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ALZHEIMER'S DISEASE AND DEMENTIA: A COMPARISON OF INTERNATIONAL APPROACHES

R E P O R T

OF THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

Pursuant to

S. RES. 81, SEC. 17(d), MARCH 2, 2011

Resolution Authorizing a Study of the Problems of Aged and Aging

DECEMBER 19, 2012.—Ordered to be printed

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U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

Hon. JOE BIDEN,
President, U.S. Senate,
Washington, DC.

DEAR MR. PRESIDENT: Under authority of Senate Resolution 81 agreed to March 2, 2011, I am submitting to you a report of the U.S. Senate Special Committee on Aging entitled: Alzheimer's Disease and Dementia: A Comparison of International Approaches.

Senate Resolution 4, the Committee Systems Reorganization Amendments of 1977, authorizes the Special Committee on Aging "to conduct a continuing study of any and all matters pertaining to problems and opportunities of older people, including but not limited to, problems and opportunities of maintaining health, of assuring adequate income, of finding employment, of engaging in productive and rewarding activity, of securing proper housing and, when necessary, of obtaining care and assistance." Senate Resolution 4 also requires that the result of these studies and recommendations be reported to the Senate annually.

I am pleased to transmit this report to you.

Sincerely,

HERB KOHL,
Chairman.

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Introduction

For many of us, the potential for an Alzheimer's disease (AD) or dementia diagnosis is terrifying. In a recent Marist poll, AD topped the list as the disease respondents feared most, with 44% naming it their biggest fear—cancer ranked second with 33%[1]. The fear is even more pronounced in seniors, with 56% of respondents over 65 revealing that AD is the illness they most want to avoid. AD promises a chilling tragedy of slowly losing both a sense of self and those we love, while simultaneously becoming dependent on others. This inevitable decline is why AD and dementia are one of the leading public health challenges we face in the 21st century.

Researchers and the health care system must face this challenge as they struggle to find new ways to prevent, detect and treat the disease. Since many people do not want to learn if they have AD, researchers find recruiting patients for early stage AD studies difficult. Even James Watson, who won a Nobel Prize for discovering the double helix structure of DNA, feared AD. Watson had his entire genome sequenced and was curious to learn all that scientists uncovered, with one exception; he did not want to know if he carried the gene for AD. In many ways, such fear is justified. A diagnosis is a death sentence. There are few treatments aimed at preventing disease advancement, and no treatment that could reverse the course of the disease progression. In the same Marist poll referenced above, respondents were split 50/50 about which option would be worse— an AD diagnosis, or caring for and living with a family member with AD.

But concerns about AD are shared beyond the personal and familial challenges. AD remains a public health challenge throughout the nation, and the world. Still, relatively little progress has been achieved in the realm of degenerative neurological disorders such as dementia.

AD is an expensive disease, both for families and governments. As the prevalence of the disorder increases, so will pressure on budgets around kitchen tables and in policy circles. The Alzheimer's Association (AA) estimates that in the next forty years, the cost of AD to all payers, including governments, insurance companies and individuals, will total $20 trillion. The care requirements of people who struggle with the disease expand with time and endure for years. In the early stages, these responsibilities may tax family members economically and emotionally, as caregivers may forgo full-time paid employment and expend time and money. AA estimates that 15 million Americans provide unpaid care for those with Alzheimer's disease or dementia valued at $210 billion[2]. In addition, in 2012 alone, AD patients and families spent an estimated $33 billion in out-of-pocket costs. Furthermore, in the last year, AD has cost $104.5 billion to Medicare services and $33.5 billion to Medicaid. And these expenses are expected to rise 500% over the next four decades.

The United States Senate Special Committee on Aging (The committee) has focused on AD and dementia as critical health problems. The committee has held a series of hearings on the disease and has heard testimony from those who suffer from the disease, their caregivers, researchers and governments on how to combat AD, dementia and their expanding impact. Prominent voices, such as former Supreme Court Justice Sandra Day O'Connor and former Speaker of the House Newt Gingrich, have testified to the importance of continued research, vigilance and appropriate care. (A list of hearings can be found in Appendix 1).

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[1]Business Wire, *Americans Rank Alzheimer's as Most Feared Disease, According to New Marist Poll for Home Instead Senior Care*November 13, 2012

[2]Alzheimer's Association, *2012 Alzheimer's Disease Facts and Figures,* March, 2012. http://www.alz.org/documents_custom/2012_facts_figures_fact_sheet.pdf

But the U.S. is not alone in facing the challenge of AD. Countries around the world have been conducting their own campaigns against this devastating disease, and this committee thought it would be instructing to examine how other countries are addressing AD. The committee's goals are to highlight efforts around the world and further the policy debate in this country about directions for AD policy.

The committee examined four countries—Japan, Australia, France and the United Kingdom—and their approaches to the growing wave of AD. These countries were chosen because they have similar economies and structures to the U.S., and also highlight different facets of the AD challenge for policy makers. Japan was a clear choice since its population has a large contingent of older adults and has had to adapt to a population that is no longer growing. Australia was included because the country, while having a much smaller population than the U.S., is in many ways demographically similar to the U.S. France has been a leader in AD policy, with the most extensive comprehensive national plan to confront and treat the disease. Lastly, the UK provides an example of how a centrally managed health care system manages the disease. The committee also thought it was important to review developing countries. Even though these nations face challenges different from our own, the committee wanted to examine how they are reacting to the 21st century's "Age Wave" and their plans to provide care for a frail population without having first developed extensive health and social services systems and the economies to support them.

As the report discusses in detail, AD is a growing public health issue everywhere as populations around the world age. Encouragingly, there are global efforts to coordinate research and work committed to early detection and interventions. The report also lays out how countries are increasingly focused both on keeping AD patients in their homes, while also developing more specialized environments for those who need intensive services.

A growing trend seems to be emerging toward specialization in dementia – both in the health and social services sectors. Perhaps there is a realization that the needs of this population are different than other seniors with chronic diseases, and that the services and institutions may need to be altered to keep the best interest of AD patients and their families in mind.

Chapter 1: Population, Life Expectancy, and Dementia Data: Selected Countries

This chapter provides information on and defines dementia and Alzheimer's Disease (AD), describing the population, life expectancy, and number of people with dementia in the selected focus countries. This provides context and data, and illustrates the magnitude of the problem.

For the purposes of research and scope, this chapter begins with definitions of dementia and AD. AD is discussed separately because it is the most common form of dementia, accounting for an estimated 60-70% of dementia cases.[3] In addition to AD, there are a variety of dementias, including some that are related to other diseases, such as Parkinson's disease, vascular disease, or HIV/AIDS.[4] The definitions of dementia and AD are followed by a discussion of the prevalence of, and the costs associated with, each condition. An additional overview will include risk factors, protective factors, and prevention efforts associated with both dementia and AD.

The chapter then discusses the data used in the country comparisons. Next, it describes the Organization for Economic Cooperation and Development (OECD)—an organization of 34 developed countries with market economies and pluralistic democracies;[5] each of the focus countries is an OECD member and will be compared with the OECD average. The OECD collects data on population, life expectancy, and dementia (among other things) from its member nations and calculates the OECD average for these data. Comparisons among OECD countries and of single countries to the OECD average are often used in international comparisons.

The chapter then profiles each of the five countries separately (in alphabetical order) comparing the countries to the OECD average. The countries are then compared to each other. The OECD and subsequent country profiles include information that focuses on three areas: (1) population, (2) health, and (3) the number of people with dementia. Specifically, general population information, population aging information, life expectancy at birth and age 65, which are commonly used health indicators, and estimates of the number of dementia and AD cases in the most recent year available and projected in 2050. Finally, at the end of this report there is discussion of how the focus countries were selected.

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[3] World Health Organization, *Dementia: A Public Health Priority, 2012,* p. 7.

[4] World Health Organization, *International Statistical Classification of Diseases and Related Health Problems, 10th Revision, (ICD-10),* United Nations, 1994, http://apps.who.int/classifications/icd10/browse/2010/en.

[5] CRS Report RS21128, *The Organization for Economic Cooperation and Development*, by James K. Jackson.

Overview of Dementia[6]

Most global medical and research scientists conceptualize dementia as deterioration in memory evident in the lack of ability to learn new information. For instance, the individual has difficulty in recording, storing, and recalling aspects of daily living, such as the location of belongings, details of social and family life, or recently communicated information. In more severe cases of dementia previously learned information erodes. Dementia is categorized by the stages of memory loss, mild, moderate, and severe; however, the boundaries of these stages are imprecise and individuals move through these stages at different rates.

1. Mild-memory loss interferes with some everyday activities, but does not interfere with independent living; this stage is often termed mild cognitive impairment (MCI);
2. Moderate memory loss presents a serious handicap to independent living; only highly learned or familiar information is retained; and
3. Severe memory loss is characterized by the complete inability to retain new information; only fragments of previously learned memory remain; and the person may fail to even remember close family members.

Vascular Dementia

Vascular dementia (VD) is the second most common type of dementia in older adults. Multi-infarct dementia is the most common form and is caused by mini-strokes, most often transient events, which are temporary or partial blockages in blood supply to the brain. Over time, increasing brain damage leads to the symptoms of dementia. It is possible to have both VD and AD simultaneously. About 50% of VD occurs due to hypertension, a treatable condition.

Source: National Institute on Aging, *Vascular Dementia: A Resource List*, National Institutes of Health, http://www.nia.nih.gov/alzheimers/vascular-dementia-resource-list.

Alzheimer's Disease

The most prevalent form of dementia is Alzheimer's Disease (AD), a neurodegenerative disease that leads to the deterioration of memory, intellectual abilities, and personality. AD is incurable, progressive, and is a cause of death. AD has a particularly severe course; for instance, AD can lead to changes in mood and behavior as well as difficulty in speaking, swallowing, and walking. AD is distinguished from other forms of dementia by the presence of unique biological changes in the brain, including a build-up of amyloid protein resulting in the formation of amyloid plaques; neurofibrillary tangles; neuronal (brain cell) death; brain atrophy; and lesions.

Recent genetic research indicates that there are two forms of AD with different genetic causes. Early-onset AD is caused by specific genetic mutations and is highly heritable, but accounts for only 5% of all AD cases. Individuals who inherit these genes are diagnosed with AD in their 30's and 40's, unlike most patients with late-onset AD who are diagnosed in their 60's and beyond. Late-onset AD is most likely a more complex illness caused by a variety of factors, including genetics, environmental influences, and other health and lifestyle factors. Distinguishing late-onset AD from other dementias is complex, and there may be situations where individuals have overlapping physiological changes from a variety of dementias, so that even post-mortem diagnosis of AD can be complex.

Sources: D. L. Hoyert and H. H. Rosenberg, "Alzheimer's Disease as a Cause of Death in the United States," *Public Health Report*, vol. 112, no. 6 (Nov/Dec 1997), pp. 497-505; and D. M. Holtzman, J. C. Morris, and A. M. Goate, "Alzheimer's Disease: The Challenge of the Second Century," *Science Translational Medicine*, vol. 3, no. 77 (April 6, 2011), pp. 1-17. Hereafter referred to as D. M. Holtzman et al., 2011.

[6] The diagnostic material in this section is drawn from the criteria in ICD-10: World Health Organization, *International Statistical Classification of Diseases and Related Health Problems, 10th Revision*, *(ICD-10),* United Nations, 1994, http://apps.who.int/classifications/icd10/browse/2010/en.

There are a variety of dementias, such as AD, vascular dementia, Lewy bodies, Pick's disease, Huntington's disease, and HIV/AIDS-related.[7] AD is the most prevalent form of dementia and is responsible for at least 60% of cases.[8] The remaining dementia cases are generally attributed to co-occurring diseases such as Parkinson's disease, vascular disease, or HIV/AIDS, and vascular dementia (VD) is the second most common form of dementia.[9]

The World Health Organization (WHO) defines dementia as:

> a syndrome due to disease of the brain—usually of a chronic or progressive nature—in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour [behavior], or motivation. This syndrome occurs in a large number of conditions primarily or secondarily affecting the brain. [10]

Dementia Prevalence

The WHO estimates that dementia affected 35.6 million people globally in 2011 with the rate expected to grow as the population ages.[11] The majority of dementia cases occur in individuals aged 65 and over, but the WHO estimates that between 2-10% of all cases occur in individuals below the age of 65 and that the prevalence of dementia increases almost exponentially with age.[12] For example, some have estimated that between 25-30% of people aged 85 and over have dementia.[13]

It is difficult to obtain precise estimates of dementia for a number of reasons related to methodological differences in studies used to obtain estimates. For example, research studies use different methodologies to estimate dementia rates and use different samples.[14] As national, regional, and global estimates are based on the rates derived from these samples, any biases present in the original sample will, in turn, bias prevalence estimates at the national, regional, or worldwide levels. Another methodological issue that may occur is that the larger population changes over time, but accurate counts of the larger population may not be regularly available (e.g., the decennial census); therefore, the larger population may differ from the sample population. For example, in the United States, the decennial census is used to estimate the U.S. population. If the rates of dementia are estimated from a study with a sample drawn in 2008 are combined with Census 2000 data to estimate the U.S. prevalence, then the estimate may be biased because the U.S. population may have changed between 2000 and 2008.[15]

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[7] Ibid.

[8] Alzheimer's Association, "2012 Alzheimer's Disease Facts and Figures," *Alzheimer's and Dementia*, vol. 8, no. 2 (2012).

[9] World Health Organization, *International Statistical Classification of Diseases and Related Health Problems, 10th Revision*, *(ICD-10),* United Nations, 1994, http://apps.who.int/classifications/icd10/browse/2010/en.

[10] World Health Organization, *Dementia: A Public Health Priority, 2012*, p. 7.

[11] Unless otherwise specified, this section is drawn from the World Health Organization, *Dementia: A Public Health Priority, 2012*, Chapter 1, Introduction.

[12] Blossom Stephan and Carol Brayne, "Prevalence and Projections in Dementia," in *Excellence in Dementia Care: Research into Practice*, ed. Murna Downs and Barbara Bowers (New York: McGraw-Hill, 2008), pp. 9-34 and Chengxuan Qui, Miia Kivipelto, and Eva von Strass, "Epidemiology of Alzheimer's Disease: Occurrence, Determinants, and Strategies Toward Intervention," *Dialogues in Clinical Neuroscience*, vol. 11, no. 2 (2009), pp. 111-128.

[13] U.S. Department of Health and Human Services National Institutes of Health, National Institute on Aging and World Health Organization, *Global Health and Aging*, NIH Publication no. 11-7737, October 2011.

[14] Blossom Stephan and Carol Brayne, "Prevalence and Projections in Dementia," in *Excellence in Dementia Care: Research into Practice*, ed. Murna Downs and Barbara Bowers (New York: McGraw-Hill, 2008), pp. 9-34.

[15] Some studies will adjust Census data to account for population changes; see, for example, Liesi E. Herbert et al., "Alzheimer Disease in the US Population," *Archives of Neurology*, vol. 60 (2003), pp. 1119-1122.

It is also difficult to estimate dementia prevalence because of challenges associated with assessing dementia in research studies.[16] Accurately assessing the presence of dementia in study participants is challenging because dementia impairs cognitive functioning, which makes self-reported data unreliable. There may also be problems with obtaining an accurate assessment from family members because of the stigma associated with having dementia in general, in some countries, and in some racial and ethnic groups.[17] Dementia diagnosis is also imprecise because clinical symptoms present differently in some individuals, which makes it difficult to make a definitive dementia diagnosis.[18]

Projecting future dementia cases is also challenging. Although there is consensus that the prevalence of dementia will increase because of population aging and increases in life expectancy,[19] the pace of this increase is debated. For example, the advocacy organization, Alzheimer's Disease International, projects that the number of dementia cases will double every twenty years;[20] whereas the WHO projects the number of dementia cases to triple by 2050.[21] Projections also incorporate assumptions about future efforts to prevent and treat dementia, which would affect projections.

Dementia Costs

Dementia is a major cause of late life disability and the leading cause of the need for care (including long-term care) in later life. Although estimates of the cost of care for dementia vary depending on the assumptions used to derive these estimates, the WHO estimates that the global cost of dementia was $604 billion in 2010 (U.S. dollars). The agency further notes that the majority of these costs are due to the custodial care these patients require and not medical treatment. The WHO also notes that in low and middle income countries much of this care is being provided informally by family; given this, global costs may be underestimated if informal care is not included in the estimation methodology. Others have noted that some of the costs of dementia are borne by their caregivers including economic costs such as foregone or curtailed employment, and health costs such as stress and worsening health—these are referred to as indirect costs.[22]

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[16] Blossom Stephan and Carol Brayne, "Prevalence and Projections in Dementia," in *Excellence in Dementia Care: Research into Practice*, ed. Murna Downs and Barbara Bowers (New York: McGraw-Hill, 2008), pp. 9-34.

[17] Alzheimer's Disease International, *National Alzheimer and Dementia Plans Planned Policies and Activities: Early Detection, Access to Diagnosis and Stigma Reduction*, April 2012, p. 12, http://www.alz.co.uk/sites/default/files/national-alzheimer-and-dementia-plans.pdf and L. Phillipson et al., *Exploring Dementia and Stigma Beliefs: A Pilot Study of Australian Adults Aged 40-65*, Alzheimer's Australia, Paper 28, June 2012, http://www.alz.org/living_with_alzheimers_stigma.asp.

[18] Blossom Stephan and Carol Brayne, "Prevalence and Projections in Dementia," in *Excellence in Dementia Care: Research into Practice*, ed. Murna Downs and Barbara Bowers (New York: McGraw-Hill, 2008), pp. 9-34.

[19] For example, see World Health Organization, Dementia: A Public Health Priority, Geneva, Switzerland, 2012, http://whqlibdoc.who.int/publications/2012/9789241564458_eng.pdf and Chengxuan Qui, Miia Kivipelto, and Eva von Strass, "Epidemiology of Alzheimer's Disease: Occurrence, Determinants, and Strategies Toward Intervention," *Dialogues in Clinical Neuroscience*, vol. 11, no. 2 (2009), pp. 111-128.

[20] Martin Prince and Jim Jackson, World Alzheimer's Report: 2009, Alzheimer's Disease International, London, http://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf.

[21] World Health Organization, Dementia: A Public Health Priority, Geneva, Switzerland, 2012, http://whqlibdoc.who.int/publications/2012/9789241564458_eng.pdf; a Swedish group of researchers affiliated with the Aging Research Center and the Stockholm Gerontology Research Center also project that dementia rates will triple by 2050; see Chengxuan Qui, Miia Kivipelto, and Eva von Strass, "Epidemiology of Alzheimer's Disease: Occurrence, Determinants, and Strategies Toward Intervention," *Dialogues in Clinical Neuroscience*, vol. 11, no. 2 (2009), pp. 111-128.

[22] See, for example, Alzheimer's Association, *2012 Alzheimer's Disease Facts and Figures*, Alzheimer's & Dementia, Volume 8, Issue 2, Chicago, IL, 2012; Margaret Nowak et al., The Burden of Alzheimer's Disease, Washington, DC, August 2008 and National Academy on an Aging Society, *Alzheimer's Disease and Dementia: A Growing Challenge*, Challenges for the 21st Century: Chronic and Disability Conditions, Washington, DC, November 11, 2000.

Alzheimer's Disease Prevalence and Costs

In 2008 (the year for which the most recent data are available), 18 million[23] people were estimated to have AD worldwide.[24] As discussed above, AD cannot be conclusively diagnosed without an autopsy; therefore estimates of AD prevalence are imprecise. There is also substantial overlap between the symptoms of AD and other types of dementia, which makes determinations of the type of dementia that an individual has difficult.[25] These difficulties complicate efforts to reliably estimate the prevalence of AD and to determine the percentage of dementia attributable to AD.[26]

AD, like general dementia, may drive health care costs both for the patients and their caregivers.[27] There are few AD specific estimates of the costs, but given that the majority of dementia cases are AD (between 60-70% of all dementia cases are estimated to be AD),[28] the costs associated with AD are included in global dementia estimates.

Risk Factors for Dementia and AD

Older age is the most significant risk factor for dementia and AD, but neither is a normal symptom of aging.[29] As discussed above, the prevalence of dementia and AD increase with age. For each five year time period over age 65, the number of individuals diagnosed with the disease increases about 5%.[30] Some research suggests that over 30% of individuals 90 and older have the AD, while other research suggests that 45% of individuals aged 85 and older have AD.[31]

Certain health behaviors and health conditions also appear to increase the risk of dementia and AD. Specifically, research has found that heavy alcohol use,[32] head injury and traumatic brain injury[33] are all associated with increased dementia and AD risk. Heart disease and stroke, and conditions that increase the risk of vascular disease such as diabetes, are also risk factors for dementia and AD.[34] Female gender appears to be associated with an increased risk of dementia and AD, but this may be exacerbated by women's higher life expectancy.[35]

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[23] This AD estimate is not consistent with the WHO estimate of the percentage of dementia cases that are AD. This is likely to occur because different methodologies are used to obtain the dementia and AD estimates, and the challenges associated with collecting this type of data (e.g., self-reporting, imprecise clinical symptoms, stigma, and statistical error).

[24] Margaret Nowak et al., *The Burden of Alzheimer's Disease*, Avalere Health, Washington, DC, August 2008.

[25] Blossom Stephan and Carol Brayne, "Prevalence and Projections in Dementia," in *Excellence in Dementia Care: Research into Practice*, ed. Murna Downs and Barbara Bowers (New York: McGraw-Hill, 2008), pp. 9-34.

[26] World Health Organization, *Dementia: A Public Health Priority, 2012,* p. 7.

[27] Alzheimer's Association, *2012 Alzheimer's Disease Facts and Figures*, pp 6-8. Alzheimer's Association, Washington, DC.

[28] World Health Organization, *Dementia: A Public Health Priority, 2012,* p. 7.

[29] Centers for Disease Control and Prevention, *Alzheimer's Disease*, Atlanta, February 23, 2011, http://www.cdc.gov/aging/aginginfo/alzheimers.htm.

[30] Ibid.

[31] Chengxuan Qui, Miia Kivipelto, and Eva von Strass, "Epidemiology of Alzheimer's Disease: Occurrence, Determinants, and Strategies Toward Intervention," *Dialogues in Clinical Neuroscience*, vol. 11, no. 2 (2009), pp. 111-128 and Alzheimer's Association Reports, "2012 Alzheimer's Disease Facts and Figures," *Alzheimer's and Dementia*, vol. 8 (2012), p.14. 136.

[32] Ibid.

[33] Alzheimer's Association Reports, "2012 Alzheimer's Disease Facts and Figures," *Alzheimer's and Dementia*, vol. 8 (2012), p. 136.

[34] Ibid.

[35] Centers for Disease Control and Prevention, *Alzheimer's Disease*, Atlanta, February 23, 2011, http://www.cdc.gov/aging/aginginfo/alzheimers.htm.

Protective Factors for Dementia and AD

It is possible that being cognitively active and obtaining higher levels of education may protect against developing dementia and AD.[36] Research has found that individuals who are highly cognitively active[37] are at a lower risk of developing mild cognitive impairment (MCI)—an early symptom of dementia and AD[38]—because they have increased cognitive reserve.[39] Research has also found that higher educational attainment and socioeconomic status may reduce the risk of developing MCI and AD.[40] There may also be genetic mutations that are protective against AD, as recent research in Iceland found.[41]

Prevention of Dementia and AD

It may not be possible to prevent all types of dementia, but those related to underlying diseases such as vascular disease or HIV/AIDS may be the most amenable to preventive efforts. Specifically, efforts that aim to reduce the incidence of vascular disease (such as those that attempt to prevent strokes by controlling blood pressure) or efforts that aim to reduce HIV infection rates may also reduce dementia. Reducing AD may be more difficult because the causes and mechanics of AD are currently unknown, which makes it difficult to develop effective preventive efforts.[42]

Data

The OECD and subsequent country profiles include information in three areas: (1) population; (2) life expectancy; and (3) number of people with dementia. The country profiles include the following information obtained from the following sources:

Population

- *Total population (in millions)*: the number of people alive in a specific country at a specific point in time.[43]
- *Percentage of population aged 65 years and over*: the percent of the population alive in a specific country at a specific point in time who are aged 65 years and over. This is a commonly used measure of the size of the older population. It is also important in

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[36] C. Sattler et al., "Cognitive Activity, Education, and Socioeconomic Statistics as Preventive Factors for Mild Cognitive Impairment and Alzheimer's Disease," *Psychiatry Research*, vol. 196, no. 1 (March 30, 2012).

[37] Such as individuals who regularly read or do crossword puzzles.

[38] Mild cognitive impairment (MCI) is isolated memory impairment that is related to the onset of incipient dementia or Alzheimer's Disease. MCI is the onset of cognitive impairment beyond what would have been expected based on age and education, but which is not significant enough to interfere with activities of daily living. See C. Sattler et al., "Cognitive Activity, Education, and Socioeconomic Status as Preventive Factors for Mild Cognitive Impairment and Alzheimer's Disease," *Psychiatry Research*, vol. 196, no. 1 (March 30, 2012).

[39] Cognitive reserve is the brain's resilience to damage so that the brain continues to function despite neuronal loss due to trauma or disease. It may function in two ways: (1) it may be "built up" by engaging in more intellectually complex tasks earlier in life; or (2) individuals with more cognitive reserve may be better able to redirect functions that had been undertaken by the damaged part of the brain to an undamaged part of the brain. Y. Stern, "Cognitive reserve and Alzheimer Disease," *Alzheimer Disease and Associated Disorders*, vol. 20 (2006), pp. 112-116.

[40] Ibid.

[41] T. Jonsson et al., "A Mutation in APP Protects Against Alzheimer's Disease and Age-Related Cognitive Decline," *Nature*, vol. 488, no. 7409 (August 2, 2012), pp. 96-99.

[42] C. Qui, M. Kivipelto, and E. von Strass, "Epidemiology of Alzheimer's Disease: Occurrence, Determinants, and Strategies Toward Intervention," *Dialogues in Clinical Neuroscience*, vol. 11, no. 2 (2009), pp. 111-128.

[43] Samuel H. Preston, Patrick Heuveline, and Michel Guillot, *Demography: Measuring and Modeling Population Processes* (Malden, MA: Blackwell Publishers Ltd., 2001).

analyses of dementia because the majority of dementia cases occur in people aged 65 years and over; therefore, countries with larger percentages of the population who are aged 65 and over have a greater percentage of the population at risk of developing dementia.[44]

Population data are drawn from the OECD.[45] Total population data, unless otherwise indicated, is for 2010. Data on the percentage of the population aged 65 years and over is from 2008.

Life Expectancy

- *Life expectancy at birth* (in years): the average number of years a group of infants in a given country could expect to live if they were to experience the current observed age-specific death rates throughout their lives.[46] It is a common measure of the health of a population as a country's life expectancy generally increases with advances in medical care and standard of living.
- *Life expectancy at age 65* (in years) (women/men): the number of additional years a woman/man who survives to age 65 can expect to live in a given country if she or he were to experience the current age-specific death rates throughout the remainder of her or his life. Data are presented separately for women and men because life expectancy for women is higher. Life expectancy at age 65 (i.e., the life expectancy of the older population) is a common measure of the health of the older population. In the case of dementia, countries with higher life expectancies may have more dementia cases because the likelihood of developing dementia increases with age (as noted above, the prevalence of dementia increases almost exponentially with age.)[47] Gender differences in life expectancy may also be important because some studies have found that women have higher rates of dementia in general and Alzheimer's Disease specifically.[48]

  Life expectancy data are from the OECD and were calculated in 2010.

Dementia[49]

- *Percentage of the population aged 60 and over with dementia*: the percentage of the population aged 60 and over who have been diagnosed with dementia. These data were most recently collected by the OECD in 2009; although data on percentages of the population aged 65 years and older would be preferable because of the relationship between dementia and age, these data are the best available comparable data.

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[44] Federal Interagency Forum on Aging Related Statistics, *Older Americans 2012: Key Indicators of Well-Being*, Washington, DC, 2012, http://www.agingstats.gov/agingstatsdotnet/Main_Site/Data/2012_Documents/Docs/EntireChartbook.pdf.

[45] *OECD Factbook 2011-2012: Economic, Environmental, and Social Statistics*, Paris, France, December 7, 2011. For general information on the OECD, see CRS Report RS21128, *The Organization for Economic Cooperation and Development*, by James K. Jackson.

[46] Samuel H. Preston, Patrick Heuveline, and Michel Guillot, *Demography: Measuring and Modeling Population Processes* (Malden, MA: Blackwell Publishers Ltd., 2001).

[47] Blossom Stephan and Carol Brayne, "Prevalence and Projections in Dementia," in *Excellence in Dementia Care: Research into Practice*, ed. Murna Downs and Barbara Bowers (New York: McGraw-Hill, 2008), pp. 9-34.

[48] Whether such gender differences exist is debated; see discussion in B.L. Plassman, et al., "Prevalence of Dementia in the United States: The Aging, Demographics, and Memory Study," *Neuro-epidemiology*, vol. 29 (October 29, 2007), pp. 125-132.

[49] Data on Alzheimer's Disease (AD) cases are not consistently available; therefore, these data are not included in the tables below. Some data on U.S. current and projected AD cases are available and are discussed in the U.S. section.

- *Number of people with dementia:* the number of people diagnosed with dementia in a given country. Data sources and years vary by country because comparable international data are not available. The most recent estimates are used.
- *Projected number of people with dementia in 2050*: the number of people projected to have dementia in 2050 in a given country. Data sources and years vary by country because comparable international data are not available. The most recent estimates are used.

  Specifically, data are drawn from published research including efforts undertaken by the WHO and AD-related associations such as the Alzheimer's Association and Alzheimer's International. Data are not available for all countries and data available differ by year in some cases. These data may also be imprecise or difficult to compare because of methodological differences used in estimates of dementia prevalence or because sample populations cannot be compared.[50] Similar concerns apply to projections because most projections are based on estimates of current year prevalence. Projections also include assumptions about the rate that the prevalence of a disease will increase over time, but there is little consensus about the rate of increase.[51]

Population Pyramids

The country profiles include population pyramids, which are graphical displays of the age structure of each country's population at four points in time: 1950, 2010, and projected to 2050 and 2100. The population pyramids are bar charts that show the distribution of a country's population by age and sex. Younger ages are at the bottom, older ages are at the top, males are on the left, and females are on the right. [52] These population pyramids were obtained from the United Nations (U.N.);[53] therefore, an OECD composite pyramid is not available.[54]

The size and age composition of a country is determined by: (1) the country's fertility in the past as well as rates projected for the future; (2) its mortality and longevity; and (3) immigration. Specifically, past fertility rates determine the number of people in a certain age group; this number may be supplemented by immigration or reduced by emigration. Mortality (how many people die) and longevity (how long people live) are also important determinants of the size and age structure of a given population. Whether there are gender differences in these three factors can also affect a country's population pyramid. Fertility rates in particular are important because whether a population is replacing itself (i.e., there are as many births as deaths) will determine both the overall size of a population and its age structure. Fewer births would mean that a population would decline (in the absence of immigration). This would also cause population aging as the percentage of people at older ages would increase because they would not be counterbalanced by growing numbers at the younger ages. In contrast, more births, such as what occurred

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[50] Blossom Stephan and Carol Brayne, "Prevalence and Projections in Dementia," in *Excellence in Dementia Care: Research into Practice*, ed. Murna Downs and Barbara Bowers (New York: McGraw-Hill, 2008), pp. 9-34. See also discussion in "Dementia Prevalence."

[51] For example, Alzheimer's Disease International projects that the number of dementia cases will double every twenty years (Martin Prince and Jim Jackson, World Alzheimer's Report: 2009, Alzheimer's Disease International, London, http://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf); whereas, the WHO projects the number of dementia cases to triple by 2050 (World Health Organization, Dementia: A Public Health Priority, Geneva, Switzerland, 2012, http://whqlibdoc.who.int/publications/2012/9789241564458_eng.pdf).

[52] CRS Report RL32701, *The Changing Demographic Profile of the United States*, by Laura B. Shrestha and Elayne J. Heisler.

[53] United Nations, Department of Economic and Social Affairs, Population Division, *World Population Prospect: The 2010 Revision*, New York, NY, May 4, 2011. The U.N. uses "medium-variant" or what the agency considers to be the most likely scenario when projecting the population of each country in future years.

