

Good Morning, Chairman Grassley, Senator Breaux and Members of the Senate Special Committee on Aging. Thank you for the opportunity to testify on one of the most important domestic issues facing our nation: long-term care for our elderly. I am joined today by two members of my team, Dr. Jeanette C. Takamura, Assistant Secretary for Aging, and Dr. Richard Hodes, Director of the National Institute on Aging (NIA). We greatly appreciate your bipartisan leadership on the elements of the President's long-term care initiative, particularly the Family Caregiver Support Program.

In fact, before I begin, I want to recognize the special leadership role that this committee has played in bringing greater focus and awareness to the many health and lifestyle issues facing our nation's senior citizens, including Alzheimer's disease and related disorders. I know the members of the audience and those they represent all across America join me in expressing our deep appreciation to you Mr. Chairman, and Senator Breaux, for the committee's fine work over the years.

Mr. Chairman, when the late Stanley Kubrick made *2001 A Space Odyssey* 30 years ago, his vision of the future was one of revolving space stations and rebellious computers. Now that 2001 is only two years away, we can argue about how close Mr. Kubrick came to the truth.

What we cannot argue about is the changing face of America over the next 30 years. For all the images we see in movies and television of a nation that is faster, younger and healthier, the fact is we are heading for a world no demographer has ever seen before. And the color of that world is gray. By the year 2030, the number of persons in our country 65 and older will double. And people 85 and older will be commonplace.

These changing demographics are no cause for alarm. But they are cause for action. We want life not only to be long - but good. That means having the tools we need to care for those ravaged by Alzheimer's and other chronic or disabling diseases. This will be one of the central challenges of the 21st century - to make dignity and comfort for the elderly as much a part of our national consciousness as education and safety for our children.

Let me emphasize that millions of families across America already face this challenge. In fact, family members provide most of the care for older persons who are no longer able to manage on their own. So one of the reasons I am here today is to convey the Administration's strong commitment to the families and caregivers of people in need of long-term care. But we need to do more than stand with them. We need to help them. That is the purpose of the President's long-term care initiative. To give these families - and the loved ones they care for - the support, guidance and financial assistance they desperately need.

Let me be clear: this initiative is not designed to just help older Americans. It is part of a much broader strategy to help Americans of all ages who are disabled. And this initiative is not just about money. It is about providing comprehensive assistance to family members who provide and receive long-term care.

That means the hundreds of thousands of Americans living in communities across our country, struggling to raise children, hold down jobs and protect their elderly parents. Let me give you an example of the type of person I am talking about. Frank is an older gentleman from the Chicago area. His wife is in a local adult day care center three days a week. Those three days are Frank's respite. They are a time of rest and relief - and also a time to buy the groceries and other supplies he needs to hold his family together. What Frank does is a 24-hour-a-day, seven day-a-week expression of love. At first the burden was manageable - and the fulfillment of a promise he had made on his wedding day. Now Frank says that although the added stress and exhaustion means he might end up going before her, "at least my

conscience will be clear."

What about our conscience? Frank and so many others like him deserve more than our admiration; they deserve our support. Mr. Chairman, 95 percent of frail older Americans who live in the community and need long-term care receive unpaid assistance from informal caregivers like Frank.

Research indicates that informal support for caregivers has a significant impact on the emotional well being of caregivers, as well as in delaying the need for nursing home services. A recent NIH study found that adult day care not only reduces caregiver stress, but delays the institutionalization of the care recipient. Another recent study indicates that counseling and support for caregivers of people with Alzheimer's can keep the care recipient out of a nursing home for an additional year.

Research also tells us that providing care to older persons exacts a heavy emotional, physical and financial toll. Almost three-quarters of informal caregivers are women. Many are older and vulnerable themselves, or are running households and parenting children. In fact, half of all caregivers are over 65 themselves. That means their own health is at risk. They suffer high rates of depression because they are emotionally strained. And not surprisingly, one third describe their own health as fair to poor. Many caregivers have had to cut back on their hours of work to provide elder care for their loved ones. Today, two-thirds of working caregivers report conflicts between work and caregiving that require them to rearrange their work schedules, work fewer than normal hours, and/or take unpaid leaves of absence.

