

EARLY ONSET DEMENTIA A NATIONAL CHALLENGE, A FUTURE CRISIS

June 2006



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Table of Contents

I. Introduction	1
Organization and perspectives of the report	3
Problems confronted by people with early onset dementia and their families	3
Steps toward solutions	5
II: Prevalence and Causes of Early Onset Dementia	8
Estimated prevalence of early onset dementia	8
Possible causes of early onset dementia	11
Possible causes of cognitive impairment that is not dementia	12
Needed research on prevalence and causes of early onset dementia	13
III: Problems Confronted by People with Early Onset Dementia and Their Families and Steps Toward Solutions	14
1. Difficulty getting an accurate diagnosis	15
2. Loss of employment and job-related income	17
3. Difficulty obtaining SSDI, SSI, and other disability benefits	21
4. Lack of health insurance and high out-of-pocket expenditures for medical care	26
5. High out-of-pocket expenditures for long-term care	34
6. Lack of appropriate medical care, residential care, and community services	40
IV: A Call To Action	52
References	54
Acknowledgements	59
Appendix A: The Health and Retirement Study	60
Appendix B: Tables	64

I. Introduction

Alzheimer's disease and other dementias are devastating conditions that create huge emotional, financial, and physical challenges for the person and his or her family. These conditions usually affect older people. When they occur in people under age 65, the conditions cause additional and unique problems because they are so unexpected and because most of the potentially helpful programs and services are designed for and targeted to older people.

The term *early onset dementia* refers to dementia that first occurs in a person under age 65.* The dementia may be caused by Alzheimer's disease or other diseases and conditions. People who have early onset dementia may be in any stage of dementia – early, middle, or late.

New data from the Health and Retirement Study (HRS), a large, nationally representative survey, indicate that in 2000, 480,000 Americans age 55-64 had cognitive impairment at a level severe enough to be considered disabling.³ The HRS data do not specify the causes of disabling cognitive impairment, and it is not clear how many of these people had Alzheimer's disease or other dementias.

Based on the HRS data and findings from several other studies, the Alzheimer's Association estimates that there are between 220,000 and 640,000 Americans with early onset Alzheimer's disease and other dementias. Additional research is needed to develop a more precise figure, but the proposed range provides a plausible first estimate and indicates that many more Americans have early onset Alzheimer's disease and other dementias than is generally acknowledged. They are people like:•

Deborah Mauro: Deborah was a physical education teacher in the Auburn, Maine, school system, a marathon runner, bicyclist, and downhill skier. She was diagnosed with Alzheimer's disease in 1999, at age 49. Her husband, John, took care of her at home until 2005. She now lives in a residential care facility in Maine. She can no longer walk and does not recognize her husband or their adult children, Krista and John.

Gerald Michalak: Jerry was an elementary school teacher in the Williamsville Central School System and an educational consultant to school districts across New York State

* Dementia is a syndrome of decline in memory and other cognitive abilities (e.g., language, judgment, recognition) that is severe enough to interfere significantly with work, usual activities, and relationships with others.¹

³ See Appendix A for a description of the HRS and detailed information about how cognitive status is measured in the study and how the term *disabling cognitive impairment* is defined for this report.

• Individuals named in this report are not HRS respondents.

for 31 years. In 1998, he began to experience memory problems. His primary care physician first diagnosed the problem as stress. Further loss of cognitive abilities led to his retirement in 2000, and he was finally diagnosed with Alzheimer's disease in 2005, at age 62. Currently, he lives at home with his wife Janet in Getzville, New York.

Woody Hoffman: Woody was a senior finance officer in the Berkeley, California, Public Works Department. He was diagnosed with Alzheimer's disease in 2002, at age 59, and had to retire in 2003, because of the disease. His diagnosis came only four months after he married Cathy Dodd. Woody was an avid weightlifter, runner, and bicyclist. He continued these activities until late 2005, when another bicyclist ran into him during his daily bicycle ride on the Golden Gate Bridge. Woody suffered severe spinal cord and traumatic brain injuries. He is now undergoing rehabilitation therapies in a skilled nursing facility in California.

Dick Ryan: Dick was a city planner in Boulder and Vail, Colorado. In his mid-40s, he left his job and met and married Darlene. He never worked again but stayed home to care for their son. He had been a quiet, gentle man who loved golf, but in his mid-50s, he began to have sudden rages and odd behaviors. Dick was diagnosed with frontotemporal dementia in 2003, at age 63. The family moved to Texas a few years ago, and Dick now lives in a secured assisted living facility there.

Tracy Mobley: Tracy was a nurse technician in a hospital intensive care unit in southwest Missouri. She was diagnosed with Alzheimer's disease in 2002, at age 38. From the onset of symptoms, Tracy kept a diary and wrote a book, *Young Hope*, which chronicles the journey she and her family took to get a diagnosis at such a young age. Currently, Tracy lives at home with her husband, Allen, and their 11-year old son, Austin, who provide much care and support.

Little research has been conducted in the U.S. about the problems confronted by Americans with early onset Alzheimer's disease and other dementias. This report uses information from the HRS, a 2004 Alzheimer's Association survey, and a few other studies to begin to piece together a picture of these problems. The picture is not complete, but the report provides a startling first view of the large, unmet needs of Americans with early onset dementia and their families.

Organization and Perspectives of the Report

The introduction briefly describes the problems confronted by people with early onset dementia and their families and lists steps that could be taken to reduce these problems. Part II discusses the available information about the prevalence and causes of early onset dementia. Part III presents more detailed information about each of the problems described in this section and analyzes possible steps toward solutions. Part IV is a call to action for organizations and individuals who interact with and advocate for people with dementia and their families. The appendices provide information about the HRS and tables based on HRS data.

The report emphasizes the perspectives of people with early onset dementia. Quotes from their responses to the Alzheimer's Association survey are used throughout to convey their perceptions and concerns about the problems they face. For people who were not able to complete their own survey, the report uses quotes from family members and other care partners to convey a personal perspective on the problems that result from early onset dementia.

Problems confronted by people with early onset dementia and their families

Six problems emerge clearly from an analysis of the HRS data, responses to the Alzheimer's Association survey, and findings from a descriptive study of 23 Americans with early onset dementia.² Not all people with early onset dementia experience each of these problems, and some people with onset of dementia after age 65 experience the same problems. The problems are common for people with early onset dementia, however, and more likely to affect people with early versus later onset dementia.

- 1. Difficulty getting an accurate diagnosis** – Dementia is usually considered a condition of older people and is not expected in younger people. When a person under age 65 goes to a doctor with symptoms of dementia, the doctor may not even think of dementia as a possibility or may not know how to diagnose it. As a result, getting an accurate diagnosis can be a long, difficult, and frustrating process.
- 2. Loss of employment and job-related income** – Most older people with dementia are retired, but many people with early onset dementia are still working when their symptoms emerge. Over time, the person loses the ability to perform his or her usual job tasks, but the reason for this change may not be understood by the person, the employer, or co-workers. As a result, the person may lose not only his or her job and job-related income but also self esteem, the feeling of being a productive person, and his or her status as a valued employee and co-worker.

Some people with early onset dementia leave their jobs voluntarily or are fired before getting a diagnosis. In these situations, work disability may not be formally recognized, and employer responses that are usually triggered by work disability, especially work accommodations and referrals for disability benefits, do not occur.

- 3. Difficulty obtaining Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), and other disability payments** - SSDI and SSI are federal government programs intended to provide a floor of income for people who cannot work because of a disability but are not old enough to receive regular Social Security retirement payments. Most U.S. jobs provide Social Security coverage, and people who have enough years of coverage may qualify for SSDI. People with very low income and assets (less than \$603 income per month and \$2,000 in assets in 2006) may qualify for SSI. And some employers have other disability programs. To apply for disability payments, however, the person or family must be aware of these programs *and* aware that the person has a disability. Thus, some people with early onset dementia never apply or apply very late, and those who do apply often experience long waits before qualifying. Some people with early onset dementia are denied SSDI and SSI because the Social Security Administration decides they can still work.
- 4. Lack of health insurance and high out-of-pocket expenditures for medical care** - Unlike almost all older people, people under age 65 generally do not have Medicare. People with early onset dementia who qualify for SSDI get Medicare, but only after a 2-year waiting period. People who qualify for SSI get Medicaid in most states. Some people with early onset dementia have health insurance through an employer-provided early retirement or disability program or through their spouse's job, and some are able to buy private health insurance. Even people who have health insurance are likely to have high out-of-pocket expenditures for premiums, deductibles, co-payments, and health care services that are not covered by their insurance. And some people with early onset dementia have no health insurance. As a result, people with early onset dementia and their families may be forced to choose between paying out-of-pocket for health insurance and needed medical care or paying for basic living expenses, not only for the person with dementia, but also for other family members, including minor children.
- 5. High out-of-pocket expenditures for long-term care** - High out-of-pocket expenditures for long-term care services are a problem for all Americans who need such services, including people of any age with dementia. In 2005, the average annual cost of nursing home care was \$64,240,³ and the average annual cost of assisted living was \$34,860.⁴ Home and community-based long-term care

services, such as adult day care and respite care, are less expensive, but total costs can add up if the services are used consistently over long periods of time, as they often should be to benefit the person and provide relief and assistance for the family.

Medicaid pays for long-term care services for people under age 65 with dementia, but only if they first qualify for SSI and then meet any additional state eligibility criteria for specific services. The Administration on Aging (AoA) pays for home and community-based services, but only for people age 60 and over. People who are under age 60 and their family caregivers are not eligible. Thus, people with early onset dementia and their families must either incur very high out-of-pocket expenditures for long-term care or do without services that could help them.

- 6. Lack of appropriate medical care, residential care, and community services** - Most services for people with dementia are designed for and targeted to older people. Many people with early onset dementia feel uncomfortable with these services. They say they need, and generally are not able to find, services specifically designed for and targeted to younger people. Family members and other care partners agree and point out that when a person with dementia feels out of place in a program or service, the person often refuses to use the service. Care partners also stress that existing information and programs do not meet their needs.

Doctors and other health care, residential care, and community service providers may not know how to treat, provide care for, or communicate with people with early onset dementia. Training to address this problem is not generally available, and much of the information that would be needed as a basis for such training does not exist. Likewise, information that government agencies and private organizations need to plan appropriate services for people with early onset dementia does not exist.

The six problems noted above are clearly interrelated. Problems in getting an accurate diagnosis contribute to lack of understanding about the reason for changes in a person's job performance and subsequent failure to apply for disability benefits. Lack of health insurance and low income limit access to potentially helpful services that could reduce the emotional, financial, and physical challenges of dementia for the person with the condition and his or her family.

Steps Toward Solutions

Many steps could be taken to reduce the problems confronted by people with early onset dementia and their families. A first step is greater general awareness of early onset dementia.

Research to develop more precise information about the number of people with early onset dementia and the diseases and conditions that cause their dementia is essential. This information is needed to support greater general awareness about early onset dementia, training for medical, residential care and community service providers, and planning for appropriate services for people with the conditions, their families, and other care partners.

Research on approaches to prevent and delay onset and progression of diseases and conditions that cause early onset dementia is also essential. Government agencies and private organizations that pay for biomedical research should solicit and fund research on early onset dementia. Advocacy for research dollars should include early onset dementia explicitly.

Also essential are steps to engage people with dementia, as individuals or in groups, such as the Alzheimer's Association's Advisory Group of People with Dementia and the Dementia Advocacy and Support Network International (DASNI), along with families, researchers, health care and community service providers, employers, human services personnel, government agencies, and private organizations -- in identifying the service needs of people with early onset dementia and planning for and implementing effective approaches to meet those needs.

Other steps that could be taken to reduce each of the problems described earlier are listed in Box 1 and discussed in greater detail in Part III of the report.

The large number of steps in Box 1 may seem daunting. Just as the problems confronted by people with early onset dementia and their families are interrelated, so are the solutions. Thus, progress on one problem is likely to reduce other problems. Greater awareness of early onset dementia among doctors, for example, would not only decrease the difficulty of getting a diagnosis but also reduce uncertainty about the reason for changes in a person's job performance, facilitate timely applications for disability benefits, and eventually lead to more appropriate ongoing medical care. Likewise, greater availability of information about SSDI and SSI and analysis of the reasons for SSDI and SSI denials could not only decrease wait times for SSDI and SSI and increase the number of people with early onset dementia who qualify for disability payments but also increase the number who have health insurance through Medicare (because they qualify for SSDI) or Medicaid (because they qualify for SSI).