[54] The OECD was created in 1960 and its members countries have changed (and may continue) to change, so a population pyramid for the member countries would involve a changing set of countries and assumptions about future membership.

during the baby boom, would mean a relatively younger population for as long as the increased birth rates continued.[55]

The population pyramids of the five focus countries show graphically how each country's population is aging and also show the country's population growth as indicated by wider population pyramids. The chapter presents and discusses the population pyramids for each of the five countries and discusses within country change over time (both in the past and predicted for the future). Then, within the section discussing country comparisons on population data, the population pyramid comparisons are discussed as relevant.

Organization for Economic Cooperation and Development

The Organization for Economic Cooperation and Development (OECD) is an organization of 34 developed countries (see **Figure 1**) with market economies and pluralistic democracies.[56] The OECD is the successor of the Organization for European Economic Cooperation, which began to administer aid for the reconstruction of Europe after World War II. Consequently, the majority of the OECD members are European countries;[57] however, the organization includes countries from the Americas, Asia, Europe, and Oceania (see **Figure 1**). The OECD, among other things, collects population and health data on its member countries. These data are used throughout the chapter.

This section describes the OECD and then presents data on the three dimensions for the OECD. The data include the OECD average that is used in the country comparisons and the range for OECD countries because the country comparisons include limited discussion of where the five focus countries are ranked relative to other OECD members.

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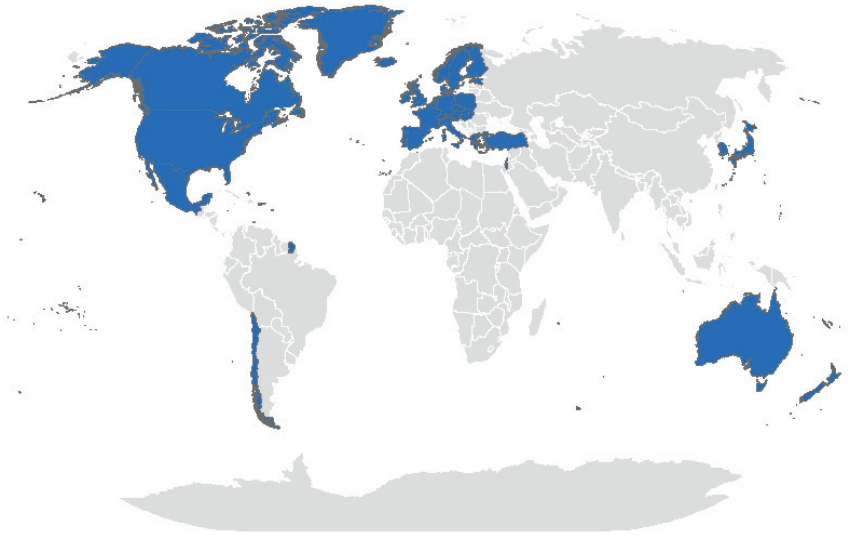
[55] The interplay of these population determinants for the United States are discussed in CRS Report RL32701, *The Changing Demographic Profile of the United States*, by Laura B. Shrestha and Elayne J. Heisler.

[56] CRS Report RS21128, *The Organization for Economic Cooperation and Development*, by James K. Jackson.

[57] The 34 OECD countries are: Australia, Austria, Belgium, Canada, Chile, the Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Japan, Korea, Luxembourg, Mexico, the Netherlands, New Zealand, Norway, Poland, Portugal, the Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Turkey, the United Kingdom, and the United States.

Figure 1. OECD Member Countries



Source: The Organization for Economic Cooperation and Development, "Members and Partners" www.oecd.org/about/membersandpartners/.

Notes: Shaded countries are OECD member nations. Territories and possessions of member nations are also shaded.

OECD Profile

Table 1 shows the OECD averages and ranges of the population and health indicators that are discussed for each of the focus countries. The OECD collects some aggregate data on health conditions such as dementia, but data collected are limited (see **Table 1**).

Table 1. OECD Profile

Indicator	Value	Range		Year of Data	Data Source
		Minimum	Maximum		
Population					
Total Population[a]	1.2 billion	309,000 (Iceland)	309.1 million (United States)	2010	OECD
Percentage of population aged 65 years and over	14.4%	5.6% (Mexico)	22.1% (Japan)	2008	OECD
Life Expectancy					
Life expectancy at birth	79.8 years	74.3 years (Hungary and Turkey)	83.0 years (Japan)	2010	OECD
Life expectancy at age 65 (women)	20.7 years	16.1 years (Turkey)	23.9 years (Japan)	2010	OECD
Life expectancy at age 65 (men)	17.4 years	13.8 years (Hungary)	19.0 years (Switzerland)	2010	OECD
Dementia					
Percentage of population with dementia (aged 60 years and over)	5.5%	3.5% (Turkey)	6.5% (France)	2009	OECD
Number of people with dementia	NA[b]	NA	NA	NA	NA
Projected number of people with dementia (2050)	NA[c]	NA	NA	NA	NA

Sources: OECD: Organization for Economic Cooperation and Development, OECD Health Data 2012 at http://stats.oecd.org/Index.aspx?DataSetCode=HEALTH_STAT; OECD Factbook 2011: Economic, Environmental and Social Statistics: Population and Migration—Population—Total Population at http://www.oecd.org/statistics/; and Health at a Glance 2011, OECD Indicators at http://www.oecd.org/els/healthpoliciesanddata/49105858.pdf.

Notes: NA=not available.

a. The total OECD population is reported here as this is likely more meaningful than the OECD average because the majority of OECD countries have small populations and the average is influence by the United States, which at 309.1 million, is an outlier that raises the OECD average.

b. The NIA and WHO estimate that globally there were 35.6 million people with dementia in 2010 and that the majority of these individuals lived in developed countries, see U.S. Department of Health and Human Services National Institutes of Health, National Institute on Aging and World Health Organization, *Global Health and Aging*, NIH Publication no. 11-7737, October 2011. Although this is not an OECD estimate, the global estimate, with its focus on developed countries, partially reflects the OECD total.

c. The World Alzheimer's Report projects that there will be 115 million people worldwide living with dementia in 2050. Martin Prince, Renata Bryce, and Cleusa Ferri, *World Alzheimer's Report 2011: The Benefits of Early Diagnosis and Intervention*, Alzheimer's Disease International, London, UK, September 2011. The Alzheimer's Association projects that there will be 108.6 million people worldwide with Alzheimer's in 2050. Ron Brookmeyer et al., "Forecasting the Global Burden of Alzheimer's Disease," *Alzheimer's & Dementia*, vol. 3 (2007), pp. 186-191.

Country Profiles

This section profiles each of the five focus countries in alphabetical order. These profiles include a discussion of the five country-specific tables that provide data on population, life expectancy, and the number of dementia cases. The discussion compares each of the five countries to the OECD average. The discussion does not assess whether differences between the focus countries and the OECD average are statistically significant. Following the country specific data tables, there are four population pyramids for each country that include data on the age and sex composition of each of the focus countries' population at four points in time: 1950, 2010, and projected to 2050 and 2100.

Australia

Australia's total population was 22.3 million in 2010. It had the 13th largest population of the OECD countries. In 2008 (the last year for which comparable data are available), 13.3% of the Australian population was aged 65 and over, which is below the OECD average of 14.4%.[58] Australia's life expectancy at birth at 81.8 was 2 years higher than the OECD average of 79.8 years. Similarly, the country's life expectancy for its population at aged 65 was 21.8 years for women and 18.9 years for men, which was 1.1 and 1.5 years higher than the OECD average for women and men respectively.

According to Alzheimer's Australia, 300,000 Australians had dementia in 2010 and they project that the number will triple (to 900,000) by 2050. According to the OECD, 5.8% of the Australian population age 60 and over had dementia in 2009; this was slightly higher than the OECD average of 5.5%.

Table 2. Australia Country Profile

Indicator	Value	Year of Data	Data Source
Population			
Total Population	22.3 million	2010	OECD
Percentage of population aged 65 years and over	13.3%	2008	OECD
Life Expectancy			
Life expectancy at birth	81.8 years	2010	OECD
Life expectancy at age 65 (women)	21.8 years	2010	OECD
Life expectancy at age 65 (men)	18.9 years	2010	OECD
Dementia[a]			
Percentage of population with dementia (aged 60 years and over)	5.8%	2009	OECD
Number of people with dementia	300,000	2010	Alzheimer's Australia
Projected number of people with dementia (2050)	900,000	2050	Alzheimer's Australia

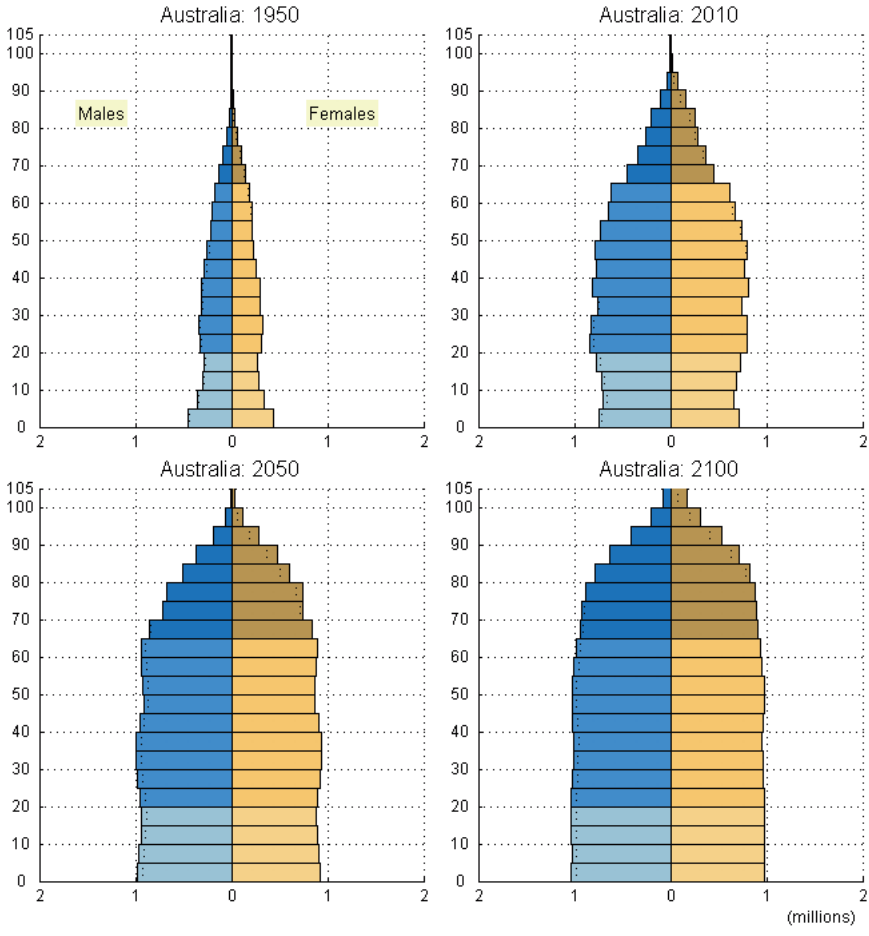
Sources: Alzheimer's Australia: Key Facts and Statistics 2010, Australia Statistics, at http://www.fightdementia.org.au/media/key-facts-and-statistics-for-media.aspx. **OECD:** Organization for Economic Cooperation and Development, OECD Health Data 2012 at http://stats.oecd.org/Index.aspx?DataSetCode=HEALTH_STAT; OECD Factbook 2011: Economic, Environmental and Social Statistics, at http://www.oecd-ilibrary.org/economics/oecd-factbook-2011-2012_factbook-2011-en; and Health at a Glance 2011, OECD Indicators at http://www.oecd.org/els/healthpoliciesanddata/49105858.pdf.

a. Estimating the number of people with dementia is imprecise; different countries use different methodologies to derive their estimates of dementia prevalence, which limits cross country comparisons.

[58] The OECD average for the population aged 65 years and over was calculated based on 2008 data because some countries did not have more recent data available. Organization of Economic Cooperation and Development, *OECD Factbook 2011-2012: Economic, Environmental, and Social Statistics*, Paris, France, December 7, 2011.

The pyramids below describe the Australian population at four points in time: 1950, 2010, projected to 2050 and 2100. The pyramids demonstrate that the Australian population is getting progressively larger (as indicated by the overall widening of the population pyramids). Australia has also aged between 1950 and 2010 as indicated by an increasing percentage of the population ages 65 and over. In 1950, Australia experienced a baby boom, which is indicated by the larger bars for the population at ages 0 through 10—this indicates larger percentages of the population at the younger ages. This baby boom population is subsequently reflected by the larger bars (percent of the populations) between the ages 55 and 65 in the 2010 pyramid. In 2010, the majority of Australia's population was working age (i.e., between 15 and 65) and the country also had a smaller child (aged 0 through 20) and smaller older (aged 65 and above) populations. By 2050, the relative size of the populations ages 0 to 70 is projected to be similar; this indicates that the population is in a steady state with no large shifts in either the child or elderly populations. This is also projected to be the case in 2100.

Figure 2. Australia Population Pyramids



Source: United Nations, Department of Economic and Social Affairs, Population Division, *World Population Prospect: The 2010 Revision*, http://esa.un.org/wpp/population-pyramids/population-pyramids.htm.

France

France's total population was 62.6 million in 2009 making it the 6th largest OECD country in terms of population size.[59] In 2008 (the last year for which comparable data are available), 16.6% of the French population was aged 65 and over, which was more than 2 percentage points higher than the OECD

[59] The OECD used 2009 data because 2010 population data were not available for all OECD countries. Organization of Economic Cooperation and Development, *OECD Factbook 2011-2012: Economic, Environmental, and Social Statistics*, Paris, France, December 7, 2011.

average of 14.4%.[60] France also had higher life expectancy than the OECD average. Its life expectancy was 81.5, which was nearly 2 years higher than the OECD average of 79.8 years. Similarly, the country's life expectancy for its population at age 65 was above the OECD averages for women and men. Specifically, the country's life expectancy for women was 1.8 years higher than the OECD average while the life expectancy for men was 1.0 year higher.

A larger percentage of the population aged 65 and over and higher life expectancy may indicate that a larger percentage of the population is at risk for dementia because dementia rates increase with age.[61] A WHO publication estimated that France, with an estimated 1.1 million people with dementia, was one of the nine countries with the highest number of dementia disease cases worldwide.[62] France also had the highest prevalence of dementia (6.5%) in the population age 60 and above among the 34 OECD countries.

Table 3. France Country Profile

Indicator	Value	Year of Data	Data Source
Population			
Total population	62.6 million	2009	OECD
Percentage of population aged 65 years and over	16.6%	2008	OECD
Life Expectancy			
Life expectancy at birth	81.5 years	2011	OECD
Life expectancy at age 65 (women)	22.6 years	2009	OECD
Life expectancy at age 65 (men)	18.4 years	2009	OECD
Dementia[a]			
Percentage of population with dementia (aged 60 years and over)	6.5%	2009	OECD
Number of people with dementia	1.1 million	2010	WHO
Projected number of people with dementia (2050)	1.8 million	2050	Mura, Dartingues, and Berr

Sources: OECD: Organization for Economic Cooperation and Development, OECD Health Data 2012 at http://stats.oecd.org/Index.aspx?DataSetCode=HEALTH_STAT; OECD Factbook 2011: Economic, Environmental and Social Statistics, at http://www.oecd-ilibrary.org/economics/oecd-factbook-2011-2012_factbook-2011-en; and Health at a Glance 2011, OECD Indicators at http://www.oecd.org/els/healthpoliciesanddata/49105858.pdf. **WHO**: World Health Organization: Dementia: A Public Health Priority, Geneva, Switzerland, 2012, http://whqlibdoc.who.int/publications/2012/9789241564458_eng.pdf. **Mura, Dartingues, and Berr**: Thibault Mura, Jean-Francois Dartigues, and Claudine Berr, "How Many Dementia Cases in France and Europe: Alternative Projections and Scenarios 2010-2050," *European Journal of Neurology,* vol. 17, no. 2 (February 2010), pp. 252-259.

a. Estimating the number of people with dementia is imprecise; different countries use different methodologies to derive their estimates of dementia prevalence, which limits cross country comparisons.

The pyramids below describe the French population at four points in time: 1950, 2010, projected to 2050 and 2100. The pyramids demonstrate that the French population is aging as indicated by the progressively larger bars (i.e., percentages of the population) at the middle and late ages. The French population experienced a post-war baby boom in 1950 as indicated by the largest population bar (i.e., percentages of

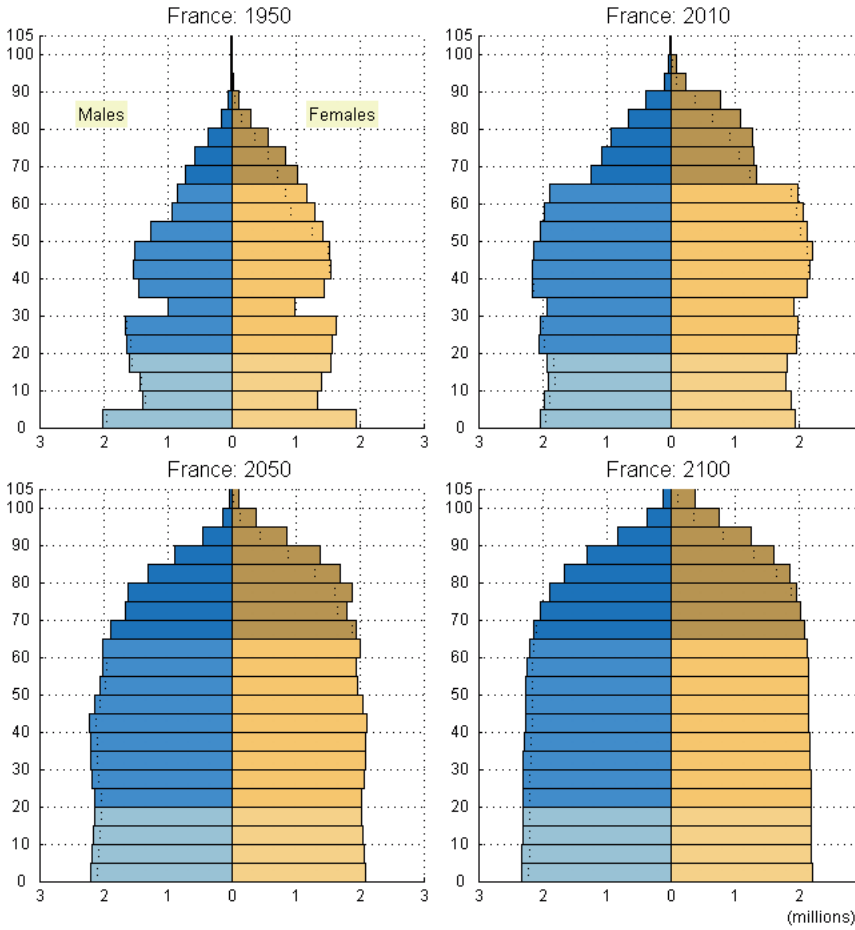
[60] The OECD average for the population aged 65 years and over was calculated based on 2008 data because some countries did not have more recent data available. Organization of Economic Cooperation and Development, *OECD Factbook 2011-2012: Economic, Environmental, and Social Statistics*, Paris, France, December 7, 2011.

[61] World Health Organization, *Dementia: A Public Health Priority, 2012,* p. 7.

[62] The other eight countries with the highest number of dementia cases and the number of cases in these countries (in parentheses) are: (1) China (5.4 million); (2) United States (3.9 million); (3) India (3.7 million); (4) Japan (2.5 million); (5) Germany (1.5 million); (6) Russia (1.2 million); (7) Italy (1.1 million); and (8) Brazil (1.0 million). See World Health Organization, *Dementia: A Public Health Priority, 2012.*

the population) at ages 0 to 10 in the 1950 pyramid. This population is subsequently ages 60 to 70 in the 2010 pyramid. The 2010 pyramid shows an overall aging population as indicated by the widest bars (i.e., percentages of the population) at the early and late middle ages. The 2050 pyramid also projects further aging of the French population with larger bars (i.e., percentages of the population) at the older ages and smaller bars at the youngest ages. According to the 2100 pyramid, the French population aging is expected to decelerate with the resulting population projected to be more evenly distributed from ages 0 to 70, with smaller percentages of the population at the oldest ages.

Figure 3. France Population Pyramids



Source: United Nations, Department of Economic and Social Affairs, Population Division, *World Population Prospect: The 2010 Revision*, http://esa.un.org/wpp/population-pyramids/population-pyramids.htm.

Japan

Japan's total population was 127.5 million in 2009. It had the second largest population of the 34 OECD countries (the United States was the largest). It was the oldest of the 34 OECD countries with more than one-fifth of its population aged 65 or older (22.1%). This percentage was 7.7 percentage points higher than the OECD average of 14.4%.[63] In addition to having a larger share of the older population, Japan also had higher life expectancy than the OECD average. Its life expectancy at birth was 83.0, which was the highest among OECD countries and is more than 3 years higher than the OECD average of 79.8 years. Similarly, the country's life expectancy for its population at age 65 is the highest among OECD countries for women and among the highest for men. Specifically, the average Japanese woman who survives to age 65 could expect to live an additional 23.9 years (i.e., to age 88.9); the OECD average was 20.7 (i.e., to age 85.7). The life expectancy for men at age 65 is 18.9 years (the highest for OECD countries was Switzerland at 19.0 years), the OECD average was 17.7 years, more than two years less than Japan's average.

Higher life expectancy and a larger percentage of the population aged 65 and over may indicate that a larger percentage of the population is at risk for dementia.[64] This seemed to be the case, as a WHO publication estimated that Japan, with 2.5 million cases, was one of the nine countries with the highest number of dementia cases worldwide.[65] Japan also had a high prevalence of dementia (6.5%) in the population aged 60 and over.

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[63] The OECD average for the population aged 65 years and over was calculated based on 2008 data because some countries did not have more recent data available. Organization of Economic Cooperation and Development, *OECD Factbook 2011-2012: Economic, Environmental, and Social Statistics*, Paris, France, December 7, 2011.

[64] World Health Organization, *Dementia: A Public Health Priority, 2012,* p. 7.

[65] The other eight countries with the highest number of dementia cases and the number of cases in these countries (in parentheses) are: (1) China (5.4 million); (2) United States (3.9 million); (3) India (3.7 million); (4) Japan (2.5 million); (5) Germany (1.5 million); (6) Russia (1.2 million); (7) Italy (1.1 million); and (8) Brazil (1.0 million). See World Health Organization, *Dementia: A Public Health Priority, 2012.*

Table 4. Japan Country Profile

Indicator	Value	Year of Data	Data Source
Population			
Total population	127.5 million	2009	OECD
Percentage of population aged 65 years and over	22.1%	2008	OECD
Life Expectancy			
Life expectancy at birth	83.0 years	2010	OECD
Life expectancy at age 65 (women)	23.9 years	2010	OECD
Life expectancy at age 65 (men)	18.9 years	2010	OECD
Dementia[a]			
Percentage of population with dementia (aged 60 years and over)	6.1%	2009	OECD
Number of people with dementia	2.5 million	2010	WHO
Projected number of people with dementia (2050)	7.5-10.0 million[a]	2010; 2009	WHO and World Alzheimer's Report

Sources: OECD: Organization for Economic Cooperation and Development, OECD Health Data 2012 at http://stats.oecd.org/Index.aspx?DataSetCode=HEALTH_STAT; OECD Factbook 2011: Economic, Environmental and Social Statistics, at http://www.oecd-ilibrary.org/economics/oecd-factbook-2011-2012_factbook-2011-en; and Health at a Glance 2011, OECD Indicators at http://www.oecd.org/els/healthpoliciesanddata/49105858.pdf. **WHO**: World Health Organization: Dementia: A Public Health Priority, Geneva, Switzerland, 2012, http://whqlibdoc.who.int/publications/2012/9789241564458_eng.pdf. **World Alzheimer's Report:** Martin Prince and Jim Jackson, *World Alzheimer's Report: 2009*, Alzheimer's Disease International, London, http://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf.

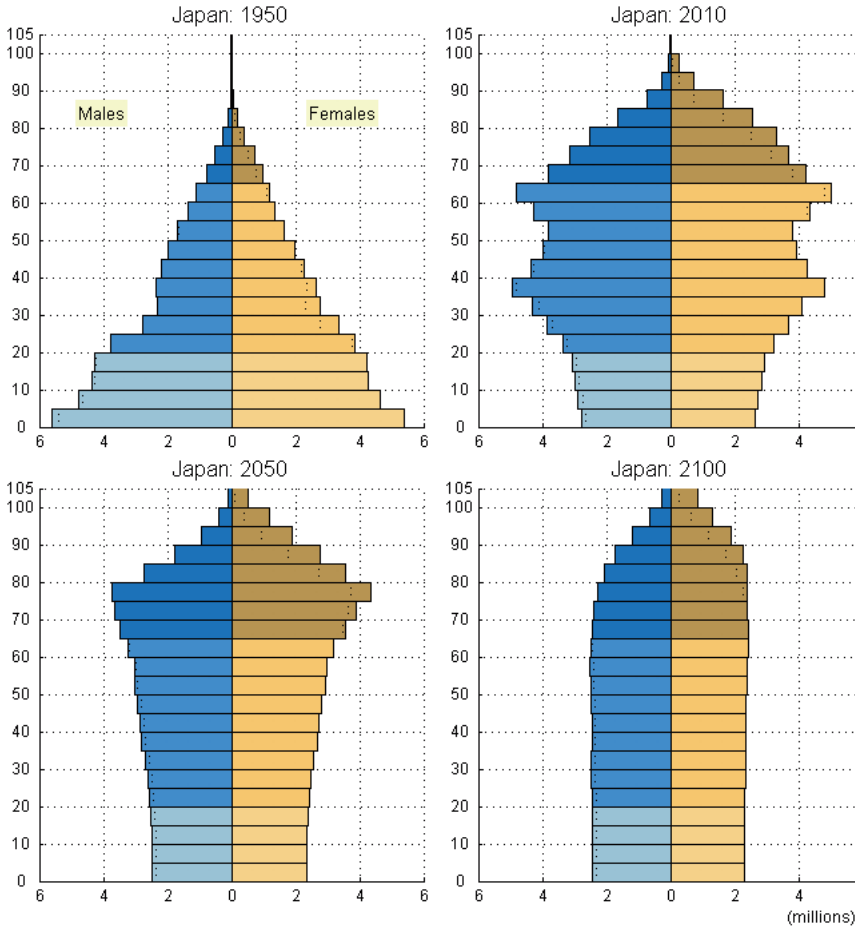
a. Estimating the number of people with dementia is imprecise; different countries use different methodologies to derive their estimates of dementia prevalence, which limits cross country comparisons.

b. The number of dementia cases is projected to double every twenty years; using this projection there would be 10 million dementia cases in 2050. See Martin Prince and Jim Jackson, World Alzheimer's Report: 2009, Alzheimer's Disease International, London, http://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf. The WHO projects the number of cases to triple by 2050; using that projection there would be 7.5 million dementia cases in Japan in 2050. See World Health Organization, Dementia: A Public Health Priority, Geneva, Switzerland, 2012, http://whqlibdoc.who.int/publications/2012/9789241564458_eng.pdf.

The pyramids below describe the Japanese population at four points in time: 1950, 2010, projected to 2050 and 2100. The pyramids demonstrate that Japan's population is rapidly aging as indicated by the progressively larger bars (i.e., percentages of the population) at the middle and late ages. In 1950, the Japanese population was a pyramid with larger populations at the youngest ages. Declining fertility[66] resulted in the 2010 population pyramid where there are fewer individuals at the youngest ages and larger percentages of the population at the late and middle ages. The 2050 pyramid shows continued population aging and that the largest age groups in the population will be ages 75 years or older. By 2100, the Japanese population is predicted to stabilize with a more even distribution throughout each of the age groups.

[66] In 2012, Japan's total fertility rate was 1.39, which is well below replacement level fertility rate of 2.1. In some developed countries replacement level fertility may be closer to 2.0 because of lower mortality rates in childhood. Central Intelligence Agency, *The World Factbook: 2012*, Washington, DC, https://www.cia.gov/library/publications/the-world-factbook.

Figure 4. Japan Population Pyramids



Source: United Nations, Department of Economic and Social Affairs, Population Division, *World Population Prospect: The 2010 Revision*, http://esa.un.org/wpp/population-pyramids/population-pyramids.htm.

United Kingdom

The total population of the United Kingdom (UK) was 61.3 million in 2010. It had the 7th largest population of the 34 OECD countries. The percentage of the population aged 65 years and over was 16.1%, which was more than 2 percentage points higher than the OECD average of 14.4%.[67] The UK also had higher life expectancy at birth and at age 65 than the OECD average. Its life expectancy was 80.6,

[67] The OECD average for the population aged 65 years and over was calculated based on 2008 data because some countries did not have more recent data available. Organization of Economic Cooperation and Development, *OECD Factbook 2011-2012: Economic, Environmental, and Social Statistics*, Paris, France, December 7, 2011.

which was higher than the OECD average of 79.8 years. Female life expectancy at age 65 was 20.9, which was slightly higher than the OECD average of 20.7; male life expectancy was 18.3, which was nearly a year higher than the OECD average of 17.4 years.

The percentage of the UK population aged 60 and over that had dementia was 6.1%, which is higher than the OECD average of 5.5%. In 2010, the number of dementia cases was 800,000.

Table 5. United Kingdom Country Profile

Indicator	Value	Year of Data	Data Source
Population			
Total Population	61.3 million	2010	OECD
Percentage of population aged 65 years and over	16.1%	2008	OECD
Health			
Life expectancy at birth	80.6 years	2010	OECD
Life expectancy at age 65 (women)	20.9 years	2010	OECD
Life expectancy at age 65 (men)	18.3 years	2010	OECD
Dementia[a]			
Percentage of population with dementia (aged 60 years and over)	6.1%	2009	OECD
Number of people with dementia	800,000	2012	Alzheimer's Society
Projected number of people with dementia (2050)	2.4 -3.2 million[a]	2010; 2009	WHO and World Alzheimer's Report

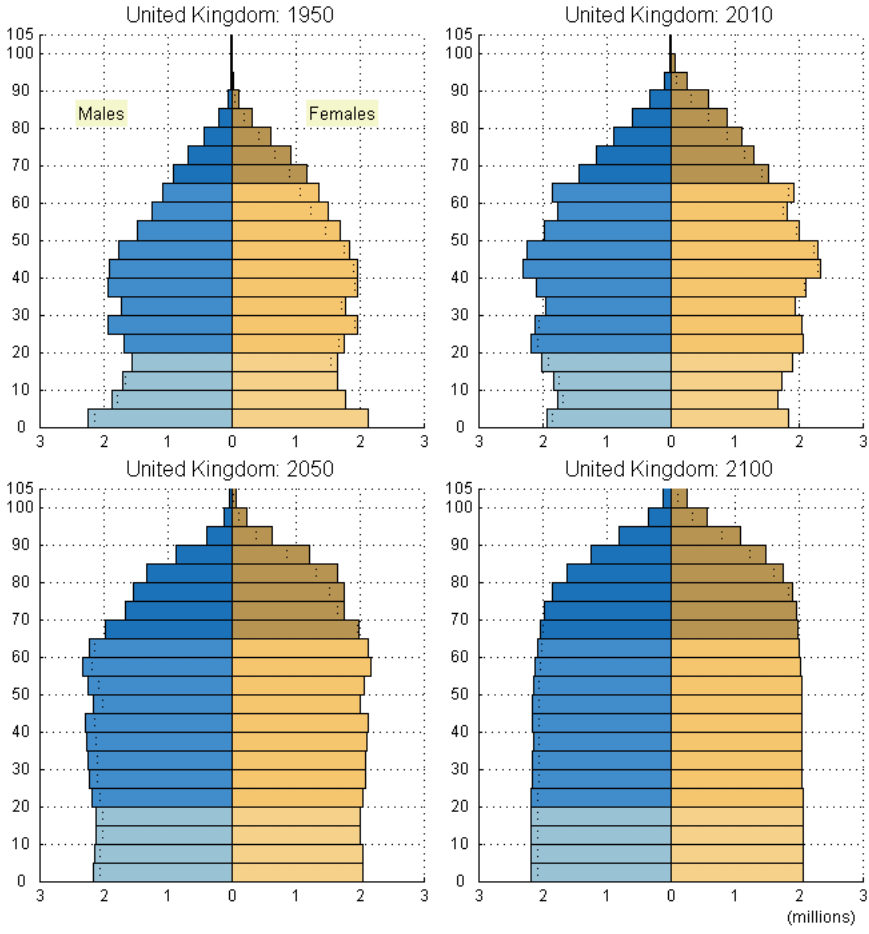
Sources: Alzheimer's Society: Alzheimer's Society, *Alzheimer's Society Dementia 2012*, London, England, March 2012, www.alzheimers.org.uk/dementia2012. **OECD:** Organization for Economic Cooperation and Development, OECD Health Data 2012 at http://stats.oecd.org/Index.aspx?DataSetCode=HEALTH_STAT; OECD Factbook 2011: Economic, Environmental and Social Statistics, at http://www.oecd-ilibrary.org/economics/oecd-factbook-2011-2012_factbook-2011-en; and Health at a Glance 2011, OECD Indicators at http://www.oecd.org/els/healthpoliciesanddata/49105858.pdf. **WHO**: World Health Organization: Dementia: A Public Health Priority, Geneva, Switzerland, 2012, http://whqlibdoc.who.int/publications/2012/9789241564458_eng.pdf. **World Alzheimer's Report:** Martin Prince and Jim Jackson, *World Alzheimer's Report: 2009*, Alzheimer's Disease International, London, http://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf.

a. Estimating the number of people with dementia is imprecise; different countries use different methodologies to derive their estimates of dementia prevalence, which limits cross country comparisons.

b. The number of dementia cases is projected to double every twenty years; using this rate there would be 3.2 million dementia cases in the UK in 2050. See Martin Prince and Jim Jackson, *World Alzheimer's Report: 2009*, Alzheimer's Disease International, London, http://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf. The WHO projects the number of cases to triple by 2050; using that projection there would be 2.4 million dementia cases in the UK in 2050. See World Health Organization and Alzheimer's Disease International, Dementia: A Public Health Priority, Geneva, Switzerland, 2012, http://whqlibdoc.who.int/publications/2012/9789241564458_eng.pdf.