The National Family Caregiver Support Program

Mr. Chairman, long-term care does indeed take a huge financial and emotional toll on the family and friends who provide most of this care. Because of its complexity, however, no single policy can "solve" this problem. Thus, the President in his FY 2000 Budget has proposed a multifaceted initiative to provide immediate assistance with long-term care and help prepare for what will surely be one of the great challenges as the baby boom generation ages.

First, the President's long-term care initiative includes \$125 million per year for the National Family Caregiver Support Program to provide assistance to people caring for older family members.

Through the established networks of the Administration on Aging (AoA), this program will enable states, working with area agencies on aging, local service providers and consumer organizations, to create a community-based infrastructure of support for family caregivers. State offices on aging would be expected to put in place at least five important program components to meet complex and diverse care needs. These components include:

- Providing information to caregivers about available services;
- Assisting caregivers in gaining access to specific services;
- Individual counseling, organization of support groups, and provision of caregiver training to help families make decisions and solve problems related to their caregiver roles;
- Respite care to enable families and other informal caregivers to be temporarily relieved from their caregiving responsibilities; and
- Providing supplemental long-term care services, on a limited basis, to complement the care provided by caregivers.

Our proposal also includes competitive grants for the development of innovative solutions to specialized caregiver problems. The results from these demonstration projects and applied research will be put into practice through ongoing state programs. This will lead to an understanding of best practices; in other

words, which programs are the most effective in helping caregivers and care recipients in the home, in the community or on tribal reservations.

Second, the President's initiative includes a targeted \$ 1,000 tax credit for people with long-term care needs or their caregivers. For some families, the tax credit will help to offset some of the direct costs of long-term care, such as adult day care or home health care visits. For others, it will help offset indirect costs such as unpaid leave taken from work.

Third, the President's initiative includes an expansive educational effort to inform all Medicare beneficiaries about long-term care 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.

Fourth, the President's proposal also calls for the federal government to offer private long-term care insurance at group rates to federal employees, annuitants and their families. Participants would be responsible for paying the full amount of the premium and the market leverage of the federal government is expected to save an estimated 15 to 20 percent from the cost of individual long-term care policies. It will also set an example for other employers.

Fifth, our FY 2000 budget would expand access to home and community-based care services to people of all ages with significant disabilities. Under this proposal, states could provide Medicaid coverage to people with incomes up to 300 percent of the federal Supplemental Security Income level who would be eligible for nursing home care but who would prefer to live in the community. This new Medicaid option will make eligibility for nursing homes and community-based services more comparable - and will eliminate one of the sources of Medicaid's "institutional bias."

Sixth, the President's budget provides \$100 million in competitive grants to enable existing HUD elderly subsidized (Section 202) projects to convert some or all units into assisted living in order to provide the additional services that many older Americans need to continue living as independently as possible. Finally, the Vice President has started a series of forums on family caregiving, raising important issues and educating people about their options.

Mr. Chairman, there are adult children in this country who - day in and day out - live in terror that their mom or dad will wander off or hurt themselves because of Alzheimer's or a similar disease. We want to keep families from having their lives wracked by stress, worry and despair. I speak from some personal experience. When I was home in Cleveland over Christmas, my cousins told me about caring for one of my aunts who has Alzheimer's disease. My cousins rush home from work in the middle of the day, every day, to make sure that their mother gets the help she needs. They are loving. But they are stressed. And they need help. Unfortunately, there is little help for them because they are middle income and do not qualify for Medicaid.

Frankly, my cousins' case is just one example of many. We know that the lives and needs of caregivers are varied. We know that there is no "one size fits all" answer. A complicated challenge requires a comprehensive solution. Overall, our initiative is a pragmatic response to the growing problems of long-term care. It provides comprehensive assistance, not just financial assistance, to those requiring or providing long-term care. Our proposal is an historic first step that represents a compassionate response to what I have already said will be one of our nation's most compelling problems in the 21st century. We must, as the President has said, "give care to caregivers." The President's initiative helps to meet that challenge.

