally, a competitive grant program would test innovative interventions (e.g., use of computer information for distant caregivers) and challenges for subgroups of caregivers (e.g., minority caregivers; caregivers for people with severe conditions like brain injuries).

- **Administration:** All state agencies on aging would receive a grant from the Administration on Aging for distribution to local area agencies on aging. These Federal grants would be matched by the states and states could not reduce their current spending on such services. States would develop a sliding fee scale consistent with its other programs.

- **Who benefits**: Altogether about 250,000 families could be served by this program.

- **Examples**: The following programs serve as models for this new, nationwide program:

  - **California:** Its Department of Mental Health developed a program in 1985 to provide caregiver support services through eleven agencies statewide. These agencies target families caring for persons with Alzheimer's disease, Parkinson's disease, stroke, and traumatic brain injury. Services include needs assessment, information and referral, family consultation and training, support groups, and respite care.

  - **New Jersey:** The Statewide Respite Care Program was established in 1988 to help unpaid caregivers of the stress arising from providing intensive personal assistance to a family member. Annually, over 2,000 families receive respite care provided through adult day care centers, short-term placement in the home of a trained individuals, or overnight nursing home stays. One quarter of the families helped by the program are caring for someone with Alzheimer's disease; heart disease, stroke and arthritis are the next most common chronic conditions of the program's care recipients. A recent evaluation found that families helped through its adult day care had much lower feelings of worry, strain and overload, and fewer experienced depression or anger. Depression is a major problem for caregivers, not only limiting their ability to help their relative but restricting their own lives and activities.

  - **Washington**: Washington State Aging and Adult Services Administration established a program in 1989 to provide assistance to family caregivers. Through its area agencies on aging, it offers respite services to 2,000 families annually. An additional 3,200 families receive caregiver training. Respite services are prioritized based on the caregiver's vulnerability, intensity of care provided by family members, and presence of other family and or community supports.

  - **Wisconsin**. Since 1986, Wisconsin Bureau on Aging has funded county aging and social services offices to work with families to identify the types and amounts of assistance needed to care for relatives diagnosed with Alzheimer's disease or a related disorder. Covered services include respite care, provided in the home or in adult day care, and in-home help. In addition, assistive devices, caregiver training, and peer group supports are financed. Families share in the cost based on income. About 1,000 families benefit from funded respite care or in-home help and another 4,600 families are helped through caregiver training, information and peer group supports.

- **Cost**: The total funding is $125 million in FY 2000, most of which would be distributed among all states, and a small part of which would be used for the competitive grant program. Additionally, funds would be set aside for an evaluation of these efforts -- in an effort to identify what works and doesn't work so that future efforts are best targeted.

LONG-TERM CARE INFORMATION CAMPAIGN FOR MEDICARE BENEFICIARIES

A National Long-Term Care Information Campaign will be conducted to help Medicare beneficiaries and their families better understand their long-term care options. All 39 million Medicare beneficiaries would receive this information through this $10 million initiative.

- **Goal**: This policy provides information on long-term care to Medicare beneficiaries -- who comprise most of the people who have or will develop long-term care needs. Since nearly 60 percent of beneficiaries do not realize that Medicare does not cover most long-term care, this information is critical to educating them about their coverage and directing them to financing and delivery systems.

- **Information provided**: The Health Care Financing Administration (HCFA), working with other components of DHHS, would conduct this information campaign. It would include information about long-term care coverage under the Medicare and Medicaid programs; what to look for in a private long-term care insurance policy; how to access home and community-based care; and other consumer information. Components of the campaign would include:

  - Developing and distributing printed educational materials about long-term care options and resources to beneficiaries and their families;

  - Incorporating information about long-term care options and resources into the Medicare handbooks, toll-free phone numbers and the consumer internet site, www.Medicare.gov;

  - Enhancing training on long-term care options in organizations that provide information to beneficiaries including state health insurance assistance programs, Medicare carriers and fiscal intermediaries, area agencies on aging and Social Security Administration offices;

  - Working with groups representing the elderly, people with disabilities, the long-term care industry, employers, states and others to disseminate information to their constituencies.

  In addition, HCFA would conduct pilot information campaign projects focusing on the needs of particular populations such as people with disabilities, people who don't speak English, or the rural elderly. An evaluation component would be included to identify what works best in assisting beneficiaries in making informed long-term care decisions.

- **Who benefits**: All 32 million seniors and 7 million people with disabilities are covered by Medicare would receive this information. Since a large proportion of people with long-term care needs are elderly or adults with disabilities, Medicare is an extremely efficient way to target such people.

- **Cost**: $10 million in FY 2000.

OFFERING PRIVATE LONG-TERM CARE INSURANCE TO FEDERAL EMPLOYEES

This proposal would authorize the U.S. Office of Personnel Management (OPM) to make private long-term care insurance available to Federal employees, retirees, and eligible family members at negotiated group rates. The cost of administration of this benefit would be about $15 million over 5 years and an estimated 300,000 people would participate.

- **Goal**: This initiative would educate Federal employees and retirees about long-term care options and encourage the purchase of high-quality, long-term care insurance at 15-20 percent below market rates. This is one in an ongoing series of efforts in which the Federal government has taken a leadership role by both guiding public policy by example and acting responsibly as the largest employer in the nation.

- **Eligibility**: People eligible to purchase this insurance would include: Federal employees and retirees, and their spouse; former spouses who are entitled to annuities under a Federal retirement system; and parents, and parents-in-law. In its first year, OPM would run a campaign to educate possible participants about long-term care insurance and solicit and evaluate potential insurers. In the second year, it would hold an open enrollment for all eligible participants. New employees and employees electing coverage during the open enrollment period would be subject to either minimal or no underwriting. All others will be required to disclose additional information about their health status in order to acquire coverage. Once enrolled, coverage would be guaranteed renewable and could not be canceled except for nonpayment of premium.

- **Types of insurance policies offered**: OPM would select a single qualified carrier, or a very small number of carriers, to provide one or more long-term care insurance policies. This selection of carriers would be based on quality, service and price. At a minimum, carriers must be licensed under state law, compliant with the Health Insurance Portability and Accountability Act standards, and offer guaranteed renewability of their policies. OPM would set a basic benefit package (e.g., with a minimum benefit level; inflation protection; contingent nonforfeiture) and may offer plans with additional coverage (e.g., higher reimbursement levels for nursing home care or a more flexible benefit that can be used for whatever type of service the beneficiary needs). OPM would have the flexibility needed to administer the program as the market for long-term care services and protections evolves over time.

- **How much participants would pay**: The full cost of premiums would be paid by the participant. OPM would negotiate group rates that it expects will be 15 to 20 percent lower than the cost of individual long-term care policies. Employee and annuitant premiums would be withheld from salary or annuity and sent directly to respective contractors.

- **Cost**: The Federal administrative costs would be about $15 million over 5 years.

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