The Alzheimer's Association hopes this report will help to increase awareness and concern about early onset dementia and encourage efforts by many organizations and individuals to begin to address and resolve the problems confronted by people with condition and their families and other care partners.

Box 1: Steps That Could Be Taken To Reduce the Problems Confronted by People With Early Dementia and Their Families

1. Difficulty getting an accurate diagnosis

- ⇒ Raise awareness among doctors about early onset dementia and the importance of accurate diagnosis.
- ⇒ Provide training for doctors about how to diagnose early onset dementia.

2. Loss of employment and job-related income

- ⇒ Raise awareness among employers and human resources personnel about early onset dementia.
- ⇒ Develop and disseminate information about work accommodations for people with early onset dementia and how the legal requirements for work accommodation apply to this condition.

3. Difficulty obtaining SSDI, SSI, and other disability payments

- ⇒ Develop and disseminate accurate, easily accessible information about SSDI, SSI, and other disability programs; encourage timely applications; and provide help with applications.
- ⇒ Analyze the reasons for SSDI and SSI denials, including denials based on a person's alleged ability to work; advocate for any needed changes in the procedures used to determine disability.

4. Lack of health insurance and high out-of-pocket expenditures for medical care

- ⇒ Eliminate the 2-year waiting period for Medicare for people who qualify for SSDI.
- ⇒ Extend Medicaid to people who qualify for SSI but have income above current income limits.
- ⇒ Exempt people with dementia from the new requirement for proof of U.S. citizenship for Medicaid if they cannot, because of their dementia, provide the required documents.
- ⇒ Consider people with early onset dementia in all initiatives to expand affordable health insurance.

5. High out-of-pocket expenditures for long-term care

- ⇒ Provide accurate, easily accessible information about all sources of funding for long-term care.
- ⇒ Reduce restrictions on Medicaid-funded nursing home care and increase access to Medicaid-funded home and community-based care for people with early onset dementia.
- ⇒ Extend eligibility for AoA-funded home and community-based services and family support to people under age 60 with early onset dementia.

6. Lack of appropriate medical care, residential care, and community services

- ⇒ Conduct research on the characteristics and service needs of people with early onset dementia.
- ⇒ Develop and deliver training for health care professionals and residential care and community service providers about treatment, services, and communication with people with early onset dementia.
- ⇒ Evaluate the effectiveness of various services for people with early onset dementia and their families.
- ⇒ Develop new services to meet the needs of people with early onset dementia and their families.

II. Prevalence and Causes of Early Onset Dementia

Estimates of the prevalence of Alzheimer's disease and other dementias in people age 65 and older are available from many studies. Figures from the studies differ, but they all show that substantial numbers of older people have the conditions. One widely cited study indicates that in 2000, 4.5 million Americans age 65 and older (13% of people in that age group) had Alzheimer's disease⁵ -- a figure that does not include people with other dementias.

No comparable information is available about early onset Alzheimer's disease and other dementias. The first person ever diagnosed with Alzheimer's disease, Frau Auguste D., was age 51 when she was diagnosed by Dr. Alois Alzheimer in 1906.⁶ U.S. studies that include people under age 65 have identified many individuals with Alzheimer's disease and other dementias.⁷⁻¹² Yet these conditions are often assumed to be so rare in younger people that it is not necessary to include the population under age 65 in research on prevalence of the conditions.

Estimated Prevalence of Early Onset Dementia

Although the prevalence of early onset dementia is often assumed to be very low, some commentators have estimated that 6-10% of all people with Alzheimer's disease may have onset of symptoms before age 65.^{13,14} One recently published study based on data from the Rochester (MN) Epidemiology Project shows that from 1990 to 1994, 4.6% of the 560 new cases of dementia occurred in people age 40-64.⁸ Another recently published study based on data from a Veterans Affairs (VA) memory clinic shows that from 2001 to 2004, 29% of the 948 veterans with dementia had onset of symptoms before age 65.⁹ No data are available from a nationally representative sample, however, to determine the proportion of people with Alzheimer's disease and other dementias that has onset of symptoms before age 65 or the prevalence of these conditions in the population under age 65.

The HRS, a large-scale, longitudinal survey conducted by the Institute for Social Research at the University of Michigan and funded by the National Institute on Aging, provides the first data on cognitive status in a nationally representative sample of Americans under age 65. This Alzheimer's Association report uses HRS data for people age 55-64.*

* The HRS sample also includes people age 50-54, but in 2000, the sample in this age group was not nationally representative because of the timing of enrollment of people age 50-52. For this reason, HRS data on the age group 50-54 are not used in this report.

The HRS uses several methods to measure cognitive status in sample members under age 65: a brief cognitive test for those who are able to complete a telephone interview, and questions for the interviewer and a proxy respondent (usually a spouse or adult child) for sample members who are not able to complete the telephone interview. For each method, criteria were selected for this report to define three levels of cognitive status: *disabling cognitive impairment*, *borderline cognitive impairment*, and *normal cognitive status* (see App. A for detailed information). The criteria for *disabling cognitive impairment* were selected with the goal of identifying a level of cognitive impairment that is consistent with a diagnosis of dementia, i.e., cognitive impairment severe enough to interfere significantly with work, usual activities, and relationships with others.

Using these criteria, HRS data indicate that in 2000, 480,000 people age 55-64 (2% of the U.S. population in that age group) had disabling cognitive impairment. An additional 590,000 (2.5% of the population age 55-64) had borderline cognitive impairment (see App. B, table 1).

The proportion of people with disabling cognitive impairment increased slightly with age, from 1.9% of people age 55-59 to 2.2% of people age 60-64. The proportion of people with borderline cognitive impairment also increased slightly with age from 2.1% of people age 55-59 to 3.1% of people age 60-64 (see App. B, Table 1).

As noted earlier, the HRS data do not specify the cause of cognitive impairment, and there is no generally accepted approach that could be used to link HRS data on level of cognitive impairment and the diagnostic criteria for dementia.

The Aging, Demographics, and Memory Study (ADAMS), also funded by the National Institute on Aging, will provide such an approach, but only for people age 70 and older. In ADAMS, in-home evaluations were conducted with a random subsample of HRS sample members age 70 and older.¹⁵ Based on information from the evaluations, an expert consensus panel of neuropsychologists, neurologists, geropsychiatrists, and internists assigned diagnoses in three general categories: dementia, cognitive impairment-not demented (CIND), and normal. The panel also assigned specific diagnoses, e.g., Alzheimer's disease and vascular dementia.

Results from ADAMS have not been published as of June 2006, but preliminary findings were presented at a national conference in November 2005.¹⁶ These findings suggest that the level of cognitive impairment defined as disabling cognitive impairment for this report may be conservative and that some people in the borderline cognitive impairment category probably also had dementia. Since the sample for ADAMS only includes people age 70 and older, however, the approach developed from ADAMS for

linking HRS data on cognitive status and diagnostic criteria for dementia may not apply to the HRS sample under age 65.

Another study, the Environmental Catchment Area (ECA) Survey, that was conducted in the 1980s in five U.S. communities, found that 1.2% of the 4,000 sample members age 45-64 had severe cognitive impairment.¹⁷ The ECA sample was not nationally representative, and its findings are not directly comparable with the HRS findings for three reasons: the level of cognitive impairment defined as severe for the ECA was probably more conservative than the level defined as disabling cognitive impairment for this report; the ECA sample included people age 45-54, who are probably less likely than people age 55-64 to have severe cognitive impairment; and the ECA included only community-dwelling people and excluded nursing home residents who are more likely to have cognitive impairment. Despite these differences, the ECA findings provide some support for the validity of the HRS data, since each of the three reasons would tend to decrease the proportion of people found to have cognitive impairment.

To create a tentative estimate of the number of Americans with early onset dementia, the Alzheimer's Association used data from the Rochester (MN) Epidemiology Project study cited earlier and a 2003 telephone survey. As noted earlier, the Rochester (MN) Epidemiology Project found that from 1990 to 1994, 4.6% of new cases of dementia occurred in people age 40-64.⁸ Extrapolating to the U.S. population and assuming that average survival time is the same for people with early and later onset dementia and that 4.5 million Americans age 65 and older have Alzheimer's disease and other dementias, one could estimate that about 220,000 Americans have early onset dementia.

The 2003 telephone survey of a nationally representative sample of Americans age 18 and older found that 34 million people in 18.5 million households said they had provided unpaid care for someone age 50 or older in the previous 12 months.¹⁸ Of these self-reported caregivers, 1.2 million people in 640,000 households said they provided care for a person age 50-64 with Alzheimer's disease, dementia, or mental confusion.¹⁹ Assuming that those in the same household provided care for the same person, one could estimate that 640,000 Americans age 50-64 had Alzheimer's disease or another dementia.

The range, 220,000 to 640,000, includes the HRS figure for the number of people age 55-64 with disabling cognitive impairment, 480,000. The 640,000 figure could be too high if some caregivers were incorrect when they said they provided care for a person with Alzheimer's disease or dementia, if the mental confusion they noted was not dementia, or if more than one household was providing care for the same person with dementia. On the other hand, the 640,000 figure does not include people under age 50 with dementia, people over age 65 with dementia that first occurred when they were under age 65, and

people with dementia who do not have a family caregiver. In addition, as noted earlier, preliminary data from ADAMS suggest that the level of cognitive impairment defined as disabling for this report may be conservative and may exclude people who had dementia with a less severe level of cognitive impairment.¹⁶ Thus, the range 220,000 to 640,000 provides a plausible first estimate of the number of Americans with early onset dementia.

Possible Causes of Early Onset Dementia

Many diseases and conditions can cause early onset dementia (see Box 2).

Box 2: Possible Causes of Early Onset Dementia

Alzheimer's disease: a progressive, neurodegenerative brain disorder that causes dementia.²⁰

Vascular dementia: dementia caused by cerebrovascular conditions, including multi-infarct disease and stroke.²¹

Mixed dementia: dementia caused by a combination of Alzheimer's disease and cerebrovascular conditions; compared with people who have only Alzheimer's disease, those with mixed dementia tend to develop symptoms earlier.^{22,23}

Frontotemporal dementia (FTD):* dementia caused by a group of conditions, including Pick's disease and primary progressive aphasia, that affect the frontal and temporal regions of the brain; the average age of onset for FTD is 50-60;²⁴⁻²⁶ although FTD is less common than Alzheimer's disease overall, one study found it is as common in people under age 65.²⁷

Lewy body disease: a progressive, neurodegenerative brain disease that causes dementia, hallucinations, and the movement and gait disorders that are common in Parkinson's disease.²⁸

Other: diseases and conditions that usually or sometimes cause dementia in people under age 65 include Parkinson's disease, Huntington's disease, progressive supranuclear palsy, amyotrophic lateral sclerosis (ALS), multiple sclerosis, Creutzfeldt-Jakob disease, traumatic brain injury, HIV/AIDS, chronic alcoholism, chronic drug abuse, brain tumors, and normal-pressure hydrocephalus.^{8,9,29,30}

Findings from several studies indicate that early onset dementia is more likely than later onset dementia to be caused by diseases and conditions other than Alzheimer's disease.^{8,9} These studies used samples from a limited geographic area and a clinical setting, however, and no comparable data are available from a nationally representative sample.

* The more familiar term *frontotemporal dementia (FTD)* is used in this report for frontotemporal lobar degeneration (FTLD), which is the increasingly preferred term in research and some clinical settings.

HRS data show that substantial proportions of people age 55-64 with disabling cognitive impairment had hypertension (64%), heart disease (34%), diabetes (28%), and stroke (24%) (see App. B, table 2). These four conditions are strong risk factors for vascular dementia and are increasingly recognized as risk factors for Alzheimer's disease.^{21,31-39} As shown in the table, the four conditions were significantly more common in the HRS sample members with disabling cognitive impairment than in the sample members people with normal cognitive status.