The pyramids below describe the population of the United Kingdom at four points in time: 1950, 2010, projected to 2050 and 2100. The pyramids demonstrate that the United Kingdom had an aging baby boom population, which was at the earliest ages in 1950 (between the ages of 0 and 10), and subsequently between ages 60 and 70 in the 2010 pyramid. By 2050, the relative size of the bars (i.e., percentage of the population) ages 0 through age 70 is projected to be similar, with slightly smaller populations at the younger ages. This would indicate slow population growth or population declines. In 2100, the UK population is projected to look similar to the population in 2050, a steady state with no large shifts in either the child or elderly populations.

Figure 5. United Kingdom Population Pyramids



Source: United Nations, Department of Economic and Social Affairs, Population Division, *World Population Prospect: The 2010 Revision*, http://esa.un.org/wpp/population-pyramids/population-pyramids.htm.

United States

The U.S. population was 309.1 million in 2010, making it the largest OECD country.[68] In 2008 (the last year for which comparable data are available), 12.8% of the U.S. population was aged 65 years and over, which was below the OECD average of 14.4%.[69] The U.S. life expectancy at birth at 78.7 was also below

[68] The OECD used 2009 data because 2010 population data were not available for all OECD countries. Organization of Economic Cooperation and Development, *OECD Factbook 2011-2012: Economic, Environmental, and Social Statistics*, Paris, France, December 7, 2011.

[69] The OECD average for the population aged 65 years and over was calculated based on 2008 data because some countries did

the OECD average of 79.8. Similarly, its life expectancy for women at age 65 was 20.3 years, which was just below the OECD average of 20.7 years. However, its male life expectancy at the age of 65 was 17.7 years, which was a few months more than the OECD average of 17.4 years.

According to OECD, 6.2% of U.S. population aged 60 and over had dementia, which was higher than the OECD average of 5.5%. This high percentage along with the large U.S. population in general and aged 65 and over means that the United States had one of the world's highest number of dementia cases with an estimated 3.9 million people with dementia.[70]

Table 6. United States Country Profile

Name	Value	Year of Data	Data Source
Population			
Total population	309.1 million	2010	OECD
Percentage of population aged 65 years and over	12.8%	2008	OECD
Health			
Life expectancy at birth	78.7 years	2010	OECD
Life expectancy at age 65 (women)	20.3 years	2010	OECD
Life expectancy at age 65 (men)	17.7 years	2010	OECD
Dementia[a]			
Percentage of population with dementia (aged 60 years and over)	6.2%	2009	OECD
Number of people with dementia[b]	3.9 million	2010	WHO
Projected number of people with dementia (2050)	11.7-15.6 million[c]	2010; 2009	WHO and World Alzheimer's Report

Sources: OECD: Organization for Economic Cooperation and Development, OECD Health Data 2012 at http://stats.oecd.org/Index.aspx?DataSetCode=HEALTH_STAT; OECD Factbook 2011: Economic, Environmental and Social Statistics, at http://www.oecd-ilibrary.org/economics/oecd-factbook-2011-2012_factbook-2011-en; and Health at a Glance 2011, OECD Indicators at http://www.oecd.org/els/healthpoliciesanddata/49105858.pdf. **WHO**: World Health Organization: Dementia: A Public Health Priority, Geneva, Switzerland, 2012, http://whqlibdoc.who.int/publications/2012/9789241564458_eng.pdf. **World Alzheimer's Report:** Martin Prince and Jim Jackson, *World Alzheimer's Report: 2009*, Alzheimer's Disease International, London, http://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf.

a. Estimating the number of people with dementia is imprecise; different countries use different methodologies to derive their estimates of dementia prevalence, which limits cross country comparisons.

b. Some data exist for U.S. AD cases. Specifically, the Alzheimer's Association estimated that there were 5.4 million people with AD in 2012. This estimate is higher than the WHO estimate of 3.9 million dementia cases, which includes AD cases. The Alzheimer's Association derived this number based on research that found that 13% of the population aged 65 and over have AD. This is more than twice the OECD percentage of the population aged 60 and over with dementia. For discussion of how the Alzheimer's Association estimate was derived, see Alzheimer's Association, 2012 Alzheimer's Disease Facts and Figures, Alzheimer's & Dementia, Volume 8, Issue 2, Chicago, IL, 2012, p. 58. Another study projects that there will be 13.4 million AD cases in 2050. See Margaret Nowak et al., The Burden of Alzheimer's Disease, Avalere Health, Washington, DC, August 2008. These discrepancies in estimates of AD prevalence may arise because of how different studies count those who had AD, as a found by a panel of experts convened by the National Institute on Aging and the Alzheimer's Association to examine discrepancies in prevalence estimates. Specifically, the panel compared estimates from two different U.S. studies of AD prevalence and concluded that differences arose because the two studies used different AD diagnostic criteria. The panel found that when the

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not have more recent data available. Organization of Economic Cooperation and Development, *OECD Factbook 2011-2012: Economic, Environmental, and Social Statistics*, Paris, France, December 7, 2011.

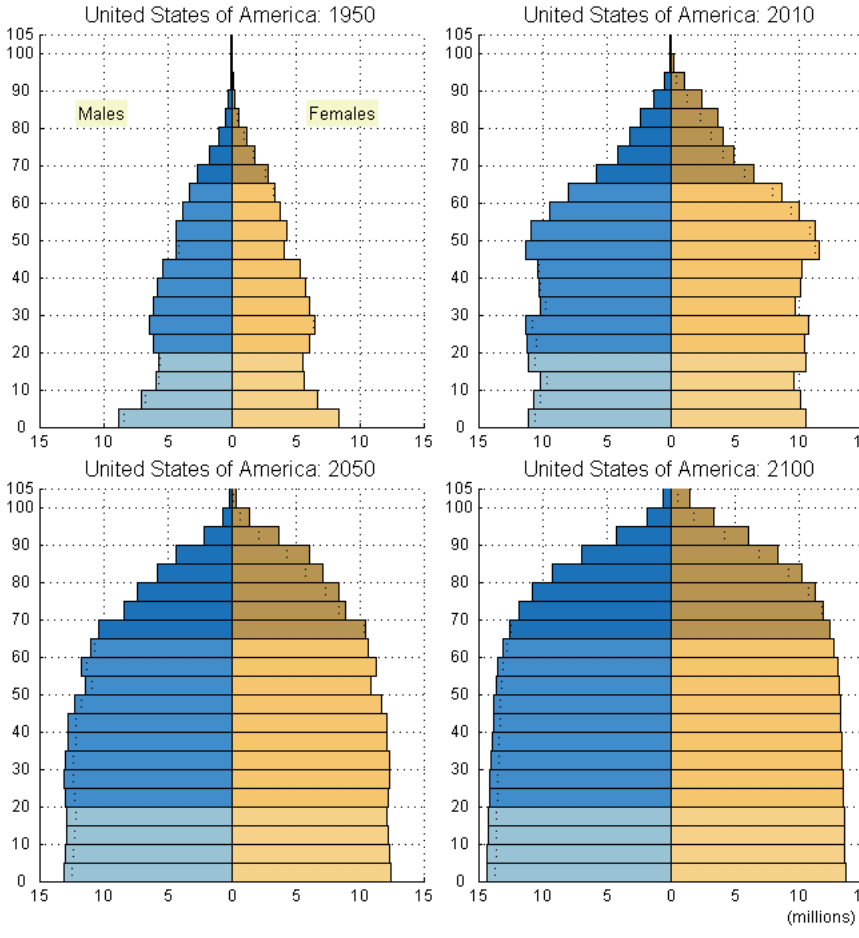
[70] World Health Organization, Dementia: A Public Health Priority, Geneva, Switzerland, 2012, http://whqlibdoc.who.int/publications/2012/9789241564458_eng.pdf.

same diagnostic criteria were applied across studies, the prevalence estimates were similar. See Robert S. Wilson et al. "Sources of Variability in Estimates of the Prevalence of Alzheimer's Disease in the United States." *Alzheimer's & Dementia*, vol. 7, no. 1 (2011), pp. 74–79.

c. The number of dementia cases is projected to double every twenty years; using this projection there would be 15.6 million dementia cases in 2050. See Martin Prince and Jim Jackson, *World Alzheimer's Report: 2009*, Alzheimer's Disease International, London, http://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf. The WHO projects cases to triple by 2050 using that projection; there would be 11.7 million dementia cases in the United States in 2050. See World Health Organization, Dementia: A Public Health Priority, Geneva, Switzerland, 2012, http://whqlibdoc.who.int/publications/2012/9789241564458_eng.pdf.

The pyramids below describe the U.S. population at four points in time: 1950, 2010, projected to 2050 and 2100. The pyramids demonstrate that the U.S. population is getting progressively larger (as indicated by the overall widening of the population pyramids. The United States has also aged between 1950 and 2010 as indicated by increasing percentages of population ages 65 and over. In 1950, the United States experienced a baby boom as indicated by larger populations at ages 0 through 10. This population is reflected by the larger population bars (representing the percentage of the population) between ages 55 and 65 in the 2010 pyramid. In 2010, the majority of U.S. population was working age (between 15 and 65) and the country also had a smaller child and aging (aged 65 and over) populations. By 2050, the relative size of the population ages 0 through age 70 is projected to be similar. This indicates that the population is in a steady state with no large shifts in either the child or elderly populations. This is also projected to be the case in 2100. The U.S. population is also expected to increase in size through 2100.

Figure 6. United States Population Pyramids



Source: United Nations, Department of Economic and Social Affairs, Population Division, *World Population Prospect: The 2010 Revision*,

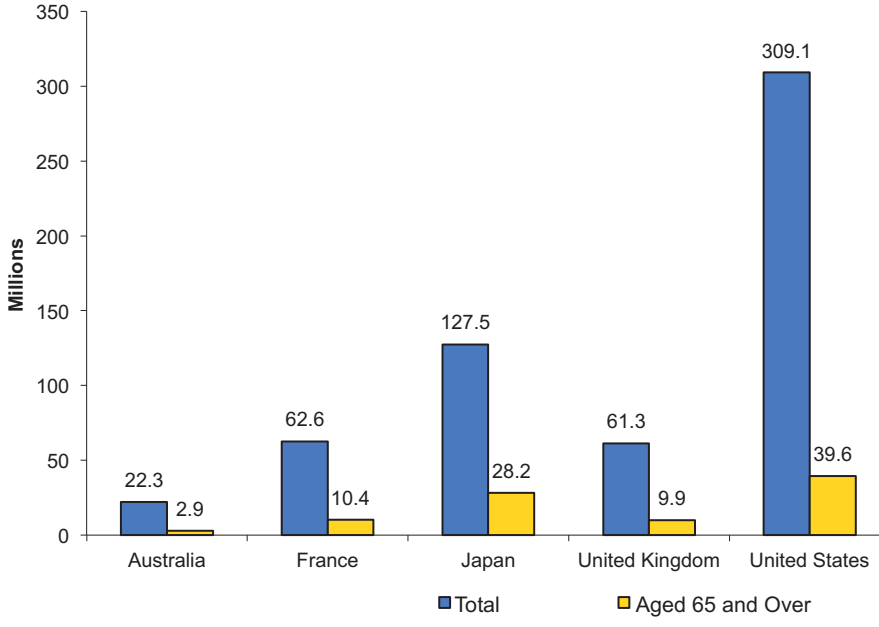
Country Comparisons

This section compares the five focus countries in the three areas discussed in the country overviews: (1) population, (2) life expectancy, and (3) dementia. Data are presented in tables or figures that are preceded by a discussion of the data. The comparisons highlight similarities and differences across the countries; whether these differences were statistically significant was not assessed. The first section on population comparisons includes a discussion of the population pyramids.

Population

The five focus countries range in size from 22.3 million (Australia) to 309.1 million (the United States). After the United States, Japan was the next largest in size with an estimated population of 127.5 million in 2009. France and the UK are similarly sized with populations of 62.6 million (2009 data) and 61.3 million respectively (see **Figure 7**). **Figure 7** shows both the total population and the number of individuals aged 65 and over in the five focus countries. For example, it shows that the number of individuals in the United States who were aged 65 and older was 39.6 million. This was 11.4 million higher than the number of individuals aged 65 and over in Japan (28.2 million). Although the United States is nearly twice the size of the Japan, Japan has a higher percentage of individuals aged 65 and over (22.1% for Japan as compared to 12.8% for the United States), which makes the absolute numbers of people aged 65 and over similar in the two countries. The figure also shows that given the small size of the Australian population relative to the other five focus countries, Australia has the smallest number of people aged 65 and over and that France and the UK, which had similarly sized populations and similar percentages of individuals aged 65 and over, had similarly sized older populations (10.4 million for France and 9.9 million for the UK). The size of the population affects the number of dementia cases. The percentage of the population that is aged 65 and over and the size a country's population, in turn, determine the number of individuals in a given country who are aged 65 or older.

Figure 7. Total Population and Population Aged 65 and Over (in Millions)



Source: OECD Factbook 2011: Economic, Environmental and Social Statistics, at http://www.oecd-ilibrary.org/economics/oecd-factbook-2011-2012_factbook-2011-en.

Notes: Data are the latest year available. The population aged 65 and over was obtained by multiplying the 2008 percentage of the population aged 65 and over by the total population in 2010 (or 2009 depending on the last year of data available). The estimated number of individuals aged 65 and over in the OECD overall is estimated at 176.9 million. This number was obtained by taking the OECD population (1,228.2 million) and multiplying it by the OECD average percentage of the population aged 65 and over (14.4%).

The percentage of the population that is aged 65 and over also influences the number of dementia cases in a country. As shown in **Table 7**, of the five focus countries Australia and the United States had percentages of the population aged 65 and over that were below the OECD average of 14.4%. The percentages in Australia and the United States were 13.2% and 12.8% respectively. Japan (22.1%), France (16.6%), and the UK (16.1%) were all above the OECD average.

Table 7. Country Comparisons: Population

Country	Australia	France	Japan	United Kingdom	United States	OECD
Total Population (in millions)	22.3	62.6	127.5	61.3	309.1	1,228.2
Percentage of the population aged 65 years and over (2008)	13.2%	16.6%	22.1%	16.1%	12.8%	14.4%

Source: OECD Factbook 2011: Economic, Environmental and Social Statistics, at http://www.oecd-ilibrary.org/economics/oecd-factbook-2011-2012_factbook-2011-en.

Notes: Data are the latest year available; in some instances total population data are 2009 data because that was the latest year reported to the OECD.

The population pyramids (see **Figures 2-6**) show some similarities across the five focus countries in 1950. Each of the focus countries was experiencing a post-war baby boom with larger percentages of the population at the youngest ages. This increase then resulted in overall population growth as the younger population moved through their child bearing years. The baby boom cohort in each of these focus countries resulted in larger populations at ages 50 to 70 in the 2010 population pyramids.

The countries differ in the percentages of the population that were children in 2010 and in the projections for 2050 and 2100. Much of this variation is driven by current and projected fertility rates and differences in life expectancy across the countries. For example, Japan is projected to maintain its relatively low fertility[71] and its high life expectancy; consequently, the country is projected to have the largest percentages of the population at ages 70 and over in 2050. In contrast, France and the United States have fertility rates that are about at replacement level (2.08),[72] this relatively higher fertility rate is projected through the 2050 and 2100 population pyramids where younger populations are expected to be about the same size as the populations that succeeded them (i.e., they will replace older populations). This would mean that these countries would maintain their age structures. However, the absolute number of people aged 65 and over may increase, in the United States in particular, because the country's population continues to grow.

[71] In 2012, Japan's total fertility rate was 1.39, which is below the replacement level fertility rate of 2.1. In some developed countries replacement level fertility may be closer to 2.0 because of lower mortality rates in childhood. Central Intelligence Agency, *The World Factbook: 2012*, Washington, DC, https://www.cia.gov/library/publications/the-world-factbook.

[72] Central Intelligence Agency, *The World Factbook: 2012*, Washington, DC, https://www.cia.gov/library/publications/the-world-factbook.

Life Expectancy

The life expectancy at birth of the five focus countries varied by 4.3 years from 78.7 years (United States) to 83.0 years (Japan). Four of the five focus countries had life expectancies at birth that were higher than the OECD average of 79.8 years; the remaining country is the United States where life expectancy was lower. In Japan (83.0 years), Australia (81.8 years), France (81.5 years) and the UK (80.6 years), the average person born in 2010 could expect to live more than 80 years. **Table 8** also includes information about life expectancy at age 65. Specifically, Japan, at 23.9 years, had the highest life expectancy for women who survive to the age of 65, while the United States, at 20.3 years, had the lowest among the five focus countries. The United States was also the only one of the five focus countries that was below the OECD average of 20.7 years. The remaining countries were above the average, although the UK's female life expectancy at age 65 was 20.9 years, which was just (0.2 years) above the OECD average. In both France (22.6 years) and Australia (21.8 years), a woman who survived to the age of 65 could expect to live to almost the age of 87, while in Japan it would be to the age of 88. The five focus countries had life expectancies for men who survive to age of 65 above the OECD average of 17.4 years. France had the lowest male life expectancy of the five focus countries at 17.5 years; next was the United States at 17.7 years. The UK (18.3), France (18.4), Australia and Japan (18.9 years in both countries) had similar life expectancies for men who survived to the age of 65. In these four countries a man who survives until the age of 65 could expect to live until at least the age of 83.

Table 8. Country Comparisons: Life Expectancy

Country	Australia	France	Japan	United Kingdom	United States	OECD Average
Life Expectancy at birth	81.8 years	81.5 years[a]	83.0 years	80.6 years	78.7 years	79.8 years
Life Expectancy at age 65 (women)	21.8 years	22.6 years	23.9 years	20.9 years	20.3 years	20.7 years
Life Expectancy at age 65 (men)	18.9 years	18.4 years	18.9 years	18.3 years	17.7 years	17.4 years

Source: Organization for Economic Cooperation and Development, OECD Health Data 2012 at http://stats.oecd.org/Index.aspx?DataSetCode=HEALTH_STAT.

Notes: Data are the latest year available; in some instances life expectancy data are for 2009, because that was the latest year of data reported to the OECD.

a. Data are for 2011.

Dementia

Each of the five focus countries had a higher percentage of the population aged 60 and over with dementia than the OECD average of 5.5%. The percentage of the population aged 60 and over with dementia was above 6.0% in four of the five countries with the exception of Australia, which, at 5.8%, had the lowest percentage among the five focus countries. The remaining four countries had similar percentages of the population aged 60 and over with dementia ranging from 6.1% (Japan and the UK) to France (6.5%). The U.S. percentage of the population aged 60 years and over with dementia was 6.2% (see **Table 9**).

Comparing the prevalence of dementia across countries is difficult both because of different methodologies used to obtain estimates and because estimating dementia prevalence is difficult.[73] Of the five focus countries, Australia had the lowest percentage of the population aged 60 and over with dementia among the five focus countries; it also had the smallest population. Given its low percentage

[73] Blossom Stephan and Carol Brayne, "Prevalence and Projections in Dementia," in *Excellence in Dementia Care: Research into Practice*, ed. Murna Downs and Barbara Bowers (New York: McGraw-Hill, 2008), pp. 9-34.

and its small population size overall, Australia had the fewest dementia cases in 2010 and is projected to have the fewest cases in 2050 (see **Table 7** and **Table 9**). Specifically, Australia had 300,000 cases in 2010 and is projected to have 900,000 cases in 2050. The UK estimates were low in 2010 at 800,000 cases, but the number of cases was expected to grow to between 2.3 million and 3.2 million cases in 2050. The United States and Japan had the two largest populations among the five focus countries; consequently, the two countries had the largest number of dementia cases both in 2010 and projected in 2050. Specifically, the United States had an estimated 3.9 million cases in 2010, which was expected to grow to between 11.7 million and 15.6 million cases in 2050. Japan had fewer cases—an estimated 2.5 million in 2010—and is predicted to have between 7.5 and 10.0 million cases in 2050.

Table 9. Country Comparisons: Dementia

Country	Australia	France	Japan	United Kingdom	United States	OECD Average
Percentage of Population with Dementia (aged 60 years and over)	5.8%	6.5%	6.1%	6.1%	6.2%	5.5%
Number of People with Dementia (2010 or closest year)[a]	300,000	1.1 million	2.5 million	800,000	3.9 million	NA[b]
Projected Number of People with Dementia (2050) (range)	900,000	1.8 million[c]	7.5-10.0 million	2.4-3.2 million	11.7-15.6 million	NA

Sources: Alzheimer's Australia: Key Facts and Statistics 2010, Australia Statistics, at http://www.fightdementia.org.au/media/key-facts-and-statistics-for-media.aspx. **Alzheimer's International**: Martin Prince and Jim Jackson, *World Alzheimer's Report: 2009*, Alzheimer's Disease International, London, http://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf. **OECD:** Organization for Economic Cooperation and Development, Health at a Glance 2011, OECD Indicators at http://www.oecd.org/els/healthpoliciesanddata/49105858.pdf. **Mura, Dartingues, and Berr**: Thibault Mura, Jean-Francois Dartigues, and Claudine Berr, "How Many Dementia Cases in France and Europe: Alternative Projections and Scenarios 2010-2050," *European Journal of Neurology*, vol. 17, no. 2 (February 2010), pp. 252-259. **WHO**: World Health Organization, Dementia: A Public Health Priority, Geneva, Switzerland, 2012, http://whqlibdoc.who.int/publications/2012/9789241564458_eng.pdf.

Notes: Ranges for Japan, the UK, and the United States were projected using assumptions by the WHO (lower bound) and the Alzheimer's Society (upper bound). The WHO projected that the number of individuals with dementia would triple by 2050, whereas the Alzheimer's Society projected that the number would double every twenty years.

a. Estimating the number of people with dementia is imprecise; different countries use different methodologies to derive their estimates of the number of dementia cases; this limits cross country comparisons.

b. The WHO estimates that globally there were 35.6 million people with dementia in 2010 and that the majority of these individuals lived in developed countries, see World Health Organization, *Dementia: A Public Health Priority, 2012*. Although this is not an OECD estimate, the global estimate, with its focus on developed countries, partially reflects the OECD total.

c. Given the number of cases in 2010, this estimate (from Thibault Mura, Jean-Francois Dartigues, and Claudine Berr, "How Many Dementia Cases in France and Europe: Alternative Projections and Scenarios 2010-2050," *European Journal of Neurology*, vol. 17, no. 2 (February 2010), pp. 252-259) seems low. Using the methodology used to project cases in Japan, the UK and the United States, the range in France would be 3.3 million to 4.4 million.

Chapter 2: International Issues in Diagnosis, Research, and Treatment of Dementia and Alzheimer's Disease

Introduction

This chapter highlights particular government initiatives and efforts in the five focus countries related to diagnosis, research, and treatment. The chapter is divided into three sections covering each of the three topics and summarizes scientific and medical issues in each area. Each section highlights specific trends, areas of consensus, and descriptions of selected efforts by the five focus countries. Where there are notable efforts in other countries, these efforts are included in text boxes. Significant efforts of each of the five countries focus solely on AD because of its severity, prevalence, and the limits of current scientific knowledge. Thus, some sections of this chapter are relevant to AD only.

Methodology

Information about diagnosis, research, and treatment in the United States was gathered from the National Institute on Aging at the National Institutes of Health, and information from non-governmental organizations such as the Alzheimer's Association. Information about the four other countries was gathered from government websites and publications; this information was limited by language barriers and different amounts of public information. Supplemental information was gathered from professional journals, professional societies, and non-government organizations (NGO), such as Alzheimer's International and Alzheimer's Europe. This chapter summarizes selected global initiatives and trends in each of the five focus countries presented in their National Plans.[74] Given the different sources available for each country, there is variation in the level of country-specific material presented. The information may underrepresent efforts in the five countries to address dementia and AD and is not an evaluation of programs or policies. Additionally, different cultural values, institutional structures, public financing mechanisms, and public policies may affect diagnosis, treatment, and research; however, including a discussion of those factors' influence is beyond the scope of this report.

Diagnosis[75]

This section presents the current international scientific consensus on the diagnosis of dementia, with a specific focus on diagnosis of AD. In general, international policy efforts found in the national plans aim to diagnose the diseases earlier and more accurately.

Current Diagnostic Tools

The diagnosis of dementia and AD is based on observable symptoms, on a patient's medical history, and at times on neurological or psychological tests that assess cognitive impairment. Symptoms observed by the clinician and reported by the family are also used to make a diagnosis.

Most countries use one of two diagnostic manuals. The clinician matches the symptoms evidenced by the patient to the symptoms listed in the manual as characteristic of the disease. One diagnostic manual is the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM) published

[74] See **Appendix 3** for a chart comparing the National Plans and a brief description of the key goals of each plan.

[75] A diagnosis has two major goals. It provides an efficient way for health care professionals to understand a patient and communicate to others in the treatment team a course of disease and prognosis. Accuracy in diagnosis is key to providing appropriate care.

by the American Psychiatric Association. The other is the *International Statistical Classification of Diseases and Related Health Problems* (*ICD*), published by the World Health Organization (WHO). There are definitional differences between the two texts, but the conceptual understanding of dementia and AD are similar.[76]

Specific clinical rating scales for AD, VD, and other dementias are growing more common to aid to diagnosis.[77] For instance, the Clinical Dementia Rating (CDR) is completed from semi-structured interviews with the patient and someone who knows the patient well.[78]

Specific Issues Related to the Diagnosis of Alzheimer's Disease

Both diagnostic manuals consider AD a diagnosis by exclusion; that is, if all other causes of dementia have been ruled out, the patient is diagnosed with AD. For instance, other diseases can cause symptoms similar to dementia and some other forms of dementia can be identified by an underlying disease (e.g., vascular dementia, HIV/AIDS). Diagnosis by exclusion can result in false positives, where individuals are diagnosed with AD when another disease or condition is causing the dementia.[79]

The diagnosis by exclusion is due to scientific limitations. It is only recently that the unique brain changes characteristic of AD have been discovered. These changes can only be verified with specific biomarker tests (see text box),[80] brain imaging, or autopsy upon death.[81] However, most individuals do not have these tests or do not receive autopsy upon death, adding uncertainty to the diagnosis of AD. Rather, most cases of dementia are diagnosed by medical professionals based on criteria that may not always distinguish AD from other dementias, as the overlap between the clinical symptoms of AD disease and other dementias is considerable.[82]

Even diagnosis by autopsy has limitations. For instance, autopsies of about 900 patients from 30 National Institute on Aging (NIA) research sites from 2005-2010 found a range of misdiagnoses. Patients diagnosed with other dementias, not AD, but who had signs of AD on autopsy occurred in 39% of the sample. Diagnosis of AD when another dementia was the underlying cause of the disorder was also as significant.[83]

Alzheimer's Disease Biomarkers

An active area of research to enhance early diagnosis is the identification of biomarkers for AD. Certain amyloid proteins, particularly A□, are found at abnormal levels in the brains of individuals with AD. These amyloid proteins may be markers of AD-related changes. Detecting these amyloid proteins is possible in several ways, including:

- Cerebral spinal fluid sampled through a spinal tap or lumbar puncture.
- Brain scans using radioactive dyes to highlight amyloid protein build up in the brain.

Source: : C. Qui, M. Kivipelto, and E. von Strass, "Epidemiology of Alzheimer's Disease: Occurrence, Determinants, and Strategies Toward Intervention," Dialogues in Clinical Neuroscience, vol. 11, no. 2 (2009), pp. 111-128.

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[76] M. B. First, "Harmonization of ICD-11 and DSM-V: Opportunities and Challenges," *British Journal of Psychiatry*, vol. 195 (2009), pp. 381-390.

[77] L. Gustafson et al., "The Accuracy of Short Clinical Rating Scales in Neuropathologically Diagnosed Dementia," *American Journal of Geriatric Psychiatry*, vol. 18, no. 9 (2010), pp. 810-820.

[78] Gustafson, et al., 2010.

[79] M. Beck, "Detective Work: The False Alzheimer's Diagnosis," *Wall Street Journal*, August 28, 2012, p. D1.

[80] A biomarker is a biological characteristic or property that can be objectively measured and evaluated as an indicator of normal biologic processes, disease processes, or pharmacologic responses to a therapeutic innovation. See Biomarkers Definitions Working Group, National Institutes of Health, "Biomarkers and Surrogate Endpoints: Preferred Definitions and Conceptual Framework," *Clinical Pharmacology and Therapeutics,* 69(3) (2001)*,* 89-95.

[81] C. Qui, M. Kivipelto, and E. von Strass, "Epidemiology of Alzheimer's Disease: Occurrence, Determinants, and Strategies Toward Intervention," *Dialogues in Clinical Neuroscience*, vol. 11, no. 2 (2009), pp. 111-128. Hereafter, C. Qui et al., 2009.

[82] Alzheimer's Association, *2012 Alzheimer's Disease Facts and Figures*, pp. 6-8. Alzheimer's Association, Washington, DC.

[83] T. G. Beach et al., "Accuracy of the Clinical Diagnosis of Alzheimer Disease at National Institute on Aging Alzheimer Disease Centers, 2005-2010," *Journal of Neuropathology and Experimental Neurology*, vol. 71, no. 4 (April 2012), pp. 266-273.

The lack of diagnostic accuracy is a problem for patients, physicians, and family members. Because most individuals do not receive an early diagnosis, by the time an individual is diagnosed with AD, it is too late to address the already irreversible neuronal loss, and treatments are unlikely to have a major impact on the disease course.[84] A 2012 global survey of physicians found that almost two-thirds identified the lack of a diagnostic test as a barrier to providing accurate diagnosis and treatment for dementia and AD.[85] This lack of diagnostic clarity is a problem for providing anticipatory guidance to families about the course of the disease in order to develop active coping and grieving strategies. As a result of these problems, the National Plans of the five selected countries identify improving diagnosis as key goals.[86]

In 2011, the NIA and the Alzheimer's Association (U. S.) empanelled a task force with the goal of revising the 1984 criteria for AD. [87] This task force included members engaged in research in this area from Australia, Canada, France, Germany, Japan, the Netherlands, the United Kingdom (UK), and the United States. The Task Force recommendations include revising the diagnosis to identify an AD spectrum. The spectrum would recognize progressive phases of the disease:

1. Pre-clinical (or pre-symptomatic) AD;
2. Mild cognitive impairment (MCI) due to AD; and
3. Alzheimer's disease.

The first two phases are identified as research criteria in need of validation especially due to the inclusion of biomarkers that have only been used in research studies, but not yet adopted for diagnostic purposes in the general population.[88] Previously only the final stage of the disease was recognized as AD. Research validating these criteria is ongoing.[89] These criteria have not yet been adopted by the standard diagnostic manuals DSM or ICD.

Research

This section presents the current global scientific consensus on research goals for dementia, with a specific focus on AD. In general, global policy efforts follow the scientific consensus, with efforts focused on understanding the biology of the disease, improving diagnosis, and developing cures. [90] Although all dementias are irreversible, knowing the cause allows medical and public health professionals to focus efforts on mitigating the progression of the disease by targeting the underlying condition.

