

March 2004

Dear Alzheimer Advocate,

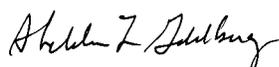
This Advocates' Guide is a critical tool for the thousands of people across the country who belong to the Alzheimer advocacy network. We have prepared it especially for distribution at the 16th Annual Public Policy Forum in Washington, DC but it has been designed for use in your advocacy throughout the year—with Congress, state legislatures, Governors and local officials.

As in past years, the *Advocates' Guide* is organized around our key advocacy issues of research funding, Medicare and Medicaid/long term care. We have taken particular care to provide advocates with more in-depth background information about the Association's key federal legislative priorities. The guide is organized into four sections:

- **Research** – contains talking points on Alzheimer research and the information you will need to ask members of Congress to continue support for the Association's billion dollar research goal.
- **Healthy Brain/CDC Prevention** – provides talking points about prevention and Alzheimer's disease, basic information about the Centers for Disease Control (CDC) and a factsheet on the Association's healthy brain initiative.
- **Medicare/Medicaid/Alzheimer Programs** – includes an overview of key Medicare issues for Alzheimer advocates, talking points about Medicaid and Alzheimer's, an overview of state and federal Medicaid reform proposals and fact sheets about Safe Return and the Alzheimer's Disease Demonstration Grants to States program.
- **Resources** – contains a glossary of acronyms frequently used in policy discussions, an overview of e-advocacy resources and a list of congressional committees with jurisdiction over Alzheimer's issues. A 2004 Congressional Calendar is on the inside back cover

This material has been assembled in a format that is easy to photocopy and reproduce for use in your advocacy activities. In addition, the entire *Advocates' Guide* is available online at www.alz.org. We encourage you to take some time to familiarize yourself with the information in this guide and share it with your Chapter's Public Policy Committee, volunteers and other interested advocates in your community. Each individual Alzheimer advocate plays an important part in continuing our tradition of steadfast advocacy on behalf of the millions of individuals and families who have been touched by Alzheimer's disease.

A final word. The most effective advocates are knowledgeable about the issues, but they also recognize that nothing can substitute for individual experiences with Alzheimer's disease. It is your personal stories that most clearly show elected representatives the human scope of this disease. We thank you for your dedication and commitment to our cause.



Sheldon L. Goldberg
President/CEO

Robert Thomas
Chair, 2004 Public Policy Forum

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Federal Legislative Priorities – 2004

108th Congress, 2nd Session

THERE IS HOPE IN THE FIGHT AGAINST ALZHEIMER'S DISEASE. WE CALL ON CONGRESS TO MAINTAIN THE HOPE BY:

Providing an immediate \$40 MILLION IN ADDITIONAL FUNDING toward our goal of \$1 billion for Alzheimer Research at the National Institutes of Health to fund:

- large scale, controlled clinical trials that will identify therapies and treatments capable of slowing or halting the onset and progression of Alzheimer's disease

Launching a "HEALTHY BRAIN" INITIATIVE in partnership with government agencies, including the Centers for Disease Control (CDC) to:

- educate the American people about ways they can maintain their brain as they age by providing \$6 million to CDC for an Alzheimer initiative
- translate scientific discoveries into effective methods that lead to prevention

Strengthening our commitment to CARE by:

- establishing a chronic care benefit in Medicare
- improving the Medicare prescription drug bill
- preserving the Medicaid safety net by maintaining the federal entitlements and quality assurance provisions of current law

Facts About Alzheimer's Disease

Alzheimer's disease is a progressive, degenerative disease of the brain and the most common form of dementia.

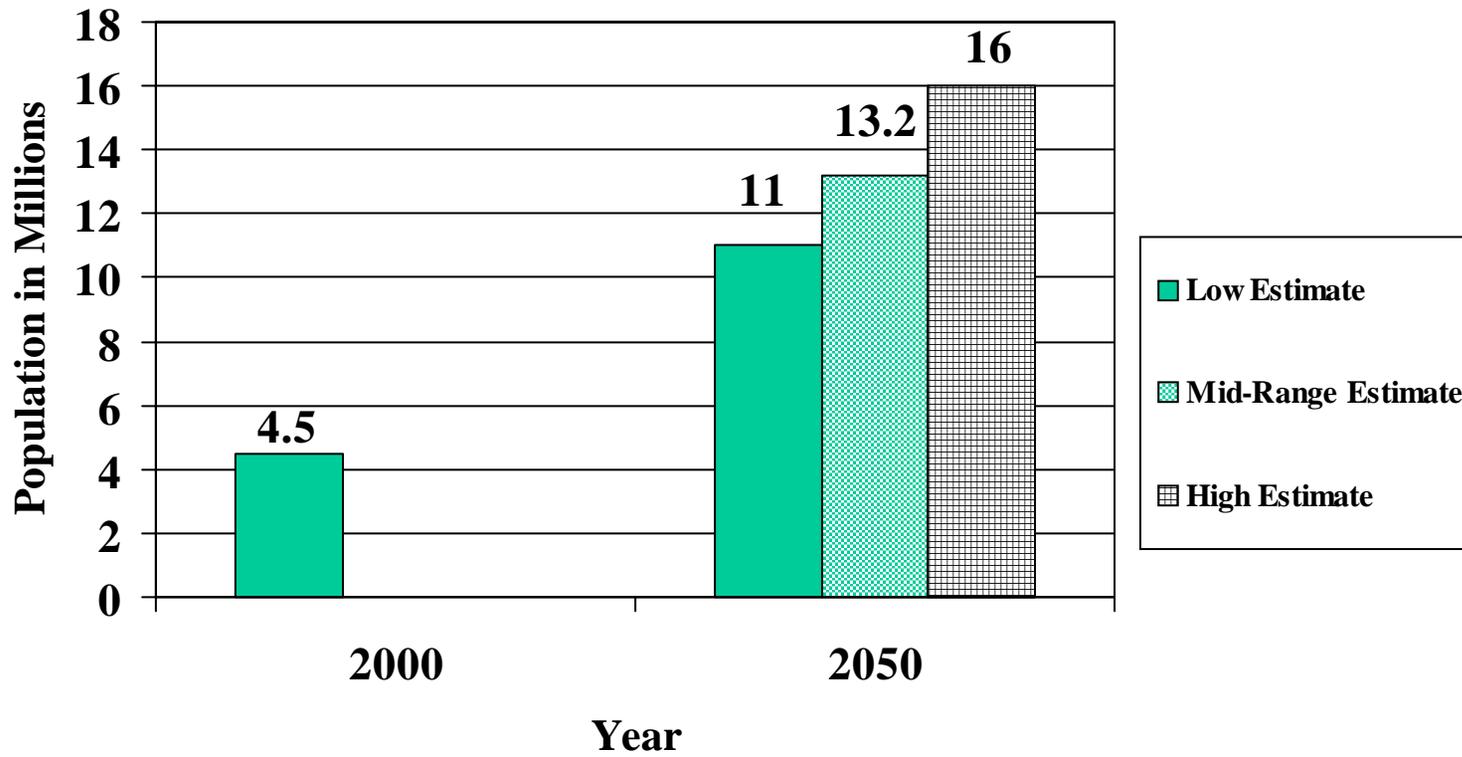
Prevalence

- An estimated 4.5 million Americans have Alzheimer's disease. A Gallup poll commissioned by the Alzheimer's Association found that 1 in 10 Americans said that they had a family member with Alzheimer's and 1 in 3 knew someone with the disease.
- By 2050, the number of individuals with Alzheimer's could range from 11.3 million to 16 million unless science finds a way to prevent or cure the disease.
- One in 10 persons over age 65, and nearly half of those over 85 have Alzheimer's. Rare, inherited forms of Alzheimer's disease can strike individuals as early as their 30's and 40's.
- The disease process may begin in the brain as many as 20 years before the symptoms of Alzheimer's appear. A person will live an average of 8 years and as many as 20 years or more from the onset of symptoms.
- residential dementia care will increase 80 percent, from \$18.2 billion to \$33 billion in 2010, according to a report commissioned by the Alzheimer's Association.
- Nearly half (49 percent) of Medicare beneficiaries who have Alzheimer's disease also receive Medicaid. Of the total population "dually eligible" for Medicare and Medicaid, 22 percent have Alzheimer's disease.
- Seven in 10 people with Alzheimer's disease live at home. While almost 75 percent of home care is provided by family and friends, the average annual cost of paid care for people with Alzheimer's disease at home is \$19,000.
- Nearly 60% of all nursing home residents have Alzheimer's disease or another dementia. The average annual cost of Alzheimer nursing home care is \$64,000. Medicaid pays nearly half of the total nursing home bill and helps two out of three residents pay for their care.

Costs

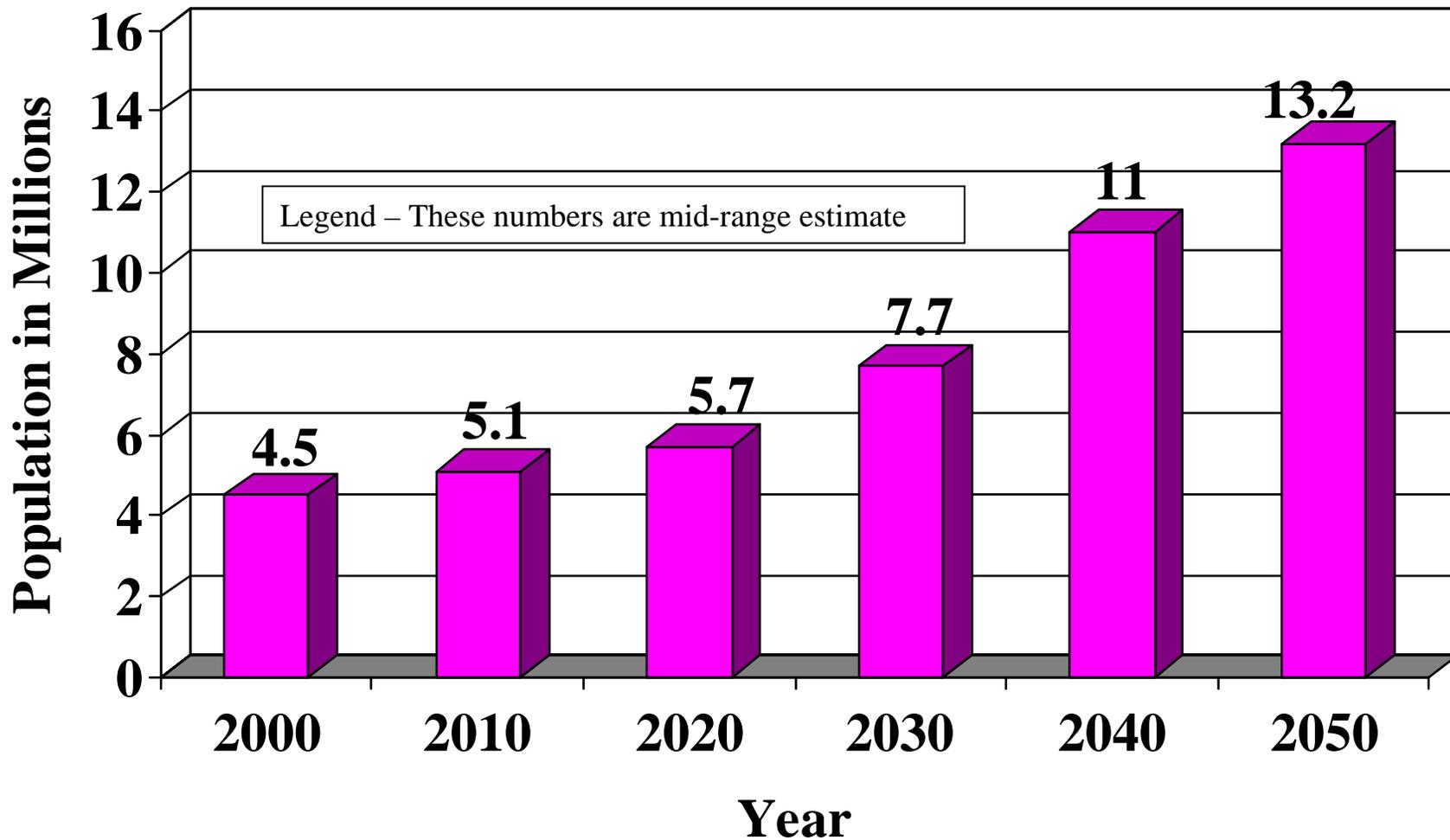
- Alzheimer's disease costs American business \$61 billion annually, \$36.5 billion of which is caused by the lost productivity of employees who are caregivers. The rest is the business share of the costs of health and long term care.
- By 2010, Medicare costs for beneficiaries with Alzheimer's are expected to increase 54.5 percent, from \$31.9 billion in 2000 to \$49.3 billion, and Medicaid expenditures on
- In fiscal year 2004 the federal government will spend an estimated \$679 million on Alzheimer research.
- The Alzheimer's Association has granted nearly \$150 million dollars in research grants since 1982.

Estimated Number of Americans with Alzheimer's Disease (In Millions)



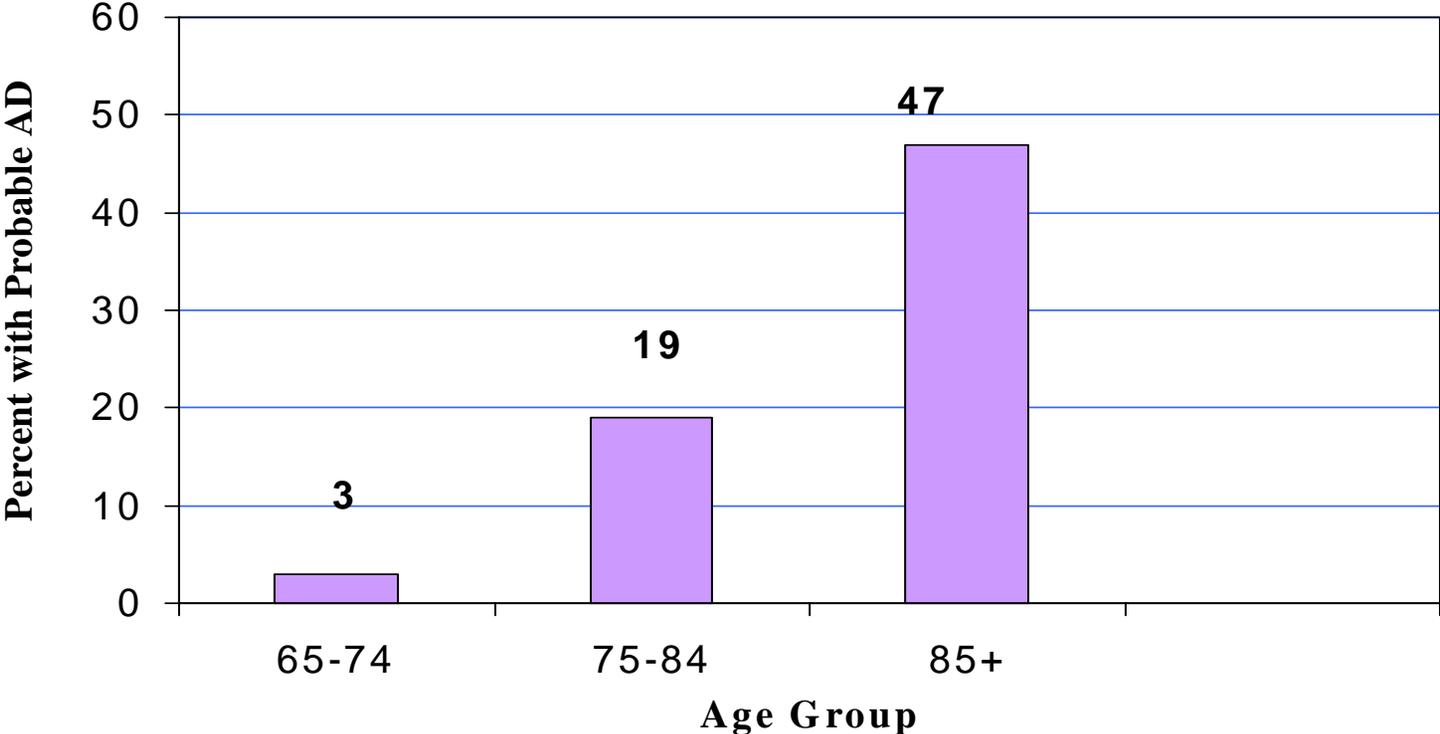
Source: Evans, D., et al. *Alzheimer Disease in the US Population: Prevalence Estimates Using the 2000 Census*. Arch. Neurol., Vol. 60, Aug. 2003

Estimated Number of Americans with Alzheimer's Disease (In Millions)



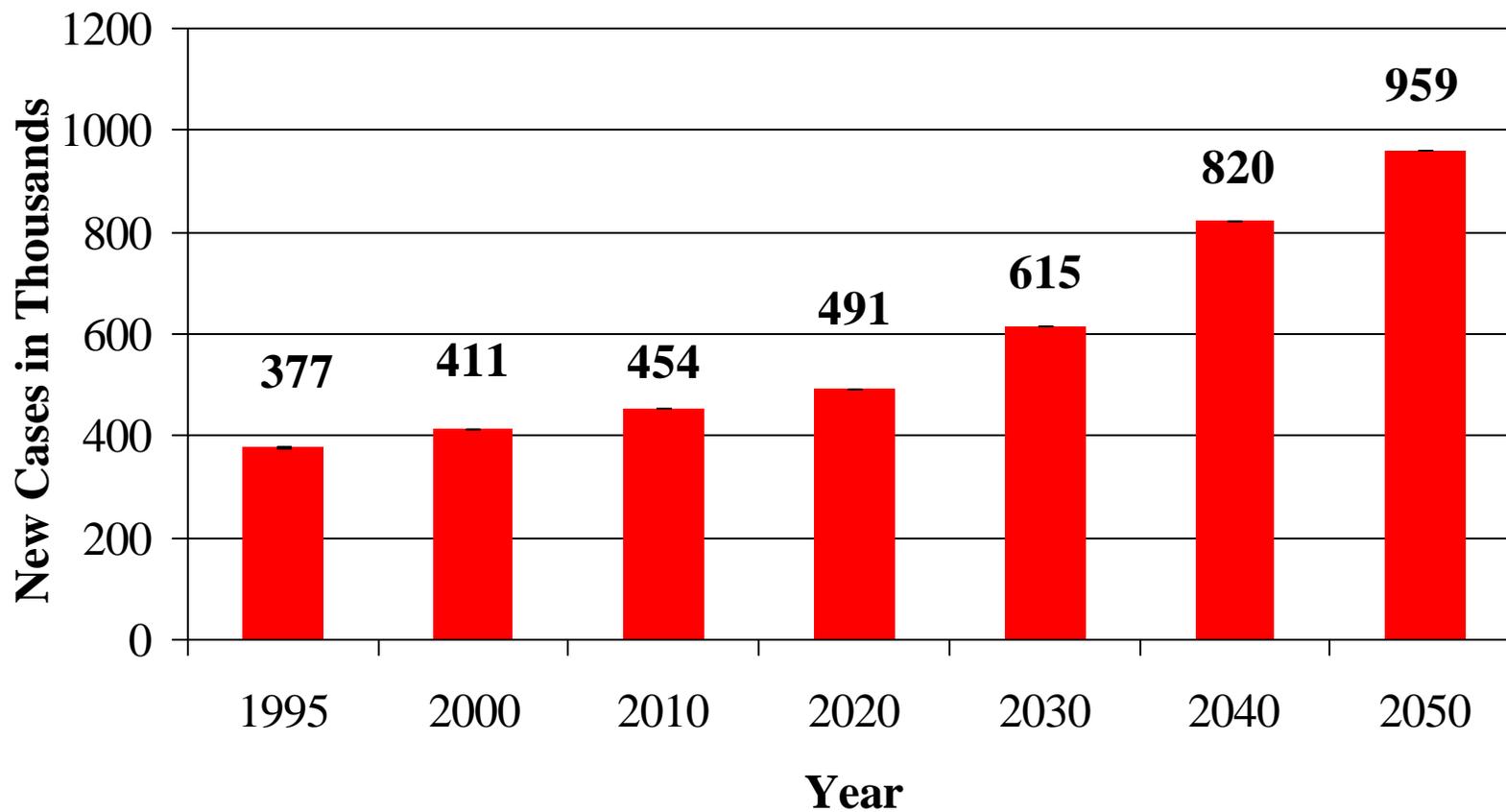
Source: Evans, D., et al. *Alzheimer Disease in the US Population: Prevalence Estimates Using the 2000 Census*. Arch. Neurol., Vol. 60, Aug. 2003.

Percent of People 65+ with Probable Alzheimer Disease



Source: Evans, D., et al. JAMA, Vol. 262, No. 18, 1969.

Estimated Number of New Alzheimer Cases (In Thousands)



Source: Herbert et al. (2001). Alzheimer Disease Associated Disorders, 15(4), 169-173.

Estimated Number of People With Alzheimer's Now and Projections for 2025

STATE	2000 TOTAL	2025 TOTAL	STATE	2000 TOTAL	2025 TOTAL
Alabama	78,160	130,319	Montana	18,419	37,221
Alaska	3,751	10,849	Nebraska	36,113	56,585
Arizona	85,472	169,389	Nevada	25,830	55,938
Arkansas	52,494	89,422	New Hampshire	20,665	34,795
California	472,660	827,392	New Jersey	152,175	216,880
Colorado	61,292	140,107	New Mexico	26,894	54,187
Connecticut	69,279	95,148	New York	329,928	431,951
Delaware	13,267	20,913	North Carolina	132,329	253,176
DC	9,816	11,861	North Dakota	15,537	24,950
Florida	395,652	712,962	Ohio	212,515	308,590
Georgia	103,115	198,149	Oklahoma	67,126	119,092
Hawaii	13,040	42,219	Oregon	68,695	142,704
Idaho	22,185	49,380	Pennsylvania	271,711	349,612
Illinois	210,669	295,847	Rhode Island	22,671	29,315
Indiana	106,072	163,364	South Carolina	62,345	119,748
Iowa	67,680	96,825	South Dakota	16,937	26,395
Kansas	53,850	80,717	Tennessee	95,890	168,656
Kentucky	67,625	110,453	Texas	280,964	552,651
Louisiana	68,958	120,790	Utah	27,815	66,932
Maine	24,461	36,254	Vermont	10,535	17,079
Maryland	79,969	129,986	Virginia	106,752	193,996
Massachusetts	126,715	172,947	Washington	97,940	206,559
Michigan	166,155	237,411	West Virginia	38,454	57,839
Minnesota	90,345	148,858	Wisconsin	103,716	160,605
Mississippi	46,654	74,486	Wyoming	8,251	19,400
Missouri	108,583	159,995			

Numbers are in actual thousand. They were derived from applying percentages of Alzheimer's prevalence to current US Census Bureau population projections. The percentages were determined from the East Boston Studies, conducted by Denis A. Evans, et. al. (JAMA 282(18):2551-6. Nov. 10, 1989.) The population projection numbers were taken from the US Census Bureau's PPL-47 Report, developed by Paul R. Campbell. This report can be found at: www.census.gov/population/www/projections/ppl47.html.