Possible Causes of Cognitive Impairment that is not Dementia

Intellectual disabilities ("mental retardation") and severe mental illness can cause cognitive impairment that is not dementia. Some people with intellectual disabilities have cognitive impairment at the level of severity defined as disabling for this report. One expert consulted for the report estimated that intellectual disabilities might be the cause of cognitive impairment for about 16% of the HRS sample age 55-64 with disabling cognitive impairment.⁴⁰ Although not definitive, combined data from other sources support this estimate.⁴¹⁻⁴⁴

Most people with mental illness do not have cognitive impairment, but some people with severe depression, schizophrenia, bipolar disorder, and other severe mental illnesses do.⁴⁵⁻⁵⁰ No information is available to estimate the proportion of HRS sample members age 55-64 with disabling cognitive impairment caused by mental illness.

Many factors, can affect a person's performance on cognitive tests and make it seem that the person has cognitive impairment when he or she does not or cause temporary cognitive impairment that later disappears: such factors include acute and chronic illnesses, delirium, medications, low literacy, low educational level, ethnicity, socioeconomic status, language difficulties, sensory deficits, and acute alcohol or drug intoxication.⁵¹⁻⁵⁹ On the other hand, cognitive impairment associated with these factors sometimes persists and is confirmed with further testing.^{55,60,61}

It is also important to note that some people with cognitive impairment caused intellectual disabilities, severe mental illness, or other factors also have dementia. People with intellectual disabilities caused by Down's syndrome, for example, have a very high rate of dementia -- an estimated 65% in those age 60 and older.^{40*} Likewise, some people with severe depression, lifelong schizophrenia, and other severe mental illnesses also have dementia.^{8,62}

* In contrast, people with intellectual disabilities caused by other conditions have rates of dementia that are similar to rates for the general population.⁴⁰

Needed Research on Prevalence and Causes of Early Onset Dementia

Additional research is needed to determine the prevalence and causes of early onset dementia. A study like ADAMS that includes HRS sample members age 50 and older is probably the best option. Such a study would miss people under age 50 with early onset dementia but would have the advantage of being able to link diagnostic information about sample members to the large amounts of other information about them that is available from the HRS. Another option is piggybacking on a new or ongoing study with a nationally representative sample of people under age 65 by adding components to identify early onset dementia. A third, less desirable, but also less costly option is new research or reanalysis of existing data on cognitive status and dementia in one or more limited geographic areas.

III: Problems Confronted by People with Early Onset Dementia and Their Families and Steps Toward Solutions

People with onset of dementia before age 65 and their families face the same problems as people with later onset dementia, but certain additional problems that are more likely to occur for those with early onset dementia. As noted in the introduction, these problems are:

- difficulty getting an accurate diagnosis
- loss of employment and job-related income
- difficulty obtaining SSDI, SSI, and other disability benefits
- lack of health insurance and high out-of-pocket expenditures for medical care
- high out-of-pocket expenditures for long-term care, and
- lack of appropriate medical care, residential care, and community services.

This part of the report discusses these problems in detail and analyzes possible steps toward solutions. The discussion is based primarily on information from three sources: the HRS, a descriptive study by Harris and Keady (2004) that was conducted in the U.S.², and the 2004 Alzheimer's Association survey. The Association is not aware of other U.S. research that focuses on the problems confronted by people with early onset dementia. Findings from a few studies conducted in the U.K. and elsewhere and U.S. studies on related topics are noted where relevant.

The HRS data pertain to Americans age 55-64 with disabling cognitive impairment, as defined for this report. The term *disabling cognitive impairment* is used throughout the report to note that the HRS data include not only people with dementia but also an unknown number of people with disabling cognitive impairment but not dementia (see Part II).

The descriptive study by Harris and Keady was conducted to increase understanding about the lived experience and unique challenges faced by people with early onset dementia.² In-depth interviews were conducted with 23 younger Americans with dementia caused by Alzheimer's disease (14), frontotemporal dementia (6), Huntington's disease (1), degenerative dementia (1), and benign brain tumor (1). Their average age at the time of diagnosis was 53 (range 42-63); 11 were under age 55; 43% were male; and all were in the early or middle stage of dementia and able to complete an interview.

The Alzheimer's Association survey was conducted to help the Association identify key issues and problems faced by people with early onset dementia and their families. A 2-page questionnaire was

mailed to 200 people and then posted on the Association's website. Responses were received for 94 younger Americans with a self-reported diagnosis of dementia caused by Alzheimer's disease (77), frontotemporal dementia (8), mild cognitive impairment (3), Lewy Body Disease (2), vascular dementia (1), stroke (1), early onset dementia (1), and corticobasal degeneration (1). Their average age at the time of diagnosis was 54 (range: 38-64); 38 of them were under age 55;* and 52% were male. No information is available about stage of dementia. One-third (32) of the questionnaires were completed by the person with dementia; 41 were completed by the care partner (usually a spouse or adult child); and the remainder were completed by the person and care partner together or by another person.

These three sources have significant limitations for developing a complete picture of problems faced by people with early onset dementia. The HRS data do not include people under age 55 or people over age 65 whose dementia first occurred when they were under age 65, and they do include an unknown number of HRS sample members with disabling cognitive impairment that is not dementia. The study by Harris and Keady and the Alzheimer's Association survey include people under age 55, but they have small samples that are probably not representative of all Americans with early onset dementia. Despite these limitations, information from the three sources is useful in beginning to understand the problems associated with early onset dementia and to identify steps to address them.

1. Difficulty Getting an Accurate Diagnosis

Dementia is generally considered a condition of older people, and it is not expected in people under age 65. As a result, getting an accurate diagnosis is often a difficult, time-consuming, and frustrating process for younger people with dementia and their families.

Available information about the problem - The HRS does not include information about this problem, but the study by Harris and Keady found that difficulty getting an accurate diagnosis is a common experience for younger people with dementia.² Some of the people in the study said their doctor first diagnosed the cause of their cognitive impairment as depression, stress, or burnout. Others said their doctor was reluctant to make a diagnosis of dementia until all other possibilities had been ruled out.

Responses to the Alzheimer's Association survey show that 14 of the 94 people with early onset dementia received a diagnosis within a month of when they first sought medical attention for their cognitive impairment. For the great majority, however, the diagnostic process took much longer. About

* Eight of the 94 respondents did not report the person's age at the time of diagnosis; the figures above for average age at the time of diagnosis and number of people under age 55 do not include these eight people.

one third received a diagnosis of dementia in six months to a year, and another third waited more than a year, including 9 individuals who did not receive a diagnosis until 4 to 6 years after they sought medical attention for their cognitive impairment.

The Alzheimer's Association survey asked for comments about the diagnostic process, and two-thirds of the survey responses include such comments. Some people said they had to go to two or more (up to six) doctors to get a diagnosis. Many said their doctor assumed they were too young to have dementia and first diagnosed their cognitive impairment as caused by something else, such as depression, stress, hormones, post traumatic stress disorder (PTSD), mental illness, alcohol abuse, diabetes, or "change of life." Some commented that their doctor was not knowledgeable about dementia, did not listen to the person or family, or did not inform them about the diagnosis in a timely way.

- Ø *"No one understood my symptoms. I had many MRIs. I was always confused, but no one understood" (person was diagnosed with Alzheimer's disease at age 50, five years after first seeking medical attention for her symptoms).*
- Ø *"I was told: 'it's only stress,' 'this is depression,' 'it's a symptom of menopause,' 'everybody slows down a little,' etc." (person was diagnosed with vascular dementia at age 52, five years after first seeking medical attention for her symptoms).*
- Ø *"After going to three different neurologists and two internists, I went to (a university medical center) and got help. All the doctors thought I was too young to have brain disease" (person was diagnosed with frontotemporal dementia at age 56, 18 months after first seeking medical attention for his symptoms).*

Some responses to the survey indicate that the person's doctor was reluctant to make a diagnosis of dementia until all other possibilities had been ruled out. A few of these responses characterized the doctor's caution as desirable, but most characterized it as undesirable. For two respondents, their doctor's reluctance to make a diagnosis of dementia left them feeling uncertain about the diagnosis.

- Ø *"Diagnosis subjective, and concrete proof is difficult to find. Also, doctors are quick to push you to accept diagnosis. Follow up is limited. Family doctor was aware of issue, but I felt that he was uncomfortable and was reluctant to get involved" (person was diagnosed with Alzheimer's disease at age 54).*

Two factors complicate the diagnostic process for doctors. Most doctors probably do not expect to see dementia in people under age 65. In addition, the cause of dementia is less likely to be Alzheimer's disease in younger versus older people.^{8,9} As a result, younger people with dementia may not come to the doctor with the more commonly recognized symptoms of memory loss that are typical of

Alzheimer's disease. People with frontotemporal dementia, for example, may come to the doctor because of personality and behavioral changes.^{25,26}

Although these factors make it difficult to diagnose early onset dementia, having an accurate diagnosis is essential for several reasons. People with early onset dementia and their families need to understand what is happening to the person. The person's doctor needs to know the cause of the dementia because cause-specific treatments may exist to slow progression and reduce symptoms. Diseases and conditions that cause dementia also differ in many ways, including average survival time and the likelihood that the person will also experience movement and gait disorders, perceptual and communication difficulties, and psychiatric symptoms, such as hallucinations and delusions.^{26,63,64} Some of these differences are more noticeable in the early stages of dementia and tend to blur as the diseases and conditions progress.²⁶ Still, health care and social service professionals and other providers need to know the cause of the dementia to give accurate information and appropriate treatment and services.^{26,63-65}

Steps toward solutions - To reduce the difficulty of obtaining an accurate diagnosis will require greater awareness of early onset dementia among doctors and other health care professionals. Research findings on the prevalence and causes of early onset dementia could eventually result in data that would support greater awareness. In the meantime, organizations that provide information and training about dementia for these professionals should include early onset dementia in their materials and programs. Doctors and other health care professionals should be attentive to expressed concerns of people under age 65 and their families about cognitive and related symptoms. Doctors should also receive training about diagnosis of early onset dementia and the disease and conditions that cause it.

Doctors could refer some or all of their younger patients with suspected dementia to a specialized diagnostic center, such as the federally funded Alzheimer's Disease Centers that now exist in 21 states. For such referrals to happen, however, doctors must first recognize possible dementia in these patients.

2. Loss of Employment and Job-related Income

Many people with early onset dementia are still working when their symptoms emerge. They are likely to lose not only their job but also job-related income and years of contributions to Social Security and other pension or retirement accounts. Without income from a job, they may have to use any retirement savings they have accumulated to pay for current expenses.

Available information about the problem – The HRS data show that only 22% of people age 55-64 with disabling cognitive impairment were still working, compared with 65% of those with normal cognitive status. The impact on income was enormous:

- Average annual income for those with disabling cognitive impairment was \$17,840, compared with \$42,852 for those with normal cognitive status, and
- 62% of those with disabling cognitive impairment had annual income of less than \$11,000, compared with 15% of those with normal cognitive status (see App. B, table 3).

Findings from the study by Harris and Keady provide insight into the experience of losing one's job as a result of early onset dementia. Some people interviewed for the study said their cognitive impairment was first noticed at work, where they were no longer able to perform their usual job tasks. Thus, they lost not only the job but also self-esteem and the feeling of being a productive person.²

Two thirds of the responses to the Alzheimer's Association survey indicate that, as a result of being diagnosed with dementia, the person retired voluntarily or was fired from his or her job. About half the respondents checked 'voluntary retirement;' half checked 'forced retirement/fired;' and some checked both. Many comments suggest uncertainty and point to factors other than or in addition to diagnosis that resulted in the person leaving his or her job, notably, problems in performing job tasks, the employer's response, and liability concerns.

- Ø *Checked 'voluntary retirement' but commented, "involuntary retirement - could no longer do my job" (person was diagnosed with Alzheimer's disease at age 53).*
- Ø *Checked 'voluntary retirement,' but commented, "Encouraged to retire" (person was diagnosed with Alzheimer's disease at age 56).*
- Ø *Checked 'voluntary retirement' but commented, "Laid off before going to the doctor" (person was diagnosed with Alzheimer's disease at age 45).*
- Ø *Checked 'forced retirement' but commented, "Actually it was mutual, but he would never have retired had it not been for his illness" (care partner of a person diagnosed with Alzheimer's disease at age 56).*
- Ø *Checked 'voluntary retirement' but commented, "The diagnosis was a liability for my job as a medical professional, and I had to retire" (person was diagnosed with mild cognitive impairment at age 51).*

Some responses indicate a series of voluntary and forced retirements: the person retired from one job, got another job, and was fired from that job; alternatively, the person was fired from one or more jobs and then voluntarily retired from his or her last job.