Much of the global research emphasis in this area focuses on AD as a world-wide problem due to its prevalence, severity, and unknown causes. These research targets include: differentiating AD from the changes of normal aging; understanding AD at the cellular and molecular levels; understanding the start and progression of the disease; early identification and diagnosis; and genetic and environmental risk factors. [91]

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[84] See C.Qui et al., 2009.

[85] Eli Lilly, Inc., press release, September 16, 2012, http://files.shareholder.com/downloads/LLY/2078942632x0x600635/5bd90bd0-2ac0-4cf7-9501-71d71f620446/LLY_News_2012_9_19_Product.pdf.

[86] For more information, see.**Appendix 3**

[87] G. M. McKhann et al., "The Diagnosis of Dementia Due to Alzheimer's Disease: Recommendations for the National Institute on Aging - Alzheimer's Association Workgroups on Diagnostic Guidelines for Alzheimer's Disease," *Alzheimer's & Dementia*, vol. 7, no. 3 (May 2011), pp. 263-269.

[88] For more information on biomarkers, see this memorandum at "Biomarkers Research in Alzheimer's Disease."

[89] Alzheimer's Association, "New Research Reported at Alzheimer's Association Global Conference Advances Validation of New Diagnostic Guidelines," press release, July 18, 2012, http://www.alz.org/aaic/wed_130pmct_nia.asp.

[90] R. J. Hodes, "Public Funding for Alzheimer Disease Research in the United States," *Nature*, vol. 12, no. 7 (July 2006).

[91] See Hodes, 2010.

Global Collaboration in Research

There has been a growing consensus that collaborating would be advantageous in researching AD. The EU has established a *European Alzheimer's Disease Consortium (EADC)* and a *Joint Research Program in Neurodegenerative Diseases (JPND)*, which include AD and dementia research. EADC is a network of 50 European centers for clinical and biomedical research in dementia and AD. EADC collaborates with a U.S. lead project *Alzheimer's Disease Neuroimaging Initiative* (ADNI) on bio-imaging research. JPND publishes a strategic research agenda identifying projects that would benefit from coordination and provides funding for research grants.[92] The focus includes origins of diseases, disease mechanisms, diagnosis, treatments and prevention, health care, and social care.

In the United States, the National Alzheimer's Plan includes an emphasis on global cooperation and coordination.[93] In response, NIA initiated a global research inventory to collect and categorize existing global research as a first step in efforts to determine where future research should be targeted.[94] This database is publicly available and searchable, but currently includes primarily U.S. projects.[95] The following countries and global associations participated in planning activities related to establishing such an inventory and may participate in registering projects: Alzheimer's Society of Canada; Canadian Institutes of Health Research; Alzheimer's Society - United Kingdom; Alzheimer's Research - United Kingdom; National Research Foundation on Alzheimer's and Related Diseases of France; Fatebenefratelli Hospital of Italy; German Government; Japan Government - New Technologies; and Alzheimer's Disease International.[96] The five focus countries in this report participate in global research efforts as listed in **Table 10**.

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[92] For more information, see http://www.neurodegenerationresearch.eu/fileadmin/Documents/2012/SRA-related/JPND_brochure_final_Hyperlink_2012.pdf.

[93] Department of Health and Human Services, *National Plan to Address Alzheimer's Disease*, May 12, 2012 (last updated), http://aspe.hhs.gov/daltcp/napa/NatlPlan.shtml.

[94] Telephone conversation between the author and the Office of Planning, Analysis, and Evaluation, National Institute on Aging, August 7, 2012.

[95] See http://iadrp.nia.nih.gov/cadro-web/.

[96] E-mail to the author from the Office of Planning, Analysis and Evaluation, National Institute on Aging, August 16, 2012.

Table 10. Overview of Selected Research Activities of Five Focus Countries

Project	Description	Australia	France	Japan	United Kingdom	United States
Alzheimer's Disease Neuroimaging Initiative (ADNI)	ADNI aims to discover and validate biomarkers (e.g., blood tests, cerebrospinal fluid, MRI/PET imaging) for early diagnosis of AD.[a]	✓	✓	✓	✓	✓
Dominantly Inherited Alzheimer Network (DIAN)	DIAN is an international research partnership to understand early-onset AD.[b]	✓	NA	NA	✓	✓
European Alzheimer's Disease Consortium (EADC)	EADC is a network of European centers of excellence in AD.[d]	NA	✓	NA	✓	NA
EU Joint Program on Neurodegenerative Disease (JPND)	JPND is an initiative is to find cures for neurodegenerative diseases and to improve early diagnosis and targeted treatments.	NA	✓	NA	✓	NA
International Genomics of Alzheimer's Disease	IGAP's aims to discover and map all the genes involved in AD.[e]	NA	✓	NA	✓	✓
NIA International Alzheimer's Disease Research Portfolio (IADRP)	IADRP aims to provide a database of current research to improve coordination, leverage of resources, and reduce duplication of effort.[g]	NA	✓	✓	✓	✓

Source: Information compiled by CRS from information detailed in Table Notes.

Notes: A check mark indicates participation. NA = does not apply.

a. For more information on ADNI see http://www.adcs.org/studies/imagineadni.aspx.

b. Germany also participates in DIAN.

c. For more information on DIAN, see http://www.dian-info.org/faq.htm.

d. For more information on EADC, see http://www.eadc.info/sito/pagine/home.php.

e. For more information on IGAP, see http://www.med.upenn.edu/aging/documents/FINALsummer2011IOAnewsletterinhouse.pdf.

f. For more information, see G. M. McKhann et al., "The Diagnosis of Dementia Due to Alzheimer's Disease: Recommendations for the National Institute on Aging - Alzheimer's Association Workgroups on Diagnostic Guidelines for Alzheimer's Disease," *Alzheimer's & Dementia*, vol. 7, no. 3 (May 2011), pp. 263-269.

g. For more information on IADRP, see http://iadrp.nia.nih.gov/cadro-web/.

Biomarkers Research in Alzheimer's Disease

Global research efforts are centered on improving the accuracy of diagnosis of dementia as well as increasing early diagnosis of AD;[97] this effort has led researchers to focus on biomarkers for AD.[98] New research in brain-imaging indicates that the physiological changes of AD may start 10-20 years before

[97] See D. M. Holtzman et al., 2011.

[98] Biomarkers also have a role in research, for more information, see http://www.businesswire.com/news/home/20120123006114/en/European-Medicines-Agency-Deems-Imaging-Biomarker-Qualified.

symptoms appear, suggesting that medical professionals may not be detecting the disease in its earliest, and possibly easiest to treat phases. The current scientific consensus is that tracking biomarkers of the disease, rather than relying solely on visible symptoms, is the most accurate means to diagnose and evaluate the progression of the illness.[99] The efforts to develop tests based on biomarkers are a global research endeavor and ADNI collaborating sites are world-wide, and include the five focus countries.[100]

Figure 8 is a representation of the course of the disease tracked by key biomarkers and the integrity of nerve cells, which is the physiological basis of adequate cognitive functioning. For instance, amyloid plaques are a key biomarker of AD, as abnormally high levels of plaque in the brain create significant nerve cell damage. Additionally, abnormal Tau proteins aggregate creating neurofibrillary tangles disrupting brain function.[101] **Figure 8** illustrates that as amyloid plaque increases and neurofibrillary tangles form, neuronal integrity and normal brain function declines. The lower section of the chart describes other physiological changes that occur with the progression of the disease, such as the presence of Tau proteins and amyloid beta (Aβ), a specific form of amyloid protein linked to AD. Figure 8. Selected Biomarkers and Progression of Alzheimer's Disease (AD)

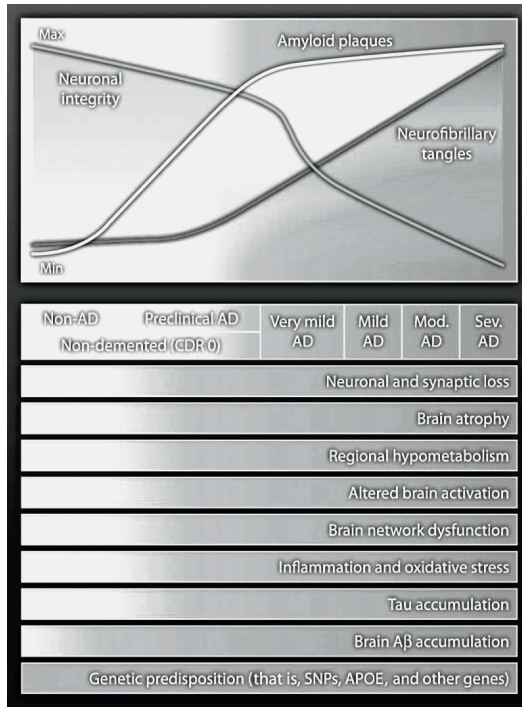
[99] See C. Qui et al., 2009.

[100] See http://www.alz.org/research/funding/partnerships/ww-adni_japan.asp.

[101] Neurofibrillary tangles are abnormal twisted masses of protein fibers within nerve cells found in patients with AD. Source: Gale Encyclopedia of Medicine, 2008.

Figure 8. Selected Biomarkers and Progression of Alzheimer's Disease (AD)

(Progression of light to dark represents movement from health to early stages of illness to most severe illness)



Source: D. M. Holtzman, J. C. Morris, and A. M. Goate, "Alzheimer's Disease: The Challenge of the Second Century," *Science Translational Medicine*, vol. 3, no. 77 (April 6, 2011), p. 5.

Notes: CDR = Clinical dementia rating scale; AD = Alzheimer's disease; Regional hypometabolism = decline in brain metabolic activity as neurons die; brain network dysfunction = communication failure in the connections of the brain; inflammation and oxidative stress = advanced physiological signs of AD; Tau accumulation = increase in another abnormal protein; brain Aβ = amyloid-beta-a specific amyloid protein linked to AD; SNPs = Single nucleotide proteins; APOE = Apolipoprotein E, a specific gene related to AD.

One of the challenges for researchers is to translate research on biomarkers from the laboratory to medical practice. Progress in this area occurred in April 2012, when the Food and Drug Administration approved a radio-diagnostic agent (florbetapir F 18) to be used for diagnostic imaging (PET scans) of amyloid plaques in patients with cognitive impairment to determine whether a diagnosis of AD is appropriate.[102] This commercially-available product allows PET scans to be used in medical practice rather than used only as a research tool. Access to this agent is somewhat limited due to its chemical composition, which loses its strength within hours, so it must be used close to its manufacturing sites.[103]

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[102] See FDA website for drug approvals: http://www.accessdata.fda.gov/scripts/cder/drugsatfda/index.cfm?fuseaction=Search.DrugDetails.

[103] See http://www.prnewswire.com/news-releases/amyvid-florbetapir-f-18-injection-now-available-in-select-us-markets-156292875.html.

Genetics Research in Alzheimer's Disease

Although individuals may have similar symptoms of AD, there may be different genetic pathways and multiple genetic origins. Familial studies indicate that early - onset AD, which accounts for about 5% of all AD cases, is caused by mutations in 3 genes located on 3 different chromosomes.[104] One mutation is in a gene that is for amyloid protein precursors, which create an abnormal form of amyloid protein amyloid-beta (Aβ). The two other genes appear to cause other abnormal proteins (presenilins) also linked to amyloid formation. Late - onset (over age 60) AD appears to be related to the inheritance of a particular variant of an apolipoprotein E (APOE) known as APOE e4.[105] APOE e4 is associated in some studies with an increased rate of cognitive decline.[106]

A recent notable discovery in genetics occurred in Iceland where researchers identified a gene that appears to play a protective role in AD (see textbox).

Genetic research on complex diseases requires large sample sizes.[107] This type of research is facilitated with collaborations between research centers to pool data. There are several examples of this type of collaboration.

In 2011, a global consortium was formed to explore the genetic origins of AD. Four groups (two from the United States), one from France and one from the UK joined together to gather appropriate numbers of patients and controls to study these issues. The groups created a shared database to record information on a pool of 40,000 individuals. This project, the *Global Genomics of Alzheimer's Project* (IGAP), pools funding from non-profit organizations, the Alzheimer's Association (U.S.) the Foundation Plan Alzheimer, a non-profit entity created to implement the research agenda of the French National Plan.[108]

In addition, NIA has funded a national genetics data repository that will be the storage site for genetic data from all information derived from NIA-funded research on late-onset AD. The *National Cell Repository for Alzheimer's Disease* maintains biological samples and patient data to aide in research. NIA also funds the AD genetics consortium and the *National Alzheimer's Coordinating Center*; all located at medical research institutions to coordinate data and patient information.

Genetic Research in Iceland

Iceland took a unique step in 1999 through a private-public partnership and created a national genetic data base by sampling all of its then 270,000 residents. This source of genetic material is unique and permits understanding of many health conditions, including dementia and AD.

A gene coding mutation, A673T, appears to be protective against AD and general cognitive decline. About 1,800 Icelanders carrying this mutation were less likely to develop Alzheimer's Disease compared to the remaining population. These individuals evidenced less cognitive decline due to general aging. The mechanism of this genetic mutation reduces amyloid beta production by reducing the formation of amyloid proteins. This mutation also slows the formation of amyloid plaques.

Source: T. Jonsson et al., "A Mutation in APP Protects Against Alzheimer's Disease and Age-Related Cognitive Decline." *Nature*, July 11, 2012.

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[104] See D. M. Holtzman et al., 2011.

[105] Ibid.

[106] Ibid.

[107] J. Craig, "Complex Diseases: Research and Applications," *Nature Education*, vol. 1, no. 1 (2008), http://www.nature.com/scitable/topicpage/complex-diseases-research-and-applications-748.

[108] See http://www.alz.org/documents_custom/final_alzassoc_igap_news_release_1-31-11.pdf.

Research on Pharmaceutical Treatments for Alzheimer's Disease

There are a number of research programs to investigate early-onset AD. For instance, the Dominantly Inherited Alzheimer Network (DIAN) is initiating an international research network for early-onset AD.[109] Another international collaboration is a study is investigating a potential drug therapy for early-onset AD (see text box). Studying patients who will most likely develop the disease, but have not yet developed symptoms, provides researchers a better chance at a significant discovery. The hope is that these drugs may be effective for all AD patients.

Global Collaboration in Genetics: Colombia

Studies of genetics pose unique problems as identifying those with specific genetic mutations often occurs only after diagnosis, if at all. A unique population in Medellin, Colombia has provided a unique opportunity to study genetics, as this rural clan has been identified as carrying the gene for early-onset AD.

The National Institutes of Health, Banner Alzheimer's Institute in Phoenix, University of Antioquia, Colombia, and Genentech are collaborating in a global study of 300 people in Medellin, Colombia who suffer from early-onset AD as well as some individuals from the United States.

Three hundred members of an isolated extraordinarily large extended family-clan affected by the disease are participating in a drug trial that will focus on amyloid plaque build-up. Early onset of AD in this family is at about age 30, with full-blown AD by the age of 45. Genentech will be conducting a 5 year trial of a novel immunotherapy, crenezumab.

This project is part of the Alzheimer's Prevention Initiative created to evaluate promising treatments and part of the U.S. National Plan. Funding is from a private-public partnership splitting costs between National Institutes of Health (NIH) and philanthropic funds from the Banner Institute.

Source: NIH Fogarty Global Center "First-ever Alzheimer's prevention trial to take place in Colombia, Press Release, May 15, 2012. http://www.fic.nih.gov/News/Pages/2012-alzheimer-prevention-trial-colombia.aspx; and, M. G. Banner "Federal Funds Launch First Alzheimer's Prevention Study, Clinical Psychiatry News, May 15, 2012.

Another international effort by Australia, the United Kingdom, and the United States is studying the development of early-onset AD and will evaluate the effect of three different drugs on those with early, pre-symptomatic AD. All volunteers have genetic mutations that have been shown to cause early-onset AD. The goal is to evaluate the drugs' abilities to slow or prevent the development of the disease in these patients. This effort is significant as it attempts to intervene in pre-symptomatic patients, and it evaluates three different drugs that affect amyloid proteins in different ways. This project is an effort of the Dominantly Inherited Alzheimer's Network Trials Unit, global research collaboration (see **Table 10**).

Most of the experimental drugs target the amyloid protein build-up and additional studies are underway to investigate anti-amyloid therapies that reduce production of proteins; reduce aggregation of proteins; and increase the removal of proteins.[110] Other research is investigating Tau proteins, which have an aberrant chemical structure in AD; cellular dysfunction; and a variety of preventive strategies such as omega-2 fatty acids.

After some initial success in developing medications that target symptoms, recent research in disease-modifying medications has led to both publicized setbacks and progress.[111] In 2011 representatives from academia and industry met, including representatives from the European Union (EU), Japan, and the United States to discuss these issues and recommend approaches to improve research.[112] Many attribute the setbacks in drug development to limitations in our knowledge of the AD disease process; problems in

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[109] For more information, see http://dian-info.org/.

[110] See http://www.alz.org/documents_custom/final_alzassoc_igap_news_release_1-31-11.pdf.

[111] Eli Lilly stopped development of two Alzheimer's Disease drugs in the last two years (http://www.bloomberg.com/news/2012-08-24/lilly-alzheimer-s-drug-slows-course-of-disease-in-some-patients.html) and Pfizer, Johnson & Johnson stopped development of an additional drug in August 2012 (http://www.bloomberg.com/news/2012-08-06/pfizer-j-j-drop-alzheimer-s-drug-studies-after-failure.html). However, Eli Lilly recently released results for a drug that may improve the symptoms of mild disease, http://www.nytimes.com/2012/10/09/business/eli-lilly-drug-shows-promise-in-treating-mild-alzheimers.html.

[112] B. Vellas et al., 2012.

diagnosis; choice of therapeutic target; and design of clinical trials.[113] For instance, one hypothesis is that the brain damage caused by the disease could be too advanced for the medication to have an effect. Alternatively, some medications could have a window of opportunity in the course of the disease that may have elapsed. In addition, some elderly patients may have multiple forms of dementia, other than AD, that are not affected by the medication. Because progress in this area faces challenges such as disparate outcome measures; high patient dropout rates; and duplication of efforts,[114] there is an increasing global effort to coordinate research and to build a global consensus on methodological issues.

Research Funding

The five focus countries provide funding for research on dementia and AD. To put these funding levels in perspective, **Table 11** provides per capita spending levels for FY2010;[115] Table 11. Total Per Capita Spending on Research on Dementia and Alzheimer's Disease by Focus Country in Millions of $U.S.

Table 11. Per Capita Spending (2010)

(population in millions)

Categories	Australia	France	Japan	United Kingdom	United States
Population	21.5	62.5	127.0	62.3	310.2
Spending	21.4	49.0	NA	42.0	450
Per Capita Spending- $U.S.	1.0	0.78	NA	0.67	1.45

Source: Compiled by CRS from OECD population statistics http://www.oecd-ilibrary.org/sites/factbook-2010-en/01/01/01/index.html?contentType=/ns/Book,/ns/StatisticalPublication&itemId=/content/book/factbook-2010-en&containerItemId=/content/serial/18147364&accessItemIds=&mimeType=text/html; and country spending levels, see Tables 6-7 converted to $U.S.

Note: NA = Not Available.

Note: CRS is not confident about the completeness of the funding level amounts listed for each country's, so that this table presents information that is potentially an under or over-estimate of spending. This accounting may underestimate total research spending as some research on aging programs may include grants and programs relevant to dementia and Alzheimer's Disease.

Australia

Australia is currently engaged in efforts to improve the understanding of dementia and AD with a special focus on causes, diagnosis, lifestyle, and diet that may influence onset and aide in prevention strategies.[116] For instance, a new priority is $10 million ($10.5 million in 2012 $U.S)[117] in funding for a program that aims to understand the causes, including lifestyle and diet.[118]

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[113] F. Mangiatasche et al., "Alzheimer's Disease: Clinical Trials and Drug Development," *Lancet Neurology*, vol. 9, no. 7 (July 2010), pp. 702-716.

[114] B. Vellas et al., "Alzheimer's Disease Therapeutic Trials: EU/U.S. Task Force Report on Recruitment, Retention, and Methodology," *Journal of Nutrition, Health & Aging*, vol. 16, no. 4 (2012), pp. 339-345. Hereafter B. Vellas et al., 2012.

[115] Due to data limitations this was the only year for which there was sufficient information.

[116] For more information and funding levels, see http://www.csiro.au/Outcomes/Health-and-Wellbeing/Prevention/AIBL-Study.aspx.

[117] Conversion rates calculated for each year based on exchange rate for September 19, published by http://www.oanda.com/currency/historical-rates/.

[118] For more information, see http://www.csiro.au/Outcomes/Health-and-Wellbeing/Prevention/AIBL-Study.aspx.

Australia's research infrastructure includes the *Dementia Collaborative Research Centres*, which are a central element of its national plan. Each center specializes in one of three areas: assessment and better care; early diagnosis and prevention; and workforce and consumers.[119]

The Commonwealth Scientific and Industrial Research Organization (CSIRO), Australia's national science agency, is home to large-scale national research programs. CSIRO provides support and funding for a variety of programs in health and technology.[120] For instance, the Australian Imaging, Biomarkers and Lifestyle (AIBL) project is a collaboration of CSIRO, the National Aging Research Institute, and Australian universities and research institutes.

AIBL aims to develop and confirm the utility of diagnostic biomarkers that could chart the course of AD.[121] Recently Australian researchers have made progress in identifying plasma biomarkers for AD that could be developed into a blood test for AD.[122] Currently biomarkers only detect amyloid proteins through cerebral spinal fluid or a PET scan, which are costly and a burden on patients.

The most recent information on research funding on dementia and AD is presented in **Table 12** as described in the Australian national plan.[123] Research funding has increased over the five-year period.

Table 12. National Health and Medical Council of Australia: Public Funding for Research in Dementia and Alzheimer's Disease

(in millions by calendar year)

Currency	2007	2008	2009	2010	2011
$AUS	12.7	17.3	21.8	22.8	23.4
$U.S.	10.7	14.4	18.9	21.4	24.2

Source: National Health and Medical Council of Australia, see http://www.nhmrc.gov.au/grants/research-funding-statistics-and-data/summary-funding-data.

Note: Conversion rates calculated for each year based on exchange rate for September 19, published by http://www.oanda.com/currency/historical-rates/.

France

France maintains a broad research program supported by public and private funding. The French *National Research and Innovation Plan* includes research into dementia and AD as major goals.[124] The *Ministry of Higher Education and Research* administers research priorities, programs, and evaluation.[125]

In 2008 France created the *French National Foundation on Alzheimer's Disease* and related disorders,[126] a non-profit foundation, to coordinate the scientific goals of the French National Plan.[127] The French

[119] See http://www.fightdementia.org.au/dementia-collaborative-research-centres.aspx.

[120] For more information see CSIRO's website: http://csiro.au/.

[121] For more information, see http://csiro.au/en/Portals/Media/Alzheimers-diseases-research-inroads.aspx.

[122] J. D. Doecke et al., "Blood-Based Biomarkers for Diagnosis of Alzheimer Disease," *Archives of Neurology*, July 16, 2012.

[123] For more information, see **Appendix 3**.

[124] Republique Francaise, *Strategie Nationale de Recherche et d'Innovation*, http://media.enseignementsup-recherche.gouv.fr/file/SNRI/69/8/Rapport_general_de_la_SNRI_-_version_finale_65698.pdf.

[125] For more information, see Ministere de L'Enseignment Superieur et de la Recherche, http://www.enseignementsup-recherche.gouv.fr/cid56382/organisation-du-systeme-de-recherche-et-d-innovation.html.

[126] For more information, see Foundation Plan Alzheimer, http://www.fondation-alzheimer.org/.

[127] Alzheimer Plan 2008-2012: L'Engagement De Tous, *Alzheimer Plan 2008-2012: L'Engagement De Tous: Implementation as of 1st February, 2012*, February 1, 2012.

government provided an initial €200 million ($292 million in 2008 $U.S.).[128] This non-profit structure allows the Foundation to gather funding from multiple sources within the government as well as EU and private funding. French efforts focus on a variety of areas within research, including neurology, epidemiology, genomics, imaging, and biochemistry. The French have increased their participation in clinical trials globally. As noted in **Table 10**, France participates in European and global research programs.[129] In addition, the network of memory clinics allows the creation of a data base for epidemiological and clinical projects, including a national prospective patient cohort.[130] **Table 13** lists the French public funding for research in dementia and AD. Research funding increased in four of the five-years.

Table 13. France: Public Funding for Research in Alzheimer's and Related Diseases

(in millions)

Currency	2008	2009	2010	2011	2012
€EU	29.0a	42.0	38.0	46.0	45.0
$U.S.	42.0	61.7	49.0	59.3	59.1

Source: Republique Francaise, *National Plan for Alzheimer and Related Diseases 2008-2012*, February 1, 2008, http://www.plan-alzheimer.gouv.fr/, p. 7.

Notes: Conversion rates calculated for each year based on exchange rate for September 17 of each year, published by http://www.oanda.com/currency/historical-rates/. It is unclear whether the funding is for calendar or fiscal year.

a. Includes €14.1 from the Foundation for Scientific Cooperation of the European Union (EU).

Japan

The Japanese National Dementia Strategy emphasizes introducing preventive measures, improving diagnosis, and developing therapeutic procedures and care.[131] The major governmental entities funding dementia and AD research in Japan include the *Ministry of Education, Science, Sports and Technology* that funds basic research (including mechanisms of disease) and the *Ministry of Health, Labor and Welfare (MHLW)* that addresses health and clinical research.[132] Over the last years funding has increased for research in genomics, large-scale basic science, and integrative neurology.

The Committee could not locate funding levels for research from government sources for the last 7 years. The Committee did locate a description of past funding levels in a journal article and that information is included in **Table 14**. Research funding increased between 2003 and 2004, but has declined across the entire five-year period reported.

[128] Calculated based on exchange rate for September 24, 2008 at http://www.oanda.com/currency/historical-rates/.

[129] Republique Francaise, *Alzheimer Plan 2008-2012: Implementation as of 1st February 2012*, http://www.plan-alzheimer.gouv.fr/IMG/pdf/Plan_Alzheimer_4th_anniversary-2.pdf.

[130] See, http://www.plan-alzheimer.gouv.fr/IMG/pdf/Foundation_Plan_Alzheimer-the_need_for_a_major_concerted_action_in_research_in_France.pdf.

[131] Y. Arai, A. Arai, and Y, Mizuno, "The National Dementia Strategy in Japan," *Global Journal of Geriatric Psychiatry*, vol. 25 (2010), pp. 896-899.

[132] T. Iwatsubo, Y. Ihara, and I. Kanazawa, "Alzheimer Disease Funding in Japan: Public Funding," *Nature Medicine*, vol. 12, no. 7 (July 2006), pp. 778-779.

Table 14. Japan: Public Funding of Research in Dementia and Alzheimer's Disease
(in millions)

Currency	2001	2002	2003	2004	2005
¥JAP	1,600	1,400	1,300	1,450	1,200
$U.S.	13.6	11.6	11.2	13.2	10.8

Source: T. Iwatsubo, Y. Ihara, and I. Kanazawa, "Alzheimer Disease Funding in Japan: Public Funding," *Nature Medicine*, vol. 12, no. 7 (July 2006), p. 778.

Note: Conversion rates calculated for each year based on exchange rates for September 17, published by http://www.oanda.com/currency/historical-rates/. It is unclear whether the funding is by calendar or fiscal year.

United Kingdom

The UK has several governmental agencies and research institutes that are responsible for research on dementia and AD. One unique aspect of UK research is a focus on evaluating treatment. For instance, the National Institute for Health Research (NIHR) performs applied health research, whose overarching goals are cause, cure, and care. Research areas include: efficacy and mechanism evaluation; health services research; health technology assessment; grants for applied research; public health research; research for patient benefit; and service delivery and organization.[133] Treatment evaluations assess the effectiveness of treatments to improve all levels of care, including evaluating medications for behavioral symptoms, evaluating cost benefit analysis of brain imaging in diagnosis, and evaluating community-based care.[134] Research into treatments is complicated by the long course of the disease. As the progression of the disease occurs over decades, assessing the success of any treatment will necessitate long observational periods.[135]

As part of his Dementia Challenge, the Prime Minister, David Cameron, has committed £66 million ($107 million in 2012 $U.S.) for dementia research by 2015, which more than doubles the 2010 funding level of £26.6 million ($42 million in 2010 $U.S.).[136] The Committee could not locate more comprehensive information on research funding.

United States

The U.S. National Plan envisions a coordinated strategy to accelerate early diagnosis, increase treatment development, and improve global research efforts.[137] Research funding for dementia and AD at the NIH dates back to the establishment of the NIA in 1974;[138] the NIA is the major research institute at the NIH for dementia and AD research grants, although many institutes have dementia and AD projects. A full list of NIA funding programs for dementia and AD can be found at the NIH website.[139] The total FY2009-FY2012 for NIH programs on AD is shown in **Table 6**.[140] Research funding was highest in 2009.

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[133] See NIHR website for a list of treatment-oriented research projects: http://www.nihr.ac.uk/research/Pages/Dementia.aspx.

[134] See http://www.nihr.ac.uk/research/Pages/Dementia.aspx.

[135] H. Hampel et al., "Biomarkers for Alzheimer's Disease Therapeutic Trials," *Progress in Neurobiology*, vol. 95, no. 4 (December 2011), pp. 579-593.

[136] Conversion rates calculated for each year based on exchange rate for September 17, published by http://www.oanda.com/currency/historical-rates/.

[137] Department of Health and Human Services, *National Plan to Address Alzheimer's Disease*, May 12, 2012 (last updated), http://aspe.hhs.gov/daltcp/napa/NatlPlan.shtml.

[138] P.L. 93-296 authorized the creation of National Institute on Aging and required the institute to develop a national comprehensive plan to coordinate the Department of Health, Education and Welfare (now Department of Health and Human Services) agencies involved in aging research.

[139] For more information, see http://grants.nih.gov/grants/guide/search_results.htm?text_curr=alzheimer%27s&scope=pa-

Table 15. U.S.: NIH Funding for Alzheimer's Disease Research

(in millions by fiscal year)

Currency	FY2009	American Recovery and Reinvestment Act of 2009[a] Funds Distributed in FY2009	FY2010	American Recovery and Reinvestment Act of 2009[a] Funds Distributed in FY2010	FY2011	FY2012
$U.S.	457	77	450	79	448	498

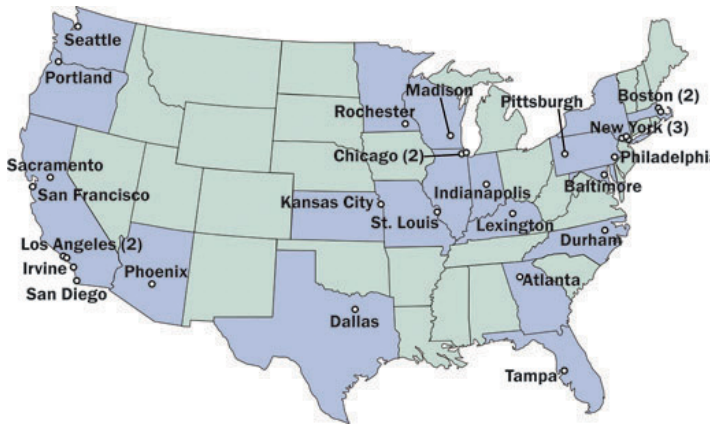
Source: National Institutes of Health, Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC) http://report.nih.gov/categorical_spending.aspx confirmed by Moyer Materials, Department of Health and Human Services.

a. P.L. 111-5.

FY2012 includes funding for National Alzheimer's Plan as authorized by P.L. 111-375. NIA established specialized AD research and treatment centers located at medical centers across the U.S to translate research to advance diagnosis and treatment. The participating centers perform basic and clinical science, as well as develop specialized expertise.[141] A shared goal is to create a collaborative network. Data and information from the centers are managed by the National Alzheimer's Coordinating Center illustrated in **Figure 9**.

Figure 9. Map of U.S. NIH Alzheimer Disease Centers

(by city and state)



Source: National Institute on Aging, NIH: http://www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers. Site has complete list of all medical centers.

Note: There are no centers in Alaska or Hawaii.

rfa&year=active&sort= and dementia; and http://grants.nih.gov/grants/guide/search_results.htm?text_curr=dementia&scope=pa-rfa&year=active&sort=.

[140] These funds may include funding for dementia and related diseases.

[141] For more information, see http://www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers.