Cognitive Impairment in Nursing Home Residents by State, 2001

State	Total Nursing Home Residents	Percent of Residents at Each Level of Cognitive Impairment		
		None	Very Mild or Mild	Moderate to Severe
Alabama	45,684	22%	25%	53%
Alaska	1,390	30	26	44
Arizona	40,983	37	22	41
Arkansas	36,405	24	25	51
California	279,249	30	24	46
Colorado	39,056	25	30	45
Connecticut	62,920	32	27	41
Delaware	8,204	29	28	43
DC	5,321	31	24	45
Florida	206,499	36	22	42
Georgia	64,779	18	25	57
Hawaii	7,325	22	22	55
Idaho	13,082	30	26	44
Illinois	181,477	30	30	40
Indiana	93,906	31	24	45
Iowa	54,770	28	28	44
Kansas	43,638	23	29	48
Kentucky	50,848	27	24	49
Louisiana	56,475	27	27	46
Maine	19,300	28	26	46
Maryland	64,744	34	23	43
Massachusetts	112,242	34	24	42
Michigan	89,279	24	26	50
Minnesota	74,787	25	29	46
Mississippi	29,131	26	24	50
Missouri	86,756	29	26	45
Montana	13,559	30	27	43
Nebraska	29,901	27	28	45
Nevada	11,571	35	23	42
New Hampshire	14,401	27	26	47
New Jersey	104,978	36	25	39
New Mexico	13,395	28	27	45
New York	209,664	27	26	47
North Carolina	77,669	27	24	49
North Dakota	10,854	23	27	50
Ohio	184,447	27	26	47
Oklahoma	47,450	26	29	45
Oregon	26,410	29	25	46
Pennsylvania	190,378	31	24	45
Rhode Island	18,345	30	26	44
South Carolina	35,274	26	21	53
South Dakota	12,197	22	28	50
Tennessee	75,944	23	23	54
Texas	188,621	23	28	49
Utah	17,136	32	27	41
Vermont	6,619	21	26	53
Virginia	59,334	24	25	51
Washington	62,197	27	26	47
West Virginia	23,981	33	21	46
Wisconsin	76,287	29	27	44
Wyoming	5,141	26	28	46
U.S. Total	3,284,003	28	26	46

Source: U.S. Department of Health and Human Services, Centers for Medicare and Medicaid, based on MDS scores and the Cognitive Performance Scale (Morris et al., *Journal of Gerontology*, 1994).

Congressional Task Force on Alzheimer's Disease

Background

The bipartisan Congressional Task Force on Alzheimer's Disease was established by Representatives **Edward Markey (D-MA)** and **Christopher Smith (R-NJ)** and Senators **Hillary Rodham Clinton (D-NY)** and **Susan Collins (R-ME)**. The Alzheimer's Task Force currently includes 169 members of the House of Representatives and 10 U.S. Senators.

Why an Alzheimer's Task Force

The Task Force grew out of a desire to create a vehicle within Congress that could focus national attention on Alzheimer's disease and the health crisis it presents. The Task Force provides a critically needed forum where issues and proposed solutions concerning Alzheimer's could be discussed and investigated.

Why Alzheimer's Disease Is an Important Policy Issue

The need for the Task Force is clear:

- 4.5 million Americans have the disease. That number will increase to between 11.3 million and 16 million by 2050.
- Medicare, Medicaid, and American families and businesses all face runaway costs related to the spread of Alzheimer's

- One in 10 persons over age 65, and nearly half of those over 85 have Alzheimer's. Nearly 60% of all nursing home residents have Alzheimer's disease or another dementia.

Goals of the Task Force

The Congressional Task Force has established three goals:

- To educate and focus attention on Alzheimer's disease
- To encourage increased research funding for the discovery of treatments and a possible cure
- To foster open bipartisan discussion about public policy solutions to help meet the long term care needs of persons with the disease

How Does A Member of Congress Join the Task Force?

Representatives and Senators who are interested in joining the Congressional Task Force should contact Michael Bailey in Representative Edward Markey's office at (202) 225-2836 or Robyn Golden in Senator Clinton's office at 224-4451. For additional information about Task Force activities, visit Representative Markey's homepage at www.house.gov/markey/alzheimers.htm.

Federal Funding For Alzheimer Research

A Race Against Time

Objective

\$40 million in additional funding this year, toward our ultimate goal of \$1 billion in annual funding, for Alzheimer research at the National Institutes of Health for:

- Large scale, controlled clinical trials to identify therapies and treatments capable of slowing or halting the onset and progression of Alzheimer's

Status

The National Institutes of Health (NIH) will spend an estimated \$680 million on Alzheimer research in fiscal year 2004. Congress is now considering funding for fiscal year 2005. Funds for Alzheimer research will be contained in a Labor, Health and Human Services and Education (Labor-HHS) Appropriations bill (no bill number yet.) Hearings will take place during the spring in the Labor, HHS Appropriations Subcommittees in the House and Senate. Initial decisions on Alzheimer funding will be made in Subcommittee "markups" following the hearings. Action by the full House and Senate will take place in late summer or early fall.

Congress has completed its 5-year campaign to double funding at NIH, which has brought significant increases for Alzheimer research. Now, the

President has proposed a minimal 2% increase in NIH funding for Fiscal Year 05. That will not be enough to keep pace with inflation, much less continue the momentum of Alzheimer research.

Key Messages

- The investment in Alzheimer research to date has brought us to a point where the goal of a world without Alzheimer's is within reach.
- The scientific opportunities exist to find the answers in time, if we make the necessary investment now.
- There is a narrow window of time – 10 years at most – to prevent the devastating impact of Alzheimer's on families, businesses, and the US economy.
- Alzheimer's disease will destroy the health care system and bankrupt Medicare and Medicaid if left unchecked.

Key Members of Congress

Members of the House and Senate Appropriations Committee, especially the Subcommittee on Labor Health and Human Services

Speaker of the House, Majority and Minority Leaders and Majority and Minority Whips of the House and Senate

Talking Points In Support Of An Additional \$40 million Federal Investment In Alzheimer Research

Alzheimer's research is producing some groundbreaking discoveries that offer hope for the 4.5 million people suffering from the disease today. It is now possible to diagnose Alzheimer's with more than 90 percent accuracy. New treatments are being introduced each year. Investments in research have set the stage for scientific and medical advances to prevent or slow the progression of Alzheimer's disease. For the first time, a "World Without Alzheimer's" is within reach.

We can treat Alzheimer's and some day we will be able to prevent this disease, but not without more research and more help from Congress. National Institutes of Health researchers need \$40 million in additional funding in this fiscal year alone to carry out large scale, controlled, clinical trials that will identify therapies and treatments capable of slowing or halting the onset and progression of Alzheimer's. Basic research has proven positive discoveries, but we need to know whether the discoveries will actually work. A single large-scale clinical trial could cost as much as \$25 million and take three to five years, but clinical trials are the only way to translate—and verify—the findings of basic research into real-world treatments. We must do more.

Alzheimer's will bankrupt Medicare and Medicaid and impose unsustainable costs on families, state and federal governments, and American business.

- Medicare costs for a person with Alzheimer's (AD) are almost 3 times higher than the average for all beneficiaries. Within a decade, annual Medicare costs for beneficiaries with AD will increase by almost 55% - to nearly \$50 billion.
 - Nearly 60% of nursing home residents have AD or another dementia. By 2010, annual Medicaid costs just for those persons with AD in nursing homes will increase by over 80% - to \$33 billion.
 - Alzheimer's costs American business \$61 billion a year – twice the cost estimated just four years ago. \$36.5 billion of that is in lost productivity of workers caring for someone with AD. \$24.6 billion is the business share of health care costs for people with AD.
 - Families provide nearly 70% of Alzheimer care themselves. The average annual cost of full-time care for an individual with AD is over \$64,000, which families bear themselves as long as they can.
- There is a very narrow window of time to prevent an epidemic of Alzheimer's that will destroy the health care system.
- 4.5 million people in the U.S. have Alzheimer's today. By the middle of the century, that number will increase to between 11.2 and 16 million.
 - The number of new Alzheimer cases each year will more than double, from a little over 400,000 a year in 2000 to nearly 1 million a year by 2050.
 - The changes in the brain that cause Alzheimer's begin 10 to 20 years before symptoms appear. Babyboomers start entering the age of greatest risk in 2010. To prevent the looming epidemic, answers have to come before then.
 - If scientists can find ways in the next 10 years to delay the onset of AD and slow its progress, the number of babyboomers who get Alzheimer's will be cut by one-third. Among those who do get AD, the numbers who need full time care could be cut by 60%.

Why Additional Funding For Alzheimer Research Now?

Answers to Real Questions from Congress

Q: Congress just finished doubling the NIH budget. Why do they need more money?

A: This prior investment in research has brought us to the point no one would have dreamed possible 5 years ago. We are on the brink of discovery, but only additional investment will maintain the momentum of research.

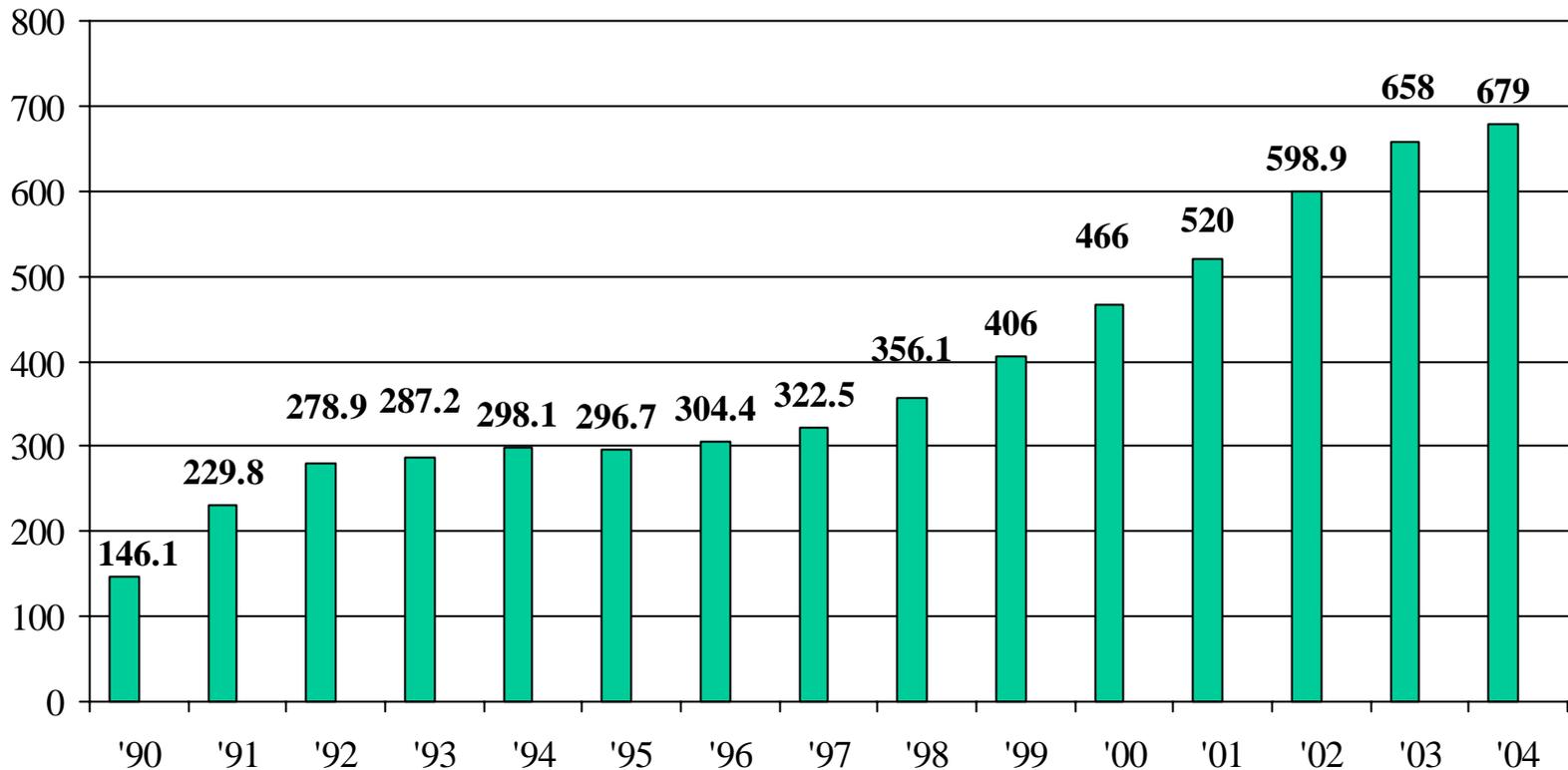
- The picture of the basic mechanisms of Alzheimer's disease is nearly complete.
- Advances in genetics and imaging give scientists the tools they need to find surrogate biomarkers and risk factors for Alzheimer's instead of waiting until symptoms appear. This is the key to a prevention strategy.
- Epidemiological research is rapidly identifying new targets for interventions – including compounds that are already widely available – that now must be tested in large scale clinical trials to see which may actually slow or prevent disease.
- The National Institute on Aging has built the interdisciplinary research infrastructure in the Alzheimer's Disease Centers and the Cooperative Study that make possible unprecedented levels of collaboration within and across academic settings – to find answers faster, cheaper and better.

Q: If Congress increases funding for Alzheimer research, could the NIH spend it well?

A: Scientists are poised to pursue very clear investigative pathways. Only the NIH, and especially the National Institute on Aging (NIA), has the infrastructure, the leadership, and the influence to bring together the public and private resources and stimulate the collaboration needed now. Additional funding would allow scientists to:

- Put together the last pieces of the basic puzzle of Alzheimer's disease. Less than one in four promising projects can be funded at current levels. Cost to fund another 10 percent of promising proposals to NIA: \$24.5 million.
- Initiate large-scale clinical trials, which are the only way to prove whether new targets for prevention will actually work. Cost per trial: \$25 to \$30 million.
- Fully implement NIA's Imaging Initiative to develop surrogate biomarkers of Alzheimer's to speed clinical trials by proving the efficacy of new drugs in the presymptomatic stage. Cost: \$60 million.
- Complete the search for genetic risk factors of Alzheimer's, to target new prevention and treatments to those who need them, through NIA's Genetics Initiative. Cost: \$60 million.
- Develop better animal models to test potential new treatments more quickly and at a fraction of the cost of human trials. Cost: \$50 million.

Federal Funding For Alzheimer Research Fiscal Years 1990-2004 (in millions of dollars)



2004 estimate based on FY 2004 appropriation

Alzheimer's Disease Centers Funded By the National Institute On Aging

ALABAMA

University of Alabama, Birmingham

ARIZONA

Sun Health Research Institute/Arizona Consortium

ARKANSAS

University of Arkansas for Medical Sciences

CALIFORNIA

University of California, Davis

Satellite(s): Oakland
Stockton

University of California, Irvine

University of California, San Diego, UCSD School of Medicine (LaJolla)

Satellite(s): Chula Vista

University of California, Los Angeles

Satellite(s): Drew Medical Center, South Central Los Angeles

University of Southern California

Satellite(s): Rancho Los Amigos Medical Center

Stanford University

FLORIDA

See Minnesota

GEORGIA

Emory University, Atlanta

ILLINOIS

Rush-Presbyterian-St. Luke's Medical Center, Chicago

Northwestern University Medical School, Chicago

INDIANA

Indiana University School of Medicine, Indianapolis

KENTUCKY

Sanders-Brown Research Center on Aging, University of Kentucky, Lexington

Satellite(s): Eastern Kentucky Satellite Diagnostic & Treatment Clinic
Meharry Medical College, Nashville, TN

MARYLAND

The Johns Hopkins Medical Institutions, Baltimore

MASSACHUSETTS

Harvard Medical School/Massachusetts General Hospital, Boston

Boston University Alzheimer's Disease Center, Bedford

MICHIGAN

University of Michigan, Ann Arbor

Satellite(s): Ypsilanti & Western Wayne County
Munson Medical Center, Traverse City

MINNESOTA

Mayo Clinic, Rochester

Satellite(s): Mayo Clinic, Jacksonville FL

MISSOURI

Washington University-St. Louis

Satellite(s): City of St. Louis
Cape Girardeau

NEW YORK

Columbia University, New York City

Satellite(s): Harlem Hospital

Mount Sinai School of Medicine, New York City

Satellite(s): Elmhurst Hospital, Queens

New York University, New York City

Satellite(s): Bellevue Hospital

University of Rochester ★ (affiliate center)

NORTH CAROLINA

Duke University Medical Center, Durham

OKLAHOMA

See Texas

OHIO

Case Western Reserve University, University Hospitals of Cleveland

OREGON

Oregon Health Sciences University, Portland

Satellite(s): Marie Smith Center Memory Assessment Clinic, Medford
Multi-Cultural Senior Center, Portland

PENNSYLVANIA

University of Pennsylvania School of Medicine, Philadelphia

University of Pittsburgh, Pittsburgh

Satellite(s): Hill House Center

TENNESSEE

See Kentucky

TEXAS

Baylor College of Medicine, Houston

University of Texas, Southwestern Medical Center, Dallas

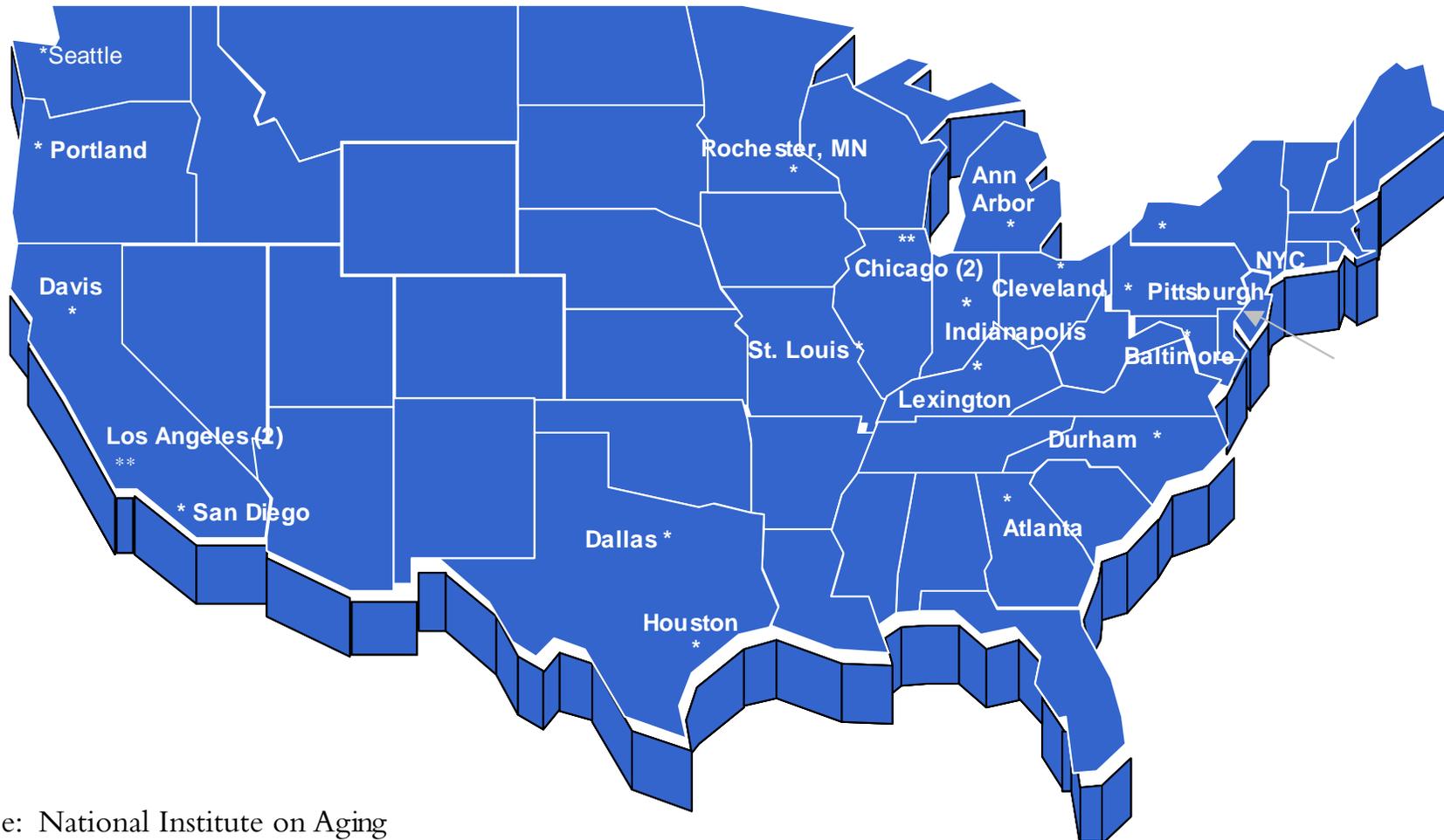
Satellite(s): Dallas County Mental Health Center
Choctaw Nation Medical Center, Tahleah, OK

WASHINGTON

University of Washington, Seattle

(updated March 2004)

Alzheimer Disease Centers Funded By The National Institute on Aging



Source: National Institute on Aging

African Americans And Alzheimer's Disease

African-Americans are among the hardest hit by Alzheimer's disease. The prevalence, incidence, and cumulative risk of Alzheimer's disease appears to be much higher in African-Americans than in non-Hispanic whites.

- Age-specific prevalence of dementia has been found to be 14% to 100% higher in African-Americans. (While the rates vary among studies, three out of four report these higher prevalence rates.)
- The cumulative risk of dementia among first-degree relatives of African-Americans who have Alzheimer's disease is 43.7%.
- For spouses (who share environmental but not genetic backgrounds), the cumulative risk was 18.4%. These findings of familial risk, reported in January 2002, are based on family histories of the largest number of African-American families ever studied for Alzheimer's disease.

The number of African-Americans entering age of risk is growing rapidly.