Title I of the Americans with Disabilities Act (ADA) prohibits discrimination on the basis of disability in any aspect of employment and requires employers to make reasonable accommodations for qualified individuals with a disability unless doing so would impose an undue hardship on an employer's business. The Alzheimer's Association survey asked about problems with "workplace accommodations," and ten responses indicate such problems occurred. One person diagnosed with Alzheimer's disease said, *"I was fired from my job, no reasons, no accommodations."* Others noted that accommodations were made but the results were not entirely satisfactory, or the person kept the job but only for a short time.

- Ø *"I am working part time... For the most part, they have been very helpful; however, there are incidents when staff are so busy that it is difficult to find a manager to discuss concerns (person was diagnosed with Alzheimer's disease at age 54).*
- Ø *"I hated to actually sue my employer to keep my job...but I won my case, got my job back, and a year later had to retire" (person was diagnosed with Alzheimer's disease at age 46).*

The ADA requirement for work accommodations assumes that a disability has been recognized. If a disability is not explicitly recognized, no one, including the employer, is likely to consider work accommodations.

- Ø *"By the time I was given a diagnosis, I had had several years of failing at my job, been forced to retire, become penniless. Had I had a diagnosis, (my employer) would have been legally bound to give me a lesser job. What a waste!" (person was diagnosed with vascular dementia at age 52).*

When a person with early onset dementia retires or is fired from his or her job, it is extremely difficult or impossible for the person and family to replace the lost income. Some people with early onset dementia have a job that provides retirement income for early retirees *and* they are old enough *and* have worked long enough to be eligible for this benefit. Most people with early onset dementia do not have this option. Either their job does not provide retirement income for early retirees, or they are too young or have not worked long enough to qualify. Another option is applying for disability benefits through Social Security or another government or private, employer-based disability program, but people with early onset dementia often have difficulty obtaining disability benefits, as discussed later in the report.

Many responses to the Alzheimer's Association survey include comments about the difficulty of coping with the loss of job-related income.

- Ø *"If you're under 65 and single income, you're in big trouble" (person was diagnosed with Alzheimer's disease at age 47).*

- Ø *“Lost \$30,000 in annual income (person was diagnosed with Alzheimer’s disease at age 48).*
- Ø *“We had much difficulty and had to file for bankruptcy” (care partner of a person diagnosed with Alzheimer’s disease at age 38).*
- Ø *“We were self-employed and had to close down our business because my husband was the only one skilled to operate the machinery. Due to the fast progression of the disease, it was not possible to sub-out the work or deal with a business and still take care of my husband” (care partner of a person diagnosed with Alzheimer’s disease at age 50).*

To replace family income that was lost as a result of the person’s diagnosis, six spouses said they had to enter the workforce. In contrast, another 16 spouses said they had to leave the workforce to take care of the person with dementia. Some spouses who were still working commented about the difficulty of maintaining a job while trying to provide care for their husband or wife with dementia.

One person who was diagnosed with Alzheimer’s disease at age 48 tried to withdraw funds from his 401 K to create an annuity to pay his ongoing expenses. His employer would not allow this unless he paid the penalty for early withdrawal.

Steps toward solutions - To reduce problems with loss of employment and job-related income will require several steps. A first step is greater awareness among employers and human resources personnel of the possibility of early onset dementia, usual symptoms, the importance of diagnosis, and procedures for referring a person to get a diagnosis. This step will not avoid loss of employment, but it will increase understanding about why the person is no longer able to perform his or her job tasks, avoid firing in some cases, and promote timely diagnosis.

A second step is greater knowledge about and availability of work accommodations. Little information is available about work accommodations for people with early onset dementia. Most diseases and conditions that cause dementia progress over time, and work accommodations are likely to be a temporary solution for people with early onset dementia. Still, being able to continue working for as long as possible is important to many younger people with dementia, and work accommodations are valuable for this reason. Potentially useful work accommodations that are mentioned in the ADA include job restructuring, part-time or modified work schedules, and reassignment to a vacant position. Information about work accommodations that may be effective for people with early onset dementia and relevant ADA requirements should be developed and widely disseminated to employers, human resource personnel, people with early onset dementia, their families, and others.

A third step is better information about retirement income. Employers and human service personnel should have easily accessible information about early retirement options for their workers, including information about whether retirement income is provided for early retirees, and if so, after what age and number of years of employment and with what effects on the availability or amount of retirement income available to the person at age 65. Organizations that provide information and counseling for people with dementia and their families should have materials that address this topic in general and suggest questions a person or family should ask the person's employer. Many employers are now reducing or eliminating retirement benefits. Information about retirement income for early retirees should note the possibility of changes and be updated regularly to incorporate the changes.

3. Difficulty Obtaining SSDI, SSI, and Other Disability Payments

People with early onset dementia often have difficulty obtaining disability payments. Most people with dementia are over age 65 and eligible for regular retirement benefits. As a result, organizations and individuals that provide information and counseling for people with dementia and their families may not know enough about disability programs to help younger people with dementia.

Almost all American workers are covered by Social Security and therefore potentially eligible for monthly SSDI disability payments. To receive SSDI payments, a person must have:

- worked in a job covered by Social Security for long enough to earn a specified number of work credits, depending on his or her age (the "duration of work" requirement), and
- earned a specified number of work credits in a specified number of years before the year in which he or she became disabled (the "recent work" requirement), and
- left work before age 65 because of a medically determinable physical or mental impairment that is expected to last at least a year or result in death *and* is severe enough that the person cannot do his previous work or any other kind of substantial gainful work that exists in the national economy (the disability requirement).⁶⁶

Once determined to be eligible for SSDI based on these requirements, the person has to wait five more months before receiving a first check.*

* The 5-month waiting period reflects the emphasis on long-term disability in Social Security disability programs and the original expectation of Congress that short-term disability and first months of long-term disability would be managed through state and private employment-based short-term disability programs.⁶⁶

Workers who are not covered by Social Security include: some federal workers who were hired before 1984, have not opted for Social Security coverage, and are covered under the Civil Service Retirement System; state and local government workers where the government entity did not choose to have its workers covered but provides alternate benefits; railroad workers who are covered under the railroad retirement system; and household, farm, and self-employed workers with earnings below specified minimums.⁶⁶ With the exception of the last group, these workers are generally eligible for disability payments through employment-based long-term disability programs.

Some private employers provide long-term disability insurance or disability pensions to supplement SSDI. If a person who receives SSDI and a payment from one of these other sources, the SSDI payment is usually reduced by the amount of the other payment.⁶⁶

Lastly, people under age 65 who meet the Social Security Administration's disability requirement and have very low income and assets are generally eligible for SSI.

Available information about the problem - The HRS data show that 29% of people age 55-64 with disabling cognitive impairment were receiving SSDI, and 3% were applying for SSDI (see App. B, table 4). Another 18% were receiving SSI, and 12% were applying for SSI (see App. B, table 5). Data are not available on the proportion receiving other disability payments.

The Alzheimer's Association survey asked about problems with SSDI, and one third of the survey responses indicate that the person with dementia had such problems. Some responses indicate that the person and family did not know the person had dementia and therefore did not apply.

Ø *"We were not aware that the problem was Alzheimer's disease when the person had to quit work two years before diagnosis. Therefore, we didn't apply for disability insurance" (care partner of a person diagnosed with Alzheimer's disease at age 64).*

Other survey responses indicate that the person was receiving SSDI, but the application process took a long time, and they had great difficulty getting by without income during that period and the additional five months between when the person was found eligible and when the first check came.

Twelve survey responses indicate the person with dementia was denied SSDI for various reasons. Some said the person had not paid into Social Security for long enough to be eligible. Others said SSDI was denied even though the person had paid in for long enough; the problem was that the person did not meet the "recent work" requirement; that is, the person had not earned enough work credits in the

specified number of years before the year in which he or she became disabled. One person was said to have been denied SSDI for this reason even though she had paid into Social Security for 29 years.

Several survey responses said SSDI was denied because the Social Security Administration decided the person with dementia was still able to work:

Ø *“Social Security denied x 2, say can work and learn new skills in spite of diagnosis”
(person was diagnosed with Alzheimer’s disease at age 40).*

Some people said they had difficulty with the forms and paperwork required for their SSDI application. Others seemed confused about the eligibility requirements, saying, for example, that the person with dementia could not apply because of his or her age. One person diagnosed with Alzheimer’s disease at age 47 said, *“They say I need two more years, ...so much wait...I forget, I think 62...They say that I maybe fight and get help early.”*

Steps toward solutions - To reduce the difficulty of obtaining disability payments will require that people with early onset and their families have easy access to accurate information about available benefits, eligibility requirements, and the application process; that they are encouraged to apply and receive assistance with the process, if needed.

SSDI is probably the most important disability program for people with early onset dementia because most American workers are potentially eligible if they meet the program requirements. Organizations and individuals that provide information and counseling for people with dementia and their families should develop and disseminate print and electronic materials about SSDI that explain what it is, why it is potentially valuable for younger people with dementia, and how to apply. They should encourage people with early onset dementia to apply for SSDI if the people worked in jobs covered by Social Security and are no longer able to work. They should be prepared to answer questions and provide assistance with SSDI applications or refer people with dementia and their families to other sources for assistance with problems they encounter in the application process.

As noted earlier, some people who responded to the Alzheimer’s Association survey said the person with dementia did not apply for SSDI because neither the person nor family was aware that the person had dementia and therefore might be eligible. Reducing the difficulty of getting an accurate diagnosis would help with this problem. Employers and human resources personnel could also help if they were more aware of early onset dementia and recognized that their employee was leaving his or her job because of a disability that could make the person eligible for SSDI.

SSDI denials can occur for many reasons. Sometimes the reason for a denial is clear and unquestionable, for example, in the case of a person who did not work in a job covered by Social Security for long enough to be eligible. Other times, the reason for the denial is less clear, notably in the case of people with early onset dementia who are denied SSDI because it is said that they are still able to work. For some people with early onset dementia, that may be a correct conclusion, but for others it is probably not. One approach is to encourage the person to appeal the decision and provide assistance with the appeal, if needed. If there are numerous denials for the same reason, a better approach is to analyze the disability requirement and related disability decision process, determine what, if any, changes are needed, and advocate for those changes.

No organization is currently tracking SSDI denials for people with early onset dementia. Thus, it is not clear whether there are numerous denials for the same reason and, therefore, a need for further analysis and advocacy.

Several responses to the Alzheimer's Association survey described situations in which a person with early onset dementia had worked long enough in a job covered by Social Security and met the disability requirement was denied SSDI because he or she did not meet the "recent work" requirement. The implications of the SSDI "recent work" requirement for a particular person depend on the person's age and details of his or her work history, and the survey responses do not provide enough details to understand exactly what happened in the reported situations. Given long delays in getting a diagnosis, however, and survey responses about people who retired from their job before getting a diagnosis, it is easy to imagine how SSDI denials could occur because of the "recent work" requirement: a person who has early onset dementia but does not have a diagnosis decides to retire because of problems in performing job tasks, receives a diagnosis some years later, eventually applies for SSDI, and is denied because he or she does not have enough work credits in the specified time period.

The number of people with early onset dementia who are denied SSDI because they do not meet the "recent work" requirement is not known. To avoid such denials, organizations and individuals that provide information and counseling for people with dementia should include information about the "recent work" requirement in print and electronic materials about SSDI and discussions with younger people with dementia and their families and encourage timely application.

To receive SSI, people must meet the same disability requirement that is used for SSDI. They do not have to meet the "duration of work" or "recent work" requirements, but they must have income below the SSI benefit level (\$603 per month in 2006) and assets below \$2,000.

As with SSDI, organizations and individuals who provide information and counseling for people with dementia and their families should have print and electronic materials about SSI, what it is, why it is potentially valuable for younger people with dementia, and how to apply. They should encourage people with early onset dementia to apply for SSI if the people have low income and assets and did not work in a job covered by Social Security for long enough to be eligible for SSDI. These organizations and individuals should also be prepared to answer questions and provide assistance with SSI applications or refer people with dementia and their families to other sources for assistance with problems they encounter in the application process.