Treatment

This section presents the most recent international consensus on the treatment of dementia, including selected efforts of the five focus countries.

Overview

The five focus countries have the same tools available for treating dementia and AD; however, access to care varies depending on the health care systems in each country. Further, the stigma of dementia and AD and the pessimism about the course of the disease have become barriers for patients to seek treatment and divulge information helpful to providers in making a diagnosis of dementia or Alzheimer's Disease.[142] As a result, some patients may still not have access to treatments that could be helpful.[143]

Expert opinion recommends focusing on early diagnosis and prompt treatment.[144] Further, a global effort is underway to develop more effective treatments for dementia and AD. Once dementia and AD are diagnosed, treatment is dependent on the stage of the disease. **Figure 10** illustrates the different treatments based on the stage of disease. Treatment is best initiated in the early phases when individuals are asymptomatic or have signs of mild cognitive impairment (MCI) before major brain damage occurs.[145] Unfortunately, current treatments are limited, and currently dementia and AD are progressive chronic diseases for which there are no known cures. The treatments that are available attempt to maintain cognitive abilities. The treatments available include prescription medications that enhance cognitive function and cognitive training that increases the ability to perform activities of daily living (ADL). For instance, cognitive training[146] appears to have a protective function and may maintain levels of cognitive functioning.[147] However, there is limited evidence that such activities prevent the eventual characteristic cognitive decline of dementia and AD.[148]

As dementia and AD progress, the ability of the patient to live independently is reduced. Over time patients are no longer able to perform certain ADLs, the self-care necessary for daily living, such as bathing, budgeting, buying and preparing food, and dressing. Eventually care in the middle to late stages of the diseases involves long-term care services, including social services and residential treatment.

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[142] Eli Lilly, Inc., press release, September 16, 2012, http://files.shareholder.com/downloads/LLY/2078942632x0x600635/5bd90bd0-2ac0-4cf7-9501-71d71f620446/LLY_News_2012_9_19_Product.pdf and Alzheimer's Disease International, *Overcoming the Stigma of Dementia, World Alzheimer Report 2012*, http://www.alz.org/documents_custom/world_report_2012_final.pdf.

[143] Alzheimer's Disease International, *National Alzheimer and Dementia Plans Planned Policies and Activities: Early Detection, Access to Diagnosis and Stigma Reduction*, April 2012, p. 12, http://www.alz.co.uk/sites/default/files/national-alzheimer-and-dementia-plans.pdf.

[144] See C. Qui et al., 2009.

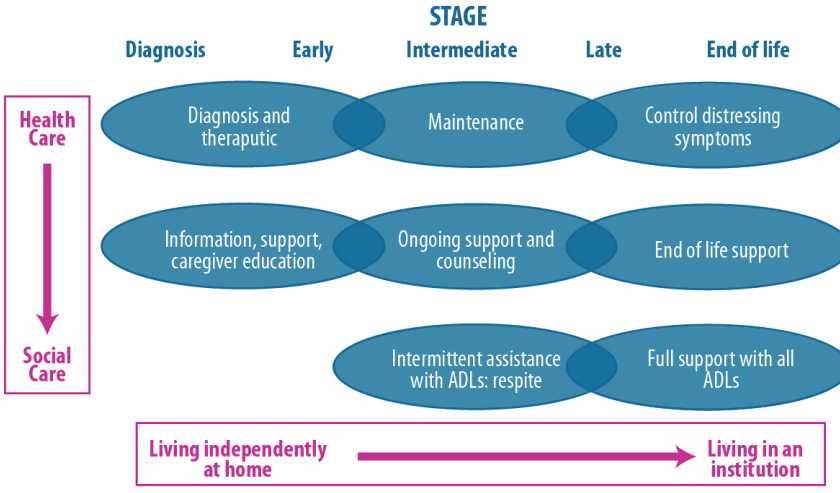
[145] J. L. Cummings, R. Doody, and C. Clark, "Disease-Modifying Therapies for Alzheimer's Disease: Challenges to Early Intervention," *Neurology*, vol. 69, no. 16 (August 15, 2007), pp. 1622-1634.

[146] *Cognitive training* consists of exercises designed to improve cognitive functioning, including memory, concentration, reasoning, and planning. Exercises for dementia and AD exercises are designed to improve learning, memory, executive functioning, and activities of daily living, depression, and general cognitive problems. See M. Crowe et al., "Does Participation in Leisure Activities Lead to Reduced Risk of Alzheimer's Disease? A Prospective Study of Swedish Twins," *The Journal of Gerontology*, vol. 58, no. 5 (2003), pp. 249-255.

[147] J. W. Williams et al., *Preventing Alzheimer's Disease and Cognitive Decline*, Agency for Healthcare Research and Quality, Evidence Report/Technology Assessment No. 193, Rockville, MD, April 2010, p. 309, http://www.ahrq.gov/downloads/pub/evidence/pdf/Alzheimers/alzcog.pdf.

[148] M. Crowe et al., "Does Participation in Leisure Activities Lead to Reduced Risk of Alzheimer's Disease? A Prospective Study of Swedish Twins," *The Journal of Gerontology*, vol. 58, no. 5 (2003), pp. 249-255.

Figure 10. Care Continuum for Dementia Patients



Source: Adapted from P. Moise, M. Schwarzinger, and M. Um, *Dementia Care in 9 OECD Countries*, Organisation for Economic Co-operation and Development (OECD), Working Paper no. 13, 2004, p. 10 by Jamie Hutchinson, CRS.

Note: ADLs means "Activities of Daily Living".

Pharmacological Treatment of Dementia and Alzheimer's Disease

There are two types of pharmacological treatments for dementia and AD: medications to improve cognitive functioning and medications to control behavioral and psychological symptoms. Each approach will be discussed separately.

Prescription Drugs to Improve Cognitive Functioning

Certain prescription drugs aim to maintain cognitive functions, manage behavioral symptoms, and delay the onset of cognitive deterioration present in dementia and AD.[149] For instance, cholinesterase inhibitors, including Donepezil (Aricept), Riastigmine, and Galantamine, are prescribed for mild to moderate AD; they may delay or prevent symptoms (e.g., memory loss) from worsening for a limited time and may control negative behavioral symptoms. Memantine is prescribed for those with moderate to severe AD to improve symptoms; however, none of these drugs stop the progression of the disease and most patients' condition will worsen over time. Serious side effects accompany many of these medications making them unsuitable for some patients.[150]

Table 6 lists the prescription drugs approved to mitigate the cognitive decline in dementia and AD in the five focus countries and the dates of their approval. Most drugs have been available in these countries for several years, with the exception of Japan that approved three of these medications only recently.

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[149] P. Moise, M. Schwarzinger, and M.Y. Um, *Dementia Care in 9 OECD Countries*, OECD, Working Paper no. 13, 2004, http://www.oecd.org/health/healthpoliciesanddata/33661491.pdf.

[150] "New Drugs," *Australian Prescriber*, vol. 26, no. 5 (2003), p. 119.

Table 16. Prescription Drugs Approved For Dementia

Selected Countries and Approval Dates

Country	Tacrine[b]	Donepezil (Aricept)	Rivastigmine	Galantamine	Memantine
Australia	1995	1998	2000	2001	2003
France	1994	1997	2000	2001	2002a
Japan	NA	1999	2011	2011	2011
United Kingdom	NA	2001	2001	2001	2002
United States	1993	1996	2000	2001	2003

Source: Moise, et al., Dementia Care in 9 OECD Countries, p. 11, http://www.oecd.org/health/healthpoliciesanddata/33661491.pdf; Editorial, "New drugs for Alzheimer's disease in Japan" *Psychiatry and Clinical Neurosciences*, 2011, 65: 399-404; and Alzheimer Research Forum: http://www.alzforum.org/new/detail.asp?id=411; and *Australian Prescriber*: http://www.australianprescriber.com/magazine/26/5/118/9/new-drugs-439/memantine.

Notes: NA = Not Approved.

a. Date of approval by the European Union's Committee of Proprietary Medicinal Products (CPMP).

b. At the present this medication is rarely used due to its side effects.

Prescription Drugs to Improve Behavioral and Psychological Functioning

Other pharmacological treatments attempt to contain the behavioral symptoms (e.g., aggressiveness, sleeplessness, and wandering) or mood disorders (e.g., anxiety, anger, delusions, and hallucinations) that can accompany dementia and AD. [151] Symptom management provides relief to the patient and can aid caregivers in maintaining the patient in their homes or in the least restrictive setting possible. A recent systematic review of the literature found evidence that certain anti-psychotic medications are useful in reducing aggression and psychosis, but these medications are associated with significant negative health effects in some patients and should not be used for routine care.[152] A separate meta-analysis found an increase in mortality with these treatments.[153] Non-medication-oriented treatments for behavioral symptoms include managing and simplifying the patient's environment and reducing change and stress.[154] The Australian, French, and English National Plans emphasize finding alternatives to these medications where appropriate due to these serious side effects.[155]

[151] Alzheimer's Disease Education and Referral Center, National Institute on Aging, "Alzheimer's Disease Medications: Fact Sheet," NIH Publication No. 08-3431, Washington, DC, November 2008 (updated December, 2010), http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-medications-fact-sheet.

[152] C. G. Ballard, J. Waite, and J. Birks, "Atypical Antipsychotics for Aggression and Psychosis in Alzheimer's Disease," *Cochrane Library: Intervention Review*, February 21, 2012.

[153] L. S. Schneider, K. S. Dagerman, and P. Insel, "Risk of Death With Atypical Antipsychotic Drug Treatment for Dementia: Meta-Analysis of Randomized Placebo-Controlled Trials," *Journal of the American Medical Association*, vol. 294, no. 15 (September 19, 2005), pp. 1934-1943.

[154] American Psychiatric Association, *Treatment of Patients with Alzheimer's Disease and Other Dementias, Second Edition*, Washington, DC, 2007, http://psychiatryonline.org/content.aspx?bookid=28&sectionid=1679489#152606.

[155] See H. Brodaty and A. Cumming, "Dementia Services in Australia" *International Journal of Geriatric Psychiatry,* vol. 25 (2010), pp. 891-892; French National Plan at http://www.plan-alzheimer.gouv.fr/IMG/pdf/Plan_Alzheimer_2008-2012_uk.pdf, 39; and Department of Health, United Kingdom, "*Living Well With Dementia: A National Dementia Strategy,*" February, 2009, p. 57. Hereafter H. Brodaty et al., 2010.

Health Care Provider Training in Dementia and Alzheimer's Disease

A growing concern in Australia, England, and Scotland is the lack of training of primary care providers in the treatment of dementia and AD.[156] Additionally, France and Japan are concerned about the lack of resources for assessment.[157] An effort is underway under the auspices of the European Alzheimer's Disease Consortium (EADC) to assess the education and training of primary care providers in dementia and AD in Europe. The initial focus is to assess current levels of education and to determine what additional training is necessary to prepare providers to care for patients with dementia and AD.[158] Australia, the UK, and the United States emphasize improving primary care provider training in their National Plans.[159] Canada has also initiated specific training efforts for primary care providers described in the adjacent text box.

Primary Care Training in Canada

Canada is creating a memory clinic training program to increase primary care capacity in dementia and AD treatment. The memory clinic program aim is to create new infrastructure as well as improve the skills of family physicians and other primary care providers. The training program trains primary care providers who then become part of a memory clinic team. These teams then provide services to other primary care providers. Providers learn to distinguish normal aging from mild cognitive impairment and other forms of dementia and develop knowledge in a variety of treatments and care management. This program addresses the lack of geriatricians and other specialists in many areas, so that primary care providers must provide more specialized services.

Source: L. Lee, M. Kasperski, & W.W. Weston, Building capacity for dementia care, *Canadian Family Physician, 57 (July, 2011),* http://cognopedia.com/images/0/00/Developing_primary_care_memory_clinics_for_dementia.*pdf.*

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[156] H. Brodaty et al., 2010, p. 893 (Australia); and Department of Health, United Kingdom, "*Living Well With Dementia: A National Dementia Strategy,*" February, 2009, pp. 64-67; and, The Scottish Government, *Scotland's National Dementia Strategy*, June 201, pp. 3-4.

[157] See Alzheimer Plan 2008-2012: L'Engagement De Tous, *Alzheimer Plan 2008-2012: L'Engagement De Tous: Implementation as of 1st February, 2012*, February 1, 2012, p. 5; and S. Awata, "New National Health Program Against Dementia in Japan: The Medical Center For Dementia," *Psychogeriatrics*, vol. 10 (2010), p. 106. Hereafter referred to as S. Awata, 2010.

[158] M. Tsolaki et al., "Consensus Statement on Dementia Education and Training in Europe," *Journal of Nutrition, Health, and Aging*, vol. 14, no. 2 (February, 2010), pp. 131-135.

[159] For more information, see Department of Health, *Living Well with Dementia: A National Dementia Strategy*, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058; and, http://www.health.gov.au/internet/main/publishing.nsf/Content/B9616604C02332D5CA25701B0075A997/$File/NFAD%20low%20res%20Web%20Version%20Oct%2006.pdf; and U.S. National Alzheimer's Plan http://aspe.hhs.gov/daltcp/napa/NatlPlan.shtml.

Stigma Reduction Efforts

In a 2012 global survey of physicians by the pharmaceutical company Eli Lilly, physicians reported that stigma and denial made discussing a diagnosis with patients and their caregivers difficult. In this study, physicians in the UK and France reported the highest level of stigma.[160] Given the symptoms, the limited treatment options, the loss of abilities, and the progressive course of the disease, fear and anxiety in patients and families with dementia and AD are expected.[161] This fear can translate into avoidance, denial, and inaction leading to delays in seeking treatment and reporting symptoms to physicians.[162] Some individuals may believe that dementia and AD are a normal part of aging and may not recognize that medical treatment is necessary.[163]

The stigma surrounding the disease can increase the isolation of the patient and the caregivers because neighbors and friends may be reluctant to have contact with the patient and his or her family. One study surveying caregivers of patients with dementia and AD found that patients experienced a loss of social relationships and were treated differently by family and members of their social network.[164]

Stigma and Research

Another reported impact of stigma appears to be increased difficulty recruiting patients and their families for research studies, especially in the early stages of the disease. Researchers attribute difficulties in recruitment to patients' and families' difficulty accepting the diagnosis, perception of limited benefit, and lack of time and resources.

Source: L. Garand et al., "Diagnostic Labels, Stigma, and Participation in Research Related to Dementia and Mild Cognitive Impairment," *Research in Gerontological Nursing*, vol. 2, no. 2 (April 2009), pp. 112-121.

The perception of exclusion by patients is corroborated by public attitudes in at least one country. A recent study by Alzheimer's Australia found significant negative attitudes toward people with dementia, including a desire to avoid those with the disease. The study found that the fear of being diagnosed with the disease was also common and could be a factor in stigma formation.[165]

Several countries have made combating the stigma surrounding the disease a central element in their National Plans.

Table 17 highlights the efforts included in the National Plans of the five focus countries.

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[160] Eli Lilly, Inc., "New International Survey Reveals Multiple Barriers to an Accurate and Timely Alzheimer's Disease Diagnosis" September 16, 2012, http://files.shareholder.com/downloads/LLY/2078942632x0x600635/5bd90bd0-2ac0-4cf7-9501-71d71f620446/LLY_News_2012_9_19_Product.pdf.

[161] Alzheimer's Disease International, *National Alzheimer and Dementia Plans Planned Policies and Activities: Early Detection, Access to Diagnosis and Stigma Reduction*, April 2012, p. 12, http://www.alz.co.uk/sites/default/files/national-alzheimer-and-dementia-plans.pdf.

[162] Ibid., and Department of Health, United Kingdom, "*Living Well With Dementia: A National Dementia Strategy,*" February 2009, pp. 25-30.

[163] Alzheimer's Disease International, *National Alzheimer and Dementia Plans Planned Policies and Activities: Early Detection, Access to Diagnosis and Stigma Reduction*, April 2012, p. 12, http://www.alz.co.uk/sites/default/files/national-alzheimer-and-dementia-plans.pdf.

[164] P. Werner and J. Heinik, "Stigma by Association and Alzheimer's Disease," *Aging and Mental Health*, vol. 12, no. 1 (2008), pp. 92-99.

[165] L. Phillipson et al., *Exploring Dementia and Stigma Beliefs: A Pilot Study of Australian Adults Aged 40-65*, Alzheimer's Australia, Paper 28, June 2012, http://www.alz.org/living_with_alzheimers_stigma.asp.

Table 17. Selected Global Stigma Reduction Efforts

National Plan		Selected Stigma Reduction Efforts
Australia		Survey of attitudes and public awareness programs
France		Survey of attitudes and public information campaign
Japan		Unable to locate information
United Kingdom		
	England	Public and professional information campaign Campaign to reduce vascular disease and VD
	Scotland	Publication on stigma Creation of a public information infrastructure
	Wales	Public information
United States		Mentioned, but no objective

Source: Alzheimer's Disease International, *National Alzheimer and Dementia Plans Planned Policies and Activities: Early Detection, Access to Diagnosis and Stigma Reduction*, April 2012, p. 12, http://www.alz.co.uk/sites/default/files/national-alzheimer-and-dementia-plans.pdf.

System Innovations in the Treatment of Dementia and Alzheimer's Disease

The National Plans of the five focus countries address two of the key issues in the treatment of dementia and AD: ensuring accurate and early diagnosis and improving pathways of care. Two of the five focus countries, France and Japan, have worked on these issues for long periods of time and have specific goals. These two countries' efforts are highlighted in this chapter because they describe in depth efforts to improve diagnosis and early treatment, coordinate medical treatment with social services, and create new dementia and AD-specific infrastructure.

France

France has had three national dementia and AD plans starting in 2001. In each plan, treatment is a prime focus. The first plan prioritized early diagnosis; creation of memory centers with staff able to provide accurate diagnosis; establishment of adult day centers and residential homes; and funding of research. Currently, France is prioritizing efforts in the following areas: changing the image of dementia to combat stigma; increasing support for care givers; coordinating care between providers; enabling more support at home; improving access to diagnostic and care pathways; increasing residential care; developing training for health professionals; and increasing resources for clinical research, epidemiology, public information, and ethics.[166]

The French treatment model envisions a continuum of care similar to the model of treatment presented earlier in this chapter (**Figure 10**); treatment evolves based on the disease stage. France aims to create the infrastructure to implement this model. Based on the two earlier plans, the most recent national plan

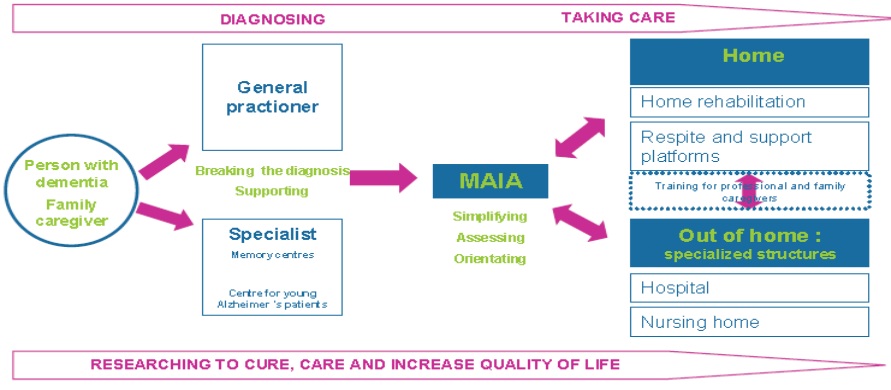
[166] Republique Francaise, *National Plan for Alzheimer and Related Diseases 2008-2012*, February 1, 2008, http://www.plan-alzheimer.gouv.fr/.

envisions an integrated pathway of care for those patients who depend and need long-term care services as shown in **Figure 11**.[167]

In this model, primary care providers and memory centers (specialized diagnosis and medical treatment centers) are the point of entry for patients for comprehensive services. The government is expanding the number of memory centers, currently 469, to ensure that all regions have a center. At the center of this new treatment plan is a new institution, the *Maison pour l'autonomie et l'integration des maladies d'Alzheimer* (MAIA), literally translated, "Home for the autonomy and integration of Alzheimer's Diseases." This model was piloted in 2009-2010 and, after some refinement, is being expanded in certain regions. These facilities' objective is to connect dependent dementia and AD patients to the services they need. The MAIA is designed to help families who are overwhelmed and/or lost in a maze of multiple and compartmentalized services.[168] In some cases, a special case manager is assigned to the patient. Evaluation indicates that MAIA reduces the number of different agencies that a patient comes into contact with, and it is hoped that the MAIA will reduce hospitalizations and other related problems. In 2011 there were 40 MAIA; France hopes to have a total of 500 MAIA by 2014.

Figure 11. French Treatment Pathway for Person with Dementia

As Envisioned in the Alzheimer Plan of France, 2012



Source: Republique Francaise, *Alzheimer Plan 2008-2012: L'Engagement de Tous,* Implementation as of 1st February 2012, http://www.plan-alzheimer.gouv.fr/IMG/pdf/Plan_Alzheimer_4th_anniversary-2.pdf, p. 4.

Notes: "MAIA" = Maison pour l'autonomie et l'integration des maladies d'Alzheimer, House for the autonomy and integration of Alzheimer's Diseases [literal translation].

France aims to integrate research with treatment, by creating a database of AD cases and related dementias, and is collecting data on patients from over 427 memory centers throughout metropolitan France and its overseas regions.[169] These memory centers can also facilitate clinical trials and treatment evaluations.[170] **Figure 12** illustrates the distribution of these centers throughout all regions. This database

[167] Republique Francaise, *Alzheimer Plan 2008-2012: Implementation as of 1st February 2012*, http://www.plan-alzheimer.gouv.fr/IMG/pdf/Plan_Alzheimer_4th_anniversary-2.pdf.

[168] Ibid., p. 5.

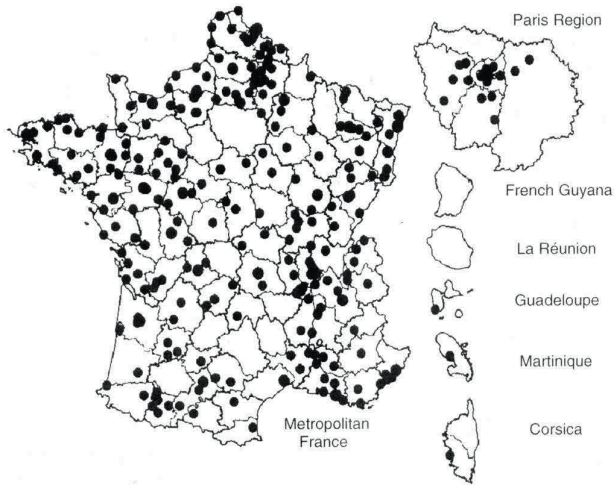
[169] France has overseas regions that are part of the French Republic and include French Guyana, La Reunion, Guadeloupe, and Martinique. The French island of Corsica also has a memory center.

[170] F. Le Duff, 2012.

will allow tracking of care and research on the course of the illness. Already France has collected data on almost 120,000 patients.

Figure 12. Distribution of Memory Centers in France and Overseas Regions Participating in Integrated Information Project

(for CY2010)



Source: F. Le Duff et al., "The 2008-2012 French Alzheimer Plan: Description of National Alzheimer Information System", *Journal of Alzheimer's disease,* 29 (2012), p. 894. Hereafter referred to as F. Le Duff, 2012.

France is also increasing the number of facilities such as cognitive-behavioral rehabilitation units, facilities for younger patients, adult day centers, and respite facilities.[171] The French plan also envisions reducing the use of psychiatric medications to control behavioral symptoms. Finally, a new health care provider, a gerontology care assistant, is being developed, and the number of physical and occupational therapists has increased.[172]

Japan

Japan introduced specific programs for dementia and AD in the late 1980s.[173] For instance, the Dementia Center for Elders (DCE) project was established in 1989 to improve local services provided in areas of medical treatment and community-based services. Given increasing numbers of patients, in 2008 Japan initiated the "Medical Centers for Dementia" (MCD).[174] The aim is to provide specialized medical services for dementia patients that are linked to community resources so as to build a comprehensive treatment network for patients. MCD provides: special medical consultations for dementia; differential diagnosis and early evaluation; medical treatment for any acute behavioral and psychological symptoms; education for general practitioners and community care providers; efforts to strengthen medical and

[171] Le Duff, 2012, p. 85.

[172] Ibid., p. 86.

[173] S. Awata, 2010.

[174] Awata, 2010, p. 105.

community care ties; and public information.[175] Japan's efforts include quality measures to ensure that all the appropriate services are provided. A special focus of the MCD effort is improving the connection between general practitioners, who may be the first medical professional making the diagnosis, and community support agencies. Japan reports that, as a result of these efforts, in one particular hospital the waiting times for consultation decreased dramatically and the number of services provided increased.[176]

[175] Ibid.

[176] Ibid., p. 106.

Chapter 3: Long-Term Care for Persons with Dementia and Alzheimer's Disease Among Selected Countries

Introduction

This chapter highlights particular government long-term care (LTC) initiatives and efforts in the five focus countries to assist individuals with dementia, including those with AD, as well as their caregivers. It is divided into three topic sections that describe the need for LTC among persons with dementia; the range of LTC services provided to such individuals; and government policies and programs to support informal caregivers of persons with dementia. Each section provides information regarding the provision of LTC in general in the five focus countries with specific information on the provision of LTC for persons with dementia, including AD, in these countries, where information is available.

Methodology

Information about LTC services for persons with dementia in the five focus countries was obtained from government websites and publications, professional journals, professional societies, and non-governmental organizations (NGOs) such as the Alzheimer's Association, Alzheimer's International, and Alzheimer's Europe. This information is limited by language barriers and the availability of up-to-date public information on these topics. This chapter highlights global trends as well as selected government programs and initiatives in the five focus countries. However, given the different sources of information, there is variation in the level of information and country-specific detail provided. Thus, the information presented in this chapter is selective and is not meant to be representative of efforts in the five focus countries to address dementia and AD. In addition, this information is descriptive and is not meant to be an evaluation or comparative analysis of government programs or policies nor is it meant to suggest any statement about the relative merit of government programs or policies in these countries. Finally, there are different cultural norms, institutional systems and structures, public and private financing mechanisms, and public policies that affect the delivery of LTC to persons with dementia in each identified country. Including a comprehensive discussion of these factors for each country is beyond the scope of this report.

Long-Term Care for Persons with Dementia

Individuals with dementia, including AD, generally have both medical and non-medical needs. Medical needs related to dementia include diagnosis, regular assessment, and symptom management, including prescription drug therapy. Non-medical needs may include assistance with personal care activities or other support services that can assist individuals to live independently. Moreover, the health and social services needs for persons with dementia can be complex and may change over time as individuals' needs or conditions change. Often such needs intensify as persons with dementia progress through more advanced and debilitating stages of illness. Thus, individuals with dementia, including AD, often develop a need for care over an extended period of time, or long-term care.

What is Long-Term Care?

Long-term care (LTC) refers to a broad range of health and social services or supports needed by individuals who lack the capacity for self-care due to a physical disability or condition, or due to a mental disability or cognitive impairment, such as dementia. Such persons may need assistance or supervision in self-care activities over an extended period of time.

The need for LTC is generally measured, irrespective of age and diagnosis, by the presence of functional limitations in the ability to perform basic activities of daily living (ADLs), or by the need for supervision or guidance with ADLs because of a mental or cognitive impairment such as Alzheimer's Disease and related dementia. ADLs generally refer to activities such as eating, bathing, using the toilet, dressing, walking across a small room, and transferring (i.e., getting in or out of a bed or chair). Instrumental activities of daily living (IADLs) are also used to measure a person's need for LTC. These activities are necessary for an individual's ability to live independently in the community. IADLs include activities such as preparing meals, managing money, shopping for groceries or personal items, performing housework, using a telephone, doing laundry, getting around outside the home, and taking medications.

Formal caregiving refers to LTC that is provided by health professionals who may be employed by a third-party, such as a nursing facility or home care provider. *Informal caregiving* refers to LTC that is provided by family members, friends, or neighbors. A substantial portion of LTC is provided by informal caregivers.

In general, LTC services for persons with dementia can be grouped into the following three categories: (1) post-diagnostic services, (2) home and community-based services, and (3) continuing care services. The following provides examples of services in each of these categories.[177]

- Post-diagnostic services—these are services to individuals with dementia and their caregivers that assist them in planning for the future; that offer information about and referral to various local health and social service providers; and that stress counseling and other types of individual or group support.
- Home and community-based services (HCBS)—these are services such as personal care, meals, and housework that allow individuals with dementia and their families to remain at home for as long as possible. Other services include adult day health services and programs; respite care for informal caregivers; and planned opportunities for social engagement of the dementia care recipient.
- Continuing care—this category of services encompasses various options for housing with supportive services, such as assisted living residences or nursing home care for persons who can no longer stay in their own home and need supervised care (e.g., in a small group home) or in an institutional living arrangement (e.g., a residential LTC facility).

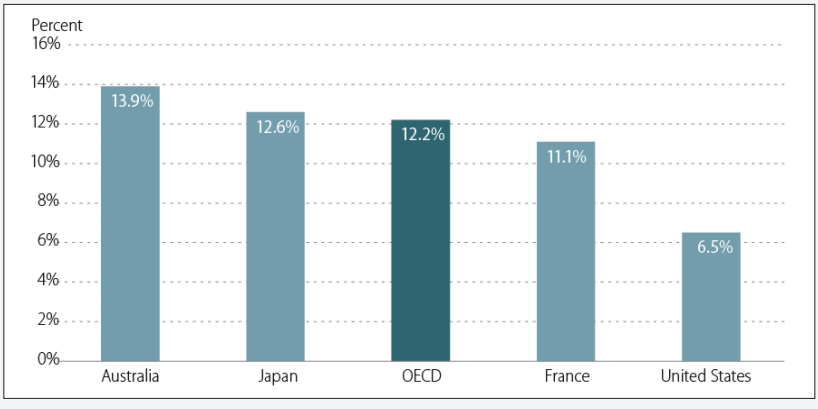
[177] World Health Organization (WHO), *Dementia: A Public Health Priority*, 2012, http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html.

Who Receives Long-Term Care?

While the need for LTC varies among individuals over the lifespan, the probability of needing and using LTC increases with age. According to the World Health Organization (WHO), individuals age 80 and over are six times more likely to receive LTC than those ages 65 to 79.[178] **Figure 13** provides information on the percent of the population aged 65 and over receiving LTC in Australia, Japan, France, and the U.S., as well as the OECD average. Data from the WHO show that the number of LTC recipients as a share of the population 65 and older was 12.2% on average across OECD countries in 2009. Australia had a higher than average share of the older population receiving paid care at 13.9% followed by Japan at 12.6%. France and the United States were lower than the OECD average at 11.1% and 6.5%, respectively. Variation in receipt of paid long-term care across the five focus countries may be related to differences in public and private financing arrangements, access to care providers, and cultural norms specific to each country, among other factors.

Figure 13. Percent of Population Aged 65 and Over Receiving Long-Term Care (LTC) in Selected Countries

(2009 or nearest year)



Source: Organization for Economic Cooperation and Development (OECD), *Health at a Glance 2011: OECD Indicators*, 2011, pp. 168–169, http://dx.doi.org/10.1787/health_glance-2011-en.

Notes: LTC recipients are defined as persons receiving LTC by paid providers and include recipients of cash benefits through consumer-choice or cash allowance programs. Data for Australia do not include recipients who access Veterans' Home Care Program and those who access services under the National Disability Agreement. Data for Japan underestimate the number of recipients in institutions because many elderly people receive LTC in hospitals. Data for France refer to people aged 60 and over. Data for the United States refer to 2007 for home care recipients and 2004 for recipients in institutions. Data for the UK are not available.

Long-Term Care in the Focus Countries

For persons with dementia who are in need of LTC, most care is provided within the country's existing LTC system. Among the five focus countries, there is wide variation in the financing and delivery of long-term care. As a result, access to and coverage of LTC services for persons with dementia, including the types and amount of coverage, varies considerably. The following provides a general overview of the LTC financing and delivery systems in each focus country. Information about specific dementia care eligibility criteria or services are provided where information is available.

[178] Organization for Economic Cooperation and Development (OECD), *Health at a Glance 2011: OECD Indicators*, 2011, http://dx.doi.org/10.1787/health_glance-2011-en.