- Age is a key risk factor for Alzheimer's disease in all racial and ethnic groups. Over 10% of all persons over 65, and nearly half of those over 85 have Alzheimer's disease.
- The number of African-Americans age 65 and over will more than double by 2030, from 2.7 million in 1995 to 6.9 million by 2030
- The number of African-Americans age 85 and over is growing almost as rapidly, from 277,000 in 1995 to 638,000 in 2030 and will increase more than five-fold between 1995 and 2050 when it will reach 1.6 million.

Genetic and environmental risk factors for Alzheimer's disease seem different in African-Americans but have not been well studied.

- Genetic risk factors seem different in African-Americans and white Americans. APOE genotype alone does not explain the increased frequency of Alzheimer's disease in older African-Americans.
- Vascular disease may be a particularly powerful factor in the prevalence of Alzheimer's among African-Americans.
- Data from a large-scale longitudinal study indicate that persons with a history of either high blood pressure or high cholesterol levels are twice as likely to get Alzheimer's disease. Those with both risk factors are four times as likely to become demented.
- Sixty-five percent of African-American Medicare beneficiaries have hypertension, compared to 51% of white beneficiaries. They are also at higher risk of stroke. (Data from the Current Medicare Beneficiary Survey)
- African-Americans have a 60% higher risk of type 2 diabetes – a condition that contributes directly to vascular disease.
- African-Americans have a higher rate of vascular dementia than white Americans.

Screening and assessment tools and clinical trials are not designed to address the unique presentation of Alzheimer’s disease in African-Americans.

- „ Ethnic and cultural bias in current screening and assessment tools is well documented. As a result, African-Americans who are evaluated have a much higher rate of false-positive results. At the same time, there is substantial evidence of underreporting of dementia among African-Americans.
- „ African-Americans tend to be diagnosed at a later stage of Alzheimer’s disease – limiting the effectiveness of treatments that depend upon early intervention.
- „ While new data from the National Institute on Aging shows that African-Americans are represented in current clinical trials of potential treatments for Alzheimer’s disease, often the overall participant number is not large enough to draw conclusions for any racial subset. This is an important issue, as genetic differences and response to drugs varies significantly by race and ethnicity.

Adapted from “African-Americans and Alzheimer’s Disease: The Silent Epidemic”, Alzheimer’s Association, February 12, 2002. Available at www.alz.org/Media/newsreleases/2003/AA_ALZ.pdf

Hispanics and Alzheimer's Disease

Dementia is a looming but unrecognized public health crisis in Hispanic/Latino communities in the United States. During the first half of the 21st century, the number of Hispanic elders suffering from Alzheimer's and related dementias could increase more than six-fold, from fewer than 200,000 today to as many as 1.3 million by 2050.

- Research is only beginning to uncover the impact of Alzheimer's disease among Hispanics, what we have learned to date suggests that Hispanics may be at greater risk to develop dementia than other ethnic or racial groups
- Hispanic/Latino family caregivers, particularly daughters and other female relatives, care longer for those who are most impaired in part because of a strong sense of filial responsibility and the role of women in these communities
- For these communities, there is a lack of culturally appropriate and responsive health and community services.

Hispanics/Latinos face high risk of Alzheimer's disease and other dementias.

- Age is the single greatest risk factor for Alzheimer's – prevalence doubles every 5 years beyond the age of 65 and reaches 47% of persons 85 and older. Hispanics are disproportionately represented in the older age groups most at risk of Alzheimer's disease. Life

expectancy for Hispanics will increase to age 87 by 2050, surpassing all other ethnic groups in the United States.

- A growing body of evidence indicates that vascular disease risk factors — diabetes, obesity, high blood pressure, and high cholesterol — may also be risk factors for Alzheimer's disease and dementia. Hispanics/Latinos have high rates of each of these risk factors
- Education appears to have some protective effect against Alzheimer's, but Hispanics have the lowest education levels of any group in the United States. One in 10 Hispanic elders have no formal education. Over half have 8 years of schooling or less.
- Complicated by the racial and cultural diversity of Hispanics in the United States, the limited research available suggests that within-group differences may affect incidence and presentation of the disease. As defined by the U.S. Census, Hispanics may be of any race and from more than 25 subgroups by country of origin.

Hispanics/Latinos Are Not Receiving the Health Care They Need to Reduce Their Risk or Manage Their Dementia

- Hispanics/Latinos with dementia are low users of formal healthcare services. They are less likely than non-Hispanics to see a physician and much less likely to use services provided by other health professionals.

Among adults with diabetes, high blood pressure, or heart disease – all potential risk factors for dementia — they are less likely to receive services to help monitor and control those conditions.

- „ Hispanics tend to be diagnosed at a later stage of Alzheimer’s disease – limiting the effectiveness of treatments and leading to high levels of impairment and heavy and prolonged caregiver burden.
- „ Large numbers of Hispanic elders – particularly the old-old who are most at risk of Alzheimer’s — are first generation immigrants who are not necessarily comfortable in English or trusting of the health care system.
- „ Cultural biases in cognitive testing and inadequate translation of diagnostic tools may skew diagnosis of dementia in Hispanics. Coupled with the lack of bilingual professionals in this field nationwide, testing and diagnosis of monolingual Spanish-speaking elders is especially challenging.

Dementia Inflicts Especially High Burdens on Hispanic/Latino Families

- „ The strong cultural value of family responsibility, notably the high sense of filial responsibility for elders, is a strength of Hispanic/Latino communities.

- „ Hispanic/Latino families, particularly daughters and other female relatives, provide a disproportionate share of Alzheimer care. They do so for longer periods of time and at higher levels of impairment than is the case in non-Hispanic families.
- „ Hispanic caregivers are reluctant to use formal services until they are completely overwhelmed. This is linked to a distrust of outsiders, acceptance of stress as a normal and expected part of the familial role, and resistance to sharing familiar problems with outsiders or admitting that care is too demanding.
- „ Hispanic families need information, help and support to sustain their role as caregivers and to assure that the person with dementia is getting treatments that may help lessen the burden of the disease. Those services must be provided in a way that reinforces family values and overcomes cultural barriers to service.

Alzheimer's Disease Initiative at the Centers for Disease Control (CDC)

Objective

Secure \$6 million in funding for an Alzheimer's disease initiative at the Centers for Disease Control (CDC)

Status

The CDC has identified healthy aging for older adults as a major focus area for future research and action. Preliminary studies suggest that some of the same strategies that preserve overall health may also help prevent or delay Alzheimer's disease and dementia. For example, epidemiological studies have revealed that individuals taking anti-inflammatory drugs to treat conditions such as arthritis appear to have a lower-than-expected occurrence of Alzheimer's disease.

A growing body of evidence appears to link known risk factors for heart disease, including high blood pressure and high cholesterol, and risk factors for Alzheimer's disease. Maintaining the brain by remaining intellectually and physically active and socially connected may also help stave off dementia.

The Alzheimer's Association is advocating for an appropriation of \$6 million for the CDC to undertake a program to educate the public about ways they can maintain their brain as they age, and to encourage state public health departments to launch prevention/early identification and intervention programs with particular attention to the link between Alzheimer's disease and co-morbidities such as diabetes and vascular disease.

Talking Points

The Alzheimer's Association recommends that Congress establish and fund a program through the CDC to educate the public about ways they can maintain their brain as they age and to encourage state public health departments to launch prevention/early identification and intervention programs with particular attention to the link between Alzheimer's disease and co-morbidities such as diabetes and vascular disease.

CDC's work on healthy aging should include efforts targeted to:

- Identification and early diagnosis of Alzheimer's and dementia
- Managing behaviors that accompany Alzheimer's to prevent decline, excess disability, caregiver stress, and premature institutionalization
- Managing comorbid conditions in people with Alzheimer's to prevent health crises
- Educating physicians about the diagnosis and treatment of Alzheimer's disease

Key Members of Congress

House Appropriations Committee
Senate Appropriation Committee

Understanding Research About Alzheimer's Disease Risk Factors and Prevention

The number of people with Alzheimer's disease in the United States is estimated to increase from about 4.5 million today to as many as 11 million to 16 million by 2050. The Alzheimer's Association is committed to turning that trend around.¹

Other research has estimated that if we could delay the onset of the disease by five years, there would be about half of the expected number of people with the disease within 50 years.²

We know that the risk of developing Alzheimer's disease increases with age, but there may be other factors at work that we can control. The research community, therefore, is asking, "How can we reduce our risk of developing the disease, delay the beginning of symptoms, prevent the disease from starting, or perhaps stop it in its tracks before it affects a person's thinking abilities?"

A combination of several research approaches, rather than a single line of investigation, is necessary to answer these questions. Advances in recent years give us reason to hope that we will find answers and eventually make Alzheimer's disease just a memory.

Where do researchers begin looking for clues about risk factors?

The main starting point for understanding factors that increase or decrease the likelihood of getting a disease is epidemiological or observational research. In these studies, scientists gather information about a large group of people who represent the general population to some extent. They are looking to see if a certain factor is more strongly associated with people who have a

particular disease than with the people who don't.

For example, scientists might follow a group of adults over a number of years, monitor them for the onset of Alzheimer's disease, and check their cholesterol levels at regular intervals during the study. At the end of the study when all the information is combined, the investigators will analyze the data to determine if high cholesterol is more strongly associated with one group than the other.

What have we learned about Alzheimer's disease from observational studies?

Scientists have found a number of factors associated with an increased or decreased risk of developing Alzheimer's disease. Some of these findings have been demonstrated fairly consistently in several studies, and some research on these factors has shown contradictory information. The contradictions may mean that the association does not actually exist, that there may be unavoidable limitations in study methods, that more studies are needed to find out why we see contradictions, or that the story of a particular factor is more complicated than originally imagined.

Some factors that may be associated with an increased risk for Alzheimer's disease:

- stroke
- high blood pressure
- high cholesterol
- diets high in saturated fats
- high homocysteine, an amino acid that is a building block of proteins
- severe head injury (usually defined as loss of consciousness for at least 24 hours)

Some factors that may be associated with a decreased risk for Alzheimer's disease:

- low fat diets
- diets with “good cholesterol,” such as the fatty acids found in some fish
- diets with high vitamin C and E
- vitamin C and E supplements
- long-term use of some anti-inflammatory drugs
- long-term use of statins, a kind of medication for controlling high cholesterol
- regular physical activity
- regular mental stimulation
- higher levels of education

What do these findings mean?

An association identified in an observational study is not the last word on a topic and does not establish cause and effect. The information needs to be interpreted carefully, particularly regarding such factors as mental stimulation that are difficult to quantify. But these findings do tell us where we should be focusing some of our research efforts.

In general, scientists take the next steps in research either by (1) conducting carefully controlled clinical trials to find more definitive answers to questions addressed in observational research and (2) laboratory studies that investigate the connections between the possible risk factors and the biological mechanisms of Alzheimer's disease.

An example of risk factor and prevention research

Research about nonsteroidal anti-inflammatory drugs (NSAIDs) serves as a good example of what we can learn from risk factor studies and why we need additional investigations. NSAIDs include

aspirin and aspirin-like compounds that are generally used to treat pain, inflammation, and fever.

The first observational studies about a reduced risk of Alzheimer's disease associated with NSAIDs started emerging in the late 1980s and the early 1990s. (At this same time, researchers started reporting evidence of inflammation in the brain related to Alzheimer's.)

A big step forward in NSAID/risk factor research came in 2001 with a report of an observational study in the Netherlands that had recruited nearly 7,000 healthy older adults in the early 1990s. Researchers monitored the participants for about seven years and tracked the use of NSAIDs through pharmacy records. This study showed a strong association between NSAID use and a lower risk of developing Alzheimer's.

The take-home lesson of the finding, however, was not that people should take NSAIDs to prevent Alzheimer's disease. The evidence did not demonstrate a clear preventive effect, and long-term use of these medications can have some serious side effects. Instead these observational studies helped shape new questions in research:

- Can we demonstrate in clinical trials that currently existing NSAIDs prevent or delay the onset of Alzheimer's disease?
- Can we demonstrate in clinical trials that currently existing NSAIDs can be used to treat people who already have Alzheimer's?
- What are NSAIDs doing in the brain that may help prevent or treat the disease?
- Is there a need to develop new drugs to target inflammation in Alzheimer's?
- What can we learn about NSAIDs and risk from additional observational studies?

Investigations regarding these questions in the past few years have revealed a complex set of answers:

- Laboratory studies and animal studies (not clinical trials) have shown that some NSAIDs may work by inhibiting the production of beta-amyloid, a protein fragment that is a key suspect in Alzheimer's disease. These NSAIDs include ibuprofen, a drug available over-the-counter, and flurbiprofen, a prescription drug.
- A second look at the Dutch study suggested that only this limited group of "anti-amyloid" NSAIDs, rather than all NSAIDs, may be associated with a lower risk of Alzheimer's.
- Although preliminary treatment trials looked promising, large-scale trials using NSAIDs to treat people with Alzheimer's disease did not demonstrate a benefit.
- A large body of evidence has revealed details about how inflammatory activity in Alzheimer's disease works and how it is related to other disease mechanisms.
- A number of investigators are analyzing Alzheimer-specific inflammatory activity in an effort to find targets for new anti-inflammatory drugs. A laboratory at Northwestern University that has received funding from the Alzheimer's Association received a \$6.8 million grant from the National Institutes of Health in 2003 to pursue this work.
- Researchers are currently conducting a large-scale, 5-7 year prevention trial of NSAIDs. This study is supported in part by the National Institute on Aging.

What can NSAID research teach us about risk factor and prevention studies in general?

- Any claim about the ability of a factor to lower risk or prevent disease cannot be supported only by observational studies. These findings need to be clarified with clinical trials and laboratory research.
- Some factors associated with lower risk, such as low-fat diets or mental stimulation, may help and won't hurt. Some factors, such as long-term use of NSAIDs, have serious health risks, which make further investigations even more critical.
- Basic science research and clinical trials are necessary to make sense of risk factors and to figure out the complex story often revealed in observational studies.
- Basic science research and clinical trials, especially trials of compounds that are already available over-the-counter, depend on additional support from the NIH.

¹ Hebert, LE; Scherr, PA; Bienias, JL; Bennett, DA; Evans, DA. "Alzheimer Disease in the U.S. Population: Prevalence Estimates Using the 2000 Census." *Archives of Neurology* August 2003; 60 (8): 1119-1122.

² Brookmeyer, R; Gray, S; Kawas, C. "Projections of Alzheimer's Disease in the United States and the Public Health Impact of Delaying Disease Onset." *American Journal of Public Health* 1998; 88 (9): 1337-1342.

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- „ They cannot follow routine physician orders or medication regimes on their own.
 - „ They cannot follow or identify early signs of infection or illness.

Current Medicare reimbursement policies discourage physicians from taking the time to diagnose and manage Alzheimer’s disease, but research and demonstration projects have documented a better way.

- „ Regular monitoring and care coordination can identify health problems early, prevent infection, reduce problem behaviors, and avoid hospitalization.
- „ Close collaboration among the physician, the patient and family, and the community care system has also been proven to improve health and functional status and to reduce hospitalizations.
- „ Palliative care designed for patients with advanced Alzheimer’s disease has proven to reduce total medical costs *2.7 times* below care in traditional settings.

At least one-third of Alzheimer caregivers are also covered by Medicare and they have high health costs directly related to their caregiving role.

- „ One in 8 Alzheimer family caregivers become ill or injured as a direct result of caregiving.
- „ One in three use medication for problems related to caregiving.

- „ Depression among caregivers is 3 times the norm for people in their age group.
- „ 36% of caregivers are over age 65; 10% of women caregivers and 40% of caregiver husbands are 75 or older. Medicare pays for their health care as well as that of the person with Alzheimer’s disease.

Simple low-cost interventions can prevent many of these caregivers’ health problems, but such interventions are not covered by Medicare because they are not recognized as legitimate health care expenses.

- „ Caregiver support – including respite, education and counseling – can enhance the ability of family to manage care at home with improved health outcomes for both the person with the disease and the caregiver.
- „ Personal assistance at home can prevent malnutrition and dehydration, falls, and infection, and protect against wandering and other risky behaviors.
- „ Therapeutic adult day care can help maintain physical function, manage behavior, and provide early warning of health problems.

Medicare Coverage of Chronic Conditions

Objective

Add a Medicare chronic care benefit and direct Medicare resources to chronic care to prevent the acute health crises and excess disability that are driving health care costs.

Status

The Alzheimer's Association has advocated for improved Medicare coverage for care of chronic conditions, and some members of Congress have focused on this issue. Findings from research and demonstrations point to effective ways to diagnose, manage, and treat Alzheimer's disease; maintain function; and prevent health care crises and excess disability. These findings place new responsibilities on clinicians to diagnose the disease earlier and begin management and treatment. However, Medicare does not pay clinicians for this type of care management and treatment.

Senator Blanche Lambert Lincoln (D-Arkansas) plans to reintroduce the *Geriatric Care Act* with support by the Alzheimer's Association. A number of provisions in this bill would provide better coverage for people with Alzheimer's disease and other chronic conditions. This legislation would improve quality of care to people with Alzheimer's and other comorbid conditions by extending Medicare coverage to geriatric assessment and care coordination.

The legislation authorizes Medicare to cover these essential services by paying physicians to manage medications effectively, work with other health care providers as a team, and provide necessary support for caregivers.

Talking Points

The combination of dementia and other chronic conditions make Medicare costs skyrocket.

- 95% of Medicare beneficiaries with Alzheimer's disease have one or more other chronic conditions that are common in the elderly – coronary heart disease (30%), congestive heart failure (28%), diabetes (21%), and chronic obstructive pulmonary disease (17%).

Medicare should provide coverage for geriatric assessment and chronic care management targeted to beneficiaries with Alzheimer's and other chronic conditions.

- Medicare Multiple chronic conditions can be effectively managed by: comprehensive assessment and management of individual needs, on-going monitoring of health status, early treatment of emerging problems, and close collaboration among the physician, the patient and family, and the community care system.
- Care coordination and management interventions have been proven to improve health status and reduce hospitalizations for people with Alzheimer's disease and in many instances, for the family caregiver.
- The demonstrations in the *Medicare Modernization Act* do not go far enough.

Overview of Chronic Care Demonstration Projects in the Medicare Prescription Drug, Improvement and Modernization Act of 2003

The Medicare Prescription Drug, Improvement and Modernization Act of 2003 established several demonstrations of new models of care for beneficiaries with chronic conditions. Two demonstrations of particular importance to people with Alzheimer's are described below.

- 1) The Chronic Care Improvement Program (Section 721/Disease Management Demonstration) is a demonstration project to implement chronic care improvement programs under fee-for-service Medicare to improve quality and beneficiary satisfaction, and to save money, for beneficiaries with certain chronic conditions. Eligible beneficiaries must have one or more "threshold" conditions such as heart failure, diabetes, chronic obstructive pulmonary disease and other diseases selected by the Secretary of the Department of Health and Human Services (HHS).

Organizations eligible to provide a chronic care improvement program include: disease management organizations, health insurers, integrated delivery systems, physician group practices or other entities selected by the HHS Secretary. The chronic care improvement organization will guide beneficiaries in managing their health, use decision-support tools, and develop a clinical information database to track and monitor beneficiaries across settings and monitor outcomes.

The law requires chronic care improvement programs to identify beneficiaries with cognitive impairment for the purpose of developing the care plan.

- 2) The Medicare care management performance demonstration (Section 649) is a three-year demonstration project in five states (including Arkansas) to encourage improved health outcomes for beneficiaries through bonus payments to physicians. The bonus payments will be based on outcomes of care. One of the sites for this demonstration project is required to focus on beneficiaries with multiple chronic conditions including dementia.

Talking Points

The Alzheimer's Association is pleased that the new Chronic Care Improvement Demonstration requires plans to identify beneficiaries with dementia for the purposes of developing the care plan.

These demonstrations should target beneficiaries with complex chronic conditions that put them at risk of poor health outcomes and high care costs, including those who cannot manage their own care because of Alzheimer's disease or another dementia. When dementia exists in beneficiaries with other costly conditions – coronary heart disease, congestive heart failure, diabetes, or COPD – Medicare costs are twice as high as for other beneficiaries with those conditions.

The Alzheimer's Association recommends that chronic care improvement organizations be required to: have staff who are trained to recognize signs and symptoms of dementia and ensure a central role for treating physicians and their primary care providers for beneficiaries with multiple chronic conditions.

For beneficiaries with Alzheimer's disease, core services should go beyond self-improvement education and patient self-management and should include: coordination of clinical care across health care providers; multidisciplinary care conferences; management of transitions of care across practice settings and between providers; medication management, review and oversight; education, counseling and ongoing consultation with the patient and family; referral to and coordination with community resources; and information about and assistance with end-of-life decision-making, including hospice and palliative care.

Any analysis or evaluation of these demonstrations should account for and analyze the impact of the presence of dementia.

Prescription Drug Coverage and Alzheimer's Disease

Objective

- Oversee the implementation of the new Medicare prescription drug benefit

Status

The Alzheimer's Association supports the Medicare Prescription Drug, Improvement, and Modernization Act of 2003. In the decision to support this new law, the Association made an assessment that this bill, on balance, would help people with Alzheimer's disease. In addition, we recognized that this was an historic opportunity to establish a Medicare drug benefit, the greatest expansion since the inception of Medicare.

To summarize the essence of our decision, the Alzheimer's Association believes this bill is worthy of our support for the following reasons:

- The legislation addresses a serious gap in Medicare for people with Alzheimer's disease – coverage for prescription drugs.
- The legislation conformed to most of the prescription drug principles established by the National board.
- The potentially negative provisions on privatization (also known as “premium support”) were changed to a demonstration and will not begin until 2010, giving us time to advocate for improvements.
- It is unlikely that \$400 billion will be put on the table again to expand Medicare benefits and we should not pass up this opportunity to help millions of Medicare beneficiaries with high drug costs.

- The legislation takes an important step toward the problem of poor quality care for people with multiple chronic conditions, including Alzheimer's disease, by establishing care management and disease management demonstrations and benefits.

Talking Points on the Medicare Prescription Drug Benefit

The Alzheimer's Association supported the passage of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003. The Association made an assessment that this bill, on balance, would help people with Alzheimer's disease. In addition, the Association recognized that this was an historic opportunity to establish a Medicare drug benefit, the greatest expansion since the inception of Medicare.

The Association is taking a lead role in establishing ABC-RX — a coalition to promote enrollment and to advocate for the interests of low-income individuals in the implementation of the Medicare drug benefit.

The new law poses many additional complexities to the Medicare program. The Association would like to work with Congress and the Department of Health and Human Services to implement strong consumer information assistance, recognizing that those with memory problems will likely have difficulty negotiating a complex, new system with multiple requirements for enrollment and other paperwork.

The “premium support” demonstration is scheduled for implementation in 2010, though many believe it will never be implemented.