Monthly SSDI disability payments are lower than the person's previous work income, with the exact amount depending on previous earnings.* The SSI disability payment is the same as the SSI benefit level, \$603 per month in 2006, minus any other income the person has.³

Since SSDI and SSI have the same disability requirement, analysis of the requirement and related disability decision process would apply to both programs. Likewise, effective advocacy for needed changes would help people who could be eligible for either program. As discussed later in the report, people who receive SSDI also get Medicare after a 2-year waiting period, and people who receive SSI generally also get Medicaid. Thus, the SSDI/SSI disability requirement and related disability decision process determine access to both income and health insurance, making advocacy for any needed changes extremely important for the well being of people with early onset dementia.

Disability payments from other government and private employment-based disability programs are available to fewer people than SSDI and SSI, but these benefits are very valuable to the people who receive them. Employers and human resources personnel should inform their employees about the availability of employment-based disability payments and help them apply. Organizations and individuals who provide information and counseling for people with dementia should provide general information about these other disability programs and suggest questions a person or family should ask the person's employer. Any general problems with the disability criteria or other requirements that restrict access to disability payments through these programs for people with early onset dementia should be identified and addressed.

* The amount of a person's monthly SSDI payment represents a larger percentage of previous earnings for people with low previous earnings than for people with high previous earnings. In 1993, for example, the average monthly SSDI payment for a person with previous earnings of \$500 a month was \$392, or 78% of the person's previous earnings. The average monthly SSDI payment for a person with previous earnings of \$4,500 was \$1,318, or 29% of the person's previous earnings.⁶⁶

³ Some states provide supplemental payments to increase the total monthly benefit above the SSI benefit level.⁶⁷

Some individuals with early onset dementia feel that taking early retirement is less stigmatizing than leaving one's job on disability, and some of them have a job that provides retirement income for early retirees *and* they are old enough *and* have worked long enough to be eligible for this benefit *and* taking these retirement payments will not reduce the amount of retirement benefits they can receive at the usual age of retirement. Most people with early onset dementia are not in this situation, and many people do not have a choice of taking early retirement or disability benefits. Given recent reductions and elimination of retirement benefits for some workers, even people who have a choice should be advised to weigh carefully the pros and cons of taking early retirement versus disability benefits.

4. Lack of Health Insurance and High Out-of-Pocket Expenditures for Medical Care

People with early onset dementia who lose their jobs are likely to lose job-related health insurance. Almost all people age 65 and older have health insurance through Medicare,^{*} but that is not true for younger people. Those who receive SSDI disability payments get Medicare, but only after a 2-year waiting period. Some people have health insurance through employment-based disability or early retirement benefits or through their spouse's employment. Some people are able to purchase private health insurance. Those who receive SSI generally get Medicaid, and some people with early onset dementia have no health insurance.

People who have health insurance may or may not have high out-of-pocket expenditures for health care, depending on the amount and types of health care services they use and the provisions of their insurance. People who do not have health insurance must either forego health care services or incur very high out-of-pocket expenditures for these services.

Available information about the problem - The HRS data show that 29% of people age 55-64 with disabling cognitive impairment had no health insurance. Another 26% had Medicare; 29% had Medicaid; and 35% had employer-provided health insurance,^{*} including some who had health insurance from two sources; for example, 11% had Medicare and Medicaid (dual eligibles) (see App. B, table 6).

The HRS data also show that 93% of people age 55-64 with disabling cognitive impairment and the same proportion of people with normal cognitive status had doctor visits in the 2-year period before

^{*} In 2000, 98% of people age 65 and older (34,261,000 people) had Medicare.⁶⁸

^{*} People age 55-64 with employer-provided health insurance include those who were still working, those with health insurance as part of employment-related disability or retirement benefits, and those who were covered under their spouse's employment-based health insurance.

the survey. In contrast, people with disabling cognitive impairment were four times more likely to have been hospitalized in that 2-year period (42% vs. 11%) and two times more likely to have received medical home health care, e.g., visiting nurse services or in-home physical, occupational, or respiratory therapy (11% vs. 5%) (see App. B, table 7).

Average out-of-pocket expenditures for health and long-term care services combined were higher for people with disabling cognitive impairment than for those with normal cognitive status (\$205 vs. \$79 per month) (see App. B, table 8). Most of the difference was due to higher out-of-pocket expenditures for prescription drugs for people with disabling cognitive impairment than for those with normal cognitive status (\$141 vs. \$33 per month) (see App. B, table 9).

The Alzheimer's Association survey asked about problems with Medicare, Medicaid, and private health insurance. Some survey respondents emphasized the 2-year waiting period for Medicare.

- Ø *"It took years after receiving SSDI" (care partner of a person diagnosed with Alzheimer's disease at age 45).*

Some, who had employment-based insurance, emphasized the cost of the insurance.

- Ø *"We have health insurance through the individual's former employer. We pay the entire cost of insurance ourselves. It is expensive, especially with our reduced income" (care partner of a person diagnosed with Alzheimer's disease at age 53).*

Some said they had been refused private insurance because of the person's dementia. Others said the premiums for their insurance had been raised because of dementia-related medical care.

- Ø *"Once our health insurance company became aware of the increased costs for diagnosis, doctor visits, and prescriptions, they increased our premiums 60%. We are stuck paying \$1,007 a month, for a family of 4, which covers the doctor and 3 prescriptions" (care partner of a person diagnosed with Alzheimer's disease at age 51).*

Still others were confused about Medicare eligibility and benefits and very worried about the impact on their families of their future care needs and the cost of their care.

- Ø *"I am too young to receive any help from Medicare. This is going to put a huge strain on the family finances. My wife may have to retire to take care of me... When she cannot take care of me anymore, I still may be too young for Medicare benefits" (person was diagnosed with frontotemporal dementia at age 57).*

Steps toward solutions – One step to reduce the problem of lack of health insurance for people with early onset dementia is elimination of the 2-year waiting period for Medicare. The waiting period was established in 1972, when Congress first extended Medicare coverage to people who receive SSDI. The objectives of the waiting period were to limit Medicare costs, avoid substitution of publicly funded benefits for private insurance, and ensure that only people with long-lasting disabilities would have Medicare coverage.⁶⁹ Since 1972, people with end-stage renal disease have had a 3-month waiting period, and in 2000, Congress eliminated the waiting period entirely for people with amyotrophic lateral sclerosis (ALS or Lou Gehrig’s disease).

Eliminating the waiting period for Medicare for people with early onset dementia would allow those who receive SSDI to have Medicare coverage two years sooner than they can now. Since the spouse and minor children of people who receive SSDI and Medicare can also have Medicare coverage, elimination of the waiting period would be very valuable for these families.

The number of people with early onset dementia that would benefit from elimination of the 2-year waiting period for Medicare is not known. HRS data noted earlier show that in 2000, 29% of people age 55-64 with disabling cognitive impairment were receiving SSDI, and 26% had Medicare. Thus, one could hypothesize that about 3% of those with disabling cognitive impairment (about 14,400 people in 2000) were in the 2-year waiting period.

In addition to Medicare, there are other options for health insurance. As noted earlier, some people with early onset dementia have health insurance through disability or early retirement benefits from their previous employer or through their spouse’s employment.

The Consolidated Omnibus Budget Reconciliation Act (COBRA), enacted in 1985, provides another option for obtaining health insurance. COBRA requires some employers to allow workers who have had group coverage to continue their coverage for 18 months after leaving their job.

A third option is private health insurance. Some people with early onset dementia who try to buy private health insurance are refused outright because of their dementia. Others are able to buy private health insurance, but the insurance will not pay for health care services for pre-existing conditions, including dementia. Two government programs are intended to help with these problems:

- **State high-risk pools** provide coverage for some people who cannot buy health insurance because of pre-existing conditions. As of 2003, 32 states had high risk pools, and 178,000 people of all ages were receiving health insurance through these risk pools.⁷⁰

- **HIPAA** (the Health Insurance Portability and Accountability Act), enacted in 1996, limits the extent to which a health insurance plan can refuse to pay for health care services for pre-existing conditions. State laws vary under HIPAA, but in general, health insurance plans must cover pre-existing conditions if the person had continuous, previous health insurance for at least a year, without a break of 63 or more days.⁷¹

Although COBRA, state high-risk pools, and HIPAA provide options for obtaining health insurance, each program has significant limitations. COBRA coverage only lasts 18 months. Moreover, many jobs do not provide employer-sponsored health insurance, and people who leave these jobs cannot benefit from COBRA. High-risk pools do not exist in some states, and HIPAA requires continuous previous health insurance coverage. For most people, however, the biggest limitation of health insurance obtained through these programs is cost. Employers that provide health insurance for their workers usually pay part of the premium, but under COBRA, the person has to pay 100% of the premium plus 2% for administration. Premiums under state high-risk pools and HIPAA are often even higher than premiums under COBRA and much higher than the premium for Medicare (\$88.50 a month in 2006).

Other limitations of health insurance obtained through COBRA, state high-risk pools, and HIPAA are restrictions on covered services and high out-of-pocket expenditures for deductibles, co-payments, and medical services that are not covered. Out-of-pocket expenditures are also a problem for people who have Medicare. In 2000, average out-of-pocket expenditures for deductibles and co-payments alone were \$1,124 per year (\$98 per month) for people under age 65 who had Medicare.⁷²

Medicaid is an option for people who have very low income and assets. In most states, anyone who receives SSI automatically gets Medicaid, but some states have other, generally more restrictive, requirements.* States can also choose to provide Medicaid for people who meet the Social Security disability requirement and at least one of the following criteria:

- have income up to 100% of the federal poverty level.³

* 39 states and the District of Columbia provide Medicaid for anyone who receives SSI. The other 11 states use the 209(b) option which allows them to establish their own criteria for disability, income, and/or assets: for example, Indiana and New Hampshire use a more restrictive disability requirement than the Social Security disability requirement, and Ohio uses a more restrictive income requirement (\$504 per month in 2006).

³ In 2006, 17 states and the District of Columbia were providing Medicaid for people who meet the disability requirement and have income up to the federal poverty level. States that supplement the SSI monthly payment generally also provide Medicaid for people who receive these supplemental payments.

- have high medical expenses in relation to their income; these people can receive Medicaid if their income minus their medical expenses is below a state-selected “medically needy income level” (about half of the SSI benefit level, on average, across states).⁷³
- are in a nursing home and have income up to 300% of the federal poverty level; these people can receive Medicaid if their medical expenses, including expenses for nursing home care, are higher than their income.⁷³

States can also apply for federal waivers to provide Medicaid for people not covered by these criteria.^{73,74}

Compared with Medicare and most other private insurance, Medicaid generally covers a more comprehensive array of services, including long-term care. Medicaid does not pay for services for a beneficiary’s spouse or children.

Despite the many limitations of health insurance under COBRA, state high-risk pools, HIPAA, and Medicaid, each program allows some people with early onset dementia to maintain or obtain health insurance. These programs are not well known, and if people do not know about the programs, they will not be able to apply. Organizations and individuals that provide information and counseling for people with dementia and their families should have readily accessible materials that describe each program, why it may be helpful, and how to apply. They should be prepared to answer questions about the programs or refer people to other sources of information, and they should encourage people to apply.

Even if all people with early onset dementia who were potentially eligible applied for and received SSDI *and* the 2-year waiting period for Medicare were eliminated, *and* all people who were potentially eligible for health insurance under COBRA, state high-risk pools, HIPAA, and Medicaid applied and received insurance, some people with early onset dementia would still not have health insurance. The number of such people is not known. There is an obvious gap, however, between the income and assets a person can have and still receive SSI and Medicaid (up to \$603 income per month and \$2,000 assets in 2006) and the amount of income and assets a person would need to pay for basic living expenses and the full cost of health insurance under COBRA, a state risk pool, or HIPAA. Even in states that provide Medicaid for people who have income up to the federal poverty level (\$817 per month in 2006), there is a gap between that amount and the amount that would be needed to pay for living expenses and the full cost of health insurance under COBRA, state high-risk pools, or HIPAA.

People who have no health insurance can decide not to use medical services, or they can use the services and end up with high medical bills. Some people have enough income and assets to pay these bills and still have adequate funds for food, housing, and other basic living expenses, but many do not.

Thus, many people decide not to use medical services, regardless of the impact on their health and well being.^{75,76} People who have health insurance sometimes make the same decision when they cannot afford deductibles and co-payments, and some drop the insurance because they cannot afford the premiums.⁷⁶⁻⁷⁸

For families, high out-of-pocket expenditures for premiums, deductibles, and co-payments associated with health insurance for the person with dementia can create huge financial strains. These expenditures and the cost of services that are not covered by insurance reduce the amount of family income and assets available for the rest of the family, including minor children.