Australia

Australia's federal government has primary responsibility for planning and funding LTC for the aged (persons aged 65 years and older) while states and territories plan and fund services to persons under age 65 with disabilities.[179] Aged care services are financed through taxes, with the provision of services largely focused on community care. The Aged Care Program includes home care and residential care services as well as service-integrated housing to individuals with a range of LTC needs. LTC delivery to older Australians is administered by the federal and state governments through public and private organizations. Eligibility for these care programs is assessed by Aged Care Assessment Teams (ACAT) that independently determine eligibility for residential care or home-based support packages based on need. Specialized home-based care packages provide services for persons with dementia. Some LTC services require copayments and/or are means-tested. Tax offsets exist for individuals whose private LTC expenditures exceed an annual threshold. Australia also provides targeted benefits to eligible informal caregivers such as cash allowances through the pension system and respite care services through a network of providers.

France

Public funding for the provision of LTC in France is provided through the public health insurance system and a social insurance system of cash support that individuals may use toward the cost of LTC. The public health insurance system covers health care services for persons who require LTC due to a chronic or acute medical condition, including institutional care and at-home nursing care. The French government also provides certain individuals aged 60 and older who also have ADL limitations with an allowance called the Allocation Personnalisée d'Autonomie (APA). Older individuals who live at home or in a community residential care setting can use the APA toward their LTC expenses. The APA is financed through general revenues funded jointly by the central and regional governments, and administered at the regional level. Those who meet the disability test are eligible for a cash benefit which is based on level of need. Benefit amounts are reduced for individuals with higher incomes. Covered LTC expenses under the APA are those identified under a personalized support plan that is established by a social-medical team. Certain tax deductions or exemptions are also available to eligible individuals for their LTC expenses. France also has a well-developed private Long-Term Care Insurance (LTCI) market, which covers individuals in both individual and group markets. In 2010, private LTCI in France covered the equivalent of 15% of the population aged 40 and older.[180] Private LTCI benefits are paid in cash similar to the public assistance program.

Japan

Japan's government has a mandatory social insurance program that covers LTC for citizens aged 65 and older.[181] LTC coverage is also available to individuals ages 40 to 64 due to an age-related illness such as dementia. The LTCI program requires all individuals aged 40 and over to contribute premiums; the benefit is managed by municipal governments. About 50% of the LTC costs are covered through government taxes (national, prefectural, and municipal), with the remaining half covered through

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[179] Information for this section was obtained from the following sources: Henry Brodaty and Anne Cumming, "Dementia services in Australia," *International Journal of Geriatric Psychiatry*, vol. 25 (2010), pp. 887–895; and Francesca Colombo, Ana Llena-Nozal, Jérôme Mercier, et al., *Help Wanted? Providing and Paying for Long-Term Care*, *Australia: Long-Term Care*, OECD Health Policy Studies, OECD Publishing, 2011, http://dx.doi.org/10.1787/9789264097759-3en.

[180] Francesca Colombo, Ana Llena-Nozal, Jérôme Mercier, et al., *Help Wanted? Providing and Paying for Long-Term Care*, *France: Long-Term Care*, OECD Health Policy Studies, OECD Publishing, 2011, http://dx.doi.org/10.1787/9789264097759-3en; data from an earlier study report 3 million policyholders in 2007, from Blanche LeBihan and Claude Martin, "Reforming Long-Term Care Policy in France: Private-Public Complementarities," *Social Policy & Administration*, vol. 44, no. 4 (2010), pp. 392–410.

[181] Mary-Jo Gibson, Steven R. Gregory, and Sheel M. Pandya, *Long-Term Care in Developed Nations: A Brief Overview*, AARP Public Policy Institute, October 2003.

insurance premiums. Those who receive care through the program are responsible for a 10% copayment, with those receiving public assistance responsible for a smaller share (2%). The program pays for public or private LTC services by certified providers in institutions, community-based settings, or in the home. Eligibility criteria are uniform across Japan with individual eligibility based on an assessment by a municipal specialist that establishes an applicant's level of impairment. Accepted applicants work with a care manager, in consultation with care providers, to develop a service plan.

United Kingdom

Long-term care services in the UK are financed by the National Health Service (NHS), by local authorities, charities, and out-of-pocket payments. Institutional LTC services, such as nursing facility care, are publicly financed under the NHS and are free at the point of service with access to such services based on need for care. However, most formal LTC is considered social care with government provided care as a separate means-tested benefit. Under the UK's LTC system, Wales, England, Scotland, and Northern Ireland manage their LTC systems separately. Access to publicly funded LTC services in the UK is mainly through an assessment of care needs coordinated by the local authority social services department.[182] Benefits include a range of home care and residential care services. The UK also has two non-means tested cash benefits, one for older disabled persons with personal care needs and one for informal caregivers called a Caregiver's Allowance.

United States

In the United States, LTC services are financed by a variety of public and private sources such as Medicaid, Medicare, private health and LTCI, and private out-of-pocket payments. The majority of LTC is paid for by public programs such as Medicaid, a means-tested program financed jointly by federal and state governments. Medicaid funds services for beneficiaries in both institutional settings and HCBS, though the portfolio of services offered differs substantially by state. Federal law requires state Medicaid programs to cover nursing facility services for Medicaid beneficiaries in need of LTC. States also have the option of offering a range of HCBS. This flexibility has led to widespread variation in state Medicaid benefit packages offered to the elderly and younger persons with disabilities. Medicaid eligibility for LTC is determined according to the state's functional eligibility requirements where beneficiaries must demonstrate a need for such care, among other requirements.[183] Private financing for LTC includes both out-of-pocket costs and some private LTCI. In 2008, about 11% of the population aged 55 and older and 12% of the population aged 65 and older owned a LTCI policy.[184]

Range of Long-Term Care Services Provided

In general, LTC services for persons with dementia are provided within each country's existing health and social services delivery systems. This next section provides information from selected health indicators with respect to the range of LTC services and settings in the five focus countries. Information presented in this section broadly describes home care services and continuing care services and is not necessarily specific to persons with dementia or AD. Information presented in this section highlights particular aspects of LTC for persons with AD and related dementia in the five focus countries, where information is available.

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[182] Adelina Comas-Herrera, Linda Pickard, Raphael Wittenberg, et al., *The English Long-Term Care System*, European Network of Economic Policy Research Institutes (ENEPRI), Research Report No. 74, May 2010.

[183] Pierre Moise, Michael Schwarzinger, Myung-Yong Um, et al., *Dementia Care in 9 OECD Countries: A Comparative Analysis*, OECD Health Working Papers, 2004.

[184] CRS Report R40601, *Factors Affecting the Demand for Long-Term Care Insurance: Issues for Congress*, by Janemarie Mulvey.

One challenge among focus countries is providing coordinated and integrated LTC across the continuum of health and social services delivery to persons with AD and other forms of dementia. The need for service coordination among persons with AD and related dementia becomes greater over the course of disease. As a result, some countries, such as France, are working toward a more person-centered approach to care that involves greater care coordination between their health and LTC systems (see text box entitled France: Care Coordination).

France: Care Coordination

France's National Alzheimer's and Related Diseases Plan for 2008 through 2012 includes, as a stated objective, strengthening coordination between actors such as hospitals, practitioners, day care centers, AD centers, social services, and home care workers, who are involved in the care and treatment of individuals with AD. The goal of the Maisons Pour L'Autonomie Et Intégration Des Malades Alzheimer (MAIA) model is to reduce uncertainty for patients and families regarding whom to contact and how to negotiate and coordinate the provision of health and LTC services. The MAIA model creates a one-stop shop through which individuals diagnosed with AD and related dementia can enter the health and LTC systems. MAIAs provide a single-point of contact through professionals known as "coordonnateurs" ("case managers") who provide personalized support to patients with AD and their families. Such professionals coordinate both medical and social interventions for AD patients and are also responsible for follow-up and on-going support for patients and their families through the disease course. According to France's AD Plan this system, which was initially designed for AD patients, will be extended to all elderly individuals with LTC needs.

Source: WHO, *Dementia: A Public Health Priority*, 2012, http://www.who.int/mental health/publications/dementia_report_2012/en/index.html; 3rd French National plan for "Alzheimer and related diseases" 2008–2012 (English version), June 2008, http://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Plans/France#fragment-1.

Home Care Services

The majority of individuals with dementia worldwide live at home in the community.[185] According to research from the OECD, in almost all countries studied, between half and three quarters of paid LTC is provided in home-care settings to persons who need LTC regardless of diagnosis or condition.[186] The WHO notes that most individuals with chronic conditions, including those with dementia, would prefer to remain in their homes for as long as possible. Moreover, there appears to be broad support among the focus countries for keeping older individuals in need of LTC, including persons with dementia, in their homes.[187] In intermediate to late stages of dementia formal home care services may support informal caregivers, particularly when there is a greater burden of care on the informal caregiver. Data indicate older LTC recipients (those ages 80 and older) are less likely to receive home-care than younger recipients which may indicate the current role of institutional care for persons with dementia where advanced age is a risk factor for AD.

According to the WHO, many OECD countries have engaged in efforts to expand the provision of LTC to individuals in their own homes. **Figure 14** provides information on the share of each country's LTC recipients that receive home care in the U.S., Australia, and Japan, as well as the OECD average. In most countries for which trend data are available, data show that the number of persons receiving care at home has increased over the past decade. This trend, in part, may be attributed to countries introducing programs to promote the delivery of LTC at home through expanded support of HCBS. The share of LTC recipients receiving care at home is greatest in Japan at 77.0% and has increased at a much faster rate in that country compared to Australia and the United States, where just over half of LTC recipients receive care at home (54.4% and 50.6%, respectively).

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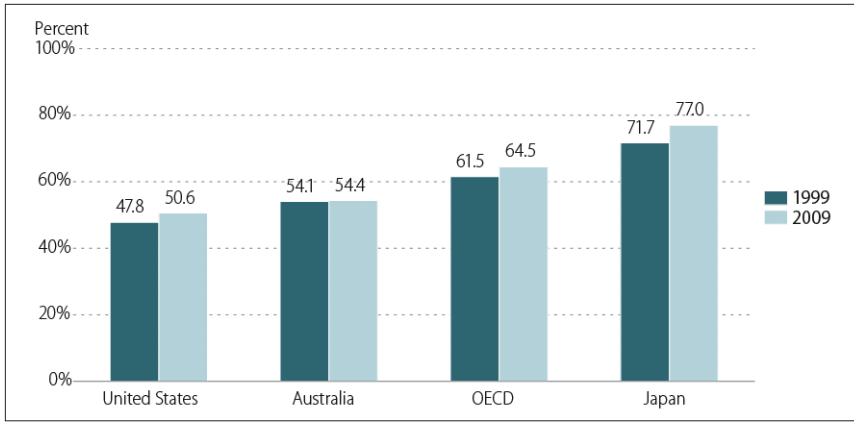
[185] Ibid., p. 53.

[186] Ibid., p. 42.

[187] Pierre Moise, Michael Schwarzinger, Myung-Yong Um, et al., *Dementia Care in 9 OECD Countries: A Comparative Analysis*, OECD Health Working Papers, 2004.

Figure 14. Share of Long-Term Care Recipients Receiving Care at Home

(1999 and 2009 or nearest year)



Source: Organization for Economic Cooperation and Development (OECD), *Health at a Glance 2011: OECD Indicators*, 2011, pp. 168–169, http://dx.doi.org/10.1787/health_glance-2011-en.

Notes: LTC recipients are defined as persons receiving LTC by paid providers and include recipients of cash benefits through consumer-choice or cash allowance programs. Data for Australia do not include recipients who access Veterans' Home Care Program and those who access services under the National Disability Agreement. Data for the United States refer to 1999 and 2007 for home care recipients. Data for France and the United Kingdom are not available.

Some research suggests a common core of home care services is provided across countries; although definitional differences in the types of services make analogous comparisons between countries difficult.[188] Research suggests that there may be wider inter-country variation in the provision of HCBS than in the provision of institutional services. Other studies note that the extent and level of services may vary among countries.[189] Despite these variations, the HCBS core services identified include: needs assessment, advice and counseling, support groups, respite care, crisis management, support centers, adult day health services and programs. Core services also include home care such as assistance with personal care activities or meals, and increasingly a range of residential housing options with services (e.g., sheltered housing, group homes, and retirement communities). Researchers also suggest that a dementia diagnosis can be a barrier to accessing appropriate care.[190]

In general, home and community-based services (HCBS) for persons with dementia are provided within each country's existing LTC delivery system (see **Table 18**). In a comparative analysis of nine OECD countries, which included the five focus countries, researchers found that most countries did not provide dementia-specific home care services. Thus, dementia care is often integrated within the larger LTC delivery system which includes care for persons with physical and developmental disabilities. One exception is Australia, which has introduced the Extended Aged Care at Home Dementia (EACHD)

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[188] Martin Knapp, Adelina Comas-Herrera, Ami Somani, et al., *Dementia: international comparisons, Summary report for the National Audit Office*, Personal Social Services Research Unit, London School of Economics and Political Science and Section of Mental Health and Ageing, The Institute of Psychiatry, King's College London, May 2007.

[189] Pierre Moise, Michael Schwarzinger, Myung-Yong Um, et al., *Dementia Care in 9 OECD Countries: A Comparative Analysis*, OECD Health Working Papers, 2004.

[190] Martin Knapp, Adelina Comas-Herrera, Ami Somani, et al., *Dementia: international comparisons, Summary report for the National Audit Office*, Personal Social Services Research Unit, London School of Economics and Political Science and Section of Mental Health and Ageing, The Institute of Psychiatry, King's College London, May 2007.

Program, a package of targeted home care services for individuals with AD and other forms of dementia (see Text Box entitled Australia: Home Care Packages).

Table 18. Available Home and Community-Based Services and Dementia Services

Country	Home Care Services	Dementia Services
Australia	Domestic assistance, personal care, home-delivered meals, adult day health services, community nursing, transportation, home modification and maintenance, and social support	Information services, education, support groups, counseling, respite support
France	Home nursing care; cash support for service plan that covers costs associated with home and community-based services, such as hiring caregivers (including certain family members) or home modifications, service plan includes case management services	Programs and services offered in memory centers which are involved in early diagnosis and treatment (greater medical focus than social services focus)
Japan	Home care, adult day health services, assistive devices, and minor home remodeling	Many services are covered: at home they include a home helper (housekeeping and personal care), visiting nurse, bathing, remodeling, assistive devices; outside of home they include institutional services including nursing homes, homes with more medical service, chronic-care hospitals. Additionally, caring costs in private nursing homes and dementia group homes are covered.
United Kingdom	Home care (home help), meals services, visiting services, support for caregivers, day activities, equipment and adaptations to the home, respite care, alarm systems, direct payments	Range of specialist residential services and community-based dementia services, memory clinics, respite care, information for caregivers
United States	Case management, homemaker/home health aide services, personal care services, adult day health services, meals services, habilitation, respite care, non-medical transportation, home modifications, adult day health services	Group residential settings, special care units in LTC facilities, Alzheimer's Disease Centers, counseling and information services

Source: Martin Knapp, Adelina Comas-Herrera, Ami Somani, et al., *Dementia: international comparisons, Summary report for the National Audit Office*, Personal Social Services Research Unit, London School of Economics and Political Science and Section of Mental Health and Ageing, The Institute of Psychiatry, King's College London, May 2007; Henry Brodaty and Anne Cumming, "Dementia services in Australia," *International Journal of Geriatric Psychiatry*, vol. 25 (2010), pp. 887–895; WHO, *Dementia: A Public Health Priority*, 2012, http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html; Inge Cantegreil-Kallen, Clément Turbelin, Pierre Angel, et al., "Dementia management in France: Health care and support services in the community," *Dementia*, vol. 5, no. 3 (2006), pp. 317–326.

Australia: Home Care Packages

The Australian government has made a concerted effort to support the preference of many older individuals to remain in the community with the policy goal of shifting the balance of care for the aged from residential to home care settings. The WHO notes that in response to projected increases in the number of persons with dementia, the Australian government has developed comprehensive plans and systems including specific services to address symptoms of AD and dementia. Since 1992, the government has provided individually tailored packages of community LTC services for older individuals that are planned and managed by an approved provider. Australia provides the following home care programs and services, often referred to as "packages" for older individuals. One type of home care in particular, the Extended Aged Care at Home Dementia (EACHD) Program, provides specialized services for persons with dementia, including AD. Services such as respite care are also available to support caregivers.

Commonwealth Home and Community Care (HACC)—Provides services that support older persons to stay in their home and be more independent in the community. Services include domestic assistance; personal care; assistance with food preparation and meal delivery; adult day health centers; community nursing; podiatry; physical therapy; speech pathology; transportation; home modification and maintenance; and social support. HACC services also include support for caregivers, including respite. HACC services are available to persons aged 65 and older (50 and older for Aboriginals and Torres Strait Islanders) who are at risk of admission to long-term residential care and their caregivers. As of July 1, 2012, HACC is funded by the Australian government in most territories with the exception of Western Australia and Victoria.

Community Aged Care Packages (CACP)—Provides a package of services for older individuals with complex care needs that assists them to remain in their own homes. CACP is targeted towards those who would be eligible for low-level residential care. CACP packages are individually planned and coordinated services that are tailored to the recipient's individual care needs. The package provides the following types of services: meal preparation; laundry; personal care assistance; social support; home help; transportation; and temporary in-home respite care. CACP packages are funded by the Australian Government with approved providers receiving a daily subsidy per package to provide services and coordinate care. Care may be provided by a variety of local organizations, but is planned by the approved service provider. Recipients may be required to contribute up to 17.5% of the maximum basic pension rate toward the cost of their care; additional contribution amounts may apply to those with higher incomes (but no more than 50% of the higher income).

Extended Aged Care at Home and Extended Aged Care at Home for Dementia (EACH and EACH D)—Provides a package of services for frail older individuals that assists them to remain in their own homes. EACH packages are targeted towards those who would be eligible for high-level residential care. Service packages are individually planned and coordinated services that are tailored to meet the recipient's individual care needs. EACH D provides a package of services for frail older individuals with dementia to assist them to remain in their own homes. EACH D packages are specifically targeted towards dementia care recipients who experience behavioral or psychological symptoms that impact their quality of life. EACH and EACH D packages provide the following types of services: registered nursing care; care by an allied health professional such as a physiotherapist or podiatrist; personal care, transportation to appointments; social support; home help; and assistance with oxygen and/or eternal feeding. EACH and EACH D packages are funded and administered similarly to the CACP program.

Source: Henry Brodaty and Anne Cumming, "Dementia services in Australia," *International Journal of Geriatric Psychiatry*, vol. 25 (2010), pp. 887–895; For more information on these programs see http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-cacp-guidelines.htm1; WHO, *Dementia: A Public Health Priority*, 2012, http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html.

Continuing Care Services

Most high-income countries are moving away from institutional care provided to older persons and persons with mental health conditions, including dementia, placing greater priority on home and community-based care.[191] Despite this shift to community service provision, the role of continuing care services, including institutional and other types of residential care that provide both housing and LTC services, remains an important setting for dementia care delivery. The OECD finds that persons in the late stages of dementia almost always require continuous care; as a result they are often admitted to a LTC facility where 24-hour supervision is provided. Moreover, two key predictors of admission to a LTC institution for persons with dementia are severity of dementia and lack of adequate informal caregiving.[192]

[191] WHO, *Dementia: A Public Health Priority*, 2012, http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html.

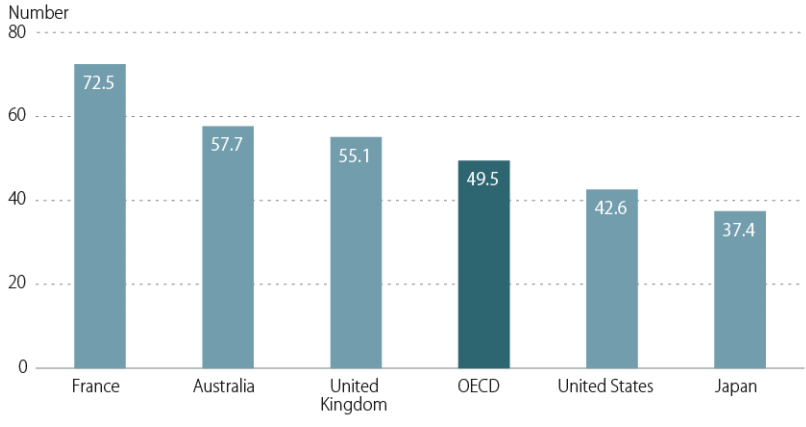
[192] Pierre Moise, Michael Schwarzinger, Myung-Yong Um, et al., *Dementia Care in 9 OECD Countries: A Comparative Analysis*, OECD Health Working Papers, 2004.

Long-Term Care Facilities

One measure that provides some information about the availability of resources to deliver LTC outside of the home is the number of LTC beds in institutions and hospitals in each country. However, it is difficult to compare data on LTC facility settings by country because there is no uniform definition for a LTC facility, other than the recognition that most persons are admitted to such settings as full-time residents. **Figure 15** provides information on LTC beds in institutions and hospitals in the five focus countries and the OECD average. Across OECD countries there were approximately 50 beds in LTC institutions and hospitals per 1,000 persons aged 65 and over. LTC institutions in this analysis refer to nursing and residential facilities that provide housing and services as a package. Among the five focus countries, France had the highest LTC bed per older person ratio, followed by Australia and the UK. The ratios for the United States and Japan were lower than the OECD average. While most institutional beds are in LTC facilities, some countries use hospitals for LTC purposes. According to the WHO, Japan has a large number of hospital beds that have traditionally been used for LTC.[193]

Figure 15. Long-Term Care Beds in Institutions and Hospitals

(Per 1,000 population Aged 65 and Over)



Source: OECD, *Health at a Glance 2011: OECD Indicators*, 2011, pp. 174–175, http://dx.doi.org/10.1787/health_glance-2011-en.

Notes: LTC institutions refer to nursing and residential care facilities which provide accommodation and services as a package. Variation in data coverage exists across countries.

An OECD comparative analysis of nine OECD countries, which includes the five focus countries, found that LTC facilities tend to admit individuals based on the level of care needed, regardless of disease type (see **Table 19**). Thus persons with dementia are assessed similarly to other persons with physical, developmental, or other cognitive impairments. Facilities may also tailor services to residents with a certain level of care need, such as low, medium, or high. As a result, persons with late-stage dementia, and in particular those with behavior problems, who tend to require higher levels of care, may have greater difficulty with admissions to facilities. Facilities may have policies that restrict or deny admission to certain individuals. For example, a survey of French residential facilities found that some may impose restrictions in accepting individuals with behavior problems.[194]

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[193] OECD, *Health at a Glance 2011: OECD Indicators*, 2011, http://dx.doi.org/10.1787/health_glance-2011-en, pp. 174–175.

[194] 3rd French National plan for "Alzheimer and related diseases" 2008–2012 (English version), June 2008,

In most countries, once admitted to a care setting, dementia residents receive the same care as other residents. However, some research indicates that specialist dementia services in institutions and other residential care homes have been developed or are in the process of being developed in many countries, including France, the UK, and the United States. Those services include special dementia care units within larger facilities or specialist dementia care facilities.[195] According to the OECD, the aim of specialized care is not to isolate dementia care residents but rather to facilitate care that can enhance quality of life as well as reduce the burden to personnel.[196] In an attempt to address access and care burden issues, one objective of the French AD plan is to improve residential care for persons with AD and dementia through increased use of specialized units in facilities, as well as emphasize smaller residential care settings; both would provide additional staffing and trained personnel for dementia residents with behavior problems.

Table 19 provides data on the number of LTC beds and rate of bed growth between 2000 and 2009, where information is available. Average annual growth rates of LTC beds, separately shown for institutions and hospitals, reveal that countries such as France and the UK experienced relatively little growth in institutional LTC beds and declines in LTC hospital beds from 2000 to 2009. Other countries such as Japan and Australia (institutional data only available) experienced growth in LTC beds over this time period. Increases in LTC beds over the past decade may reflect demand for institutional services in certain countries due to an aging population as well as government policies that provide greater coverage and financing for institutional care, among other factors. Conversely, stagnation or decline in the rate of LTC beds may reflect government policies that have emphasized home care and as a result may have shifted public financing away from institutional care toward home and community-based settings. Estimates of the proportion of residents with dementia receiving institutional care are also provided in **Table 19**. Countries also report a substantial proportion of residents with dementia in LTC facilities. Three out of four focus countries for which data are available report about half or more residents in LTC facilities with dementia.

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http://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Plans/France#fragment-1.

[195] Martin Knapp, Adelina Comas-Herrera, Ami Somani, et al., *Dementia: international comparisons, Summary report for the National Audit Office*, Personal Social Services Research Unit, London School of Economics and Political Science and Section of Mental Health and Ageing, The Institute of Psychiatry, King's College London, May 2007.

[196] Pierre Moise, Michael Schwarzinger, Myung-Yong Um, et al., *Dementia Care in 9 OECD Countries: A Comparative Analysis*, OECD Health Working Papers, 2004.

Table 19. Long-Term Care (LTC) Facilities

Country	Eligibility	Number of LTC Beds	Average Annual Growth Rate of LTC Beds (2000–2009)[a]		Residents with Dementia	Other Information
			Institu-tions	Hospitals		
Australia	Persons with a high level of disability and care needs, assessed by ACATs	143,000	7.8%	NA	50% to 55% of people with dementia in residential care[b]	Dementia is not a specific condition for admission; funding is provided by the Australian Government according to the Resident Classification Scale (RCS)
France	Persons who require long-term care due to a chronic or acute medical condition	684,159[c]	0.3%	-6.1%	Not available	LTC facilities are defined as medicalized institutions where medical care is provided; institutional care is a covered service under the public health insurance system
Japan	Persons aged 65 and older needing nursing care who are insured by LTCI	NA	3.6%	3.3%	30% of nursing facility residents had dementia[d]	Dementia is one of 15 age-related diseases that determine eligibility for LTCI; nursing care is provided by local government or private licensed providers
United Kingdom	Persons eligible for local authority funded services who pass the means test; eligibility criteria set by the local authority	441,335[e]	NA	NA	60% of persons in care homes have dementia	Institutional care includes residential care homes and nursing homes, and long-stay hospitals. Long-stay hospital coverage is under the National Health Service
United States	Persons in need of LTC generally measured by limitations in activities of daily living or need for supervision in such activities	1,704,182[f]	0.9%	-1.9%	48.40%[f]	LTC facilities include either skilled nursing facilities (SNFs) or nursing facilities (NFs) certified to participate in Medicare and/or Medicaid

Source: Martin Knapp, Adelina Comas-Herrera, Ami Somani, et al., *Dementia: international comparisons, Summary report for the National Audit Office*, Personal Social Services Research Unit, London School of Economics and Political Science and Section of Mental Health and Ageing, The Institute of Psychiatry, King's College London, May 2007; Pierre Moise, Michael Schwarzinger, Myung-Yong Um, et al., *Dementia Care in 9 OECD Countries: A Comparative Analysis*, OECD Health Working Papers, 2004; OECD, *Health at a Glance 2011: OECD Indicators*, 2011, http://dx.doi.org/10.1787/health_glance-2011-en, pp. 174–175.

Notes: ACAT = Aged Care Assessment Teams; LTC = long-term care; LTCI = long-term care insurance; NA = not available.

a. "Institutions" data for France is from 2003 to 2007; "Hospitals" data for United States is from 2000 to 2007, from OECD, *Health at a Glance 2011: OECD Indicators*, 2011, http://dx.doi.org/10.1787/health_glance-2011-en.

b. Henry Brodaty and Anne Cumming, "Dementia services in Australia", *International Journal of Geriatric Psychiatry*, vol. 25 (2010), pp. 887–895.

c. 2009 data, as reported in Marie-Eve Joël, Sandrine Dufour-Kippelen, Catherine Duchêne, et al., "Long-Term Care in France", European Network of Economic Policy Research Institutes (ENEPRI), Research Report No. 77, June 2010.

d. Data from the late 1990s, as reported in Martin Knapp, Adelina Comas-Herrera, Ami Somani, et al., *Dementia: international comparisons, Summary report for the National Audit Office*, Personal Social Services Research Unit, London School of Economics and Political Science and Section of Mental Health and Ageing, The Institute of Psychiatry, King's College London, May 2007.

e. 2006 data for England, as reported in Martin Knapp, Adelina Comas-Herrera, Ami Somani, et al., *Dementia: international comparisons, Summary report for the National Audit Office*, Personal Social Services Research Unit, London School of Economics and Political Science and Section of Mental Health and Ageing, The Institute of Psychiatry, King's College London, May 2007.

f. American Health Care Association, *Nursing Facilities' Operational Characteristics Reports*, June 2012, analysis of Centers for Medicare and Medicaid Services (CMS) Form 1539 data; and American Health Care Association, *Nursing Facilities' Patient Characteristics Report, June 2012*, analysis of CMS Form 672 data.

In general, providing LTC in institutions is more expensive than home-based care. Yet, researchers caution against the assumption that government policies that attempt to shift the balance between institutional and community-based care will achieve cost-savings for providers or payers.[197] Others note that continuing care options may be a more appropriate and effective way to provide for the LTC needs of persons with dementia, particularly in advanced stages of illness and in the absence of informal or other community-based supports.[198] This has led countries to explore alternative models of residential care delivery, such as those in small group homes that provide an intermediate level of care that may fall somewhere between home care and institutional care.

Alternative Residential Care Models

Approaches to alternative residential care models focus on care that is patient-centered with respect to the patient's preferences and needs. Services are arranged to support older persons with dementia to maintain their autonomy and quality of life. These alternative models tend to focus on a psycho-social model of care delivery that emphasizes normalization of daily life for persons with dementia with a focus on both psychological and social aspects of behavior. These care settings differ from traditional institutional care settings that emphasize a medical model of care delivery in which the focus is on curative care and treatment of disease. As there is no cure for dementia yet, care delivery has shifted toward development of various purpose-built environments, which offer residential care that emphasizes a psycho-social model of care delivery. Such approaches also consider the importance of the physical environment in the provision of dementia care. For example, residential care settings might include features such as communal kitchens and living rooms, outdoor seating areas and gardens, private bedrooms, and in some models private bathrooms. Some care settings encourage residents to bring their own furniture and decorations. According to researchers, some studies have suggested that small, home-like environments can be beneficial to older persons with dementia.[199]

Table 20 provides a brief summary of various models of small, home-like residential care environments in each of the five focus countries across certain characteristics including their physical setting, the number of residents, residents' characteristics, and domestic characteristics and care concepts found in each model. In general, these smaller residential settings provide care to anywhere from 5 to 15 residents. Physical features that are similarly found in these settings include common spaces such as kitchens,

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[197] Martin Knapp, Adelina Comas-Herrera, Ami Somani, et al., *Dementia: international comparisons, Summary report for the National Audit Office*, Personal Social Services Research Unit, London School of Economics and Political Science and Section of Mental Health and Ageing, The Institute of Psychiatry, King's College London, May 2007.

[198] WHO, *Dementia: A Public Health Priority*, 2012, http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html.

[199] Hilda Verbeek, Erik van Rossum, Sandra M.G. Zwakhalen, et al., "Small, home-like care environments for older people with dementia: a literature review," *International Psychogeriatrics*, vol. 21, no. 2 (2009), pp. 252–264.

dining areas, and living rooms. Care to persons in these settings is typically focused around daily life with resident opportunities to participate in daily household or housekeeping activities. Some models have a home for life care concept where care needs may intensify as residents' needs increase over time, it is expected that individuals will receive care in these settings until their death. (As a further example of small group homes for persons with dementia, see Text Box entitled Japan: Small Group Homes.)

Table 20. Selected Models of Residential Care Settings for Persons with Dementia

Model (Country)	Physical Setting	Number of Residents	Residents' Characteristics	Domestic Characteristics	Care Concept
CADE units (Australia)	Purpose built environment; proximity to local community	8–14	Moderate to severe dementia; ambulant, with no significant physical problems; behaviorally disturbed; few psychiatric problems	Opportunities to participate in household activities; familiar decor	Based on normalization; staff work patiently at the resident's pace; needs of the resident take precedence over the needs of the unit; staff include registered nurses and residential care assistants
Cantou (France)	Community living in a separate enclosed area; large kitchen and living room, with adjacent private bedrooms	12–15	Senile dementia	Participation in daily activities	Non-medical, communal care; stable multi-purpose staff; home for life
Domus philosophy (United Kingdom)	Purpose built facility or conversion of existing facility; private bedroom with shared bathroom and living room	9–12	Dementia, requiring intensive nursing care; elderly psychiatric patients		Psychological/ emotional needs of residents above physical aspects; emphasis on maintaining independence and residual capacities; home for life
Green House (United States)	Self-contained semi-attached private homes; large kitchen and living room, with adjacent private bedrooms and bathrooms	7–10	Dementia-specific or general nursing home level of care	Garden/fireplace; participation in typical home activities	Social model with necessary clinical care; emphasis on competence; universal worker concept where direct care worker provides housekeeping and personal care assistance
Group Homes (Japan)	Self-containing residences or attached to larger facility	5–9	Mild to moderate dementia	Residents participate in daily housekeeping, if possible	Care around daily life; specialized in-home care services with mutual support for elderly with dementia

Source: Excerpted from Hilda Verbeek, Erik van Rossum, Sandra M.G. Zwakhalen, et al., "Small, home-like care environments for older people with dementia: a literature review", *International Psychogeriatrics*, vol. 21, no. 2 (2009), pp. 252–264.