The Association did not support the inclusion of any premium support provision. If it moves forward, Congress should ensure that the implementation and evaluation of a such a demonstration will not: 1) place beneficiaries with Alzheimer's at risk by destabilizing traditional, fee-for-service Medicare; 2) incur substantially higher costs for beneficiaries who prefer to stay in traditional Medicare; 3) limit choice and penalize older, sicker beneficiaries.

Talking Points On Prescription Drugs And Alzheimer's Disease

Prescription drug coverage is particularly important for people with Alzheimer's disease or vascular dementia. They use more prescriptions drugs than the average Medicare beneficiary. The cost of those drugs is nearly three times higher. And those costs come on top of heavy out-of-pocket expenses for personal care and long term care.

- The mean monthly cost of prescription drugs for persons with AD is \$246.46 (\$2958 annually – nearly 3 times the annual cost of \$1,099 for all Medicare beneficiaries.)
- People with Alzheimer's disease need drugs not just for treatment of their Alzheimer's, but also for treatment of behavioral symptoms associated with the disease, and for coexisting medical conditions.
- 88% of people with Alzheimer's take at least one prescription drug a month (compared to all Medicare beneficiaries – 82% of whom fill at least one prescription a year.)
- 68% of people with Alzheimer's take at least two prescriptions each month. 35% take four or more.

- The cost of drugs is directly related to coexisting medical conditions. Monthly costs ranged from \$227 for those who had no medical conditions other than Alzheimer's, to \$470 for those with 7 comorbid conditions.
- In the study on which these data are based, over 70% of people with Alzheimer's or vascular dementia had at least one other chronic medical condition. 50% have two or more additional chronic conditions.

(This data is based on a review of medical records of a sample of community-dwelling patients with Alzheimer's and/or vascular dementia seen at the Memory Disorders Clinic at the Johns Hopkins University Hospital. Calculations are based on conservative assumptions – lowest appropriate dosage, use of generics if available, and average wholesale price (AWP). Elderly persons who do not have prescription drug coverage may pay more than the AWP as well as a dispensing fee.

The Hopkins data on use of prescription drugs in persons with Alzheimer's is compared with data published in Health Affairs, March-April 2000 on prescription drug use and cost for all Medicare beneficiaries.

Basic Facts about the Medicare Drug Benefit: How it will Impact Medicare Beneficiaries with Alzheimer's Disease

What Will the Bill do for People with Alzheimer's?

For the first time, Medicare will provide a new prescription drug benefit:

- \$35 monthly premium
- \$250 annual deductible
- 75% coverage until \$2250 total costs
- No coverage between \$2200-\$5100
Annual out-of-pocket limit \$3600/yr (plus 5% over \$5100)
- 95% coverage above \$5100 total

It will provide additional help for low-income beneficiaries and for people with the highest drug costs.

It provides a start on providing care coordination for people with Alzheimer's and other chronic health conditions.

Summary of New Benefit

The following is a summary of the drug benefits that will be available to Medicare beneficiaries as a result of the new prescription drug bill recently passed by Congress. More specific information will be available in the future as the Centers for Medicare and Medicaid Services (CMS) develops the rules and regulations to implement the new benefits.

From Spring 2004 –December 2005

Interim discount card

Beneficiaries can choose to buy a card (for about \$30) estimated to save 10 to 15 percent off drug prices at the pharmacy.

Interim low-income help

People with incomes below \$12,390 (\$16,720 for couples) in 2004 will each get \$600 subsidy a year on the card.

Beginning January 2006

Coverage choice

Beneficiaries can choose to:

- 1) stay in traditional Medicare, a current Medicare HMO or a retiree plan **without** signing up for the drug benefit;
- 2) stay in traditional Medicare and enroll in a stand-alone drug plan; or,
- 3) enroll in a private managed care health plan that offers drug coverage and Medicare health services.

Drug benefit: Enrollees will have an annual deductible of \$250, an estimated premium of \$35 a month (may vary in private plans) and a 25 percent copayment of covered drug costs up to \$2,250 in a year. After that, enrollees pay all drug costs until they have spent \$3,600 out of pocket (equal to \$5,100 in annual costs for those with no other drug insurance). At that point catastrophic coverage kicks in, and enrollees pay 5 percent of prescriptions or copays of \$2 for generics and \$5 for brand names (whichever is greater). These terms are outlined below.

Annual deductible: \$250

Copayment: Beneficiary must pay 25% of covered drug costs from \$250 to \$2,250 in a year 100% of all *drug costs* from \$2,251 to \$3,600 in a year (This is referred to as the coverage gap or the "donut hole".) 5% of prescription costs or \$2 for generic drugs and \$5 for brand name drugs, whichever is greater, for all drug costs above \$3,600 out of pocket. (This is also referred to as catastrophic coverage.)

Estimated Premium: \$35 a month, which may vary among private plans.

'Dual eligible' subsidies

People eligible for Medicaid and Medicare will pay:

Deductible: None

Copayments: \$1 per prescription for generic drugs

\$3 per prescription for brand name drugs

There are no copayments for individuals in nursing homes.

Coverage: There is no gap in coverage ("donut hole")

Premium: None

Other low-income subsidies

People with incomes below \$13,000

(\$17,600 for couples) in 2006 and assets of under \$6,000 (\$9,000 for couples)

Deductible: None

Copayments: \$2 per prescription for generic drugs

\$5 per prescription for brand name drugs

No copayments for prescription drugs above \$3,600. catastrophic limit

Coverage: There is no gap in coverage ("donut hole")

Premium: None

People with incomes between \$13,000 and \$14,400

(\$17,600 and \$19,500 for couples) in 2006 and assets under \$10,000 (\$20,000 for couples):

Deductible: \$50

Copayments: 15% of drug costs up to \$3,600 catastrophic limit

After \$3,600, \$2 per prescription for generic drugs \$5 per prescription for brand name drugs

Coverage: There is no gap in coverage ("donut hole")

Premiums: on a sliding scale

Medicare Part B changes

The annual deductible for Part B (for outpatient care) will increase from \$100 to \$110 in 2005, then rise annually. The Part B premium will be linked to income for the first time, starting in 2007. People with incomes over \$80,000 (\$160,000 for couples) will pay more on a sliding scale.

Prevention Services

Beginning January 1, 2005, the following preventive services will be covered by Medicare Part B:

Initial preventive physical examination within 6 months of Part B coverage

Cardiovascular disease screening blood tests

Diabetes screening for at-risk individuals

Obstacles to Medicare Coverage And Reimbursement For Beneficiaries With Alzheimer's Disease

Local Coverage Determinations developed by Medicare carriers and intermediaries restrict coverage of services to individuals with Alzheimer's disease.

- Medicare carriers and intermediaries are permitted to develop Local Coverage Determinations, also known as Medical Review Policies pertaining to Medicare coverage of medical services and procedures. If the carrier does not include the diagnosis code for Alzheimer's disease in the local coverage determination, then the carrier has determined that the service/procedure is not medically reasonable and necessary for that diagnosis, and the service will not be covered.
- In September 2001, The Centers for Medicare and Medicaid Services (CMS, formerly HCFA) issued a Program Memorandum, which prohibits the automatic denial of claims for medical services based solely on the diagnosis of dementia. A Program Memorandum provides specific rules and guidelines for the Medicare program. Medicare will not use the dementia diagnostic codes alone as a basis for determining whether Medicare covered services are reasonable and necessary.

Although the issuance of this Program Memorandum is significant, it is only the first step to removing the barriers to medically necessary care for Alzheimer's beneficiaries. We have to educate providers, beneficiaries and caregivers about the new policy, as well as monitor its implementation by the insurance

companies that process the Medicare claims (called carriers and intermediaries.)

- On July 25, 2003, the Centers for Medicare and Medicaid Services issued a revision to the Medicare Manual that expands the prohibition of computer edits to automatically deny payment of services based solely on diagnosis of a "progressively debilitating disease." The Alzheimer's Association advocated for this modification to assure that Medicare pays for medically necessary services for individuals with Alzheimer's disease and related dementias, as well as other progressive disease. The new policy further clarifies that the appearance of a "progressively debilitating disease" on a claim or history does not permit the automated denials that presume a stage of that disease negates the effectiveness of treatment.
- Medical researchers and clinicians encourage the early diagnosis of Alzheimer's disease in order to maximize the benefits of early intervention and treatment. However, Medicare beneficiaries are confronted with a Catch 22; early diagnosis of Alzheimer's disease often results in the denial of Medicare coverage and subsequent denial of access to care. Medicare carriers and intermediaries must remove these impediments to medically necessary care and cover the medical services that are consistent with current clinical practices for the diagnosis and treatment of individuals with Alzheimer's disease.

Coverage of mental health services is often limited by Medicare carriers' policies that incorrectly assume that individuals with Alzheimer's disease, at any stage, cannot benefit from psychotherapy or other psychiatric care.

- Many Medicare beneficiaries with Alzheimer's disease experience depression, agitation, personality changes, and other behavioral disturbances. Geriatric psychiatrists and psychologists can provide behavior management, especially for agitation, psychosis or aggressive behavior, management of suicidal behavior and treatment of major depression. (*Consensus Statement, Diagnosis and Treatment of Alzheimer's Disease and Related Disorders, JAMA, 1997, Vol. 278, No. 16, 1363*).
- Current research clearly supports the need for involvement of skilled mental health professionals in evaluating mental health problems, developing treatment approaches, and monitoring their effectiveness in people with Alzheimer's disease. The Alzheimer's Association has offered to assist CMS and its carriers in identifying appropriate clinical experts to assure coverage of medically appropriate psychiatric services for beneficiaries with dementia.

Some Medicare carriers' policies restrict physical, occupational or speech therapies for Alzheimer's beneficiaries regardless of stage or functional capacity.

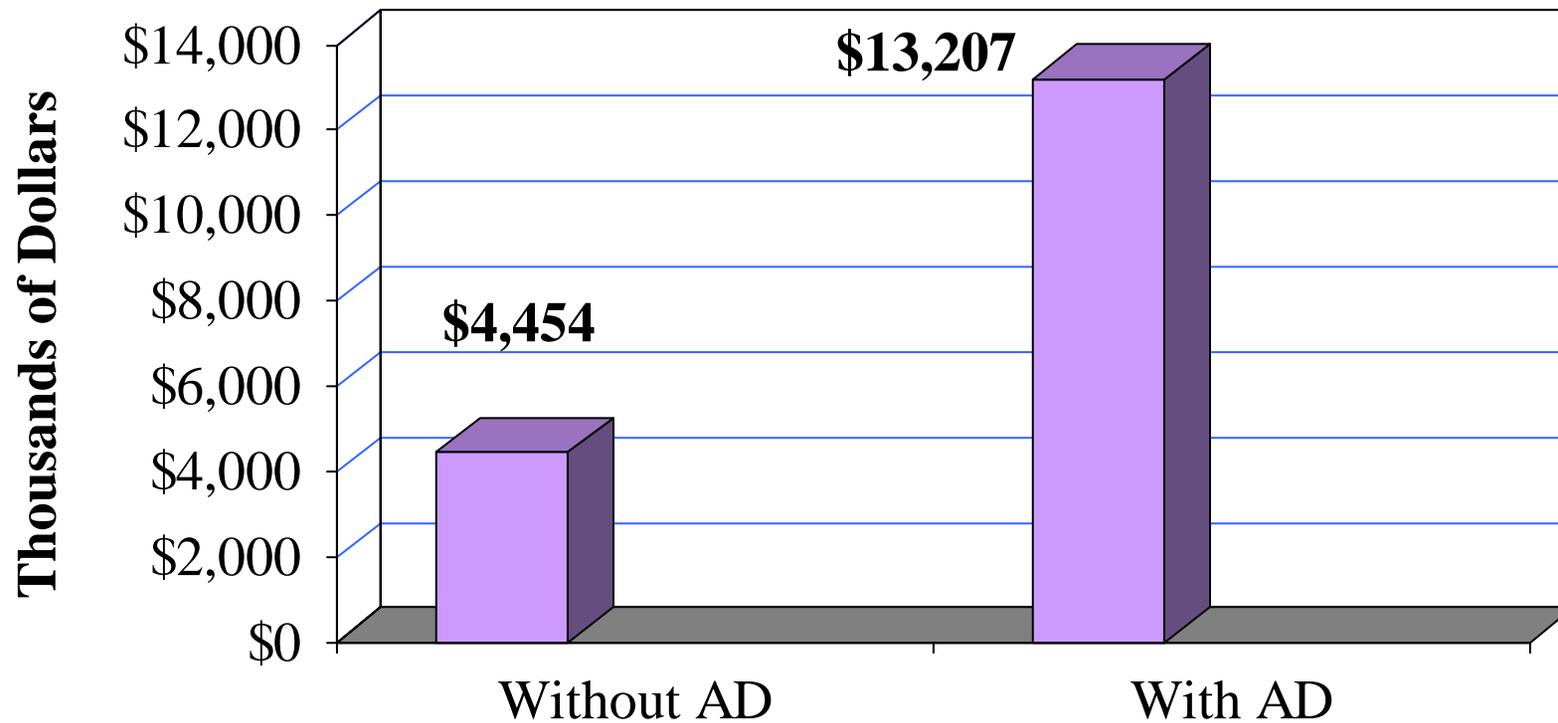
- Carriers/intermediaries have advised therapists/providers that in order for these therapies to be covered for a person with a primary or secondary diagnosis of Alzheimer's disease, an individual must have the ability to learn and retain new information. These policies fail to recognize the benefit of occupational, physical and speech therapy to maximize functioning for the individual.

- As with mental health services, there are a growing number of research studies that substantiate the benefits of rehabilitation therapies to maximize functioning or slow deterioration for individuals with Alzheimer's disease. It is crucial that Medicare carriers remove the impediments to medically necessary care. The Association urges CMS and its carriers to reevaluate local medical policies and develop new policies that are fair, reasonable and consistent with current clinical standards, best practices and research.

CMS instructs Medicare carriers/intermediaries to establish open process for the development of local coverage review policies.

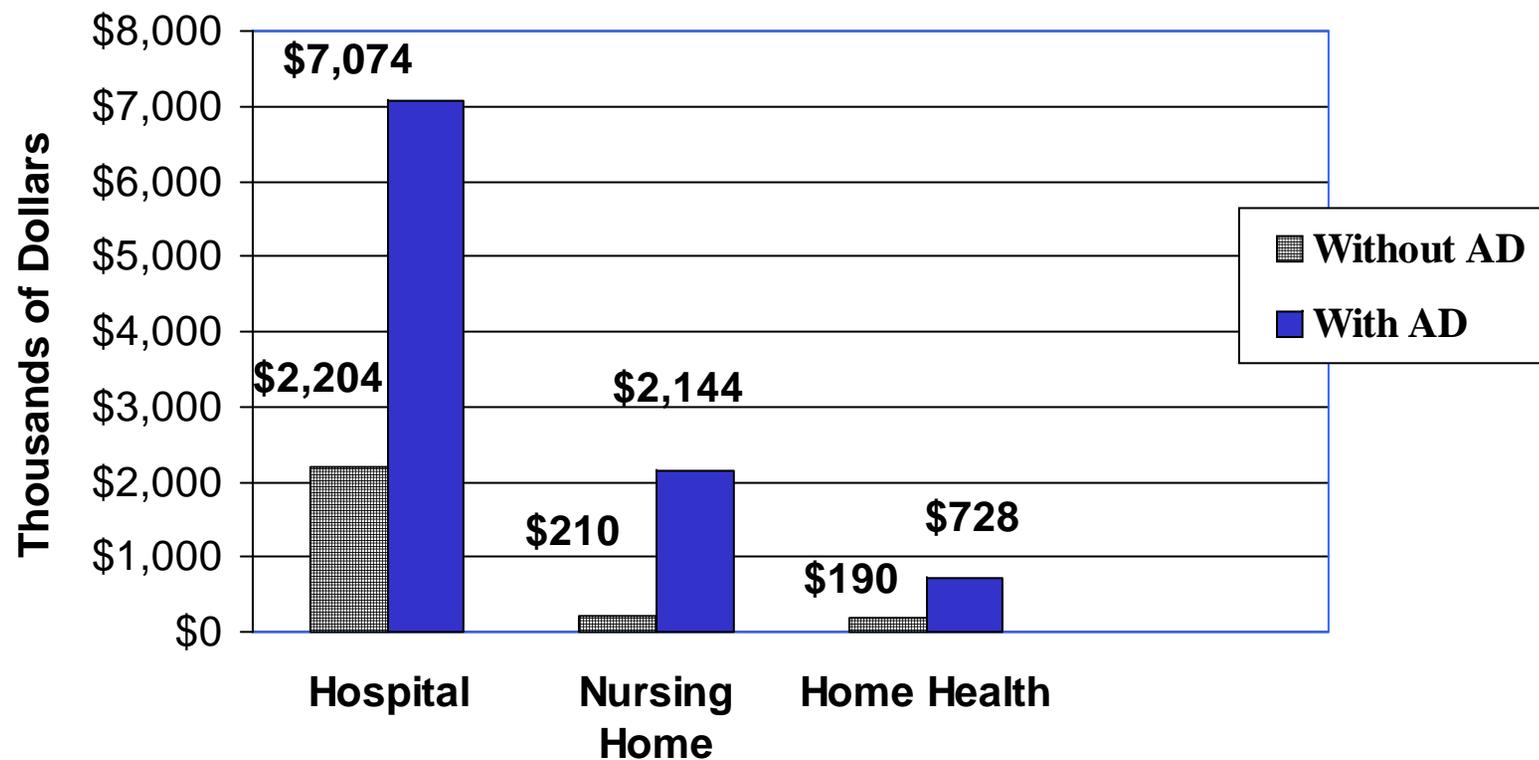
- CMS has issued instructions to their carriers/intermediaries to describe the process to develop local medical review policies. CMS requires that there be ample opportunity for members of the general public, as well as the medical community, to submit scientific, evidence-based information, professional information and other relevant information to the carrier/intermediary. The Medicare carriers/intermediaries must hold open meetings to discuss the draft local policies.
- All carriers/intermediaries must post all of their draft local policies on their website and include information about how to comment on the draft policies. The carriers/intermediaries must also include this information on the CMS website at www.cms.hhs.gov/coverage/default.asp.
- Chapters and advocates can have a significant impact on Medicare coverage in their communities by commenting on local policies. The Medicare Advocacy Project is available to assist chapters and advocates to identify important issues and prepare comments on draft policies.

Average Medicare Costs for Beneficiaries with Alzheimer's Vs. All Beneficiaries



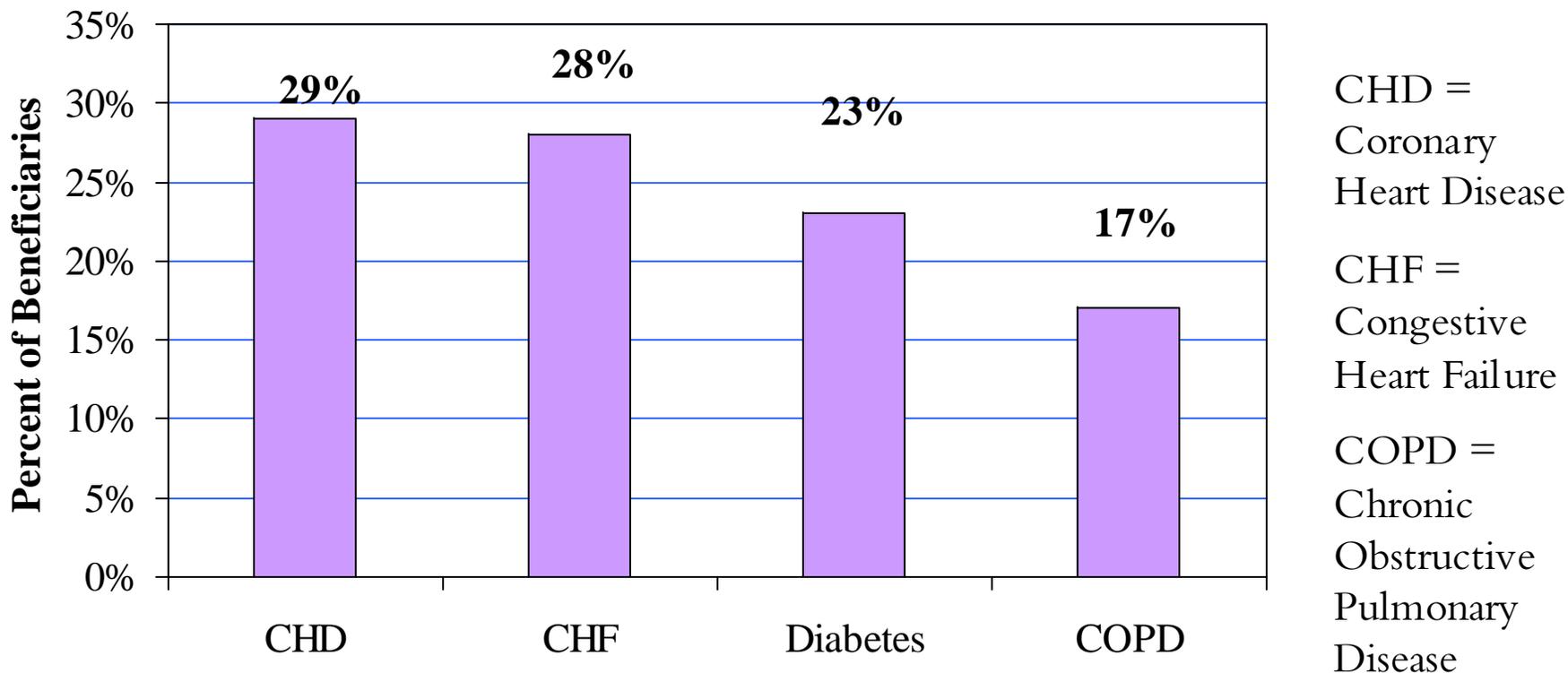
Source: Centers for Medicare & Medicaid Services, FY 2000 Medicare claims data for a 5% random sample of Medicare beneficiaries

Average Medicare Costs for Beneficiaries with Alzheimer's Vs. All Beneficiaries (By Type of Service)



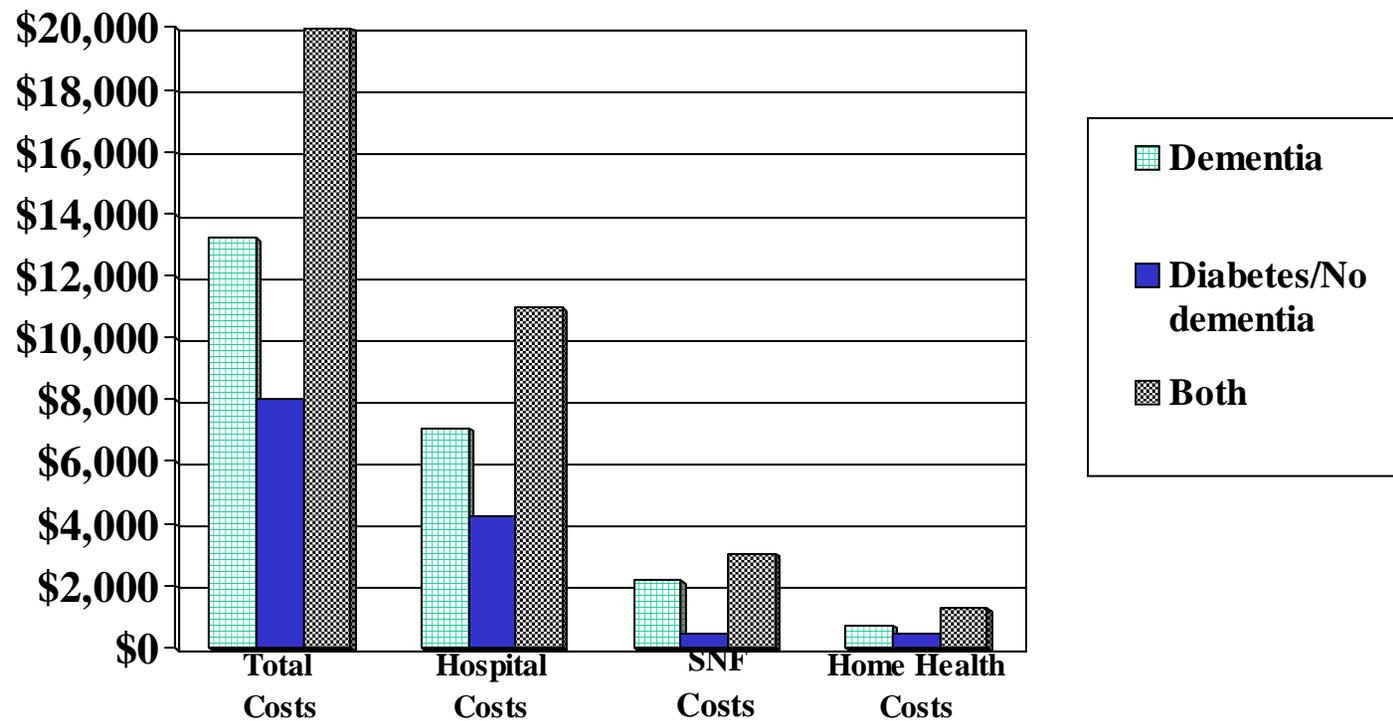
Source: Centers for Medicare and Medicaid Services, FY 2000 data for a 5% random sample of Medicare beneficiaries.