Ongoing changes in employer-sponsored health insurance are likely to exacerbate the problem of lack of health insurance and high-out-of-pocket expenditures for people with early onset dementia. With the rising cost of health insurance and health care, some employers are eliminating health insurance for their employees and retirees, and other employers are increasing premiums, deductibles, and co-payments.^{76,79-81} Employer-sponsored health insurance is a prerequisite for inclusion of health insurance in disability and early retirement benefit packages, COBRA, and access to insurance through a spouse's employment. Thus, any steps that help to maintain employer-sponsored health insurance are important.

Ongoing changes in Medicaid could also exacerbate the problem. These changes result primarily from the Deficit Reduction Act of 2005, which was enacted in early 2006. The act does not change basic Medicaid eligibility or covered services for people who meet the Social Security disability requirement, but several provisions of the act have the potential to increase out-of-pocket expenditures and even to take Medicaid away from some people who have it now. These provisions are as follows:

- **Premiums** - The act *allows* states to charge unlimited premiums for Medicare beneficiaries with income above 150% of the federal poverty level (nursing home residents are exempt). Prior to the act, states generally could not charge premiums for Medicaid.
- **Co-payments** - The act *allows* states to increase co-payments for Medicaid beneficiaries (nursing home residents are exempt). Since 1982, states have been allowed to charge Medicaid beneficiaries a "nominal" co-payment (up to \$3 each for most items and services).⁷⁵ The act *requires* that the amount of the "nominal" co-payment be increased with inflation.* For beneficiaries with income up to 100% of the federal poverty level, the act *allows* states to charge the "nominal" co-payment for any Medicaid item or service. For beneficiaries with income from 100% to 150% of the federal poverty level, the act *allows* states to charge a co-payment up to

* The amount of the "nominal" co-payment must be increased annually by the annual percentage increase in the medical component of the consumer price index.

10% of the cost of any Medicaid item or service. For beneficiaries with income above 150% of the federal poverty level, the act allows states to charge a larger co-payment, up to 20% of the cost of any Medicaid item or service. Total premiums and co-payments for those with income above 100% of the federal poverty level cannot exceed 5% of the beneficiary's income.*

- **Enforcement of premiums and co-payments** - The act *allows* states to suspend Medicaid after 60 days if a beneficiary fails to pay the required premium. The act also *allows* states to allow health care and other Medicaid service providers to require beneficiaries to pay the co-payment as a condition of receiving care. Prior to the act, providers were not allowed to deny services to Medicaid beneficiaries because of unpaid co-payments.
- **Proof of U.S. citizenship** - The act *requires* states to have proof of U.S. citizenship for all Medicaid beneficiaries, including people who are applying and people who already have Medicaid.³ Proof of U.S. citizenship can be provided by a U.S. birth certificate, a U.S. passport, a certificate of naturalization, or a certificate of U.S. citizenship. A driver's license can only be used if a state requires proof of U.S. citizenship before issuing the license, which is generally not the case at present.

For people with dementia who have Medicaid, the provisions of the Deficit Reduction Act could result in higher out-of-pocket expenditures for co-payments for those at all income levels and premiums for those with income above 150% of the federal poverty level (except nursing home residents, who are exempt). The provisions could also result in a suspension of Medicaid for beneficiaries who fail to pay a required premium and denial of particular Medicaid services if they fail to pay a required co-payment. These changes will occur only if states decide to implement them.[•] Thus, advocacy with respect to the changes will have to occur primarily at the state level. The requirement for proof of U.S. citizenship is not up to states, and advocacy with respect to this requirement will have to occur at the federal level.

Through federal Medicaid waivers, some states are planning to extend Medicaid to people who are not currently eligible, often with a package of health care services, sometimes referred to as a "basic health plan," that is more limited than the services usually covered by Medicaid or by allowing the people to enroll in a managed care plan or purchase private health insurance that would probably also cover a limited package of health care services. These changes could provide health insurance for some people

* Because of a drafting error, the Act does not place any limit on the allowed amount of total co-payments for Medicaid beneficiaries with income up to 100% of the federal poverty level (\$817 per month in 2006). Efforts are being made to have this error corrected.⁸²

³ Aliens who are receiving SSI legally are exempt from this requirement.

[•] An exception is the increase in the "nominal" co-payment for beneficiaries with income up to 100% of the federal poverty level, which is required if states choose to charge a "nominal" co-payment.

with early onset dementia who do not have it now, but the covered health care services could be too limited to meet their needs.

Lastly, some states have or are planning initiatives to reduce the number of uninsured state residents by expanding access to affordable insurance through high-risk pools and other mechanisms. These initiatives could allow some people with early onset dementia who do not have health insurance to obtain it. To control the overall cost of the initiatives, however, some states are providing access to only a limited package of health care services that may not meet the needs of people with dementia.

In the context of these ongoing changes, advocacy to reduce the problem of lack of health insurance and high out-of-pocket expenditures for people with early onset dementia could focus on any of the following areas:

- **Employer-sponsored health insurance** – Employers could be encouraged or required to provide health insurance and to include health insurance in their disability and early retirement benefit packages; as noted earlier, the existence of employer-sponsored health insurance is a prerequisite for inclusion of health insurance in disability and early retirement benefit packages, COBRA, and access to insurance through a spouse’s employment.
- **Medicaid eligibility and covered services** - States could be encouraged to provide Medicaid for people who meet the disability requirement for SSI but have income above the SSI benefit level and to cover the range of health care services they need whether the services are provided through a managed care plan or paid for directly by Medicaid or a private insurance plan.
- **Medicaid premiums and co-payments** - States could be encouraged not to charge or to limit the amount of premiums and co-payments charged to Medicaid beneficiaries; states could also be encouraged not to suspend Medicaid if a beneficiary fails to pay a required premium or to create an exception to the requirement for people with dementia who may not be able to understand or comply with the requirement; likewise, states could be encouraged not to allow health care and other Medicaid providers to deny services to beneficiaries because of unpaid co-payments or to create an exception to the requirement for people with dementia who may not be able to understand or comply with the co-payment requirements.
- **Medicaid requirement for proof of U.S. citizenship** - The federal government could be encouraged to create an exception for people with dementia who cannot, because of their dementia, provide a birth certificate, passport, or other document that would meet the requirement for proof of U.S. citizenship.

- **Federal and State programs to create affordable health insurance for all residents** - The federal government could be encouraged to provide access to affordable health insurance for all residents; likewise, states could be encouraged to provide or create access to affordable health insurance for all state residents; in either case, the insurance should cover the range of health care services needed by people with dementia.
- **State high-risk pools** - States that do not have high-risk pools could be encouraged to develop them, and all states could be encouraged to subsidize premiums, limit deductibles, and expand covered services.*
- **Buy-in to Medicare** - The federal government could be encouraged to allow people under age 65 to purchase Medicare coverage; advocacy for this change has generally focused on people age 55-64; the age range should be extended to include people under age 55 with dementia.
- **Buy-in to the Federal Employees Health Benefits Plan (FEHBP)** - The federal government could be encouraged to allow people who are not currently eligible to purchase health insurance through the FEHBP.
- **Buy-in to Medicaid** - The federal government could be encouraged to allow, or give states the option to allow, people who meet the Social Security disability requirement and have income up to 450% of the federal poverty level to purchase Medicaid coverage; this is now allowed for people who meet the disability requirement and are still working.⁵⁰ The Deficit Reduction Act also allows states to let parents of a child who meets the disability requirement to buy-in to Medicaid for the child if the parents have income below 300% of the federal poverty level.

5. High Out-of-Pocket Expenditures for Long-Term Care

Families generally provide care at home for as long as possible for people with dementia, regardless of the person's age. Some people with dementia use paid home and community-based long-term care services, such as adult day, respite, and in-home personal care. Most people with dementia spend some time in a nursing home in the later stages of their illness, although some receive a similar level of care in an assisted living facility or at home with help provided by paid and unpaid caregivers.

Depending on the services they use and the amount of financial support they receive from public and private sources, people with dementia and their families can incur very high out-of-pocket

* The Trade Act of 2002 authorized federal funding to encourage the development of state high-risk pools, expand coverage, and assist states with operating costs, but this funding generally did not result in reduced premiums, expanded coverage, or higher enrollment.⁷⁰ Legislation was enacted in 2006 to extend and increase federal funding for state high-risk pools, with new rules intended to limit premiums at or below 150% of private market rate.

expenditures for long-term care. In 2005, the average annual cost of nursing home care was \$64,240;³ the average annual cost of assisted living was \$34,860;⁴ and costs were much higher for some facilities and in some parts of the country. Home and community-based services generally cost less, and some are free or available on a sliding scale fee basis. When a person needs services frequently or over a long period of time, however, the total cost for even these services can be high.

Medicare does not cover long-term care. Thus, people age 65 and older with dementia, the great majority of whom have Medicare, are not thereby more protected than people under age 65 from high out-of-pocket expenditures for long-term care. Some sources of financial support for long-term care are more available, however, to people age 65 and older than to people under age 65, as discussed below. As a result, younger people with dementia and their families probably face greater difficulties in paying for long-term care services. (The difficulty of finding appropriate services is discussed later in the report.)

Available information about the problem - The HRS data show that people age 55-64 with disabling cognitive impairment were more likely than those with normal cognitive status to use some long-term care services. In the two years preceding the interview, they were:

- 8 times more likely to have been admitted to a nursing home (8% vs. 1%); and
- 6 times more likely to have received non-medical in-home care (6% vs. less than 1%) (see App. B, table 7).

The proportions of people age 55-64 with disabling cognitive impairment that used nursing home care and non-medical home care (8% and 6%, respectively) are considerably smaller than the proportions that used hospital care, medical home health care, and doctor visits (42%, 11%, and 93%, respectively). The reason for this difference is not clear: it could reflect lower perceived need for the long term care services, greater difficulty paying for long-term care services, or a combination of these and other factors.

The Alzheimer's Association survey did not ask about the cost of long-term care services, but some respondents commented on this issue.

- Ø *“Regular adult day care around here... is far too expensive for the average person to afford” (care partner of a person diagnosed with Alzheimer's disease at age 56).*
- Ø *“Would like to get more respite care but the cost is prohibitive” (care partner of a person diagnosed with Alzheimer's disease at age 50).*
- Ø *“There are issues about paying for care. Will I eventually have to use my husband's retirement savings to pay for nursing home care? As someone who has spent the last 18 years mostly caring for a family, I have very little in retirement savings of my own...If*

my husband had been diagnosed with cancer or kidney disease, rather than Alzheimer's, health insurance would cover the costs of his care with less impact on family finances" (care partner of a person diagnosed with Alzheimer's disease at age 53).

Medicaid is the single largest source of financial support for long-term care in the U.S., accounting for 47% of the nation's spending on long-term care for people of all ages in 2003.⁸³ As discussed earlier in the report, people with early onset dementia who receive monthly SSI disability payments generally get Medicaid. People with early onset dementia who meet the Social Security disability requirement and live in states that provide Medicaid for those who meet one or more of three additional criteria (i.e., they have income up to 100% of the federal poverty level; they are "medically needy" according to state standards; or they are nursing home residents with income below 300% of the SSI benefit level) also get Medicaid.

No information is available about how many people with early onset dementia have or could have Medicaid if all those who are potentially eligible applied. HRS data noted earlier show that in 2000, 29% of people age 55-64 with disabling cognitive impairment had Medicaid.

States are required to provide nursing home care for Medicaid beneficiaries age 21 and older who meet the state's functional or "level of care" criteria for this service. States are also required to provide home health care for Medicaid beneficiaries who meet the state's functional criteria for nursing home care. States have the option to provide other long-term care services, including personal care, case management, and home health care for Medicaid beneficiaries who do not meet the state's criteria for nursing home care. If provided, these optional services must be available statewide and for all Medicaid beneficiaries who need them.

Since 1981, states have been allowed to apply for a federal 1915(c) waiver to provide additional home and community-based services, such as adult day care, respite care, homemaker and chore services, and home modifications. If provided under a 1915(c) waiver, these services can only be provided for Medicaid beneficiaries who meet the state's functional criteria for nursing home care. They can be provided for beneficiaries with higher income, up to 300% of the SSI benefit level; they can be restricted to specified regions of the state, specified age groups, or people with certain conditions;⁸³ and states can establish waiting lists for the services.