Japan: Small Group Homes

Research suggests that the establishment of the LTCI program in Japan has led to innovative models for care delivery, many of which are directed at assisting those with dementia. In particular, Japan has introduced small group homes, many in rural areas, as an intermediate level of care between home and institutional care for persons with dementia. In 2000, there were approximately 369 group homes nationwide; by 2006 that number had increased to 8,052. Authors suggest that the growth of group homes increased not only because of the LTCI program, which reorganized the way LTC is paid for in Japan, but changes to government policies created new opportunities for care delivery in the private sector. One model program, Welfare Foundation Zenjinkai located in Iwate Prefecture, provides adult day health services to those with dementia, but does not exclusively target such persons. For those with dementia, Zenjinkai also offers a hotel and two group homes. Other group-living units in Japan exist within traditional nursing homes. Traditional nursing homes in Japan are based on a medical model where residents usually share bedrooms. These smaller group residential units provide a home like environment where residents have a private room with common areas, such a dining rooms, to facilitate interaction between residents and staff. There are also stable staff assignments in these homes. Some evidence suggests that residents with dementia have improved quality of life in Japan's small group-living situations compared to their traditional nursing homes.

Source: John W. Traphagan and Tomoko Nagasawa, "Group Homes for Elders with Dementia in Japan," *Care Management Journals*, vol. 9, no. 2 (2008); Miharu Nakanishi, Taeko Nakashima, and Kanae Sawamura, "Qualify of life of residents with dementia in group-living situation: an approach of creating small, homelike environments in traditional nursing homes in Japan," *Nihon Koshu Eisei Zasshi*, Institute for Health Economics and Policy, vol. 59, no. 1 (2011).

Informal Caregiving

Informal caregivers are often referred to as the backbone of the LTC system.[200] However, it is also noted that variation exists across countries in the use of informal caregiving relative to formal LTC providers. In developed countries the presence of informal caregiving may reflect the extent of available formal services and providers, financial support provided by governments to encourage informal caregiving, as well as cultural norms concerning the role of family members in providing needed care. The following provides information about informal caregiving to persons with dementia with some data on caregiving to those in need of LTC, including persons with AD and related dementia. The next sections provide selected information on programs and policies in the five focus countries that can assist caregivers such as targeted services or interventions to reduce caregiver stress and burden, financial support to caregivers, and respite care services and programs.

Caregiving to Persons with Dementia

Informal caregiving to persons with dementia encompasses a wide range of activities and assistance that may change over time as the needs of the care recipient progress. In early stages of dementia, informal caregivers may support family members in accessing the health care and social services systems and communicating with providers. For persons with moderate to severe dementia, caregiving activities may include assistance with personal care needs, such as bathing, dressing, or eating, as well as other activities that are necessary for community living, such as shopping, managing medications, and preparing meals. In addition, caregivers may also arrange, supervise, or pay for formal care provided to the care recipient. For persons with dementia, the availability of informal care may influence the amount of formal care a beneficiary receives. As dementia progresses into later stages of the illness and individuals develop greater care needs the role of informal caregiving may shift to formal care providers, if available.[201]

The OECD comparative analysis of dementia care found that support for informal caregivers is a shared policy goal among the countries studied, including the five focus countries. As dementia care has shifted

[200] WHO, *Dementia: A Public Health Priority*, 2012, http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html.

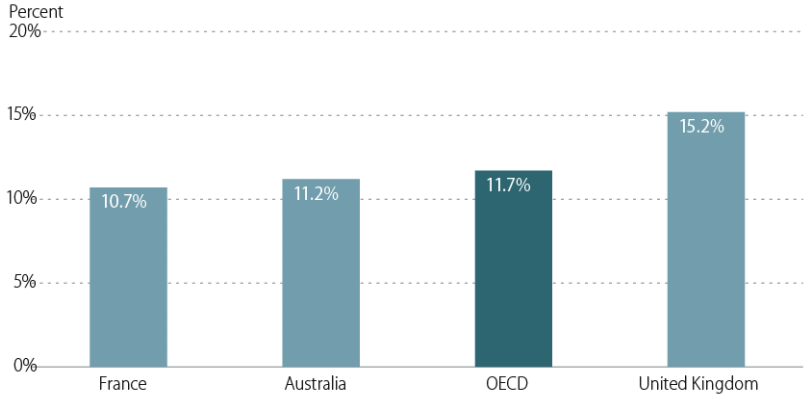
[201] Martin Knapp, Adelina Comas-Herrera, Ami Somani, et al., "Dementia: international comparisons," Summary report for the National Audit Office. Personal Social Services Research Unit, London School of Economics and Political Science and Section of Mental Health and Ageing, The Institute of Psychiatry, King's College London, May 2007.

to community-based settings, researchers have noted that the role of informal caregiving is an essential element. According to the WHO, there is some concern that there may be too few informal caregivers over the long term as globally the number of persons with dementia is projected to increase substantially. Demographic trends, such as smaller family sizes, may limit the number of available caregivers to persons with dementia, as well as the capacity for caregivers to provide needed care. Increased labor market participation among women, who traditionally have assumed the role of informal caregiver, may make them unavailable to take on this role as well.[202]

Figure 16 provides information about the percentage of the population reporting to be caregivers in France, Australia, and the UK, compared to the OECD average. In OECD countries, on average, during a period around 2007, one-in-nine persons aged 50 and older reported providing assistance with activities of daily living (ADLs) for a relative, regardless of diagnosis or condition. A higher proportion of the population 50 and older reported providing care in the UK than in France or Australia. The higher proportion of family members reporting that they provided care to relatives may be associated with limited availability of accessible or affordable paid LTC and/or government policies that financially support informal caregiving.

Figure 16. Percent of Population Aged 50 and Over Reporting to be Informal Caregivers

(around 2007)



Source: OECD, *Health at a Glance 2011: OECD Indicators*, 2011, http://dx.doi.org/10.1787/health_glance-2011-en, pp. 170-171.

Notes: Informal caregivers are defined as persons aged 50 and older providing assistance to a family member with basic activities of daily living (ADLs) for at least one hour per week. Data are based on national and international health surveys; OECD estimates based on the 2005-2007 HILDA survey for Australia; the 2007 BHPS survey for the United Kingdom, and the 2004-2006 SHARE survey for other European countries. Survey results may be affected by reporting biases and recall problems. Data were not reported for Japan and the United States.

Family members are most likely to provide informal care, and most informal caregivers are women. On average, about two-thirds (66%) of caregivers ages 50 to 64 in OECD countries are women. Adult children or spouses tend to take primary responsibility for informal caregiving. However, different cultural norms about responsibility for providing care for aging parents exist across countries. One example is in Japan where changing attitudes about the responsibility of adult children, and in particular

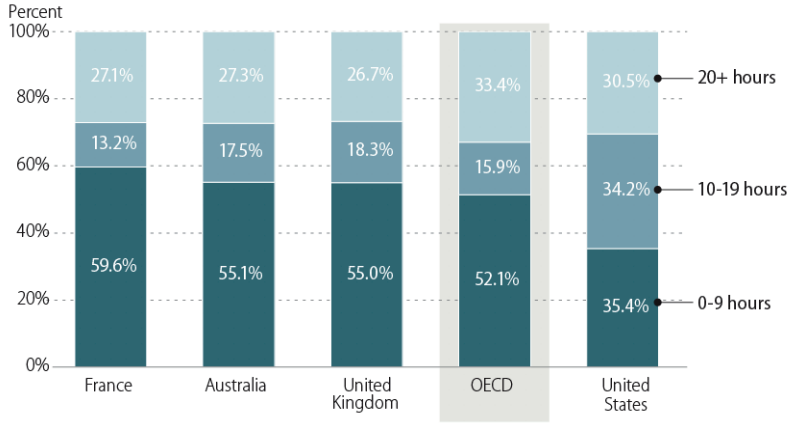
[202] U.S. Congress, House Committee on Foreign Affairs, Subcommittee on Africa, Global Health, and Human Rights, *Global Strategies to Combat the Devastating Health and Economic Impacts of Alzheimer's Disease*, 112th Cong., 1st sess., June 23, 2011, H.Hrg. 112-96 (Washington: GPO, 2011).

daughters-in-law, to care for elderly parents has led to changes in approaches to care, such as coverage of formal care including adult day health centers.[203]

Figure 17 provides information on the percent distribution of informal caregivers providing certain hours of care in France, Australia, the U.S., and the UK as well as in comparison to the OECD average. On average, across OECD countries the majority (52%) of informal caregivers reported providing less than 10 hours of care per week. In the United States, 34% of informal caregivers reported providing 10 to 19 hours of care per week, a percentage twice the OECD average and greater than any of the other focus countries. It may be that efforts in certain focus countries to reduce caregiver burden, possibly through formal care for those with significant LTC needs, reduce the amount of time informal caregivers may spend providing needed care.

Figure 17. Percent Distribution of Weekly Hours of Care Provided by Informal Caregivers

(around 2007)



Source: OECD, *Health at a Glance 2011: OECD Indicators*, 2011, http://dx.doi.org/10.1787/health_glance-2011-en, pp. 170-171.

Notes: Informal caregivers are defined as persons aged 50 and older providing assistance to a family member with basic activities of daily living (ADLs) for at least one hour per week. Data are based on national and international health surveys; OECD estimates based on the 2005-2007 HILDA survey for Australia; the 2007 BHPS survey for the United Kingdom, and the 2004-2006 SHARE survey for other European countries; and the 2006 HRS survey for the United States which includes care provided for parents only. Survey results may be affected by reporting biases and recall problems. Data were not reported for Japan.

Caregiver Interventions

Some observers have expressed concern over the stress informal caregivers to persons with dementia may experience, particularly in caring for persons with advanced stages of illness. In addition to memory loss, persons with moderate to advanced dementia may have challenging behavioral symptoms that include failing to recognize the caregiver, a tendency to become lost in familiar places or frequently wandering from home. Other behavioral problems that can pose challenges to caregivers include repeated questioning, aggression, and disturbed sleeping. These behaviors can be emotionally and physically stressful for caregivers. Some research suggests that there may be adverse health outcomes related to

[203] Nanako Tamiya, Haruko Noguchi, and Akihiro Nishi, et al., "Population ageing and wellbeing: lessons from Japan's long-term care insurance policy," The Lancet, vol. 378, pp. 1183-1192.

caregiving, including elevated blood pressure, an impaired immune system, and potential increased risk for cardiovascular disease.[204] Research has also documented high levels of depressive symptoms and other mental health problems among those who provide care compared with those who do not. In particular, higher levels of depression are associated with caregivers assisting those individuals with dementia. Studies in the United States have shown that about 30% of dementia caregivers suffer from depression, and more than 40% report high levels of emotional stress as a result of caregiving.[205]

Most focus countries offer information, education, and training programs, to help informal caregivers provide care to persons with dementia as well as provide emotional support for the caregiver role. Many of these dementia-specific programs are provided through AD organizations and in some countries the government provides funding to support these initiatives. One example of such a program in Australia aims to provide individuals in early stages of dementia and their caregivers with information, education, and support with diagnosis and treatment of the disease and its symptoms.

Australia's National Dementia Support Program

The Australian government funds Alzheimer's Australia to deliver the National Dementia Support Program (NDSP) which provides a range of programs and services for persons with early stages of dementia and their caregivers. Some of these programs and services are described below, many of them are free of charge:

- The National Dementia Helpline–provides a centralized telephone number for persons with dementia, family members, and caregivers seeking advice, information, and referral services.
- Dementia and Memory Community Centers–provides a range of services including counseling, recreational activities, education courses, and informational resources to persons with dementia, family members, and caregivers.
- The Living with Memory Loss Program–provides individuals with dementia and their caregivers with a structured group program that provides participants with information, advice and peer support to assist them in understanding the condition and in planning for the future. Persons with dementia and their caregivers meet separately in small groups for 2 hours a week for seven weeks.[206]
- Counseling and Caregiver Support Groups–provides the opportunity for persons with dementia, their family members, and caregivers to discuss issues confidentially or with others in similar situations in supportive environments with skilled counselors.
- Education and Training–provides a nationally accredited competency based training course in dementia for families and dementia caregivers and others who work with persons with dementia.

Source: Alzheimer's Australia, http://www.fightdementia.org.au/about-us/what-we-do.aspx.

Other caregiver interventions have been developed to specifically target stress and burden associated with caregiving to persons with dementia. In the United States, the REACH II intervention to reduce stress and burden among caregivers to persons with AD has shown positive improvements to caregiver quality of life through clinical trials.

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[204] Carolyn C. Cannuscio et al., "Reverberation of Family Illness: A Longitudinal Assessment of Informal Caregiver and Mental Health Status in the Nurses' Health Study," *American Journal of Public Health*, vol. 92, iss. 8, pp. 1305-1311; Nadine Marks et al., "Transitions to Caregiving, Gender, and Psychological Well-Being; A Prospective U.S. National Study," *Journal of Marriage and Family*, vol. 64, no. 3, pp. 657-667.

[205] Kenneth E. Covinsky et al., "Patient and Caregiver Characteristics Associated with Depression in Caregivers of Patients with Dementia," *Journal of General Internal Medicine*, vol. 18 (2003), pp. 1006-1014.

[206] Sallyanne Aarons, "Living with Memory Loss: A Program for People with Early Stage Dementia and their Carers: A Case Study," *Clinical Psychologist,* vol. 7, no. 1 (2003), pp. 63-66.

United States: Resources to Enhance Caregiver Health II (REACH)

Resources for Enhancing Alzheimer's Caregiver Health II (REACH II) is an intervention designed to reduce stress, burden, and depression in caregivers of persons with AD and dementia. Funded by the NIH and tested in a randomized clinical trial, the intervention aims to improve caregivers' ability to provide self-care, provide caregivers with social support, and help caregivers learn how to manage difficult behaviors in care recipients. REACH II was also designed to address the needs of culturally diverse caregivers of persons with AD and dementia, including White, Hispanic, and African-American caregivers. The REACH II protocol includes a variety of targeted intervention strategies selected to address the caregiver's needs that are based on an individualized assessment.

Intervention strategies include: the provision of educational information; skills training to manage care recipient behaviors; social support; cognitive strategies for reframing negative emotional responses; and strategies for enhancing healthy behaviors and managing stress. Methods used in the intervention include: didactic instruction, role-playing, problem-solving tasks, stress management techniques, and telephone support groups. Results from the REACH II intervention show improvements in caregiver quality of life for all racial and ethnic caregiver groups. Compared to caregivers who did not receive the intervention, REACH II caregivers reported better self-rated health, sleep quality, physical health, and emotional health, which was related to less burden with their caregiving role. REACH II has also been effective in delaying the time of institutionalization in individuals with AD and dementia, so that are able to spend more time at home with their families and loved ones.

The REACH II intervention has been disseminated in the United States through the Administration on Aging (AoA) and the Department of Veterans Affairs (VA). NIH is also looking to disseminate the REACH II intervention internationally. Most recently, efforts have been undertaken to adapt the intervention to caregivers in Hong Kong.

Source: Amanda F. Elliott, Louis D. Burgio, and Jaime DeCoster, "Enhancing Caregiver Health: Findings from the Resources for Enhancing Alzheimer's Caregiver Health II Intervention," *Journal of the American Geriatrics Society,* vol. 58, no. 1 (2010); SAMHSA's National Registry of Evidence-Based Programs and Practices: Resources for Enhancing Alzheimer's Caregiver Health II (REACH II), http://nrepp.samhsa.gov/ViewIntervention.aspx?id=129; U.S. Congress, House Committee on Foreign Affairs, Subcommittee on Africa, Global Health, and Human Rights, *Global Strategies to Combat the Devastating Health and Economic Impacts of Alzheimer's Disease*, 112th Cong., 1st sess., June 23, 2011, H.Hrg. 112-96 (Washington: GPO, 2011).

Financial Support

In the five focus countries government policies that provide financial support to informal caregivers either in the form of tax relief or direct financial support may assist dementia caregivers. While these policies are not specifically targeted at dementia caregivers, financial support can assist family members who may make employment and other workplace adjustments to provide dementia care, such as reducing paid employment hours or taking a leave of absence from paid work to care for a relative with dementia. Some countries provide allowances directly to caregivers to help compensate. Other countries provide cash payments that are paid directly to persons with disabilities. In the five focus countries these policies include caregiver payments (Australia and UK); cash allowances to beneficiaries that can pay informal caregivers (France and the United States); and tax relief (France and the United States). **Table 21** provides a brief description of selected government financial support programs and benefits in the five focus countries.

Table 21. Financial Support Programs for Informal Caregivers

Country	Program Description
Australia	Caregiver Support–Provides a Carer Payment, which is considered financial support to caregivers to persons with a severe disability or medical condition, or a frail older individual, who are unable to work in paid employment because they provide full-time daily care. The Carer Payment is subject to an income and assets test and individuals may not receive a Carer Payment and another income support payment such as an Age Pension. The Carer Payment rate for a single individual in 2012 is $712 Australian dollars (AUD) per month ($739 U.S.). Also provides a Carer Allowance to informal caregivers providing care at the caregiver's or care recipient's home. The Carer Allowance is not subject to income and assets tests and is not taxable. In 2012, the Carer Allowance is $114 AUD per month ($118 U.S.). Informal caregivers receiving either the Carer Payment or Carer Allowance are also eligible for an annual Carer Supplement of up to $600 AUD per year ($623 U.S.), per person who qualifies the caregiver for other financial support.
France	Cash Allowance to Beneficiaries—Provides a personalized allowance to individuals age 60 and older in need of LTC services who meet a needs test (L'Allocation personnalisée d'autonomie). Individuals with income above a certain threshold receive a benefit reduction. There are four benefit levels with a maximum benefit amount for each level. In 2007, benefit amounts ranged from up to 525 Euros ($667 U.S.) in the lower level of dependency to 1,245 Euros ($1,582 U.S.) in the highest level of dependency, with an average benefit amount 494 Euros ($628 U.S.). The cash benefit pays for a benefit package that is defined by care professionals. Family members can be hired as informal caregivers, with the exception of spouses. Tax Policy–Offers the following tax benefits: income tax reduction for the out-of-pocket costs associated with hiring and individual to support with personal care activities; exemption from employer contributions for individuals aged 70 and older who hire a personal care provider; income tax reduction to individuals living in institutions for out-of-pocket costs associated with their care.
Japan	Not Applicable–Does not provide financial support to caregivers. Japan's Long-Term Care Insurance System provides formal LTC services directly to older individuals, which provide paid services that may supplement informal caregiving or provide respite to caregivers.
United Kingdom	Caregiver Support–Provides a caregiver's allowance, which is considered compensation to the informal caregiver for loss of earnings, instead of a wage for providing informal care. In 2010, the allowance, which amounts to £58.45, or approximately $93 U.S., a week is provided to informal caregivers who provide at least 35 hours of informal care per week, earn less than £100 (or $159 U.S.) per week, and are not full-time students or receiving any qualifying disability benefits.
United States	Tax Policy–Offers tax relief to employed family caregivers, which includes the dependent care tax credit (DCTC) and the exclusion from income for employer-provided dependent care assistance programs (DCAP). Other tax provisions may provide indirect assistance to family caregivers, regardless of employment status. These provisions are: (1) the dependency exemption, (2) the head of household filing status, and (3) deductions for unreimbursed medical expenses. Rules regarding eligibility and other limitations sometimes restrict the use of these benefits for certain taxpayers. Cash Allowance to Beneficiaries—State Medicaid programs may offer beneficiaries the ability to hire family members to provide care. Under these consumer-directed service delivery models, the Medicaid beneficiary may receive a cash allowance for their LTC services that they can then use to pay an informal caregiver, including family members. In some situations, spouses and other legally liable relatives can be hired to provide personal care.

Source: Pierre Moise, Michael Schwarzinger, Myung-Yong Um, et al., *Dementia Care in 9 OECD Countries: A Comparative Analysis*, OECD Health Working Papers, 2004; Information for Australian obtained from Australian Government, Department of Human Services web-site, at http://www.humanservices.gov.au/customer/themes/carers; Information for France obtained from Barbara DaRoit and Blanche LeBihan, "Similar and Yet So Different: Cash-for-Care in Six European Countries' Long-Term Care Policies," *The Milbank Quarterly*, vol. 88, no. 3, 2010, pp. 286-309; and WHO, *Dementia: A Public Health Priority*, 2012, http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html; Information for UK obtained from Adelina Comas-Herrera, Linda Pickard, Raphael Wittenberg, et al., *The English Long-Term Care System*, European Network of Economic Policy Research Institutes (ENEPRI), Research Report No. 74, May 2010; Information for the United States from CRS Report RL34123, *Family Caregiving to the Older Population: Background, Federal Programs, and Issues for Congress*, by Kirsten J. Colello.

Note: All currency conversion amounts were obtained by using the XE currency conversion tool found at http://www.xe.com. For Australia, currency conversion from Australian dollars to U.S. dollars was obtained for November 9, 2012. For France, currency conversion from Euros to U.S. dollars was obtained for January 1, 2007. For the UK, currency conversion from British pounds to U.S. dollars was obtained for November 9, 2012, eligibility rules and benefit amounts were obtained from the following sources: http://www.dwp.gov.uk/docs/benefitrates2012.pdf and http://www.carersuk.org.

Respite Care

Most countries also support informal caregivers in general through respite care programs and services. Respite care provides caregivers with a temporary break from caregiving responsibilities, with the aim of reducing caregiver stress and associated burden. The term "respite care" is used to describe a range of services from paid care provided in the home, to community-based care provided in a adult day health center, to residential care provided for a short duration in a care home or nursing facility. Respite care is typically the most requested form of support by caregivers. Some focus countries indicate that demand for respite care services is greater than the available supply. For example, in Japan respite care appointments must be made weeks in advance in many areas, which may be difficult for informal caregivers needing access to respite care in emergencies or time-limited situations.[207] **Table 22** mentions selected respite care programs and benefits in the five focus countries; descriptive information is provided when available.

[207] Nanako Tamiya, Haruko Noguchi, and Akihiro Nishi, et al., "Population ageing and wellbeing: lessons from Japan's long-term care insurance policy," The Lancet, vol. 378, pp. 1183-1192.

Table 22. Selected Respite Care Services: Community-Based and Residential

Country	Community-Based Respite Care	Residential Respite Care
Australia	Network of adult day health centers and in-home respite services with at least one Carer Respite Center in each region; centers have pooled funds, or brokerages, which can be used to purchase short-term or emergency respite care; centers are encouraged to develop respite care services and link caregivers to appropriate respite care services including residential respite care; benefit is non-means tested.	Annual subsidies for short-term care in aged care homes for person who need temporary residential care; may be used on a planned or emergency basis. The benefit is means-tested.
France	Therapeutic day care centers and respite centers	Respite Hospitalization Program; respite care associated with group living is restricted to persons with dementia living in residential institutions
Japan	Day care, day care with rehabilitation	Short-stay respite care in an institutional setting; group living for the elderly with dementia; provides up to one week of respite stay per month for care recipients in the highest level of disability and shorter periods for lower levels of disability
United Kingdom	Day care respite, which is restricted to persons living at home; sitter services	Respite admissions to hospitals and nursing homes, or residential homes
United States	State Medicaid programs can offer in-home respite care and adult day health services as covered services to beneficiaries in need of LTC who typically have a level of care need that is equivalent to nursing facility care.	Limited provision of residential respite care options that are provider specific, mostly financed privately.

Source: Pierre Moise, Michael Schwarzinger, Myung-Yong Um, et al., *Dementia Care in 9 OECD Countries: A Comparative Analysis*, OECD Health Working Papers, 2004; Information for Australia from Gibson, Mary-Jo, Steven R. Gregory, and Sheel M. Pandya, *Long-Term Care in Developed Nations: A Brief Overview*, AARP Public Policy Institute, October, 2003; Joost van Hoof, Helianthe S.M. Kort, and Hugo van Waarde, "Housing and care for older adults with dementia: a European perspective," *Journal of Housing and the Built Environment*, vol. 24 (2009), pp. 369-390; Nanako Tamiya, Haruko Noguchi, and Akihiro Nishi, et al., "Population ageing and wellbeing: lessons from Japan's long-term care insurance policy," *The Lancet*, vol. 378, pp. 1183-1192.

Chapter 4: Prevalence of Dementia and Alzheimer's Disease in Low- and Middle-Income Countries

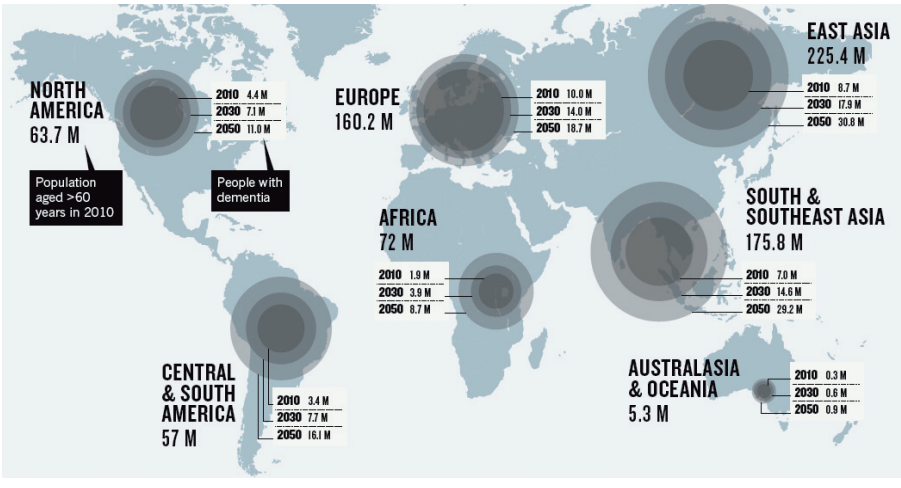
Introduction

This chapter will discuss the prevalence of dementia and Alzheimer's disease in middle and low-income countries, the unique challenges facing these regions, and the international efforts being undertaken to address and raise awareness about mental health issues, including dementia.

Prevalence

According to WHO, an estimated 35.6 million people are living with dementia worldwide as of 2010. This population is projected to nearly double every 20 years (**Figure 18**).[208] Researchers are developing a stronger understanding about dementia and its prevalence[209], though the bulk of prevalence data that WHO collects continues to be sourced mostly from high-income countries.[210]

Figure 18. Estimated and Projected Prevalence of Dementia by Region



Source: Alison Abbott, "A Problem for Our Age," *Nature*, vol. 475 (July 14, 2011), p. S3.

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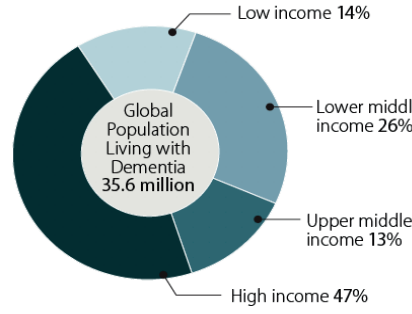
[208] WHO, *Dementia: A Public Health Priority*, 2012, p. 2, http://whqlibdoc.who.int/publications/2012/9789241564458_eng.pdf.

[209] Prevalence is the percentage of a population that is infected with a particular disease at a given time.

[210] The income groups are: low income, ≤$1,025; lower middle income, $1,026-$4,035; upper middle income, $4,036-$12,475; and high income, ≥$12,476. See http://data.worldbank.org/about/country-classifications/country-and-lending-groups.

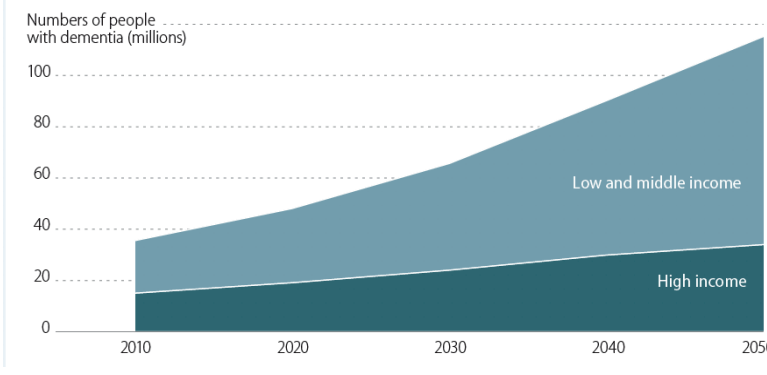
WHO estimates that more than half of global dementia cases occur in low- and middle-income countries (LMIC, **Figure 19**),[211] where this is projected to become a growing problem should prevalence continue to rise as expected (**Figure 20**). LMIC are an aggregate of countries with gross national income (GNI) ranging from <$1,025 through $12,475 (**Figure 21**). In 2010, roughly 53% of dementia cases were in LMIC. By 2050, WHO expects 70% of all cases to be found in the region.[212]

Figure 19. Share of Global Dementia Cases by Income Group, 2010



Source: Created by CRS from WHO, *Dementia: A Public Health Priority*, p. 13.

Figure 20. Estimated and Projected Prevalence of Dementia by Income Group



Source: Edited by CRS from WHO, Dementia: A Public Health Priority, 2012, p. 19.

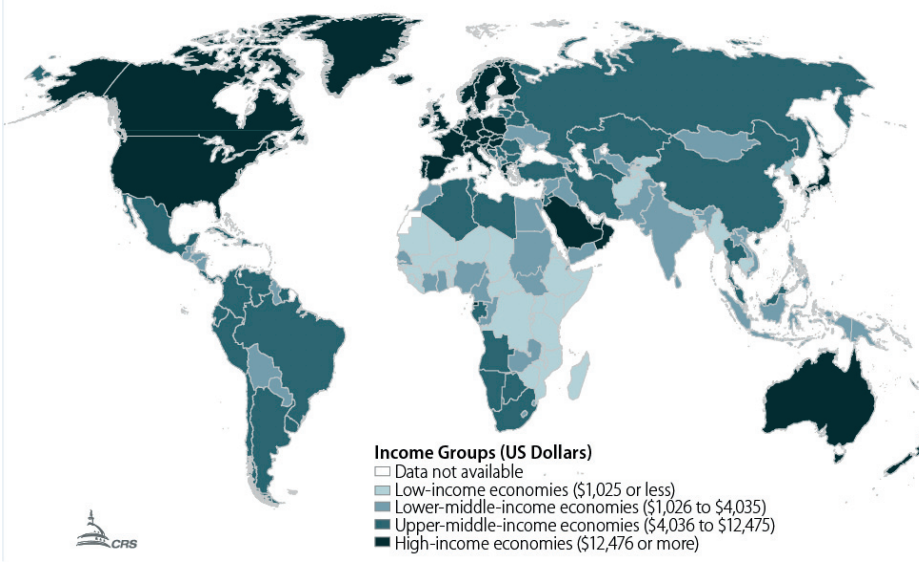
Challenges Facing Low- and Middle-Income Countries

In high-income countries, familial efforts to care for those affected by dementia are augmented by pharmaceutical therapies and formal care provided in institutional and home- and community-based settings, which are often funded through insurance or other governmental programs. In the majority of LMIC, however, low awareness of dementia and its impact are reflected in few government policies and programs aimed at addressing the disease. As a result, care for people living with dementia in these regions falls predominantly on families. This dynamic exemplifies unique challenges facing people living

[211] WHO, *Dementia: A Public Health Priority*, 2012, p. v.
[212] Ibid, p. 13.

with dementia in these regions, as well as their caretakers. The section below highlights additional challenges.