Percent of Beneficiaries with Dementia and Selected Co-Existing Conditions



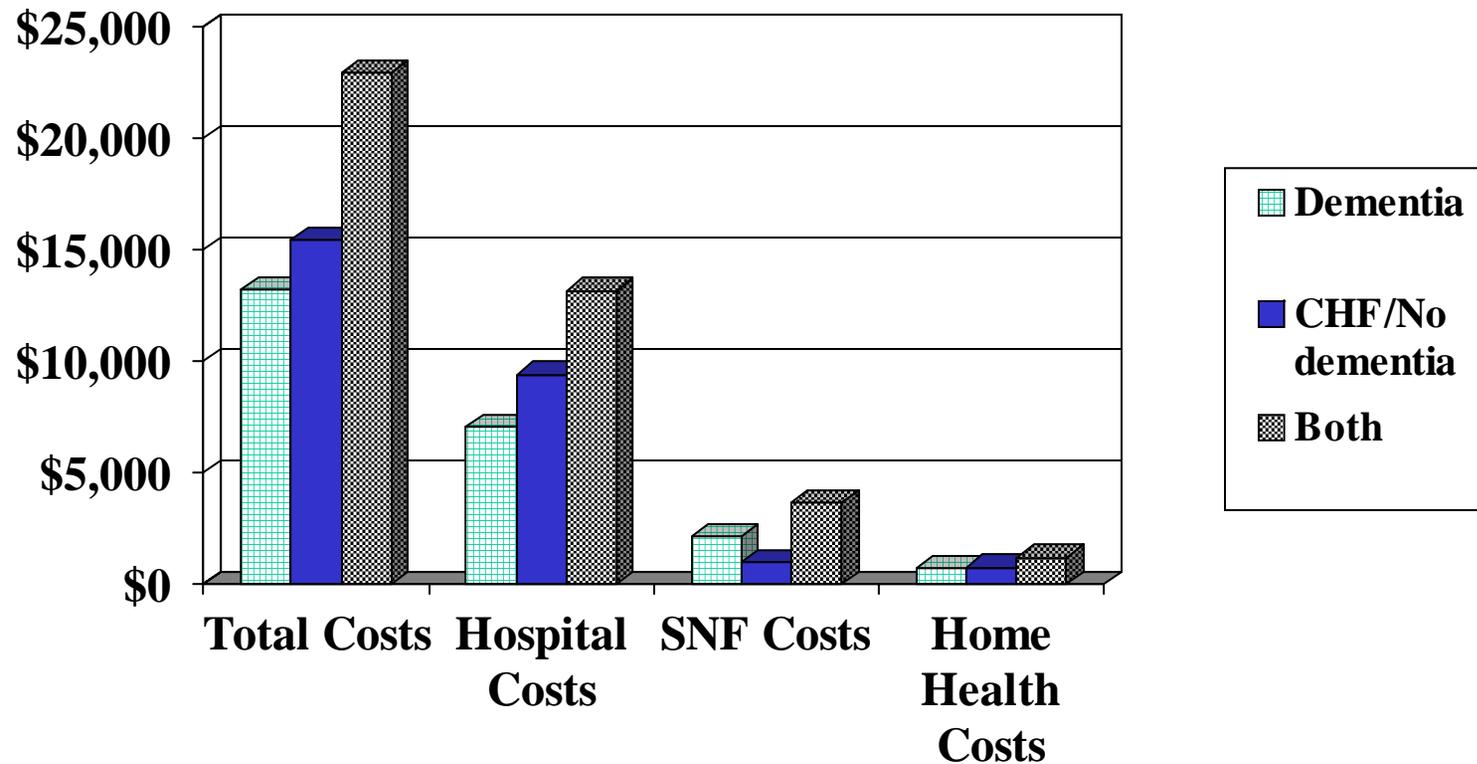
Source: Centers for Medicare and Medicaid Services, FY 2000 Medicare claims data for a 5% random sample of Medicare beneficiaries.

Average Medicare Costs for People with Reported Dementia, Diabetes, Diabetes/No Dementia, or Both, 2000



Source: Centers for Medicare and Medicaid Services, FY 2000 Medicare claims data for a 5% random sample of Medicare beneficiaries.

Average Medicare Costs for People with Reported Dementia, Congestive Heart Failure (CHF)/No Dementia, or Both, 2000



Source: Centers for Medicare and Medicaid Services, FY 2000 Medicare claims data for a 5% random sample of Medicare beneficiaries.

Medicare and Medicaid Expenditures for Individuals With Alzheimer's (2000)

State	Medicare (in Millions)	Medicaid (in Millions)	Total Govt Expenditures (in Millions)
National	\$31,879	\$18,200	\$50,079
Alabama	\$546	\$305	\$851
Alaska	\$14	\$28	\$42
Arizona	\$445	\$7	\$453
Arkansas	\$305	\$140	\$444
California	\$3,433	\$1,016	\$4,449
Colorado	\$378	\$167	\$545
Connecticut	\$485	\$453	\$938
Delaware	\$57	\$43	\$100
District of Columbia	\$122	\$65	\$186
Florida	\$3,164	\$731	\$3,895
Georgia	\$547	\$349	\$895
Hawaii	\$96	\$69	\$165
Idaho	\$96	\$51	\$147
Illinois	\$1,216	\$697	\$1,913
Indiana	\$735	\$354	\$1,089
Iowa	\$247	\$232	\$480
Kansas	\$298	\$160	\$459
Kentucky	\$417	\$257	\$673
Louisiana	\$602	\$237	\$839
Maine	\$92	\$92	\$183
Maryland	\$630	\$288	\$918
Massachusetts	\$767	\$640	\$1,407
Michigan	\$969	\$740	\$1,709
Minnesota	\$509	\$390	\$899
Mississippi	\$309	\$176	\$485
Missouri	\$630	\$334	\$963
Montana	\$85	\$59	\$144
Nebraska	\$188	\$160	\$348
Nevada	\$141	\$40	\$180
New Hampshire	\$85	\$99	\$184
New Jersey	\$1,134	\$757	\$1,891
New Mexico	\$109	\$76	\$185
New York	\$2,482	\$2,911	\$5,394
North Carolina	\$848	\$383	\$1,231
North Dakota	\$86	\$83	\$169
Ohio	\$1,431	\$1,002	\$2,433
Oklahoma	\$342	\$144	\$485
Oregon	\$286	\$110	\$397
Pennsylvania	\$2,034	\$1,747	\$3,811
Rhode Island	\$160	\$114	\$274
South Carolina	\$974	\$165	\$539
South Dakota	\$83	\$48	\$130
Tennessee	\$693	\$473	\$1,165
Texas	\$2,171	\$663	\$2,834
Utah	\$141	\$43	\$184
Vermont	\$38	\$36	\$74
Virginia	\$598	\$225	\$823
Washington	\$409	\$283	\$692
West Virginia	\$235	\$126	\$361
Wisconsin	\$554	\$412	\$960
Wyoming	\$33	\$22	\$56

Source: The Lewin Group estimates based on data from the 1996 MCBS, Evans et. al. (1989), the 2001 Medicare Trustees' Fund Reports, and HCFA Medicaid Form 64.

Medicare and Medicaid Expenditures for Individuals With Alzheimer's (2010)

State	Medicare (in Millions)	Medicaid (in Millions)	Total Govt Expenditures (in Millions)
National	\$49,283	\$33,018	\$82,301
Alabama	\$840	\$554	\$1,394
Alaska	\$32	\$50	\$82
Arizona	\$763	\$13	\$776
Arkansas	\$465	\$253	\$718
California	\$5,256	\$1,814	\$7,090
Colorado	\$707	\$303	\$1,010
Connecticut	\$713	\$821	\$1,535
Delaware	\$90	\$78	\$168
District of Columbia	\$155	\$117	\$272
Florida	\$5,090	\$1,327	\$6,416
Georgia	\$893	\$632	\$1,523
Hawaii	\$171	\$124	\$295
Idaho	\$171	\$93	\$264
Illinois	\$1,753	\$1,264	\$3,017
Indiana	\$1,119	\$642	\$1,762
Iowa	\$362	\$422	\$784
Kansas	\$437	\$291	\$728
Kentucky	\$634	\$465	\$1,100
Louisiana	\$966	\$430	\$1,396
Maine	\$131	\$166	\$298
Maryland	\$981	\$522	\$1,502
Massachusetts	\$1,094	\$1,161	\$2,256
Michigan	\$1,442	\$1,342	\$2,785
Minnesota	\$783	\$708	\$1,491
Mississippi	\$463	\$320	\$783
Missouri	\$952	\$605	\$1,525
Montana	\$146	\$108	\$254
Nebraska	\$284	\$291	\$574
Nevada	\$259	\$72	\$331
New Hampshire	\$135	\$179	\$314
New Jersey	\$1,662	\$1,373	\$3,036
New Mexico	\$187	\$137	\$324
New York	\$3,462	\$5,281	\$8,743
North Carolina	\$1,427	\$695	\$2,121
North Dakota	\$136	\$150	\$286
Ohio	\$2,160	\$1,818	\$3,978
Oklahoma	\$547	\$260	\$807
Oregon	\$494	\$200	\$694
Pennsylvania	\$2,956	\$3,169	\$6,125
Rhode Island	\$225	\$207	\$432
South Carolina	\$633	\$299	\$931
South Dakota	\$126	\$86	\$212
Tennessee	\$1,103	\$857	\$1,960
Texas	\$3,652	\$1,203	\$4,855
Utah	\$264	\$79	\$343
Vermont	\$58	\$66	\$123
Virginia	\$985	\$408	\$1,393
Washington	\$702	\$513	\$1,215
West Virginia	\$350	\$229	\$579
Wisconsin	\$838	\$748	\$1,586
Wyoming	\$63	\$40	\$103

Source: The Lewin Group estimates based on data from the 1996 MCBS, Evans et. al. (1989), the 2001 Medicare Trustees' Fund Reports, and HCFA Medicaid Form 64.

Medicaid Issues For Alzheimer's Advocates

Federal objective: Preserve the long term care safety net that Medicaid provides.

This includes maintaining the federal entitlements and quality assurance provisions of current law, providing additional financial assistance to the states to maintain current benefits and to improve quality, particularly through improved payment for staffing and expanding options for family-centered home and community based care.

Why Medicaid is so important for persons with Alzheimer's and their families

Medicaid is the nation's major public insurance program for providing health and long term care coverage to millions of low-income people. In 2002, Medicaid insured more than 51 million individuals at a total cost (federal and state share) of approximately \$216 billion. To receive Medicaid, people must fall into certain categories, such as those receiving cash assistance, low-income children and pregnant women, and elderly people who require long term care but no longer have the resources to pay for it.

Medicaid is the single largest public payer for long term care services in the United States and a last resort for persons with Alzheimer's who have no other way to pay for the help they need. Half of all Medicare beneficiaries with Alzheimer's also received Medicaid to help pay for long term care, prescription drugs, and other medical care because they have "spent down" their own resources and qualify for assistance.

In 2000, Medicaid spent an estimated \$18.2 billion on nursing home care for people with Alzheimer's.

Medicaid At The Federal Level Status

On Monday, February 2, 2004, President Bush released his FY 2005 budget proposal that funds all federal government programs. Although the budget does not officially mention a Medicaid reform plan, the one described in last year's budget is still up for consideration this year.

Likely to be the subject of an ongoing effort by House and Senate leaders to craft a Medicaid reform vehicle, the Bush proposal would generally offer greater "flexibility" and cap federal funding to states. The President's budget suggests that the Administration is interested in seeing a Medicaid block grant proposal move forward. In addition, the Bush budget proposes to reduce waste, fraud and abuse in Medicaid through increased audits of state program financing methods and by working on legislation that will restrict states use of inter-governmental transfers and upper payment limit arrangements that states have previously used to draw down federal funds.

The Alzheimer's Association opposed the President's proposal last year and would oppose any reform proposals that cap Medicaid funding as a method of giving states more flexibility regarding benefits and services that could leave many of society's most vulnerable citizens in jeopardy.

Medicaid At The State Level

Objective: Preserve the long term care safety net and prescription drug benefits that Medicaid provides.

Status

Medicaid is now one of the largest and fastest growing components of state budgets, comprising approximately 20 percent of state spending. States were able to rein in costs during fiscal year 2004 with a combination of \$20 billion in emergency federal aid and aggressive program cuts. On June 30, 2004 that emergency aid is set to expire, and state lawmakers will again be faced with very tight budget constraints.

Strategies states plan to use to reign-in overall Medicaid costs in 2004:

- 43 states plan to control drug costs,
- 39 plan to cut or freeze payments to health care providers,
- 17 plan to reduce benefits,
- 21 to bump up co-payments, and
- 18 to restrict or reduce eligibility.

States will also be facing decisions about how their prescription drug programs will operate in conjunction with the new Medicare drug law

Because several states have a richer drug benefit than the new Medicare benefit, some Medicaid beneficiaries could see a reduction in benefits (depending on the action of states.) Some existing state pharmacy assistance programs also are more generous than the new Medicare drug benefit. It is not clear how these programs will operate in conjunction with the new benefit; states will be making some difficult decisions regarding the fate of their programs.

National Governors Association (NGA) initiative

The NGA, which is chaired this year by Gov. Kempthorne of Idaho, has announced a program to focus on long term care issues. The initiative includes 4 key components:

- Identify best practices to encourage community based care
- Support families caring for elderly family members by identifying innovative practices to encourage and assist caregivers
- Promote wellness and disease management
- Encourage personal financial planning for health care costs and work to create public/private partnerships.

The Alzheimer's Association is working with the NGA to showcase Alzheimer's issues in that effort. We will also use this as an opportunity to advance our Medicaid priorities.

Key Policymakers

State Governments

- Governors
- State Legislatures – Finance/Appropriations Committees
- State Medicaid Directors

For updates of the Association's ongoing work on Medicaid visit us online <http://www.alz.org/Advocacy/priorities/overview.asp>

The New Medicare Prescription Drug Benefit & Medicaid

The new Medicare drug benefit has huge implications for beneficiaries of current state-based programs. Many low-income Medicare beneficiaries who do not qualify for Medicaid will receive substantial assistance under the new law. It is less clear how the 6.4 million low-income Medicaid beneficiaries who now receive drug coverage through Medicaid will fare. Starting in 2006, those beneficiaries will receive coverage through Medicare.

Under current law, when a benefit or service is covered by both Medicare and Medicaid, Medicare serves as the primary payer, and Medicaid “wraps around” that coverage filling in the gaps in coverage. Medicaid also picks up most or all of the beneficiary co-payments that Medicare charges.

The new law eliminates Medicaid’s supplemental — or “wrap around” — role, which means some elderly poor and disabled people would have to pay more for their prescriptions than they now do. Also, in cases where Medicaid covers a prescription drug but the private plan that administers the Medicare drug benefit in the local area does not provide that drug under Medicare, beneficiaries who now receive the drug through Medicaid could lose access to it.

Because several states have a richer drug benefit than the new Medicare benefit, some Medicaid beneficiaries could see a reduction in benefits (depending on the action of states.)

Some existing state pharmacy assistance programs also are more generous than the new Medicare drug benefit. It is not clear how these programs will operate in conjunction with the new benefit.

Rebalancing Long Term Care Programs

A number of “New Freedom Initiatives” are also referenced in the President’s budget proposal including:

- a demonstration to address shortages of community direct care workers
- a five-year “Money Follows the Individual” rebalancing demonstration in which the federal government will fully reimburse the states for one year of Medicaid services for individuals who move from institutions into “at-home care”
- a respite care demonstration for caregivers of adults with disabilities and children with severe disabilities

These proposals are part of the broader “New Freedom Initiative” announced by President Bush in 2001. The initiative is a nationwide effort to remove barriers to community living for people of all ages with disabilities and long term illnesses.

Talking Points about Medicaid and Alzheimer's Disease

- Medicaid is the only significant source of financial assistance for long-term care for persons with Alzheimer's disease.
- Half of all Medicare beneficiaries with Alzheimer's also receive Medicaid to help pay for long term care and prescription drugs, because they have "spent down" their own resources and qualify for assistance. This population is referred to as the "dual-eligibles."
- Total Medicaid long-term care expenditures were \$75 billion in 2001- approximately 35 percent of total Medicaid expenditures.
- In 2000, Medicaid spent an estimated total of \$18.2 billion on nursing home care for people with Alzheimer's disease.
- By 2010, Medicaid expenditures for persons with Alzheimer's will increase by over 80% - skyrocketing to \$33 billion.
- The elderly account for just 9 percent of Medicaid enrollees -or 4.5 million people. Yet spending on this group totals 27 percent of all Medicaid expenditures -or \$58 billion.
- Medicaid now pays for half of all nursing home costs in the country. Two-thirds of nursing home residents receive some help from Medicaid.
- Nearly 60% of nursing home residents are there because they have Alzheimer's or another dementia. They tend to have the longest nursing home stays and are among those most likely to "spend down" to Medicaid. The same holds true for the explosive growth in assisted living.
- While more than two-thirds of Medicaid long term care dollars are spent on institutional care (including nursing homes,) states are trying to move resources into home and community based care because it is less expensive for Medicaid and preferred by families.

Overview of The “Money Follows The Person” Initiative

President Bush announced the “New Freedom Initiative” on February 1, 2001, as part of a nationwide effort to remove barriers to community living for people with disabilities. Today, there are more than 54 million Americans living with a disability, representing a full 20 percent of the U.S. population. Almost half of these individuals have a severe disability affecting their ability to see, hear, walk or perform other basic functions of life. In addition, there are more than 25 million family caregivers and millions more who provide aid and assistance to people with disabilities. The New Freedom Initiative is a comprehensive plan that represents an important step in working to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives and participate fully in community life.

One of the centerpieces of the broader “New Freedom Initiative” (NFI) is the “Money Follows the Person” Rebalancing Demonstration (\$500 million over five years) to help Americans with disabilities transition from nursing homes or other institutions to living in the community. This five-year demonstration would assist states in developing and implementing a strategy to “re-balance” their long term care systems so that there are more cost-effective choices between institutional and community options, including payment of all expenses for a package of community-based Medicaid services in the first year that individuals transition from institutions to the community. Federal grant funds would pay the full cost of home and community-based waiver services for one year, after which the participating states would agree to continue care at the regular Medicaid matching rate through a home and community-based care waiver program

or state plan services. This significant demonstration would build upon existing state programs in Texas, Wisconsin, Michigan and Washington. It also provides incentives to states for increased use of home and community-based services and would help provide information on costs of different approaches.

On July 11, 2003, Senator Tom **Harkin (IA)** introduced S 1394, the “Money Follows the Person Act of 2003”. The purpose of the bill is to allow states to apply to the Secretary of Health and Human Services for approval to conduct a demonstration project under which the State shall provide community-based services and supports to Medicaid-eligible individuals residing in a Medicaid long-term care facility for at least 90 days. The bill is currently cosponsored by **Senators Kennedy (MA), Landrieu (LA), Kerry (MA), Lautenberg (NJ), Smith (OR), Breaux (LA), Schumer (NY), Specter (PA) and Clinton (NY)**. S 1394 was drafted in consultation with the disability community and encompasses the legislative language for the Bush initiative.