The Department's Alzheimer's Initiatives

Alzheimer's disease exacts a heavy toll on its victims, their families, and our health care system. Each year new research helps to sharpen the effectiveness of care for people with Alzheimer's disease. Nevertheless, the nearly four million people in the United States who have Alzheimer's disease, or related disorders, is expected to double in the next 20 years. Each victim will eventually require full-time care. This dreaded disease affects patients, their families, caregivers and society. We must continue to evaluate the various models of care for people with Alzheimer's and models of support for their families so that successful approaches can be given broader implementation.

That is why I have directed the National Institute on Aging, under the leadership of Dr. Hodes, to step up its efforts to study Alzheimer's disease and related disorders. The NIH Alzheimer's disease prevention initiative is being developed to expedite our progress in delaying or preventing the onset of Alzheimer's disease. In collaboration with other federal agencies and the private sector, this initiative will foster new approaches to basic biological and epidemiological research; increase focus on drug discovery and development; improve methods for early identification of people at increased risk of developing Alzheimer's; and facilitate testing of possible new treatments in clinical trials. The initiative will also develop strategies for improving patient care and alleviating the burden of caregiving.

Just last week NIA launched a nationwide treatment study targeting people with mild cognitive impairment, also known as MCI, a condition characterized by memory deficit, but not dementia. Accurate and early evaluation and treatment of MCI individuals might prevent further cognitive decline, including the development of Alzheimer's disease. This study is the first such Alzheimer's disease prevention clinical trial carried out by NIH, and will be conducted at 65-80 medical research institutions throughout the United States and Canada. Other trials are in the pipeline, many of which will piggy back cognitive studies onto ongoing trials for the treatment or prevention of other conditions.

For those who now have Alzheimer's disease, research and information efforts are being intensified to help alleviate part of the overwhelming patient and caregiver burden, with special emphasis on the needs of a diverse patient population. The NIA is also taking steps to make information about Alzheimer's disease clinical trials more accessible to the general public. As part of a NIH-wide initiative on all major clinical trials, the NIA's Alzheimer's Disease Education and Referral Center (ADEAR), in collaboration with the Food and Drug Administration, is developing a database of ongoing Alzheimer's disease clinical trials. When complete, both government and commercial trials will be represented. The database will be accessible on the World Wide Web, and information will also be available through trained information specialists of the ADEAR toll-free hotline (1-800-438-4380).

The Administration on Aging's Alzheimer's disease demonstration grants will help states to take advantage of research findings and demonstrate effective models of non-medical care for people with Alzheimer's disease. The demonstration programs have proven to be very successful in reaching out to, and providing support services to people with Alzheimer's disease and their family caregivers. Special attention is being paid to minority, low-income and rural families. Building on the approach instituted by the Health Resources Services Administration (HRSA), AoA supports states in developing model practices for serving people with Alzheimer's disease and their families. Of the 15 grantees, 12 are state offices on aging, two are state health departments, and one is a state mental health agency. Nationally, almost 150 agencies are involved in the program. State and local Alzheimer's Association chapters are active in all of the projects. Approximately 8,000 families have been assured that their loved ones with Alzheimer's disease are able to maintain the highest possible quality of life.

I also want to note the Administration on Aging's highly successful national toll-free Eldercare Locator (1-800-677-1116). The Locator provides important information and assistance to long distance caregivers who are seeking help for their loved ones. We have found that many of the individuals who call our Eldercare Locator are caregivers for family members with Alzheimer's disease.

Let me close, Mr. Chairman, by saying that the need for support for family caregivers has never been greater. Caring for our elders has become a deeply emotional, sometimes heartrending matter for millions of families across America. The number of those families will only grow - as will the need for caregiving resources. The new century will bring longer life spans, more changes in family structure, more women in the work force, more geographic mobility and more delayed child rearing. We believe that the President's long-term care initiative, in particular the National Family Caregiver Support Program, offers an important first step towards ensuring that American elders and their families are able to enjoy a good quality of life, optimal health and access to critical supportive services.

Chairman Grassley, Senator Breaux, members of the Special Committee on Aging, I greatly appreciate your leadership on long-term care and other issues affecting senior Americans. I look forward to working with you to meet the challenges and opportunities of the gift of longevity. We have much to accomplish and many families to help. They are our friends, our neighbors, our fellow citizens. The time to offer them the supportive hand they need is now.

My colleagues and I would be happy to address any questions you might have.