Figure 21. Map of World Bank Income Groups, 2011



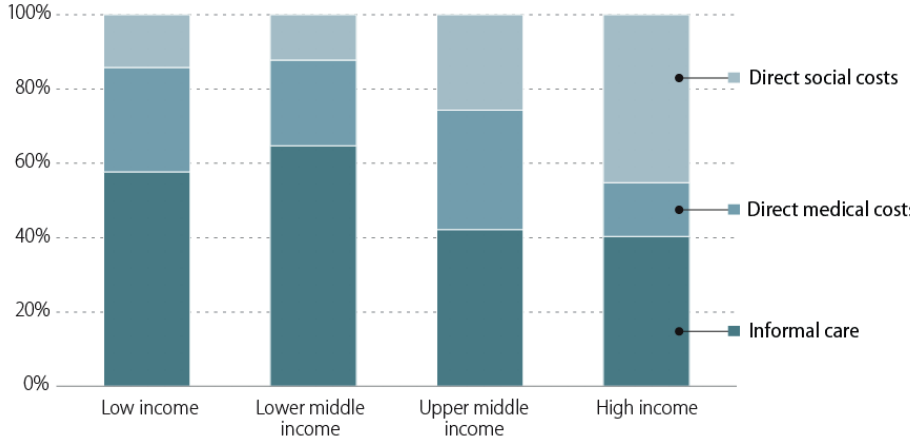
Source: Created by CRS based on the World Bank's income groups categories. See http://data.worldbank.org/about/country-classifications/country-and-lending-groups.

Cost of Care

WHO estimates that total global spending on care for people living with dementia reached $604 billion in 2010.[213] Roughly 90% of those resources were spent in high-income countries. Support for people with dementia is funded differently across the world. In high-income countries, roughly 40% of associated costs are borne by the family through informal care, whereas in LMIC, nearly 60% are (**Figure 22**). Health insurance or other social safety net schemes are typically employed in high-income countries to alleviate some of the financial burden associated with caring for loved ones with dementia. Such fiduciary supports are not widely available in most LMIC (**Figure 23**) and the formal social care sector in these areas is ill-equipped (**Figure 24**), requiring families to assume not only the cost of care, but also the delivery of care. WHO estimates that while 30% of people with dementia live in assisted living facilities or nursing homes in high-income countries, only 11% do in LMIC.

[213] Unless otherwise indicated, data in this paragraph was taken from WHO, *Dementia: A Public Health Priority*, 2012.

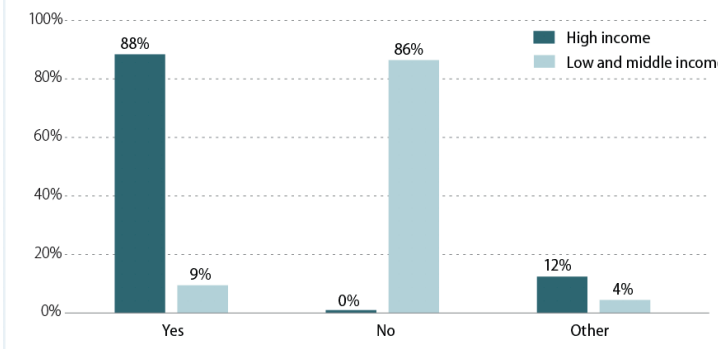
Figure 22. Sources of Funding for Dementia Care by Income Group, 2010



Source: Created by CRS from WHO, *Dementia: A Public Health Priority,* 2012, p. 27.

Note: Direct social costs are those associated with the provision of care by a trained professional; direct medical costs relate to the expenses associated with medical treatment (e.g., pharmaceutical treatments, medical screening and hospital stays); and informal care refers to uncompensated care provided by untrained persons, usually family members.

Figure 23. Availability of Social/Financial Benefits for People With Dementia by Income Group, 2010

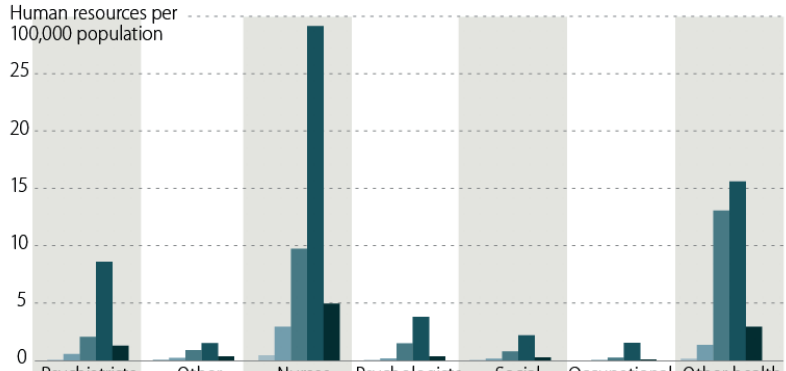


Source: WHO, *Dementia: A Public Health Priority,* 2012, p. 44.

Notes: Results reflect a survey conducted by WHO of 41 countries including: 8 high-income; 9 upper middle-income; 8 lower middle-income; and 5 low-income countries.

Figure 24. Median Rate of Mental Health Personnel by Income Group, 2011

(Per 100,000 Population Working in the Health Sector)



Income level	Psychiatrists	Other medical doctors	Nurses	Psychologists	Social workers	Occupational therapists	Other health workers
Low	0.05	0.06	0.42	0.02	0.01	0	0.12
Lower middle	0.54	0.21	2.93	0.14	0.13	0.01	1.33
Upper middle	2.03	0.87	9.72	1.47	0.76	0.23	13.07
High	8.59	1.49	29.15	3.79	2.16	1.51	15.59
World	1.27	0.33	4.95	0.33	0.24	0.06	2.93

Source: Created by CRS from WHO, *Mental Health Atlas 2011*, 2011, p. 57.

Productivity

The World Bank (the Bank) expects LMIC to experience higher rates of economic growth than high-income countries. In 2012 and 2013, the Bank projects economies in LMIC will expand by 5.4% and 6.0%, respectively, while anticipated growth in high-income countries is 1.4% and 2.0%.[214] Trends indicate that populations age as they become increasingly prosperous. With immature health systems and inadequate health resources, ailments that afflict the elderly, such as dementia, risk derailing economic growth as the productive population attempts to care for their older loved ones. Caring for loved ones with dementia consumes familial resources and can decrease productivity. Without a formal social sector upon which to rely, adults of productive working age in LMIC face lost work hours as they struggle to care for older family members with dementia. Several studies have revealed a high proportion of caretakers had stopped or reduced paid work to care for loved ones affected by dementia. Researchers also found alarming rates of food insecurity among households caring for someone afflicted with dementia and little to no access to any pension.[215]

At the same time, traditional familial networks weaken as countries become increasingly prosperous and larger segments of societies enter the workplace (particularly women), further complicating efforts to care for dementia sufferers in LMIC.

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[214] The World Bank, *Global Economic Prospects: Uncertainties and Vulnerabilities*, Volume 4, January 2012, p. 1, http://siteresources.worldbank.org/INTPROSPECTS/Resources/334934-1322593305595/8287139-1326374900917/GEP_January_2012a_FullReport_FINAL.pdf.

[215] WHO, *Dementia: A Public Health Priority*, 2012, p. 43.

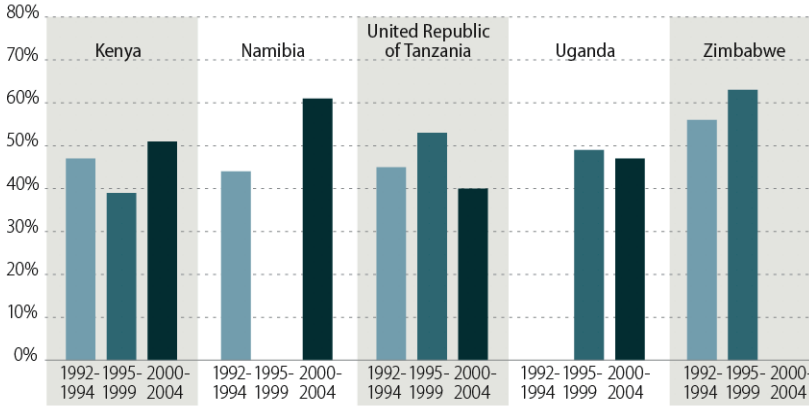
Demographic Shifts

Prosperity is often linked with declines in birth rates. Industrialized countries are already facing economic and societal challenges associated with aging populations. LMIC will soon face these challenges while attempting to sustain economic advancement. China faces particular challenges as its "one child policy", which was enacted in 1978, has reduced family size and indirectly weakened the capacity of family members to care for their elderly relatives. While unpaid informal care is the dominant source of care in LMIC, declining birth rates and aging population trends erode familial capacity to assume the bulk of dementia-related costs, which can lead to greater demand for government services.

HIV/AIDS and Dementia

HIV/AIDS poses an additional challenge to older persons in LMIC. In the wake of the global HIV/AIDS epidemic, thousands of children have been orphaned by the disease. Nearly 17 million children worldwide are estimated to have lost at least one parent to HIV/AIDS, almost 90% of whom reside in Africa.[216] In the region, the elderly play a large role in caring for children orphaned by HIV/AIDS. In some countries, more than half of all children who lost a parent to HIV/AIDS are being cared for by their grandparent (**Figure 25**).[217]

Figure 25. Share of Orphans Aged 0–14 Living with Grandparents



Source: UNAIDS, *Africa's Orphaned and Vulnerable Populations: Children Affected by AIDS*, 2010, p. 16.

Elderly caretakers of orphaned children may be contending with dementia and may need additional care themselves. At the same time, HIV-associated dementia is also a growing problem in LMIC, particularly in high-prevalence countries like South Africa.[218] LMIC face the prospect of contending with the intersection of HIV/AIDS and dementia both as a possible outcome of HIV infection and as a consequence of aging.

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[216] UNAIDS, *UNAIDS Report on the Global AIDS Epidemic*, 2010, p. 112, http://www.unaids.org/documents/20101123_globalreport_em.pdf.

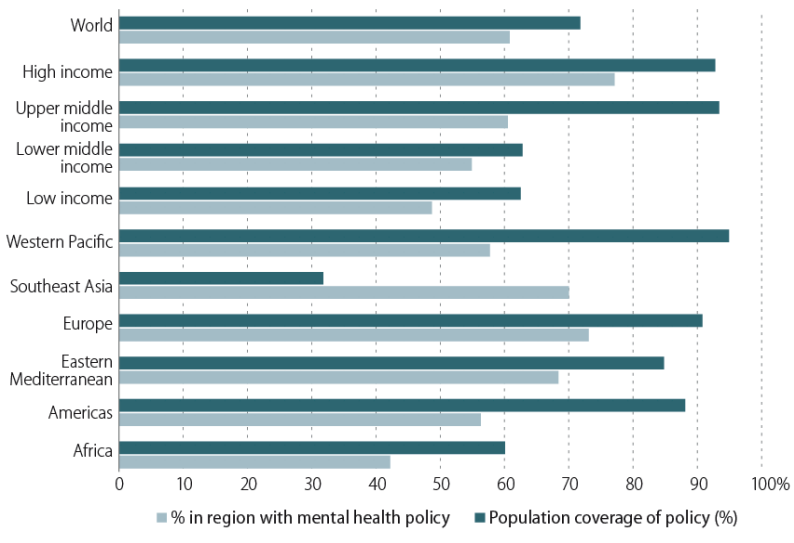
[217] UNAIDS, *Africa's Orphaned and Vulnerable Populations: Children Affected by AIDS*, 2010, p. 16, http://www.unicef.org/publications/files/Africas_Orphaned_and_Vulnerable_Generations_Children_Affected_by_AIDS.pdf.

[218] See John A. Joska, "Clinical Correlates of HIV-Associated Neurocognitive Disorders in South Africa", *AIDS and Behavior*, vol. 14, no. 2 (2010), pp. 371–378.

Policy Reforms

Health systems in many LMIC are under-resourced and predominantly focused on combating infectious diseases. Health-related consequences of aging is an emerging issue that has not historically been prioritized in most LMIC. In fact, some LMIC have placed the responsibility of care and financial support of the elderly squarely upon the shoulders of family members. The parliament in India, for example, passed a law in 2007 that could impose fines or imprisonment on adult children who fail to care for their parents.[219] At the same time, the legislation authorized the establishment of old-age homes for the poor and childless. Despite this example, LMIC are increasingly recognizing the need to address ageing and its health consequences. October 17–20, 2012, the International Association of Gerontology and Geriatrics will host its first conference in Africa.[220] At the conference, leaders are expected to affirm their support for improving national responses to issues facing older persons, including dementia and its related illnesses.

Figure 26. Countries With National Mental Health Policies by Income Group and Region



Source: Created by CRS from WHO, *Mental Health Atlas 2011*, 2011, p. 17.

Role of International and Non-Governmental Organizations

A variety of organizations are engaged in ameliorating living conditions for elderly persons. Below is an illustrative list of some of these groups. The summary below is not intended to endorse or prioritize a particular institution. Instead, it offers examples of the types of groups engaged in enhancing the livelihood of older people and their caretakers, including advocating for improved dementia care. For an

[219] WHO, *Dementia: A Public Health Priority*, 2012, p. 43.

[220] The Web page for the conference is http://iagg.cmc-uct.co.za/.

additional list of organizations working on dementia and Alzheimer's Disease, see http://www.helpage.org/who-we-are/our-affiliates-/affiliates-list/.

AARP International. Based in the United States, AARP International raises awareness about issues facing the elderly, shares best practices on related policy issues, and builds alliances with other groups to advance policies and programs that "help people live longer, healthier, more financially secure and productive lives." The association also serves as a convening body that facilitates information sharing among experts around the world through international conferences and other forums on "health and long-term care, older workers, financial security, retirement income, and livable communities." In those efforts, AARP International has established relationships with a variety of international actors, including several bodies of the U.N. system like the International Labor Organization (ILO) and the World Health Organization (WHO), the Organization for Economic Cooperation and Development (OECD), the European Commission, the World Bank and the International Monetary Fund (IMF). AARP International regularly hosts international visitors and facilitates their outreach efforts.

Alzheimer's Disease International (ADI). Based in Britain, ADI empowers local and international Alzheimer's Disease associations "to promote and offer care and support for people with dementia and their carers, while working globally to focus attention on dementia." The organization aims to improve quality of life for people with dementia and their families. In that capacity, ADI serves as the international federation of Alzheimer's Disease associations worldwide and maintains official relations with WHO. One of its most prominent accomplishments is co-publishing the 2012 global dementia report with WHO. The organization also holds an annual international conference on dementia and runs the Alzheimer University—a workshop series aimed at bolstering capacity of Alzheimer's Disease associations.

HelpAge International. Based in Britain, HelpAge International is an organization that advocates for and implements programs that help "older people discrimination and overcome poverty, so that they can lead dignified, secure, active and healthy lives." In 2011, the organization reached 750,000 older people and their families through Help Age health, emergency, and finance services. The group also helped two million older people in filing for or increasing their pensions; offered legal support to 50,000 older people in their fight against abuse and discrimination; trained 25,000 professionals and 16,000 community members to provide healthcare, legal advice and financial support for older people. HelpAge International also enables other groups who do similar work. In 2011, the organization supported 2,700 related groups.

International Association of Gerontology and Geriatrics (IAGG). Based in France, IAGG partners with WHO to "promote the highest levels of achievement in gerontological research and training worldwide, and to interact with other international, inter-governmental and non-governmental organizations in the promotion of gerontological interests globally and on behalf of its member associations." It also sponsors the World Congress of Gerontology and Geriatrics, which is held every four years. The conference is a forum through which experts share their knowledge.

World Health Organization (WHO). Based in Switzerland, WHO is the directing and coordinating authority for health within the United Nations (U.N.) system. In this capacity, WHO serves as a convening body for information sharing; assists countries in strengthening their health systems; and raises awareness about key health issues. In addition, WHO leads the Mental Health Gap Action Program (mhGAP), which seeks to bolster "political commitment of governments, international organizations and other stakeholders" to address mental health needs.[221]

Key International Actions

The international community is increasingly recognizing the impact of mental disorders associated with aging, including Alzheimer's Disease. Below are a list of actions taken by global actors to address and

[221] WHO, *Scaling Up Care for Mental, Neurological, and Substance Use Disorders*, 2008, p. 1.

raise awareness about mental health issues, including dementia. Regional actions, such as those taken by the European Union and the African Union are not included here.

- In May 1975 and May 1986, the World Health Assembly adopted resolutions (WHA28.84 and WHA39.25, respectively) that urged Member States to strengthen mental health components within their general health services and public health programs.
- In July 1982, the United Nations convened the first international conference on aging in Vienna, Austria. At the conference, Member States agreed to the *Vienna International Plan of Action on Aging*, which was the first international policy document guiding the formulation of policies and programs on global aging. The plan called on Member States to develop, among other things, "comprehensive mental health care services ranging from prevention to early intervention, the provision of treatments services and the management of mental health problems in older persons." Endorsed by the United Nations General Assembly through (A/RES/37/51), the plan specified these plans were to target Alzheimer's Disease and other dementia-related diseases.
- In 2001, discussions about mental health were incorporated into the annual WHO World Health Report for the first time.
- In April 2002, the United Nations sponsored the *Second World Assembly on Ageing* to assess the progress made by Member States since implementing the Vienna Plan of Action. Participating countries adopted two key documents: the *Political Declaration on Ageing* and the *Madrid International Plan of Action on Ageing*. Both documents included commitments from governments to devise and implement measures to address the challenges posed by aging, including Alzheimer's Disease and other dementia-related diseases. Through these documents, governments agreed to link questions of aging to other frameworks for social and economic development and human rights for the first time.
- In May 2002, the World Health Assembly adopted a resolution (WHA55.10) that urged Member States to support the WHO global action program for mental health and bolster investments in mental health through national budgets and foreign aid.
- In May 2008, the WHO Mental Health Gap Action Program (mhGAP) was launched.
- In September 2011, the U.N. General Assembly adopted a resolution (A/RES/66/2) that recognized that mental and neurological disorders, including Alzheimer's Disease, are an important cause of morbidity and contribute to the global non-communicable disease burden, for which there is a need to provide equitable access to effective programs and health care interventions.
- In May 2012, the World Health Assembly adopted a resolution (WHA65.4) on the global burden of mental disorders, urging countries to develop national responses that are comprehensive and coordinated across health and social sectors.

Conclusions

We all have a shared interest in deepening common understandings about the best strategies and solutions for addressing the immense challenge posed by dementia and specifically Alzheimer's Disease to our aging societies. In issuing this report, it is the hope of the committee that the facts and findings presented here will contribute to the sense of urgency felt by many policymakers, researchers, and families around the world to address this growing public health threat.

With the number of individuals with AD in the U.S. set to triple during the next quarter century, both the pace of research and the quality and cost-effectiveness of services must improve. Recommendations from the World Health Organization's 2012 report titled "Dementia: A Public Health Priority," are a useful guide. The recommendations include:

- improving public and professional attitudes about, and understanding of, dementia;
- investing in health and social systems to improve care and services for people with dementia and their caregivers;
- promoting a dementia-friendly society globally;
- making dementia a public health and social care priority worldwide; and
- increasing the priority given to dementia in the public health research agenda.

Among the countries analyzed in this report, there appears to be considerable consensus in goals for diagnosis, treatment, and research; however, some variations exist in treatment due to different countries' policy priorities, health care systems, and resources. Most countries prioritize developing a more accurate and earlier diagnosis; identifying biomarkers for diagnosis and charting the course of the disease; translating genetic advances into treatments; committing resources to reduce the stigma associated with the disease; improving the continuity of care; and developing a trained workforce. There is widespread global collaboration in basic and clinical research within the scientific community independent of governmental efforts, especially in the area of biomarkers, pharmacology, and genetics.

However, researchers do not definitively know the cause(s) of AD, and medical professionals do not and cannot always properly diagnose it. To date, there is no cure for the disease in sight. These difficulties highlight and demonstrate the vital need for investing in research for improved treatments of AD and other dementias. Therefore, both international collaborations and national investments in research should be applauded.

Despite challenging fiscal climates in many countries, investments in scientific research should remain a priority. According to the Alzheimer's Association, absent significant progress, the cost of AD to the United States alone could be as high as $20 trillion over the next 40 years. These staggering projections underscore not only the human, scientific and clinical challenges, but also the financial impact of AD without new discoveries in treatments, cures, treatment and care for AD.

A principle shared policy goal among the focus countries identified in this report is to craft policies that can enable individuals with dementia to live in their own homes for as long as

possible.[222] To this end, countries have engaged in efforts to expand the provision of LTC through programs and policies that support home and community-based services within their existing health and social services delivery systems. Some countries have established, or plan to establish, specialized home care services and specialized dementia care units in LTC facilities that are designed to focus on meeting the particular needs of individuals with dementia. A common challenge faced by the countries analyzed in this report is the ability to provide coordinated and integrated care across their health and social services systems to persons with dementia, particularly to those in more advanced and debilitating stages of illness. Several countries have looked to person-centered care and service coordination as objectives of their national AD plans by emphasizing targeted programs and services, such as those that offer designated case managers who are trained in dementia care in order to facilitate access to the most appropriate services.

Another shared policy goal among the countries that the committee examined is support of informal family caregivers as primary care providers to persons with dementia. Reliance on informal caregiving may partly reflect the extent of locally available formal services and providers. The extent to which families provide informal care may also reflect cultural norms about the willingness of families to provide extended care to loved ones. Among the focus countries, efforts to support caregivers include providing various interventions targeted at reducing caregiver stress and burden. While assessing the effectiveness of these caregiver interventions is beyond the scope of this report, caregiver support services in these countries include targeted financial support to compensate caregivers for their specific activities or initiatives that provide general income support to offset a lack of income from other sources, such as paid employment. There is some indication among focus countries that demand for targeted services to caregivers, such as respite care, is greater than the available supply of such services.

With a majority of global dementia cases expected to occur in low and middle-income countries in the coming decades, the unique challenges facing these regions will become a growing concern for those living with the disease as well as their family caregivers. These challenges include low awareness of the signs of dementia, the high cost of care, and few dementia-related policies and programs to address the need. However, many international and non-governmental organizations are taking steps to address and raise awareness about mental health issues, including dementia.

The growing need for Alzheimer's disease and dementia research and development, diagnosis and treatment, as well as long-term services and supports are well documented. It is also clear that continued dialogue among the international community is necessary for lasting progress in this global public health plight.

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[222] Pierre Moise, Michael Schwarzinger, Myung-Yong Um, et al., *Dementia Care in 9 OECD Countries: A Comparative Analysis*, OECD Health Working Papers, 2004.

Appendix 1: Alzheimer's Disease and Dementia Hearings and Forums Held by the Special Committee on Aging

Congress	Date	Hearing
112	November 30, 2011	Overprescribed: The Human and Taxpayers' Costs of Antipsychotics in Nursing Homes
111	December 8, 2010	Forum: Until There's a Cure: How to Help Alzheimer's Patients and Families NOW
	March 25, 2009	The Way Forward: An Update from the Alzheimer's Study Group
110	May 14, 2008	The Future of Alzheimer's: Breakthroughs and Challenges
108	March 22, 2004	Crime Without Criminals? Seniors, Dementia and the Aftermath
104	April 23, 1996	Alzheimer's Disease in a Changing Health Care System: Falling Through the Cracks
98	September 12, 1983	Endless Night, Endless Mourning: Living With Alzheimer's, New York, NY

Appendix 2: Country Selection[223]

The four chapters describe five focus countries that were selected by the committee. These countries were selected after review of the data available and National Alzheimer's Disease Plans. The five focus countries are not intended to represent world-wide dementia and Alzheimer's Disease trends or efforts. Rather, these focus countries, along with efforts in additional countries that are highlighted throughout the report, provide examples of single and multi-country dementia and Alzheimer's Disease diagnosis, research, treatment, and care activities. The committee chose OECD members so that countries could be compared with OECD averages. Additionally, the committee included countries that could be instructive to the United States because of similar age structures (Australia)[224] or because of disproportionately "older populations" (Japan).[225] The committee was also interested in including European countries because of research and long-term care activities occurring in both the United Kingdom and France and because of existing European Union-wide activities. With these specifications, the following five focus countries were selected: (1) Australia, (2) France, (3) Japan, (4) the United Kingdom, and (5) the United States.

[223] This appendix does not apply to the fourth chapter that focuses on the prevalence of dementia and Alzheimer's Disease in low and middle income countries because that chapter does not discuss the five focus countries.

[224] Although the absolute size of the Australian population is smaller than that of the United States, it has a similar percentage of its population aged 65 and over and its population pyramids look similar to those of the United States (see **Figure 2** and **Figure 6**).

[225] For example, Japan was included as a focus country because it has the largest percentage of its population aged 65 and over of OECD countries; therefore, it may have greater need for dementia care and services. For information about OECD populations aged 65 and over, see Organization for Economic Cooperation and Development, OECD Factbook 2011: Economic, Environmental and Social Statistics, at http://www.oecd-ilibrary.org/economics/oecd-factbook-2011-2012_factbook-2011-en.

Appendix 3: National Plans and Strategies of Focus Countries

The five selected countries included in this chapter have national plans that address dementia and AD. These documents outline policy efforts in each country and are the source of most of the information in this chapter.

The national plans provide policy road maps for each of the five countries.[226] The major features of the plans are highlighted below and **Table 23** provides identifying information on the national plan by country (in alphabetical order).

Table 23. National Dementia and/or Alzheimer's Plans in Selected Countries

Country	Date or Years Covered[a]	Plan Title	Source
Australia	2006–2010	*National Framework for Action on Dementia: 2006–2010*	http://www.health.gov.au/internet/main/publishing.nsf/Content/B9616604C02332D5CA25701B0075A997/$File/NFAD%20low%20res%20Web%20Version%20Oct%2006.pdf
France	2008–2012	*National Plan for Alzheimer and Related Diseases 2008–2012*	http://www.plan-alzheimer.gouv.fr/IMG/pdf/Plan_Alzheimer_2008-2012_uk.pdf (in English)
Japan	2008–(no end date)	*Emergency Project for Improvement of Medical Care and Quality of Life for People with Dementia*	http://www.mhlw.go.jp/houdou/2008/07/dl/h0710-1a.pdf (in Japanese)
United Kingdom: England[b]	2009	*Living Well with Dementia: A National Dementia Strategy*	http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058
United Kingdom: Northern Ireland[b]	2011	*Improving Dementia Services in Northern Ireland: A Regional Strategy*	http://www.dhsspsni.gov.uk/improving-dementia-services-in-northern-ireland-a-regional-strategy-november-2011.pdf
United Kingdom: Scotland[b]	2010	*Scotland's National Dementia Strategy*	http://www.scotland.gov.uk/Resource/Doc/324377/0104420.pdf
United Kingdom: Wales[b]	2011	*National Dementia Vision for Wales: Dementia Supportive Communities*	http://wales.gov.uk/docs/dhss/publications/110302dementiaen.pdf
United States	2012	*National Alzheimer's Plan*	http://aspe.hhs.gov/daltcp/napa/NatlPlan.shtml

Source: Alzheimer's Disease International, Government Alzheimer Plans, at http://www.alz.co.uk/alzheimer-plans.

a. This refers to the year that the plan was published. If the publication year is not available, then the dates covered are presented.

b. Each country in the United Kingdom (England, Northern Ireland, Scotland, and Wales) has a separate plan.

[226] The dementia and Alzheimer's Disease plan for the United Kingdom is divided into a group of plans. The UK includes England, Northern Ireland, Scotland, and Wales. The plan for England is a national plan covering England and national health policy. The plans for Northern Ireland, Scotland, and Wales are regional plans.

Brief Description of the National Plans

Australia

The Australian "National Framework for Action on Dementia" (2006–2010) identifies five key areas: care and support, access to care and equitable care, information and education, research, and workforce and training.[227] A priority of the National Plan envisions activities in population-based prevention efforts to reduce chronic health problems such as diabetes and improve cardiovascular health that can lead to vascular dementia.[228]

France

France has had three national dementia and AD plans starting in 2001. In each plan treatment is a prime focus. The first plan prioritized early diagnosis; creation of memory centers with staff able to provide accurate diagnosis; establishment of adult day centers and residential homes; and funding of research. Currently, France is prioritizing efforts in the following areas: changing the image of dementia to combat stigma; increasing support for caregivers; coordinating care between providers; enabling more support at home; improving access to diagnostic and care pathways; increasing residential care; developing training for health professionals; and increasing resources for clinical research, epidemiology, public information, and ethics.[229]

Japan

The Japanese national strategy includes: (1) understanding the realities of daily life for patients with dementia; (2) performing epidemiology surveys; (3) improving prevention and diagnosis; (4) developing therapeutic tools; (5) facilitating and disseminating guidelines for care; (6) strengthening the diagnostic infrastructure; (7) providing education in schools and through a public campaign; and (8) increasing public information.[230]

United Kingdom

The English national plan "*Living Well With Dementia*" is a five-year strategy focused on improving awareness and reducing stigma; increasing early diagnosis and intervention; and ensuring a high quality of care.[231] The plan also encourages public awareness, early diagnosis and intervention, prevention of chronic diseases linked to dementia and AD (such as vascular disease), and better planning for caregivers. The plan also stresses linkages between medical and social services especially in the area of housing and community care.[232] There is concern that primary care physicians do not diagnosis dementia and AD as early as possible and may not have received sufficient training in assessment, so that British efforts

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[227] K. Rosow et al., "Countrywide Strategic Plans on Alzheimer's Disease: Developing the Framework for the Global Battle Against Alzheimer's Disease," *Alzheimer's & Dementia*, vol. 7 (2011), p. 618.

[228] Australian Health Ministers' Conference, *National Framework for Action on Dementia 2006–2010*, North Sidney, AU, May 2006, http://www.health.gov.au/internet/main/publishing.nsf/Content/B9616604C02332D5CA25701B0075A997/$File/NFAD%20low%20res%20Web%20Version%20Oct%2006.pdf.

[229] Republique Francaise, *National Plan for Alzheimer and Related Diseases 2008–2012*, February 1, 2008, http://www.plan-alzheimer.gouv.fr/.

[230] Y. Arai, A. Arai, and Y. Mizuno, "The National Dementia Strategy in Japan," *Global Journal of Geriatric Psychiatry*, vol. 25 (2010), pp. 896–899.

[231] S. Banerjee, "Living Well with Dementia-Development of the National Dementia Strategy for England," *Global Journal of Geriatric Psychiatry*, vol. 25 (2010), pp. 917–922.

[232] Ibid.

include enhanced provider training. In addition, the UK is focusing on improving home care, developing quality assessment and treatment, and supporting caregivers.

Northern Ireland, Scotland, and Wales have their own regional plans. Northern Ireland's plan focuses on preventing disease, and delaying the onset of the most serious symptoms, raising awareness, improving initial assessment and diagnosis, and supporting patients and their families across the spectrum of care.[233]

Scotland's National Dementia Strategy focuses on developing common standards of care for dementia; improved provider knowledge and skills; advancing early and accurate diagnosis; upgrading the response to behavioral and psychological problems; integrating care pathways; supporting research through a patient registry; and developing a specialized workforce, such as "specialist dementia nurse." An additional initiative is dedicating some of lottery revenues for programs that help dementia patients and their caregivers.[234]

Wales prioritizes integrated and comprehensive services and reduction of stigma.[235] This is seen in four priority areas: improved services by integrating health, social services, and other programs; early and accurate diagnosis; increased access to information and support for caregivers and patients; research; and additional training for health care providers. The Welsh plan includes employing a new type of health care professional, specialized dementia clinical co-coordinators, to help with access and integration of care.

United States

The U.S. National Plan identifies the following goals: increasing research for prevention and early diagnosis; enhancing care quality; supporting patients and caregivers; increasing public awareness and engagement. Within each of these goals there are multiple objectives. In the area of treatment, the U.S. National Plan identifies building a skilled workforce; ensuring accurate and timely diagnosis; increasing education for patients and families; identifying care guidelines across all settings; exploring the effectiveness of new care models; ensuring effective and safe care transitions; advancing coordinated and integrated treatment; improving outcomes for those at higher risk of the disease, including ethnic minority populations; and global coordination.[236] The plan also provides an inventory of all federal programs that affect dementias and AD and a timeline to achieve different goals.

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[233] Department of Health, Social Services, and Public Safety, *Improving Dementia Services in Northern Ireland*, November 2011, http://www.dhsspsni.gov.uk/improving-dementia-services-in-northern-ireland-a-regional-strategy-november-2011.pdf.

[234] The Scottish Government, *Scotland's National Dementia Strategy*, June 2011, http://www.scotland.gov.uk/Resource/Doc/350341/0117259.pdf.

[235] See *National Dementia Vision for Wales: Dementia Supporting Communities*, http://wales.gov.uk/docs/dhss/publications/110302dementiaen.pdf.

[236] Department of Health and Human Services, *National Plan to Address Alzheimer's Disease*, May 12, 2012 (last updated), http://aspe.hhs.gov/daltcp/napa/NatlPlan.shtml.

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