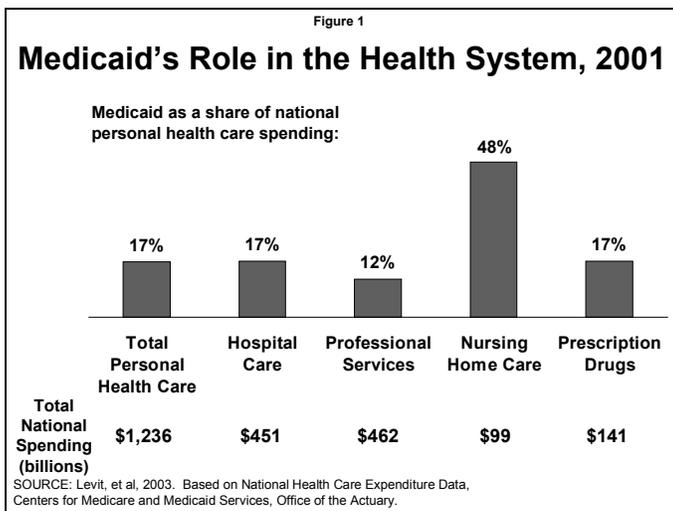
The Senate Finance Committee is expected to hold a hearing later this year to take a closer look at the “Money Follows the Person” initiative as well as other proposals included in the broader “New Freedom Initiative”. The committee aims to gain a better understanding of the “Money Follows the Person” initiative and to gauge the disability and aging community’s viewpoints on the proposal.

January 2004

THE MEDICAID PROGRAM AT A GLANCE

Medicaid is the nation's major public health program for low-income Americans, financing health and long-term care services for more than 50 million people—a source of health insurance for 38 million low-income children and parents and a critical source of acute and long-term care coverage for 12 million elderly and disabled individuals, including more than 6 million low-income Medicare beneficiaries.

Medicaid accounts for 17% of all personal health care spending, finances 17% of hospital care, 12% of physician and other professional services, 17% of prescription drug spending, and nearly half of all nursing home care (Figure 1).



Authorized by Title XIX of the Social Security Act, Medicaid is a means-tested entitlement program for low-income people. The federal and state governments jointly finance Medicaid and the states administer it within broad federal guidelines. The federal government matches state Medicaid spending with the federal share of Medicaid spending ranging from 50% to 77% depending on state per capita income. In 2002, the federal government financed 57% of the \$250 billion in total Medicaid spending.

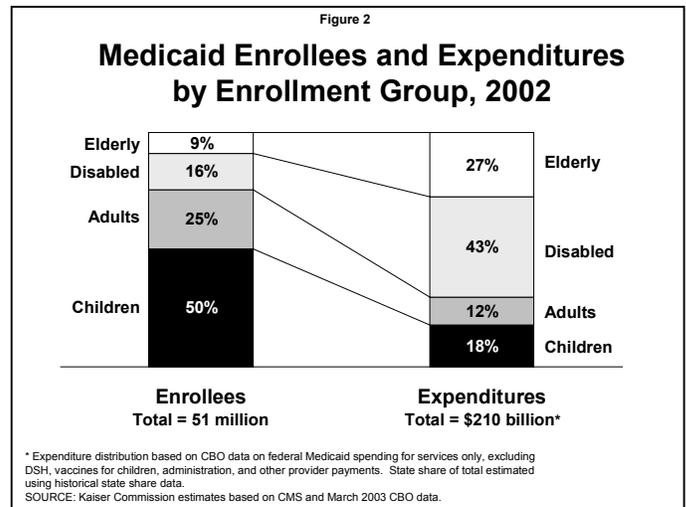
Who Is Covered by Medicaid?

To qualify for Medicaid, an individual must meet financial criteria and also be part of a group that is "categorically eligible" for the program, such as low-income children, pregnant women, the elderly, people with disabilities, and parents. Federal law mandates coverage of some groups below specified minimum income levels, but also gives states broad optional authority to extend Medicaid eligibility beyond these minimum standards. This flexibility has produced wide state-to-state variation in Medicaid coverage.

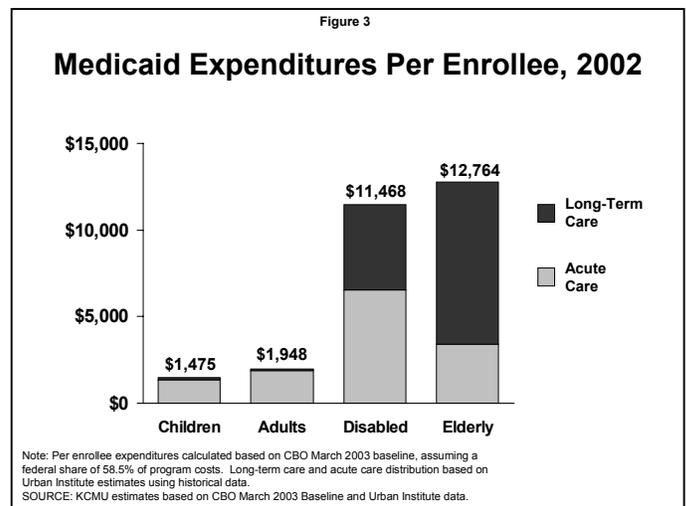
In 2002, Medicaid provided coverage to:

- 25 million children – more than one in four in the U.S.
- 13 million adults, primarily low-income working parents
- 5 million seniors
- 8 million persons with disabilities

Although low-income children and their parents make up three-fourths of Medicaid beneficiaries, they account for only 30% of Medicaid spending. The elderly and people with disabilities comprise one-quarter of beneficiaries and 70% of Medicaid spending for services (Figure 2).



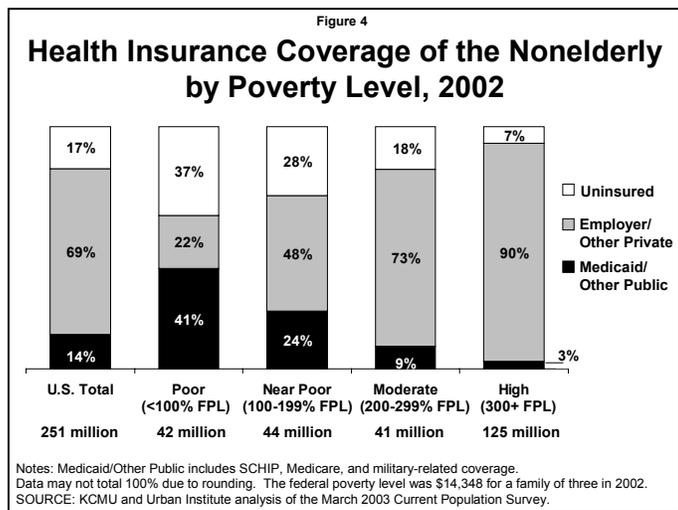
In 2002, estimated Medicaid spending per child was \$1,475, compared to \$11,468 per disabled enrollee and \$12,764 per elderly enrollee reflecting their intensive use of acute and long-term care services (Figure 3).



Over 40% of all Medicaid spending is attributable to "dual eligibles," who have both Medicare and Medicaid. These Medicaid payments go toward Medicare premiums and services not covered by Medicare, including prescription drugs and long-term care.

Beginning in January 2006, “dual eligibles” will be offered drug coverage under new Medicare Part D prescription drug plans, in lieu of Medicaid drug coverage.

Because low-income working families often do not have access to health insurance through their jobs, Medicaid is a key source of coverage for this population (Figure 4). Two-thirds of all Medicaid enrollees are in working families and one in three children in rural America relies on Medicaid for coverage.



The recent economic downturn has caused more families to qualify for Medicaid as income has fallen. With rates of employer-sponsored coverage dropping, Medicaid and the State Children’s Health Insurance Program have stemmed the increase in the number of uninsured. Yet, eligibility restrictions, especially for adults and recent immigrants, together with enrollment obstacles for those who are eligible, continue to limit Medicaid’s reach.

What Does Medicaid Pay For?

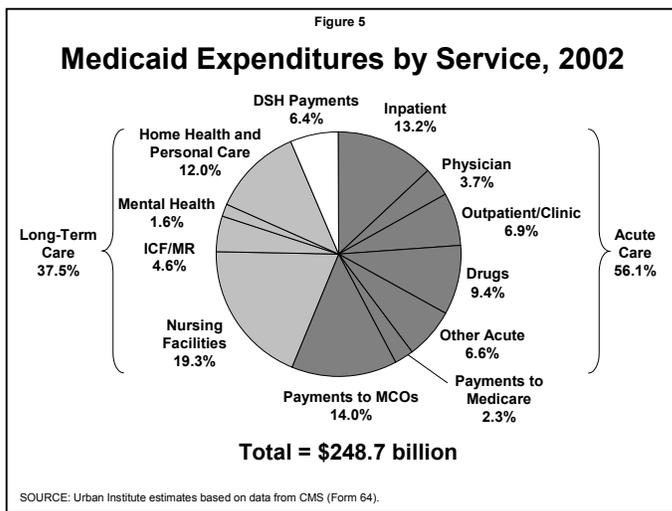
Medicaid covers a broad range of services to meet the complex needs of the diverse populations it serves. Because Medicaid beneficiaries have limited financial resources, cost sharing is limited and not permitted for children and pregnant women. State Medicaid programs must cover:

- inpatient and outpatient hospital services
- physician, midwife, & certified nurse practitioner services
- laboratory and X-ray services
- nursing home and home health care
- early and periodic screening, diagnosis, and treatment (EPSDT) for children under age 21
- family planning
- rural health clinics/federally qualified health centers

States have the option of covering additional services with federal matching funds. Commonly covered optional services include prescription drugs, clinic services, prosthetic devices, hearing aids, dental care and intermediate care facilities for the mentally retarded (ICF/MR). The majority of state spending on optional services (83%) goes toward the elderly and those with disabilities. Over two-thirds of optional spending is for long-term care and prescription drugs. In addition to matching funds for services, states also receive supplemental Medicaid payments (about \$9 billion in 2002) to aid their hospitals serving a disproportionate share of indigent patients (DSH).

Of the \$249 billion in total Medicaid spending in 2002 (Figure 5):

- Acute-care services comprised about half (56%)
- Long-term care services made up 38%
- Payments for Medicare premiums accounted for about 2%
- DSH payments represented about 6% of spending



As of June 2002, 58% of Medicaid beneficiaries—mostly children and their parents—were enrolled in managed care. Managed care accounted for 14% of total Medicaid spending in 2002.

Long-term care accounts for 38% of Medicaid spending. Medicaid finances care for nearly 70% of nursing home residents and accounts for 42% of overall long-term care spending. While over two-thirds of Medicaid spending for long-term care is on institutional services, home and community-based services (HCBS) waivers enable states to deliver community-based care.

Future Challenges Affecting Medicaid

Many states are facing the most challenging fiscal conditions in a decade. As state revenues have plunged, states have been reluctant to cut Medicaid because of the population it serves and because state reductions mean a loss of federal matching funds. For many states, cost containment efforts have been unavoidable. Between FY2002 and FY2004, 50 states reduced provider rates, and 50 took action to limit prescription drug costs; 34 reduced eligibility, 35 reduced benefits and 32 increased copayments. States received \$20 billion in federal fiscal relief for FY2003 and 2004, which helped many avoid deeper Medicaid cuts, but this fiscal relief expires in June 2004. States are expecting significant budget gaps in FY2005, and most will likely look for additional ways to curb Medicaid spending.

Since its enactment in 1965, Medicaid has improved access to health care for low-income individuals, financed innovations in health care delivery and community-based long-term care, and functioned as the nation’s primary source of long-term care financing. As Medicaid struggles under fiscal pressure, the program continues to meet multiple responsibilities, playing a critical role in providing acute and long-term care services for more than 50 million Americans. Proposals to restructure the program merit careful consideration as reductions in benefits or eligibility could lead to greater numbers of uninsured, reduce community-based care options for the disabled, limit help for those who have great medical needs and expenses, and undermine economic recovery.

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January 2004

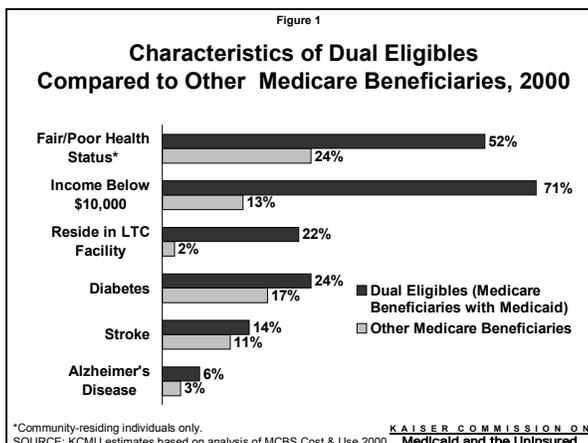
Dual Eligibles: Medicaid's Role for Low-Income Medicare Beneficiaries

Over 7 million of Medicaid's 50 million beneficiaries are "dual eligibles," low-income elderly and individuals with disabilities who are enrolled in both Medicaid and Medicare. While Medicare covers basic health services, including physician and hospital care, dual eligibles rely on Medicaid to pay Medicare premiums and cost-sharing and to cover critical benefits Medicare does not cover, such as long-term care. Although starting in 2006, coverage of prescription drugs for dual eligibles will shift from Medicaid to Medicare, financing coverage of dual eligibles will continue to pose a challenge to fiscally-pressed Medicaid programs.

Who Are Dual Eligibles?

Eighteen percent of Medicare beneficiaries are dual eligibles receiving supplemental coverage through Medicaid. Dual eligibles account for one in seven Medicaid enrollees, including virtually all the elderly and about one-third of non-elderly beneficiaries with disabilities in Medicaid.

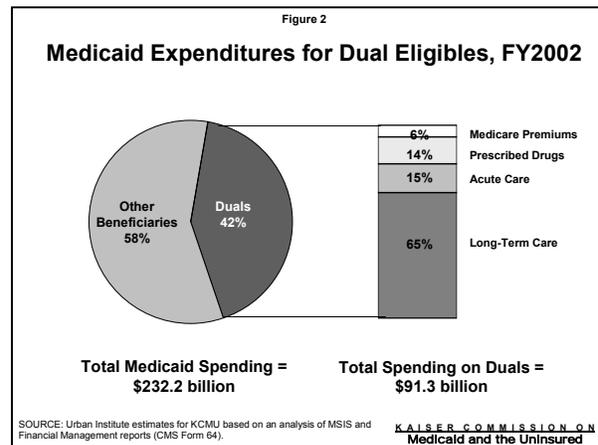
Most dual eligibles are very low-income individuals with substantial health needs: 71% have annual income below \$10,000, compared to 13% of all other Medicare beneficiaries. High-cost and sick or frail Medicare beneficiaries are concentrated among the dually eligible. Nearly one-quarter of dual eligibles are in nursing homes, compared to 2% of other Medicare beneficiaries. Over half are in fair or poor health, twice the rate among others in Medicare. A third of dual eligibles have significant limitations in activities of daily living, compared to 14% of other Medicare beneficiaries. The prevalence of chronic conditions is also higher among dual enrollees (Fig. 1).



The distribution of Medicare and Medicaid spending also reveals the concentration of need and costs among the dually eligible. Dual eligibles comprised 18% of all Medicare beneficiaries in 2000, but they accounted for 24% of total Medicare spending. Similarly, they represented 16% of all Medicaid enrollees but 42% of program spending.

Dual eligibles rely on a wide range of services, which are paid for by either Medicare or Medicaid (Fig. 2). The majority of Medicaid expenditures for dual eligibles are for long-term care services (65%); prescription drugs accounts for 14% and other acute care services to supplement Medicare account for 15%. Payment of Medicare premiums accounts for 6% of Medicaid expenditures.

How Does Medicaid Assist Dual Eligibles?



Medicare beneficiaries can obtain Medicaid through different eligibility "pathways," and the kind of assistance that Medicaid provides varies accordingly (Fig. 3). The poorest Medicare beneficiaries, including those who have exhausted their resources paying for health and long-term care (sometimes known as "medically needy" or "spend-down"), receive full assistance with Medicare premiums and cost sharing and coverage of all Medicaid benefits. Most dual eligibles qualify for Supplemental Security Income (SSI) or have incurred nursing home costs and are thus entitled to this comprehensive protection.

For Medicare beneficiaries with more income or resources, Medicaid's assistance is more limited, primarily covering Medicare premiums. This assistance is referred to as the "Medicare Savings Programs" or "buy-in programs," and the beneficiaries who qualify for it are known as Qualified Medicare Beneficiaries (QMB), Specified Low-Income Medicare Beneficiaries (SLMB), and Qualifying Individuals (QI) – after the provisions that added these programs.

Figure 3

Medicaid Eligibility for Medicare Beneficiaries, 2004

Pathway	Income Eligibility	Asset Limit	Medicaid Benefits
Mandatory			
SSI Cash Assistance*	≤ 74% of poverty (SSI income eligibility)	\$2,000 (individual) \$3,000 (couple)	Full "wrap-around" Medicaid benefits, Medicare Part B premium and cost sharing.
Qualified Medicare Beneficiary (QMB)	≤ 100% of poverty	\$4,000 (individual) \$6,000 (couple)	No Medicaid benefits. Medicaid pays Medicare Part B premium and cost-sharing.
Specified Low-Income Beneficiary (SLMB)	100-120% of poverty	\$4,000 (individual) \$6,000 (couple)	No Medicaid benefits. Medicaid pays for Medicare Part B premium.
Optional			
Medically Needy	Individuals who spend their income down to a specified level	\$2,000 (individual) \$3,000 (couple)	Full "wrap around" Medicaid benefits which may be more limited than for SSI.
Poverty-Level	≤ 100% of poverty	\$2,000 (individual) \$3,000 (couple)	Full "wrap-around" Medicaid benefits, Medicare Part B premium and cost sharing.
Special Income Rule for Nursing Home Residents	Individuals in institutions with income <300% of the SSI level	\$2,000 (individual) \$3,000 (couple)	Full "wrap around" Medicaid benefits, Medicare Part B premium and cost-sharing.
Home and Community-Based Services Waivers	Individuals who would be eligible if resided in an institution		Full "wrap around" Medicaid benefits including long-term care and prescription drugs.

* States that elect the so-called "(209b)" option can set lower levels.

KAISER COMMISSION ON
Medicaid and the Uninsured

Why Do Medicare Beneficiaries Need Medicaid?

Medicaid helps relieve the financial burdens facing low-income Medicare beneficiaries in several ways. First, it pays their monthly Medicare Part B premium, which now amounts to \$800 per year. Second, Medicaid pays the cost-sharing charged for many Medicare services. Finally, Medicaid covers a range of important benefits excluded from Medicare, such as long-term care, dental and vision care, and other key services.

Because of their extensive health care needs, dual eligibles require and use more services than others in Medicare. On average, total health care costs for dual eligibles are double those of other Medicare beneficiaries. Medicaid covers 38% of total health care costs for dual eligibles – nearly as much as the 43% that Medicare covers – with out-of-pocket spending comprising most of the remainder.

Implications of the Medicare Prescription Drug Benefit

On January 1, 2006, the 6.4 million dual eligibles that receive the full Medicaid benefits package will lose their Medicaid prescription drug coverage but can enroll in the Medicare Part D prescription drug benefit. The

legislation establishes a low-income subsidy program that will offer substantial assistance with cost-sharing to dual eligibles and other low-income individuals. Medicare will pay the Part D deductible on behalf of all dual eligibles, as well as their premiums if they enroll in an average or low-cost Part D plan. These subsidies will eliminate the gap in coverage for dual eligibles that other Medicare beneficiaries will face, referred to as the "doughnut hole". Dual eligibles will face small co-pays ranging from \$1-5. Dual eligibles residing in nursing homes or other institutions are exempt from co-pays because they already must contribute all but a small portion of their income to the cost of nursing home care.

Although the new law shifts drug coverage for dual eligibles from Medicaid to Medicare, it does not provide full fiscal relief to states. States are required to finance a large share of the cost of providing the Medicare Part D prescription drug benefit to dual eligibles through payments to the federal government.

It is unclear how dual eligibles will fare under the Medicare Part D prescription drug benefit when it is implemented in 2006. The array of drugs covered by Part D plans may fall short of those currently covered by Medicaid. In about half the states, Medicaid co-pay requirements for dual eligibles currently fall below the levels that most dual eligibles will face when they enroll in Part D plans in 2006. Dual eligibles may find that their out-of-pocket costs for prescription drugs increase when they enroll in Part D plans. Dual eligibles will also have to pay 100% of the costs of drugs that are not covered by their Part D plans. Under the bill, states are not allowed to use federal Medicaid matching funds to supplement prescription drug coverage for dual eligibles under Part D plans, however, a state can choose to use state-only funds to wrap-around the prescription drug benefit.

Future Challenges

Dual eligibles rely on Medicaid primarily for long-term care and for other services not covered by Medicare. Because dual eligibles have significant health needs and few resources to obtain the range of services they require, Medicaid provides critical assistance.

It will be some time before individual states are able to fully evaluate the effect of the new Medicare prescription drug benefit on their Medicaid budgets and dual eligible populations. Given the health needs of dual eligibles, it will be important to assure adequate safeguards are in place to protect access to prescription drugs for this population as the new Medicare law is implemented and as other options for Medicaid reform are considered.

For additional copies of this publication (#4091-02) please visit our website www.kff.org/kcmu.

Medicaid and Prescription Drugs for Alzheimer's Disease

Why prescription drugs are an important Alzheimer issue

In addition to Alzheimer treatment drugs, people with Alzheimer's disease often take multiple medications for one or more other chronic conditions that are common in the elderly—e.g. coronary heart disease, congestive heart failure, diabetes, and chronic obstructive pulmonary disease. A review of medical records of a sample of community dwelling patients with Alzheimer's and or vascular dementia found that:

- 88% of people with Alzheimer's take at least one prescription drug a month.
- 68% of people with Alzheimer's take at least two prescriptions each month. 35% take four or more.
- Over 70% of people with Alzheimer's or vascular dementia had at least one other chronic medical condition. 50% have two or more additional chronic conditions¹.

Medicaid pays for prescription drugs for many people with Alzheimer's disease

Whether a person with Alzheimer's takes just one prescription drug or is part of the 68% taking at least two each month, affordability is of enormous concern. The mean monthly cost of prescription drugs for persons with Alzheimer's disease is \$246.46, or nearly \$3000 annually¹. Many low-income individuals receive drug coverage through their state Medicaid program. Currently, prescription drug coverage is an optional benefit that all state Medicaid programs provide to those who qualify. With limited exceptions, state Medicaid programs must cover older people and people with disabilities with incomes up to 74% of the federal poverty level.

States are seeking ways to curtail drug spending in the Medicaid program because of rising costs

Medicaid spending accounted for 20 percent of state general fund expenditures in fiscal 1999; approximately 10 percent of those expenditures were for prescription drugs, according to the Kaiser Commission on Medicaid and the Uninsured (KCMU). States concerned about the increasing burden Medicaid and Medicaid prescription drug costs are placing on their budgets are taking action and making changes in their programs including cutting benefits, increasing cost-sharing, implementing drug formularies. The Alzheimer's Association is very involved in this issue and continues to advocate for people with Alzheimer's disease who rely on Medicaid for prescription drugs.