Because of the many options available to states, Medicaid-funded long-term care services vary greatly from one state to another. Thus, Medicaid beneficiaries with dementia have access to different long term care services, depending on where they live. States' functional criteria for nursing home care

also differ in ways that are more or less likely to include people with dementia. Since the nursing home criteria are used for mandatory home health care and home and community-based services provided under a 1915(c) waiver, Medicaid beneficiaries with dementia are more likely to have access to these services in some states than in others. These criteria generally affect Medicaid beneficiaries of any age with dementia. It is possible, however, that in some states, Medicaid beneficiaries age 65 and older with dementia have access to optional services, such as personal care, at a lesser level of impairment than beneficiaries under age 65 with dementia, just because those age 65 and older do not have to meet the Social Security disability requirement to get Medicaid.

The Deficit Reduction Act of 2005 makes changes in Medicaid that could increase or decrease the problem of high out-of-pocket expenditures for long-term care for people with early onset dementia by increasing or decreasing their access to Medicaid-funded services. In addition to the provisions described in the previous section, other provisions of the act pertain specifically to long-term care:

- **Increased penalties for unlawful transfer of assets:** the act requires states to consider whether a Medicaid applicant transferred assets for less than their fair market value for the purpose of qualifying for Medicaid-funded nursing home care during the five years prior to applying for Medicaid, and if so, to delay the applicant's Medicaid eligibility for a period starting with the application date and depending on the value of the transferred assets.* This requirement could cause a delay in Medicaid eligibility and so, higher out-of-pocket expenditures for nursing home care for some people with dementia, either because they transferred assets for the purpose of qualifying for Medicaid or because they cannot remember or document the reason for an asset transfer that occurred in the previous five years. The new requirement is probably less likely to affect people under age 65 with dementia than those age 65 and older because younger people may be less likely to transfer assets at all or to anticipate a need for nursing home care.
- **Restricted eligibility for people with substantial home equity:** the act requires states to deny Medicaid to people who have home equity that exceeds \$500,000. States can raise this amount to \$750,000. The requirement does not apply to beneficiaries whose spouse, minor child, or disabled child of any age lives in the home. The Congressional Budget Office estimated that less than half of one percent of unmarried applicants for Medicaid-funded nursing home care have home equity greater than \$750,000.⁸⁴ To the extent that people with dementia are affected by the

* Prior to the act, states were required to consider assets transferred in the three years prior to a Medicaid application and to begin the period of Medicaid ineligibility on the date the assets were transferred; this requirement had relatively little effect because the period of ineligibility often expired before the person applied for Medicaid.

new requirement, those under age 65 are probably less likely to be affected than those age 65 and older because the younger people are less likely to have built up that much equity in their home.

- **New state option for home and community based services:** the act allows states to provide home and community-based services as an optional benefit for Medicaid beneficiaries who have income up to 150% of the federal poverty level (\$1,226 per month in 2006) and do not meet the state's functional criteria for nursing home care. This provision takes effect in January 2007. To implement it, states are required to establish functional criteria for the benefit that are less stringent than the state's functional criteria for nursing home care. The new benefit could cover home and community-based services for people with early onset dementia who have Medicaid but have not previously had access to Medicaid funding for these services, either because their state did not provide home and community-based services for nonelderly adults through a 1915(c) waiver or because they did not meet the state's functional criteria for nursing home care.

In addition to Medicaid, other government programs pay for some home and community-based long-term care services for some people with early onset dementia. The federal Administration on Aging pays for a wide range of home and community-based services for people age 60 and older. Funding for these services could reduce out-of-pocket expenditures for long-term care for people age 60-64 with early onset dementia, but not for those under age 60.

The National Family Caregiver Support Program, which is administered by the Administration on Aging, pays for services, such as respite care, to help family caregivers of people age 60 and over. Funding for these services could also reduce out-of-pocket expenditures for people age 60-64 with early onset dementia and their families, but not for those under age 60.

Many states pay for some home and community-based services using state general funds. To the extent that people with early onset dementia meet the state's eligibility criteria for these services (e.g., with respect to age, cause of impairment, level of need, income, and assets), state funding for the services could reduce their out-of-pocket expenditures for long-term care.

Non-government sources of funding for home and community-based services include various community agencies and charitable organizations that provide services at no cost or for a sliding scale fee based on the person's or family's income. Although potentially very valuable for people with early onset dementia, these services are often available on a one-time or short-term basis, to a small number of people, and only in some communities.

Private long-term care insurance is a potential source of funding for long-term care services. Most people with early onset dementia do not have long-term care insurance, although some do. In response to the Alzheimer's Association survey, the sibling of a person diagnosed with Alzheimer's disease at age 44 commented, *"Because our mother had early onset Alzheimer's disease, many of us obtained long-term care and other insurances in our late 30s and early 40s."*

Despite the various sources of funding for long-term care described in this section, most people with early onset dementia are not covered. Those with very low income and assets who receive SSI disability payments and therefore get Medicaid are covered for some services, and some people receive financial support for long-term care services from other government programs, community agencies, charitable organizations, and private long-term care insurance. By and large, however, people with early onset dementia must either forego the services or use them and incur high out-of-pocket expenditures that severely limit the amount of income and assets they have to pay for basic living expenses and medical care for the person with dementia and other family members, including minor children, if any.

Steps Toward Solutions - A few steps could be taken to reduce the problem of high out-of-pocket expenditures for long-term care services for people with early onset dementia. One step is the provision of accurate information about sources of funding for long-term care for people under age 65. Organizations and individuals that provide information and counseling for people with dementia and their families should develop and disseminate such information. They should be prepared to answer questions about the programs or refer people to other sources of information, and they should encourage people to apply for programs that might help them.

Other steps involve advocacy to maintain and extend existing government funding for long-term care services. This advocacy could address the following issues:

- **Medicaid functional criteria for nursing home care:** states could be encouraged to use functional criteria that include people with dementia who need nursing home care; if states change their functional criteria for nursing home care in the process of developing criteria for the new Medicaid home and community-based services benefit, they could be encouraged to ensure that the new criteria include people with dementia who need nursing home care.
- **New Medicaid optional benefit for home and community based services:** states could be encouraged to provide the new benefit and develop functional criteria for the benefit that include people with dementia who need home and community-based services.

- **Medicaid income limits for long-term care services:** states could be encouraged to provide Medicaid for people with income up to the federally allowed maximum, if they do not already do so, and to cover long-term care services for all Medicaid beneficiaries who need them.
- **Administration on Aging programs that pay for home and community-based services:** the federal government could be encouraged to extend access to Administration on Aging programs that provide home and community-based services, including the National Family Caregiver Support Program, to people under age 60 with early onset dementia and their family caregivers.
- **Lifespan Respite Care:** the federal government could be encouraged to enact a new program of grants to states to pay for respite care for family caregivers of people of all ages with disabilities.
- **State programs that pay for home and community-based services:** states could be encouraged to extend access to state-funded home and community-based services to people with early onset dementia who need the services.

In addition to these specific steps, advocates should encourage all groups and organizations that are seeking solutions to the general societal problem of lack of funding for long-term care to consider explicitly how various solutions would work for people with early onset dementia. This means considering how the solutions would work for nonelderly adults; how they would work for people with cognitive impairments; and how they would work for people with families, including minor children.

Lastly, it is important to re-emphasize the critical role of the Social Security disability requirement, which determines whether people with early onset dementia who have low income and assets get Medicaid and, therefore, access to any Medicaid-funded long-term care services.

6. Lack of Appropriate Medical Care, Residential Care, and Community Services

Almost all services for people with dementia are designed for and targeted to people age 65 and older. People with early onset dementia and their families often cannot find services that meet their needs. Lack of funding is a factor, but even with funding, some of the services needed by people with early onset dementia and their families do not exist at all or are not available in most communities.

People with early onset dementia differ in many ways that affect the kinds of services they need. One difference is the current stage of their dementia -- whether early, middle, or late. A second difference is the disease or condition that causes their dementia. Other differences include employment status, income, marital status, living arrangements, co-existing medical conditions, and general health. Some of these factors change over time, and the changes affect the kinds of services the person needs.

Basic information that would be required for government and private organizations to plan for the services needed by people with early onset dementia and their families does not exist. The HRS data and findings from the studies discussed in this report are helpful in understanding service needs, but much additional information is required.

Available information about the problem - The HRS data show that almost half (48%) of people age 55-64 with disabling cognitive impairment were married and living with their spouse; 31% were living alone; and 21% were living with others, including family members and nonrelatives (see App. B, table 10). About one-third (31%) had children living at home (see App. B, table 11), but it is not clear from the data whether these are minor children or adult children who are living with their parent(s).

As noted earlier, the HRS data show that many people age 55-64 with disabling cognitive impairment had other serious medical conditions. The conditions include hypertension (64%), arthritis (47%), heart disease (34%), diabetes (28%), lung disease (11%), and cancer (8%) (see App. B, table 2). Except for arthritis and cancer, these conditions were significantly more common in people with disabling cognitive impairment than in people with normal cognitive status. Almost half (48%) of those with disabling cognitive impairment were reported to be in poor health, compared with only 6% of those with normal cognitive status (see App. B, table 12).

The study by Harris and Keady (2004) of 23 younger Americans with dementia provides information about their concerns and feelings that is useful in thinking about their service needs.² For purposes of comparison, Harris also conducted interviews with 18 older Americans with dementia that was diagnosed after age 65; their average age at the time of the interview was 75 (range 66-91), and 38% were male.⁸⁵ All individuals in both groups were in the early or middle stage of dementia and able to complete an interview.

Comparing the concerns and feelings that emerged in the younger and older groups, Harris identified four themes that were raised in both groups and seven themes that were raised primarily in the younger group. The four themes raised in both groups were:

- Feelings of loss on multiple levels;
- Awareness of changes in one's abilities;
- Boredom and feelings of uselessness; and
- Issues of selfhood and self-esteem.⁸⁵

The seven themes that were raised primarily in the younger group were:

- Difficulty obtaining an accurate diagnosis;
- Worry about work, retirement, and financial issues;
- “Off-time” dependency; that is, dependency that is not expected at such a young age;
- Changing relationships with one’s spouse, young children, and elderly parents;
- Extreme feelings of social isolation and being marginalized;
- More energy and need for physical activity; and
- Concerns about genetic transmission.⁸⁵

Many of the themes that emerged primarily in the younger group relate to their stage in the family life cycle. Younger individuals with dementia were more likely than older individuals with dementia to express concerns about the effect of their dementia on usual family roles and responsibilities with respect to income generation, childcare, and other family activities.⁸⁵

Responses to the Alzheimer’s Association survey echo many of the same themes. The last item on the survey said, “Please provide suggestions for the Alzheimer’s Association regarding programs and services for people diagnosed with Alzheimer’s disease and other dementias under age 65.” Most respondents provided suggestions, with some differences in content and emphasis depending on whether the survey was completed by the person with dementia, a family member or other care partner, or both.

People with early onset dementia who completed their own survey made many suggestions. Their main suggestions and typical comments are as follows:

1. Provide services that reflect the needs of people with early onset dementia based on their perceptions of their needs

- Ø *“Create services based upon what we need, not from the caregiver’s viewpoint” (person was diagnosed with Alzheimer’s disease at age 51).*
- Ø *“You state ‘careGIVER support.’ From the point of view of a person with Alzheimer’s disease, my concern lies with support, counseling, etc. for the person with the diagnosis” (person was diagnosed with Alzheimer’s disease at age 45).*

2. Do not assume that the person with dementia is doomed or incapable

- Ø *“Misrepresentation of dementia has given people a doomed outlook. This can be far from the reality. Many rash decisions are made in haste -- end of life decisions*

demanded of the person (at the time of diagnosis)” (person was diagnosed with Alzheimer’s disease at age 45).