For more information about the Alzheimer's Association's work on Medicaid visit <http://www.alz.org/Advocates/priorities/medicaid/overview.html>

¹ A. Lyles and C. Steele. "A descriptive study of co morbidities, medication use and drug product costs for patients with Alzheimer's disease and vascular dementias." *Unpublished manuscript prepared for the Alzheimer's Association, 2002*

Home and Community Based Waivers-1915(c)

STATE & TARGET

POPULATION	CLIENTS	ADMINISTRATIVE AGENCY
Alabama		
A/D*	6,881	Program Management of Al. Medicaid-Long Term Care Division
Alaska		
elderly	1,100	Division of Senior Services
Arkansas		
	8,430	Division of Aging and Adult Services
California		
	8,004	Department of Aging
Colorado		
A/D	14,081	Community Based Long Term Care
Connecticut		
A/D	8,955	Department of Social Services
Delaware		
A/D	752	Department of Health and Social Services
Florida		
A/D	13,752	Department of Elder Affairs
elderly	1,501	Agency for Health Care Administration
Georgia		
	13,831	Division of Aging
Hawaii		
A/D	762	Department of Human Services
Idaho		
A/D	1,000	Department of Health and Welfare
Indiana		
A/D	2,327	Department of Human Services

* A/D – Aging and Disabled

STATE & TARGET

POPULATION	CLIENTS	ADMINISTRATIVE AGENCY
Iowa elderly	4,671	Department of Human Services
Kansas elderly	6,701	Department on Aging
Kentucky A/D	13,339	Department of Medicaid Services
Maryland A/D	132	Department of Aging
Michigan *A/D	6,328	Department of Community Health
Minnesota elderly	11,309	Department of Human Services
Mississippi A/D	6,951	Division of Medicaid
Missouri A/D	24,284	Department of Health and Senior Services
Nebraska A/D	836	Health and Human Services
Nevada elderly	1,240	Division of Aging
elderly	166	Division of Aging
New Hampshire elderly & chronically ill	1,367	Division Of Elderly and Adult Services
New Jersey A/D	4,497	Department of Health and Senior Services

* A/D – Aging and Disabled

STATE & TARGET POPULATION	CLIENTS	ADMINISTRATIVE AGENCY
New Mexico A/D	1,404	Department of Health
New York A/D	19,915	Department of Health
North Carolina	10,908	Division of Medical Assistance
North Dakota A/D	381	Aging Services Division
Ohio A/D	24,072	Department of Aging
Massachusetts elderly	5,115	Elder Affairs
Oklahoma A/D	9,042	Department of Health Services/Aging Services
Oregon A/D	26,410	Senior and Disabled Services Division
Pennsylvania elderly	2,016	Department of Aging
Rhode Island A/D	1,704	Department of Human Services
South Carolina A/D	14,431	Bureau of Senior and Long Term Care Services
South Dakota elderly	522	Department of Social Services

* A/D – Aging and Disabled

STATE & TARGET

POPULATION	CLIENTS	ADMINISTRATIVE AGENCY
Tennessee		
A/D	390	Bureau of TennCare
A/D	101	Bureau of TennCare
Texas		
A/D	24,191	Department of Human Services
Utah		
elderly	810	Division of Aging and Adult Services
Vermont		
A/D	118	Department. of Aging and Disabilities
Virginia		
A/D	25,776	Medicaid Agency
Washington		
A/D	25,713	Department of Social Services and Health Services
West Virginia		
A/D	3,272	Bureau of Senior Services
Wyoming		
A/D	1,095	Department of Health, Aging Division

Additional Medicaid Resources

The Kaiser Commission on Medicaid and the Uninsured and Families USA are valuable sources of information for advocates on developments in Medicaid. Here is a brief summary of these organizations' recently published work:

From the Kaiser Commission on Medicaid and the Uninsured

- *The Medicaid Resource Book*
<http://www.kff.org/medicaid/2236-index.cfm>
- *State Fiscal Conditions & Health Coverage: An Update on FY 2004 and Beyond*
<http://www.kff.org/medicaid/kcmu092203package.cfm>
- *States Respond Fiscal Pressure: A 50-State Update of State Medicaid Spending Growth and Cost Containment Actions*
<http://www.kff.org/medicaid/7001.cfm>
- *Is the State Fiscal Crisis Over? A 2004 State Budget Update Report*
<http://www.kff.org/medicaid/7003.cfm>
- *Medicaid Outpatient Prescription Drug Benefits: Findings from a National Survey, 2003*
<http://www.kff.org/medicaid/4164.cfm>
- *Financing the Medicaid Program: The Many Roles of Federal and State Matching Funds*
<http://www.kff.org/medicaid/7000.cfm>

From Families USA

- *Medicaid Action Center*
http://www.familiesusa.org/site/PageServer?pagename=Medicaid_Action

Family Caregiver Support Program

Objective

- Continue to finance and build on the National Family Caregiver Support Program established under the 2000 amendments to the *Older Americans Act* to fill gaps in existing state and community respite care, adult day care and caregiver support programs.

Status

In November 2000 Congress passed legislation (Public Law 106-501) to reauthorize the *Older Americans Act* (OAA) through 2005 and establish a new National Family Caregiver Support Program (NFCSP). The program provides federal grants to all 50 states to expand and enhance existing caregiver support services, particularly respite care and adult day care. Although many states had programs in place that offered supportive services to caregivers, these state programs often had long waiting lists, restrictive eligibility criteria or limited service delivery areas. The caregiver support initiative was designed to allow for the continued growth of the state programs as well as reduce the number of families on waiting lists.

Under the NFCSP, State Agencies on Aging are collaborating with local Area Agencies on Aging (AAA's) and community and service provider organizations to provide supportive services, including information and assistance, individual counseling, organization of support groups, caregiver training, respite care and adult day care, to families caring for frail older loved ones. The State Agencies on Aging and AAA's have the authority to determine the funding allocated for specific services.

The NFCSP is authorized under Title III-E of the OAA and is administered by the Administration on Aging (AoA). Each state receives a share of federal funds based on the percentage of the state's population age 70 or older. Fiscal year 2004 funding for the caregiver program is \$153.6 million. President Bush's Fiscal Year 2005 budget request includes \$162 million for the NFCSP. Future funding for the program will be determined by the House and Senate Labor/HHS/Education Appropriations bills that Congress will begin work on later this summer. The Alzheimer's Association supports increasing funding for the caregiver support program.

Alzheimer's Association chapters are actively involved in program implementation efforts in their states. Chapters are providing substantive input to State Agencies on Aging and AAA's regarding allocation of the program funds. Additional information about the NFCSP can be found on AoA's website at <http://www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp>.

Key Members of Congress

House Appropriations Committee, Labor/HHS/
Education Subcommittee
Senate Appropriations Committee, Labor/HHS/
Education Subcommittee

The Lifespan Respite Care Act

Objective

- To increase the availability of respite care services and provide training for respite care workers and volunteers by enacting the *Lifespan Respite Care Act*.

Status

On March 5, 2003, Senators **Clinton (NY)**, **Warner (VA)**, **Mikulski (MD)**, **Snowe (ME)**, **Breaux (LA)**, **Jeffords (VT)**, **Murray (WA)**, **Collins (ME)**, **Kennedy (MA)** and **Smith (OR)** introduced the *Lifespan Respite Care Act of 2003* (S 538). A companion bill, HR 1083, was introduced in the House of Representatives by **Langevin (RI)** and **Greenwood (PA)** and 50 additional cosponsors the same day. Over 150 national, state and local organizations, including the Alzheimer's Association, have endorsed the bill.

S 538/ HR 1083 would authorize competitive grants to states and other eligible entities to make respite care available and accessible to family caregivers, regardless of age or special need. The bill requires state grantees to identify, coordinate and build on already existing, but sometimes limited, respite efforts at the state and local levels. The bill would also establish a National Resource Center on Lifespan Respite Care.

Funds would be provided to state agencies, other public or private nonprofit entities capable of operating on a statewide basis, a political subdivision of a state that has a population greater than three million, or any already recognized state respite coordinating body. Priority would be given to applicants who show the greatest likelihood of implementing or enhancing lifespan respite care statewide.

Grant funds could be used for the development of lifespan respite care programs at the state and local

level, evaluation of lifespan respite programs, planned or emergency respite care services, training and recruitment of respite care workers and volunteers and caregiver training to help make informed decisions about respite care services.

The *Lifespan Respite Care Act* requires the Secretary of Health & Human Services (HHS) to work in cooperation with the Maternal & Child Health Bureau at the Health Resources & Services Administration (HRSA), the Administration on Aging (AoA), the Administration for Children, Youth & Families (ACYF), the Administration on Developmental Disabilities (ADD) and the Substance Abuse & Mental Health Services Administration (SAMHSA) to ensure coordination of respite care for family caregivers. The bill authorizes \$90.5 million for fiscal year 2004 and such sums as necessary for fiscal years 2005–2008.

On March 19, 2003, the Senate Health, Education, Labor & Pensions (HELP) Committee approved S 538. Less than a month later, on April 10 the Senate passed the bill by unanimous consent. A companion bill (HR 1083) is currently awaiting consideration by the House Energy & Commerce Committee.

The chief cosponsors of HR 1083, Representatives **Greenwood (PA)** and **Langevin (RI)**, will be reaching out to Energy & Commerce Committee Chairman, Rep. Joe **Barton (TX)**, to seek support for consideration of the bill this year. Additional information about the *Lifespan Respite Care Act* is available at <http://www.archrespice.org/tforce.htm>.

Key Members of Congress

House Education and the Workforce Committee
Senate Health, Education, Labor and Pensions Committee

Talking Points on Family Caregivers

Families continue to be the backbone of the long term care system, especially for loved ones who have Alzheimer's disease

- The estimated annual value of the informal caregiving system is \$257 billion — far more than the \$32 billion cost of paid home health care and the \$92 billion cost of nursing home care.
- At least 70% of people with Alzheimer's disease live at home, where families provide 75% of their care.
- Three of four caregivers are women. One in three have children or grandchildren under the age of 18 living at home. Caregiving leaves them less time for other family members; they give up vacations and they are much more likely to report family conflicts because of their caregiving role.

Caregiving takes a high economic toll on families and employers

- Caregivers are not wealthy — in a recent survey only 11% reported household incomes over \$75,000 and one in five reported incomes under \$15,000. Yet 70% contribute part of their personal income or savings to their loved one's care.
- Most Alzheimer caregivers work outside the home before beginning their caregiving careers. But caregiving forces them to miss work, cut back to part-time, take less demanding jobs, choose early retirement, or give up work altogether. As a result, Alzheimer's disease is costing American business an estimated \$36.5 billion a year in lost productivity, as well as an additional \$24.6 billion toward the total cost of care.

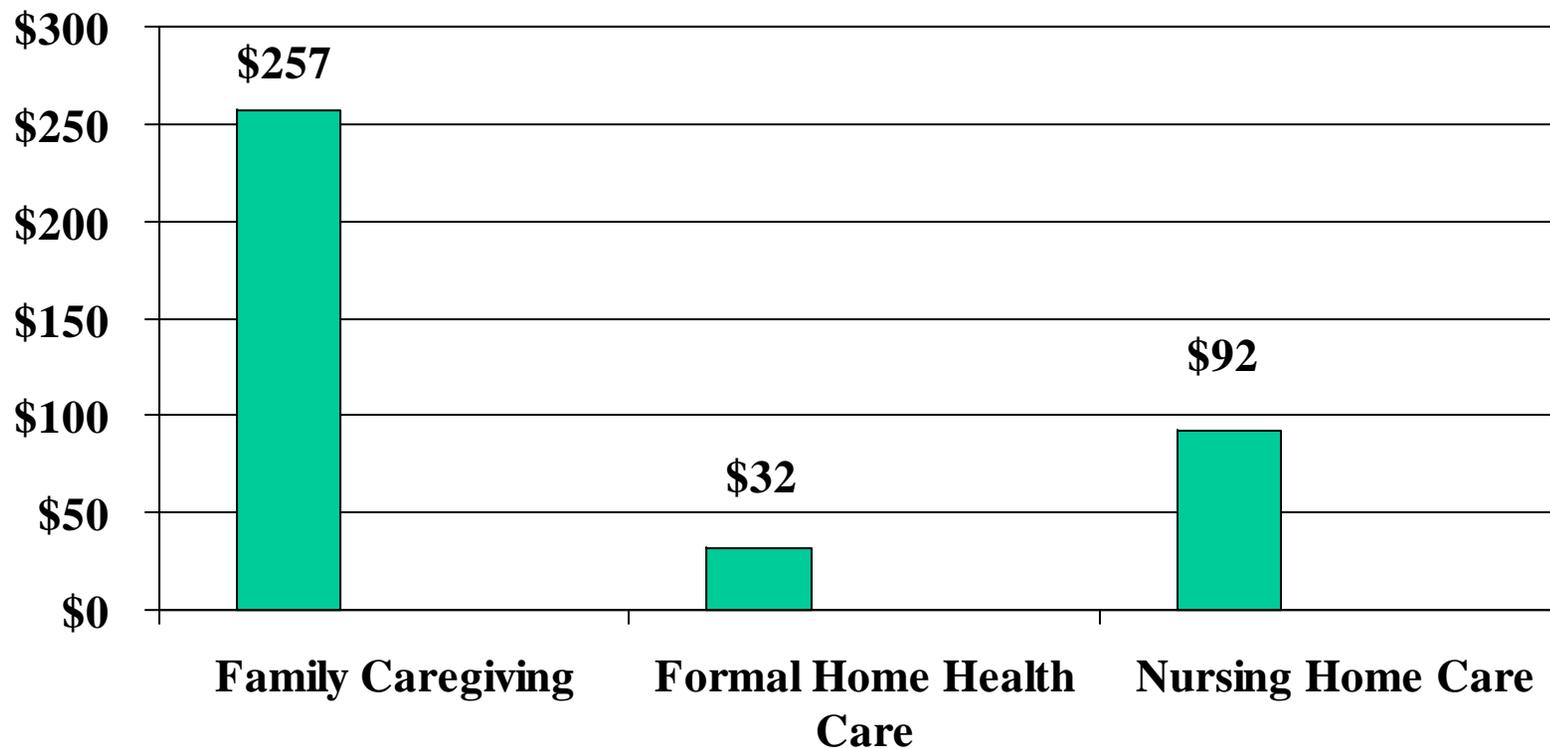
Caregiving takes a high physical and emotional toll on families and contributes directly to higher health care costs

- One in 8 Alzheimer caregivers becomes ill or injured as a direct result of caregiving. One in 3 uses medication for problems related to caregiving. Older caregivers are 3 times more likely to become clinically depressed than other in their age group.
- Elderly spouses strained by caregiving were 63% more likely to die during a four year period than other spouses their age.

Simple caregiver interventions, like respite, counseling, and supportive services, can have major impact on health care costs, economic well being, and quality of life

- Counseling, support programs and respite care (brief time off for the family caregiver) can substantially increase the time spouse-caregivers care for a person with early to middle stages of dementia, significantly delaying nursing home placement of a person with Alzheimer's disease. Adult day care not only benefits the person with the disease, it also reduces stress and burden in caregivers and extends the time when they can provide care.
- Delaying nursing home admissions for people with Alzheimer's disease by just one month could save at least \$1.12 billion a year. The one-month delay would save on average, \$1,863 for an Alzheimer's patient.

Economic Value of Informal Caregiving in the U.S. (billions of dollars)



Source: Peter Arno, "Economic Value of Informal Caregiving", presented at the American Association of Geriatric Psychiatry, Orlando, FL, Feb. 24, 2002.

Prevalence and Economic Value of Family Caregiving: State-by-State Analysis

States	Number of Caregivers	Caregiving Hours per Year (Millions of Hours)	Annual Market Value (Millions of Dollars)
Alabama	434,289	465	\$4,099
Alaska	56,566	61	\$534
Arizona	488,129	523	\$4,607
Arkansas	260,432	279	\$2,458
California	3,184,776	3,412	\$30,056
Colorado	414,417	444	\$3,911
Connecticut	337,446	361	\$3,185
Delaware	76,822	82	\$725
District of Columbia	58,656	63	\$554
Florida	1,623,320	1,739	\$15,320
Georgia	778,491	834	\$7,347
Hawaii	119,576	128	\$1,128
Idaho	119,625	128	\$1,129
Illinois	1,193,025	1,278	\$11,259
Indiana	586,101	628	\$5,531
Iowa	285,579	306	\$2,695
Kansas	256,493	275	\$2,421
Kentucky	397,485	426	\$3,751
Louisiana	422,067	452	\$3,983
Maine	128,473	138	\$1,212
Maryland	517,124	554	\$4,880
Massachusetts	633,549	679	\$5,979
Michigan	958,512	1,027	\$9,046
Minnesota	472,445	506	\$4,459
Mississippi	268,262	287	\$2,532
Missouri	544,310	583	\$5,137
Montana	88,154	94	\$832
Nebraska	163,857	176	\$1,546
Nevada	193,720	208	\$1,828
New Hampshire	121,467	130	\$1,146
New Jersey	831,953	891	\$7,851
New Mexico	170,908	183	\$1,613
New York	1,867,458	2,000	\$17,624
North Carolina	791,741	848	\$7,472
North Dakota	62,320	67	\$588
Ohio	1,107,578	1,186	\$10,453
Oklahoma	332,969	357	\$3,142
Oregon	336,491	360	\$3,176
Pennsylvania	1,229,219	1,317	\$11,600
Rhode Island	104,140	112	\$983
South Carolina	391,159	419	\$3,691
South Dakota	71,725	77	\$677
Tennessee	560,462	600	\$5,289
Texas	1,929,789	2,067	\$18,212
Utah	191,090	205	\$1,803
Vermont	60,506	65	\$571
Virginia	696,303	746	\$6,571
Washington	570,620	611	\$5,385
West Virginia	184,891	198	\$1,745
Wisconsin	520,561	558	\$4,913
Wyoming	47,569	51	\$449
Total	27,242,621	29,182	\$257,096

These state-by-state statistics on the *Prevalence and Economic Value of Family Caregiving* were developed in 2003 by the National Family Caregivers Association in conjunction with Peter S Arno, PhD, Department of Epidemiology and Population Health, Montefiore

Medical Center and Albert Einstein College of Medicine based on Dr. Arno's previous study, *Economic Value of Informal Caregiving: 2000* presented at the American Association for Geriatric Psychiatry conference, Orlando, FL., February 24, 2002.

The Alzheimer Demonstration Grant Program

Objective

- Appropriate \$25 million for the Alzheimer Matching Grant Program to develop and replicate innovative models of service for Alzheimer families in underserved areas, particularly minority and rural communities, in all 50 states.

Status

2004 funding for the Alzheimer's Disease Demonstration Grants to States (ADDGS) Program is \$11.9 million. The President's Fiscal Year 2005 budget request includes \$12 million for the ADDGS Program.

The purpose of the program is to foster the development of innovative models of care for persons with Alzheimer's disease and their caregivers. The target population includes underserved minority, rural and low-income persons.

Although grant funds are distributed directly to state governmental agencies, Association chapters benefit from the program because the services provided are Alzheimer specific and are tailored to local community needs. In addition, the program gives Association chapters the opportunity to collaborate with state agencies and other community-based service providers to meet the needs of local Alzheimer families.

39 states are currently participating in the ADDGS Program. States receive a federal share of approximately \$220,000 to \$350,000 per year for three years.

AoA expects to award grants to several additional states this year. States currently funded by the program will not be eligible and preference will be given to states not funded in previous years. A request for proposals (RFP) and grant announcement will be published in the Federal Register later this spring and on the AoA website at www.aoa.gov.

The House and Senate Labor/HHS/Education Appropriations bill will determine future funding for the Alzheimer Disease Demonstration Program. Congress is expected to begin work on the Labor/HHS bill in spring 2004.

For more information about the Alzheimer's Demonstration Grants, visit the Alzheimer's Resource Room on AoA's website at www.aoa.gov/alz/public/alzabout/aoa_fact_sheet.asp or contact Jennifer Zeitzer in the Public Policy Division at 202/393-7737 ext. 223 or Jennifer.Zeitzer@alz.org.

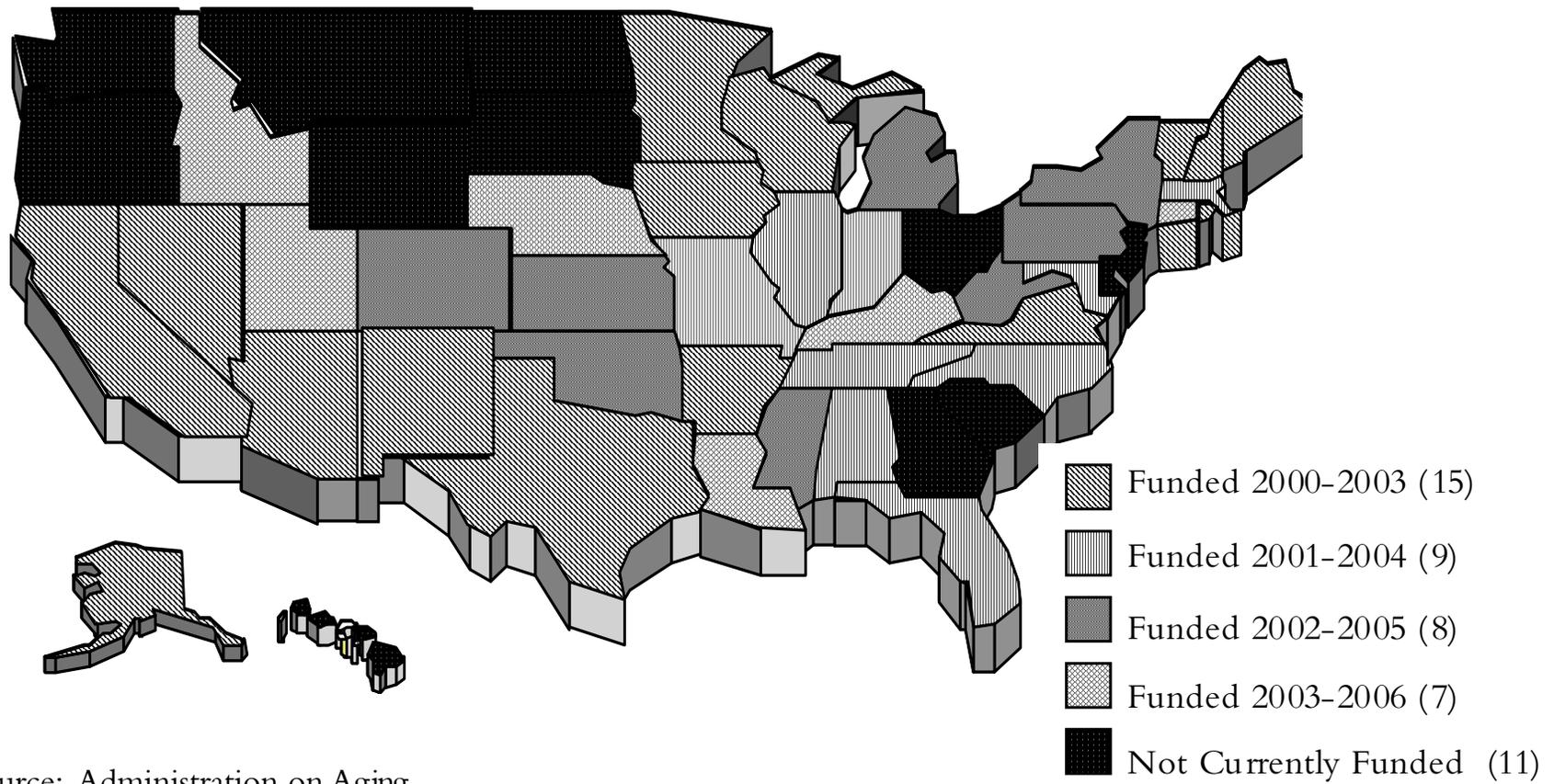
Key Members of Congress

Senate Appropriations Committee, Labor/HHS/
Education Subcommittee
House Appropriations Committee, Labor/HHS/
Education Subcommittee

TALKING POINTS:

- Although this is a tiny program in federal budget terms, it is a model of how federal funds can be channeled to stimulate the kind of creative thinking that makes sense out of a fragmented local services delivery system.
 - The original 15 projects demonstrated how existing public and private resources can be used to enhance educational and services delivery systems for people with Alzheimer's disease, their families and their caregivers. The grants have resulted in a number of "best practices", and information is being disseminated on successful innovative approaches and replicable programs.
 - The emphasis of the program over the past several years has been on developing materials, training, and mentoring to replicate the successful models in new communities.
 - The Administration on Aging and the grantees worked together to plan grants that link public and non-profit agencies; deliver services, including primary health care physician education and support services; improve access to home and community based long term care services; and provide individualized and public education and referrals.
 - The projects focus on making existing services work better, through coordination, family caregiver support, and physician education. More than 250 local and community agencies have participated in the projects.
 - Projects focus on hard-to-reach and particularly underserved populations and communities, including cultural minorities, rural, and inner city.
 - 53% of participating families live in rural areas; half are ethnic minorities
 - 44% never had access to formal services before
 - Average age was almost 79 years.
 - More than 1 million units of services have been delivered to 7000 Alzheimer families — mostly in-home respite and adult day care.
 - In addition to direct services to families, the program has provided educational seminars and workshops for nearly 400,000 caregivers, community service providers, and volunteers
 - For the past several years, emphasis has been placed on improving health care delivery by linking projects to primary health care providers, including community health centers and managed care organizations, to:
 - Train physicians and nurses in dementia assessment and treatment,
 - Conduct dementia screening and appropriate follow-up,
 - Provide technical assistance and support to community health centers,
 - Provide dementia training opportunities for medical and nursing students,
 - Provide training in appropriate use of occupational therapy, assistive technology, and home modification to enable persons with dementia to live at home.
- The current grantee states are: Alaska, Alabama, Arizona, Arkansas, California, Colorado, Connecticut, Florida, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Hampshire, New Mexico, New York, North Carolina, Oklahoma, Pennsylvania, Rhode Island, Tennessee, Texas, Utah, Vermont, Virginia, West Virginia, Wisconsin and Puerto Rico.**

States Receiving Alzheimer Demonstration Grants (2000-2006)



Source: Administration on Aging

Safe Return

Objective

Appropriate \$900,000 for fiscal year 2005 to continue the Safe Return Program, a nationwide effort to assist in locating individuals with Alzheimer's disease and related disorders who wander and become lost.

Status

Congress first authorized the Safe Return Program in 1993 in response to the growing number of missing Alzheimer's patient incidents reported by cities and towns across the country. The Alzheimer's Association has asked Congress to appropriate \$900,000 for the program for fiscal year 2005, the same amount as was appropriated for this year. The House and Senate Appropriations Committees will consider the Association's request later this spring.

Key Members of Congress

- House Appropriations Committee, Commerce, Justice, State & the Judiciary Subcommittee.
- Senate Appropriations Committee, Commerce, Justice, State & the Judiciary Subcommittee.

Talking Points

- An estimated 4.5 million Americans suffer from Alzheimer's disease, 60% of whom will likely wander from their residence.
- Studies have shown that if not found within 24 hours, 46% of persons with Alzheimer's who wander may die, succumbing to dehydration or hypothermia.

- Research estimates that over 127,000 critical wandering incidents occur each year, with only 34,000 being reported to law enforcement.

The Safe Return Program has been highly successful.

- More than 113,000 individuals who are at risk of wandering have been registered in the Safe Return Program.
- The program has responded to over 14,544 calls for help, and has successfully recovered 99% of registrants who were reported missing.

The Safe Return Program is a public/private partnership.

- In addition to funding from the Justice Department, the program is supported by grants from the Janssen Research Foundation, other private donations and by volunteer time devoted by the Alzheimer's Association's nationwide network of chapters and community-based support groups.
- The program works cooperatively with local law enforcement agencies throughout the country.
- Attorneys General in several states have launched efforts to train law enforcement officials about Alzheimer's disease and heighten awareness of the Safe Return Program.

Jurisdiction of Key Congressional Committees

HOUSE COMMITTEES

Ways & Means

- Tax Credits/ Tax Deductions

Ways & Means: Subcommittee on Health

- Long Term Care, Medicare

Energy and Commerce: Subcommittee on Health

- Long Term Care, Medical Research, Alzheimer's Disease
- Matching Grants Program, Medicaid, Medicare,
- Health Professions Training

Education and the Workforce

- Older Americans Act

Appropriations: Subcommittee on Labor, Health and Human Services & Education

- Annual Appropriations for Alzheimer's Research,
- Alzheimer's Disease Matching Grant Program,
- Health Professions Training,
- Family Caregiver Initiative

Appropriations: Subcommittee on Commerce, Justice, State & Judiciary

- Annual Appropriations for Safe Return

Budget

- Overall Spending Limits on Federal Programs
- Jurisdiction Of Key Congressional Committees

Jurisdiction Of Key Congressional Committees

SENATE COMMITTEES

Finance

- Long Term Care, Medicare, Medicaid, Tax Credits/ Tax Deductions

Health, Education, Labor and Pensions

- Medical Research, Alzheimer's Disease Matching Grants Program,
- Health Professions Training, and Older Americans Act

Appropriations: Subcommittee on Labor, Health and Human Services & Education

- Annual Appropriations for Alzheimer's Research,
- Alzheimer's Disease Matching Grants Program,
- Health Professions Training, and Family Caregiver Initiative

Appropriations: Subcommittee on Commerce, Justice, State & the Judiciary

- Annual Appropriations for Safe Return

Budget

- Overall Spending Limits on Federal Programs

Glossary Of Frequently Used Acronyms

AAHSA (American Association of Homes and Services for the Aging)

The national trade association of nonprofit nursing home, senior housing, and other long term care providers.

ABA (American Bar Association)

The national voluntary professional association of the legal profession comprised of practicing lawyers, judges, law teachers, public service lawyers and court administrators. **The Commission on Legal Problems of the Elderly (CLPE)** is the arm of the ABA dedicated to examining the law-related concerns of older persons and improving legal services for the elderly (the Association's Medicare Advocacy Project is housed at the Commission).

AD

A common abbreviation for Alzheimer's disease.

ADA (Americans with Disabilities Act)

An act prohibiting discrimination on the basis of disability in employment, by state and local government entities and by places of public accommodation.

ADL's (Activities of Daily Living)

Basic personal activities that include bathing, dressing, transferring from bed to chair, toilet assistance, mobility and eating. ADL's are used to measure how dependent a person may be on requiring assistance in performing any or all of these activities.

ADRC or ARC (Alzheimer's Disease Research Center).

Centers of basic, clinical and behavioral research on Alzheimer's disease, located in major universities throughout the country, funded by the National Institute on Aging (NIA).

AHCA (American Health Care Association)

The national trade association of for-profit and nonprofit nursing homes.

AHCPR (Agency for Health Care Policy and Research)

Government agency that studies health care trends and conducts health care research projects. AHCPR published Guidelines for Screening for Dementia.

ALFA (Assisted Living Federation of America)

A national trade association of for profit and nonprofit assisted living facilities.

AoA (Administration on Aging)

Federal agency within the Department of Health and Human Services (DHHS) that administers the Older Americans Act (OAA), including the new Family Caregiver Support Program, as well as the Alzheimer's Disease Demonstration Grant Program.

ApoE (Apolipoprotein E)

A plasma protein involved in the transport of cholesterol and other hydrophobic molecules. ApoE4 is a major risk factor for Alzheimer's disease and may play a similar role in other types of dementia.

ASA (American Society on Aging)

A national, multidisciplinary coalition of public and private sector executives, educators, advocates, social service professionals, researchers and students in the field of aging.

ASHA (American Seniors Housing Association)

A trade association formed in 1991 to represent providers of senior housing. ASHA provides leadership for the seniors housing industry on legislative and regulatory matters and promotes research on all types of seniors housing.

ASPE (Assistant Secretary for Planning and Evaluation)

The leading office of research on health and long term care policy within the Department of Health and Human Services.

BBA (Balanced Budget Act)

Major legislation passed in 1997 that established the Bipartisan Commission on Medicare Reform, created the Medicare+ Choice program, authorized prospective payment systems for the Medicare SNF and home health benefits and made other sweeping changes in Medicare law.

CBO (Congressional Budget Office)

The agency of Congress that develops budget estimates for legislative purposes.

CDC (Centers for Disease Control)

The lead federal agency for protecting the health and safety of the people of the United States and for developing and applying disease prevention and control, environmental health and health promotion and education activities.

CLTC (Citizens for Long Term Care)

A broad-based coalition of consumers, workers, providers and insurers led by former Senator David Durenberger (MN). CLTC works to raise awareness about the need for comprehensive long term care financing reform.

CMS (Centers for Medicare and Medicaid Services)

The new name for the federal agency within DHHS that is responsible for administering the Medicare and Medicaid programs. (Formerly HCFA)

CNA (Certified Nurse Assistant)

Nursing home, assisted living or other residential care staff who provide the majority of the hands-on caregiving and assistance to residents.

DASN (Dementia Advocacy and Support Network)

Dementia Advocacy and Support Network International is a non-profit organization for persons with dementia and their supporters dedicated to improving the lives of all people living with early stage dementia of any kind.

DHHS (Department of Health and Human Services)

The U.S. government's principal agency for protecting the health of all Americans and providing essential human services. The department includes AoA, NIH, CMS, CDC and other agencies.

DOJ (Department of Justice)

The federal agency that helps fund the Alzheimer's Association's Safe Return program.

DRG (Diagnosis Related Group)

A classification used by Medicare to determine payment for in-patient care. DRG's are based on age, type of diagnosis, sex, complications and anticipated procedures.

DSH (Disproportionate Share Hospital Adjustment)

An additional payment through Medicaid and Medicare for hospitals that serve a relatively large volume of uninsured, Medicaid and Medicare patients.

FDA (Food and Drug Administration)

The federal agency that approves the sale and manufacturing of drugs and other pharmaceutical devices.

FFS (Fee For Service Insurance)

Health insurance plans reimburse physicians and hospitals for each individual service they provide. These plans allow clients to choose any physician or hospital. Managed care is an alternative to fee-for-service medicine.

FI (Fiscal Intermediary)

A private organization, usually an insurance company, that has a contract with CMS to process claims under Part A of Medicare.

FMAP (Federal Medical Assistance Percentage)

The federal share of the Medicaid program which is based on the relationship between each state's per capita personal income and the national average per capita personal income over three calendar years.

FPR (Federal Poverty Rate)

Guidelines established by the Department of Health and Human Services that are used to determine an individual's and families' eligibility for various federal and non-federal programs.

GAO (General Accounting Office)

Fiscal watchdog of the federal government.

GSA (Gerontological Society of America)

The professional organization for gerontologists and other executives in the aging field.

HCFA (Health Care Financing Administration)

The former name of the federal agency responsible for administering the Medicare and Medicaid programs (now called CMS).

HHA's (Home Health Agencies)

Agencies and/or private provider organizations that provide acute and skilled nursing health care services to Medicare beneficiaries in their homes.

HCBS (Home and Community Based Services)

Services designed to help people remain independent and in their own homes. May include home health, adult day care, respite, personal care and homemaker services.

HIFA (Health Insurance Flexibility and Accountability)

A new policy that allows broad waivers of Medicaid law to allow states to expand Medicaid coverage to certain populations not covered in the past.

HMO (Health Maintenance Organization)

A type of managed care health plan that provides offers or arranges for coverage of designated health services need by plan members for a fixed, prepaid premium.

HRSA (Health Resources and Services Administration)

Federal agency within DHHS that helps provide health resources for medically underserved, vulnerable and special-need populations.

ICF/MR

Intermediate Care Facility for the Mentally Retarded (a Medicaid term).

JCAHO (Joint Commission on the Accreditation of Health Care Organizations)

A national organization that performs quality reviews on hospitals, outpatient facilities, other institutional facilities and HMO's.

KFF (Kaiser Family Foundation)

An independent source of health care facts and analysis for policymakers, the media, the health care community, and the general public.

LCAO (Leadership Council of Aging Organizations)

A coalition of national aging organizations. The Alzheimer's Association is a member.

LMRP's (Local Medical Review Policies)

Guidelines that describe when and under what circumstances Medicare will pay for a specific medical item, service or procedure. Every Medicare Carrier and Fiscal Intermediary has the authority to develop and adopt their own local coverage policies for use in their region/jurisdiction.

LTC (Long Term Care)

Includes nursing home care, care in the home, adult day care and respite care.

MDS (Minimum Data Set)

A standardized tool for assessing the functional capacity of residents of long term care facilities that must be completed as a condition of participation in the Medicare and Medicaid programs.

MedPAC (Medicare Payment Assessment Commission)

An independent body established by Congress to advise policymakers and Congress on Medicare's hospital payment system and physician payment policies. Formerly organized into two entities known as the **PPRC** (Physician Payment Review Commission) and **ProPAC** (Prospective Payment Assessment Commission).

NAAAA or N4A (National Association of Area Agencies on Aging)

A national, non-profit organization that provides information and assistance to Area Agencies on Aging (AAA's).

NASBO (National Association of State Budget Officers)

A professional membership organization for state finance officers that conducts research, policy development, education, training, and technical assistance on state budget practices. A self-governing affiliate of the National Governors' Association.

NASMD (National Association of State Medicaid Directors)

A bipartisan, professional, non-profit organization of representatives of the state Medicaid agencies. The primary purpose of the organization is to serve as a focal point of communication between the states and the federal government and to provide an information network among the states on issues pertinent to the Medicaid program.

NASUA (National Association of State Units on Aging)

A national, non-profit, public interest organization dedicated to providing general and specialized information, technical assistance and professional development support to State Units on Aging.

NCCNHR (National Citizens Coalition for Nursing Home Reform)

A national, non-profit membership organization dedicated to improving the long term care system and the quality of life for nursing home residents.

NCOA (National Council on Aging)

A national organization that advocates for public policies that promote the dignity, self-determination, well being, and contributions of older persons.

NCSL (National Conference of State Legislatures)

The premier membership organization dedicated to improving the quality and effectiveness of state legislatures, fostering interstate communication and cooperation and ensuring legislatures a strong voice in the federal system.

NGA (National Governors' Association)

The only bipartisan national organization of, by and for the nation's governors. NGA provides a forum for governors to exchange views and experiences and to establish, influence and implement policy on national issues.

NIA (National Institute on Aging)

Located within NIH, it is the leading center for aging research, and for Alzheimer research in particular.

NIH (National Institutes of Health)

The federal agency that is the nation's premier center for biomedical and health research.

NIMH (National Institutes of Mental Health)

Located within NIH, it is the leading center for mental health research.

NINDS (National Institute of Neurological Disorders and Stroke)

Located within NIH, it is the leading center for research on strokes and neurological disorders.

NSCLC (National Senior Citizens Law Center)

A public interest law organization that represents low-income elderly clients and client groups, focusing on issues of income and health security.

OAA (Older Americans Act)

Legislation that authorizes federal funding for programs and services such as Meals on Wheels and community services for senior citizens.

OBRA (Omnibus Budget Reconciliation Act)

OBRA'87 contained the Nursing Home Reform Law that provides basic protections for nursing home residents.

OMB (Office of Management and Budget)

The budget office in the White House.

PBM's (Pharmacy Benefit Managers)

Private companies that contract with health plans to arrange discounts from retail pharmacies and managed distribution of drugs.

PCP (Primary Care Physician)

The physician in a managed care system whom a patient consults first when a health problem occurs and on whom the patient relies for advice, referrals and on-going care.

PhRMA (Pharmaceutical Research & Manufacturers of America)

A trade association representing prescription drug manufacturers.

PPS (Prospective Payment System)

The Medicare system used to pay hospitals for inpatient hospital services based on the DRG classification system.

PwiD (Person with Dementia)

A term coined and used by Dementia Advocacy and Support Network (DASN) members.

QMB (Qualified Medicare Beneficiary)

Medicare beneficiaries whose incomes are below the federal poverty guideline and whose Medicare Part B premiums, copayments and deductibles are paid by Medicaid.

RFP (Requests for Proposals)

A Request for Proposal is a tool that can be used to facilitate the selection of a qualified service provider and assist with the contracting process such as in the Alzheimer Disease Demonstration Grant Program.

SEIU (Service Employees International Union)

The largest union of health care workers in the country, representing workers who deliver a range of services in a variety of settings to seniors and people with disabilities who need long term care.

SNF (Skilled Nursing Facility)

A Medicare and Medicaid term referring to a nursing home or other institutional-based setting.

SSA (Social Security Administration)

The federal agency that administers the Social Security and Disability Insurance Programs.

SSDI (Social Security Disability Insurance)

The portion of Social Security that pays monthly benefits to disabled workers under age 65 and their dependents. SSDI recipients (but not their dependents) automatically become eligible for Medicare after a two-year waiting period.

SSI (Supplemental Security Income)

Program administered by the Social Security Administration that provides monthly benefits to people who are 65 or older, disabled or blind who have very limited income and personal property. Many states supplement SSI benefits with additional payments ranging from \$15 to more than \$150 per month.

SMI (Supplementary Medical Insurance or Medicare Part B)

The portion of the Medicare program that covers the cost of physician's services, outpatient laboratory and x-ray tests, durable medical equipment and outpatient hospital care.

VA (Department of Veterans Affairs)

Provides veteran benefits and services including medical care. VA's health care system includes 163 hospitals, with at least one in each of the 48 contiguous states, Puerto Rico and the DC, 850 ambulatory care and community-based outpatient clinics, 137 nursing homes, 43 domiciliary and 73 comprehensive home-care programs.

WIG (Women in Government)

A bi-partisan educational association for elected women in state government. WIG promotes informed policymaking and the leadership role of women by providing issue education and opportunities for idea and information exchange. Women In Government is a non-profit association.

Title XIX (Medicaid Program)

Statutory authority for the Medicaid program.

Title XVIII (Medicare Program)

Statutory authority for the Medicare program.

Alzheimer's Association Web Resources for Advocates

Alzheimer's Association Advocacy Web Page

<http://www.alz.org/Advocacy/overview.asp>

Provides an overview of the Association's advocacy program and tools you can use as an advocate to advance our mission. Includes links to more in depth information on our priority issues, such as: the National Program; Advocates Guide; Congressional testimony; and other advocacy resources.

Become An Advocate!

<http://www.alz.org/Advocacy/join/overview.asp>

Sign up for The National Alzheimer Advocate Network (NAAN) and encourage others to join. Alzheimer Advocates are kept up to date on public policy issues via updates and action ALERTs.

Write Congress!

<http://www.alz.org/Advocacy/join/write.asp>

Type your zip code, submit your search and the names and contact information of your Members of Congress appears. Click the [View Detail](#) button to get his or her address and then click the [Write Legislator](#) button to compose your letter or click to see a [Sample Letter](#). **Sending bulk e-mail or spamming congressional offices with form letters is not appropriate or helpful to our cause.**

State Policy Clearinghouse

<http://www.alz.org/Advocacy/resources/state.asp>

A resource for information sharing on state legislation and other chapter advocacy activities that affect the lives of people with Alzheimer's disease and their care partners. Support for Alzheimer's Association chapters and state coalitions through legislative analysis, issue kits, and the development of strategies on a variety of issues such as Medicaid, assisted living and long term care workforce.

Non-Association Sponsored Web Resources

National Institutes of Health

<http://www.nih.gov/>

Provides a calendar of events, press releases, information about NIH health resources and a catalog of diseases under investigation at NIH. Provides information about NIH research grants and how to apply for them.

Centers for Medicare & Medicaid Services (formerly HCFA)

<http://www.cms.hhs.gov>

Offers access to information about Medicare and Medicaid, research on health care, health care statistics and access to health care laws and regulations. Provides full texts of many CMS (HCFA) publications and manuals and includes basic information about the Department of Health & Human Services (DHHS).

Medicare.Gov

<http://www.medicare.gov>

Provides information on Medicare coverage and eligibility. Also allows consumers to search for information on health plans, nursing homes, and Medigap policies. Links provided to the **Nursing Home Compare** tool and **Prescription Drug Assistance Programs**.

Thomas: Federal Legislative Information

<http://thomas.loc.gov/>

A service from the U.S. Library of Congress. Includes a schedule of current floor activities in Congress, documentation of all major legislation, summaries of bills and their status, text of the Congressional Record, and committee reports.

National Conference of State Legislatures

<http://www.ncsl.org>

Source for information and research on critical state issues, including long term care. Provides informative publications, which often include 50-state comparative data and case studies.

State and Local Government on the Net

<http://www.statelocalgov.net/>

Directory of official state and local government websites. Links to sites for governors, state legislatures, bill information, state statutes and state agencies.

National Governors Association

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

Highlights the nation's governors, key state issues, NGA policy positions, press releases and reports.

2004 Congressional Calendar

April 5-16
House Easter/Spring Recess

April 12-16
Senate Easter/Spring Recess

May 24-31
Memorial Day Recess

June 28-July 5
Independence Day Recess

July 26-September 6
Summer Recess

July 26-29
Democratic Convention

August 30-September 2
Republican Convention

September 15
Rosh Hashanah

September 25
Yom Kippur

October 1
Target adjournment

November 2
Election Day