- Ø *“Please don’t pull the plug too early. I am still quite capable of many things and continue to strive to maintain self reliance” (person was diagnosed with Alzheimer’s disease at age 62).*

3. Increase knowledge about early onset dementia and sensitivity to the feelings of people with the condition among doctors and other health care professionals

- Ø *“EDUCATE the medical profession that we are still people with feelings and thoughts. Educate medical facilities with in-services on the appropriate care of people with dementia” (person was diagnosed with Alzheimer’s disease at age 47).*

4. Provide support groups specifically for people with early onset dementia

- Ø *“We need support groups specifically for early onset people, say 40-65. The issues for us are different” (person was diagnosed with Alzheimer’s disease at age 48).*
- Ø *(We need) “early onset support groups (with) education about the symptoms and cognitive behavioral techniques to use to talk to ourselves about the crazy experiences we have” (person was diagnosed with vascular dementia at age 52).*

5. Provide opportunities for social interaction

- Ø *(We need) “more contact...Once per month is not enough. Conduct activities other than sitting and talking” (person was diagnosed with Alzheimer’s disease at age 55).*
- Ø *“I like being with people, and it’s been hard for me to at home so much” (person was diagnosed with Alzheimer’s disease at age 59).*

6. Provide opportunities to work on a volunteer or part-time basis

- Ø *“We need volunteer opportunities in order to maintain function and self esteem” (person was diagnosed with dementia caused by a stroke at age 58).*
- Ø *“(We need) supported employment” (person was diagnosed with vascular dementia at age 52).*

7. Provide adult day programs for people with early onset dementia

- Ø *“We need adult day care that is active and socially oriented, with other young people – not centarians!” (person was diagnosed with vascular dementia at age 52).*

- Ø *“I would not attend the adult day care program willingly because the people are older and more advanced than me” (person was diagnosed with Alzheimer’s disease at age 54).*

8. Provide help for the person’s family, especially young children and teenagers

- Ø *“I would like a support group for my family, so they could talk to others dealing with this” (person was diagnosed with Alzheimer’s disease at age 40).*
- Ø *“The children need help – lots of help – someone to talk to who understands what they are going through – a parent that acts like a child at times -- a parent that cannot make decisions” (person was diagnosed with Alzheimer’s disease at age 54).*

Family members and other care partners who completed the survey had some of the same and some different suggestions, reflecting their need to help and locate appropriate services for the person with dementia while continuing to work and fulfill parenting and other responsibilities. Suggestions and typical comments include the following:

1. Provide information about early onset dementia and available services

- Ø *“Keep people informed about latest research, including nonpharmacological approaches to treatment of Alzheimer’s disease” (care partner of a person diagnosed with Alzheimer’s disease at age 56).*
- Ø *“The hard part was not knowing where to start or who we needed to see first. We felt like we were just hanging out there for awhile...This was a very stressful experience” (care partner of a person diagnosed with Alzheimer’s disease at age 54).*
- Ø *“I always feel ALONE in dealing with someone diagnosed sooo early in life” (care partner of a person diagnosed with Lewy body dementia at age 57).*

2. Increase knowledge about early onset dementia among health care professionals

- Ø *“I think health care professionals should be more informed about this disease” (care partner of a person diagnosed with Alzheimer’s disease at age 50).*
- Ø *“Doctors (should) understand the effects of early onset dementia on the patient and family” (care partner of a person diagnosed with Alzheimer’s disease at age 44).*

3. Provide support groups that are specifically intended and convenient for families of people with early onset dementia

- Ø *“Most of the support groups relate to families with grandchildren or children of much older age” (care partner of a person diagnosed with Alzheimer’s disease at age 45).*

- Ø *“Caregiver support groups are held during the day for folks that are retired” (care partner of a person diagnosed with Alzheimer’s disease at age 51).*
- Ø *“It is an hour and a half travel time each way for me to attend” (care partner of a person diagnosed with Alzheimer’s disease at age 54).*
- Ø *“Caregiver support groups are available in nearby suburbs, but the people who attend these support groups are not raising children while caring for a spouse with Alzheimer’s disease. The needs and priorities of these caregivers are very different from mine. When I spend time with older caregivers who devote themselves 24/7 to caring for an individual with Alzheimer’s disease, I walk away feeling guilty, inadequate, and angry” (care partner of a person diagnosed with Alzheimer’s disease at age 53).*

4. Provide adult day care that meets the needs of younger people

- Ø *(There is) “none available for someone in her 40’s or with similar problem” (care partner of a person diagnosed with Alzheimer’s disease at age 43).*
- Ø *“Individual attends day care, but not a program specifically for Alzheimer’s disease. The model Alzheimer’s disease day care program is too far away to attend – it’s a 45-minute drive. There are several adult day care programs in our area, but only one will take someone as young as 54. The others have contracts with the state that allow them to serve only the elderly. The program the individual currently attends serves only one or two people with memory loss. Most of the clients have some kind of brain injury or other diagnoses that make them seem different. The individual with Alzheimer’s disease feels that he is not like these people and shouldn’t be there. This has made him resistant to going” (care partner of a person diagnosed with Alzheimer’s disease at age 53).*

5. Provide in-home respite care and supervision

- Ø *“We have a (respite) program here, but it’s done on a grant which lasts only 2/3 of a year. Once very couple of weeks, someone would come out for 3 hours and do just about anything the person wanted to do or wanted done. This was great. Problem is, it just lasted for 9 months, and the grant was gone” (care partner of a person diagnosed with Alzheimer’s disease at age 50).*

6. Provide transportation

- Ø *(We need) “transportation – due to age, local caregiver groups (volunteers throughout the city, through local churches) will not provide transportation” (care partner of a person diagnosed with Alzheimer’s disease at age 58).*
- Ø *“Help us with transportation. We have these great respites in town, but due to the locations are not able to use local bus services” (care partner of a person diagnosed with Alzheimer’s disease at age 57).*

7. Provide work and volunteer opportunities

Ø *“Help create job and volunteer opportunities (and provide transportation) so the person with Alzheimer’s disease can feel like they still contribute to society for as long as possible” (care partner of a person diagnosed with Alzheimer’s disease at age 54).*

Steps toward solutions - Many steps could be taken to reduce the problem of lack of appropriate services. The ideal would be a community service environment in which the kinds of services needed by people with early onset dementia are available when the services are needed, and information is easily accessible to help the person, family, and others learn about and arrange services.

To progress toward that ideal will require information, research, awareness, training, analysis, policy changes, and the creation of services that do not exist at present. As noted earlier, information about the number of people with early onset dementia and the diseases and conditions that cause their dementia is essential to plan for appropriate services.

Additional information about the service needs of people with early onset dementia and their families is also essential. Findings from the study by Harris and Keady and the Alzheimer’s Association survey are valuable but limited in that they reflect the views of only a small number of people who may not be representative of all people with early onset dementia. Qualitative and quantitative research is required to learn about the needs of a larger number and proportion of people with early onset dementia.

To progress toward a service environment that meets the needs of people with early onset dementia will require greater awareness of these people and their service needs among health care and social service professionals, other providers, and government and private organizations that plan, administer, provide, and pay for services. Moving toward the desired service environment will also require training for health care and social service professionals and other providers about the characteristics and concerns of people with early onset dementia and the problems they confront. Such training is not generally available now.

For services that are usually provided for an individual, e.g., counseling and in-home respite care, increased awareness and training for health care and social service professionals and other providers may be sufficient to ensure that the services are appropriate for people with early onset dementia. For services that are usually provided in groups, e.g., support groups and adult day care, additional analysis is needed to determine how services should be designed and targeted to best meet the needs of people with early onset dementia; that is, should services be designed and targeted by age, stage of dementia, or cause of dementia, and if by age, what age, or if by stage or cause of disease, what stage, and which causes?

With respect to age, the convention has been to define early onset dementia as dementia that first occurs before age 65. Using age 65 as a cut point makes sense for services that focus on issues, such as employment, disability, and health insurance, that generally differ for people under and over age 65. In contrast, age 65 may not be the most appropriate cut point for services that focus on issues, such as self esteem and a need for meaningful activities, that may not differ so much by age. Moreover, some people with early onset dementia will be over age 65 by the time they need particular kinds of services. Using age 65 as a cut point would exclude them.

Using stage of dementia as a criterion for the design and targeting of services raises similar questions about the appropriate cut point for particular services and how to define the stages precisely enough to be helpful for planning and targeting purposes. Using cause of dementia as a criterion raises questions about which diseases and conditions should be combined or separated. Are people with dementia caused by Alzheimer's disease sufficiently different from those with frontotemporal dementia, for example, to need separate services? If so, do meaningful differences persist into the middle and late stages of dementia, or is the need for separate services limited to those with early stage dementia?

These important questions should be discussed and analyzed by people with dementia, their families, researchers, health care and social service professionals, and other service providers. Valuable insights could be provided by the Alzheimer's Association Advisory Group of People with Dementia, which includes people under and over age 65, the Association's Early Stage Professional Task Force, members of the Dementia Advocacy and Support Network International (DASNI), and other internet-based and in-person groups that include people with dementia caused, for example, by frontotemporal or Lewy body disease and their caregivers.

In considering whether services should be designed and targeted by age, stage, or cause of dementia, it would be helpful to know how many people in a given geographic area might use a service, such as an adult day program, if the service were designed for and targeted to people under age 65, or instead to people of any age with early stage dementia, or to people of any age or stage with Alzheimer's disease or frontotemporal dementia. Unfortunately, that information is not available. Travel distance to a service is an important determinant of service use, as noted in responses to the Alzheimer's Association survey. Acceptability is another important determinant of services use, and some survey responses noted that younger people with dementia who feel out of place in a support group or adult day program designed for and targeted to older people sometimes refuse to use the service. In many communities, planners and providers are likely to face trade-offs between providing a service that is designed for and

targeted to a narrowly defined group, e.g., only those under age 65, and requires some people to travel considerable distances to reach the service versus providing a service that is more broadly targeted and more accessible but may be rejected by younger people with dementia.

Such trade-offs can sometimes be avoided for some kinds of services, such as in-person support groups, by substituting telephone and internet-based programs. One example is the national telephone and email communication network established by the Oklahoma and Arkansas Alzheimer's Association Chapter for people with early onset dementia and their families.⁸⁶ Such substitutions may not be possible, however, for other services, such as adult day care.

This Alzheimer's Association report relies mainly on available information about early onset dementia in the U.S., but findings from research and practice in other countries are valuable in thinking about how to design and target services to meet the needs of people with early onset dementia. Since the 1980s, early onset dementia has received more attention from researchers in the United Kingdom (U.K.) than in the U.S. A review of English-language research articles about services for people with early onset dementia that were published from 1985-1999, found, for example, that 93% came from the U.K.⁸⁷

Early onset dementia has also received more attention from advocates in the U.K. than in the U.S. In 1991, advocates in the U.K. developed a charter for people with early onset dementia that was revised and published by the London-based Alzheimer's Society in 1996 (see Box 3).⁸⁸

One study conducted in London from 1995-1997 attempted to identify every person with early onset dementia in two city burroughs.⁸⁹ The study found 185 people, including six people with onset before age 35. About one-third of the 185 people had Alzheimer's disease; 18% had vascular dementia; 12% had frontotemporal dementia; and the rest had other dementias. On average, they had a high rate of behavioral symptoms; female caregivers, in particular, had very high rates of anxiety and burden; and available services did not meet their needs. Other studies conducted in the U.K. had similar findings,⁹⁰⁻⁹³

On the basis of these research findings and strong advocacy for appropriate services, some specialized community services were created for younger people with dementia in the U.K. Researchers, service providers, and advocates have also debated the pros and cons of services specifically designed for and targeted to younger people with dementia versus individualized or person-centered services which would respond to an individual's needs, regardless of his or her age, stage, or cause of dementia.^{90-92,94-96}

Box 3. Charter for Younger People with Dementia and Their Carers

All younger people with dementia, their families and carers should have access to comprehensive, specialist services from diagnosis to long-term care.

Early Diagnosis, Assessment and Referral: GPs should have the relevant skills, training and support to recognise the symptoms of dementia in all age groups and refer people to a specialist consultant who can make a diagnosis and provide ongoing medical supervision.

Access to Specialist Services: Younger people with dementia should have access to a full range of specialist services including home, day, respite, and continuing care which recognize the different life circumstances and environment of younger people and their carers. Specialist counseling should also be made available.

Adequate financial support: There should be adequate financial support for younger people with dementia and their carers to enable them to meet the extra costs of caring for dementia.

Good employment practice: Employers and the social security system should adopt good employment practices which recognise dementia as grounds for early retirement and which protect a person's entitlement to pension rights and other benefits.

Education, training and information: There should be appropriate education, training and information for all health and social service professionals to ensure an effective and sensitive response to the needs of people with dementia and their carers.

Despite differences in government programs and service delivery systems in the U.S and the U.K., research findings and practice experience in the U.K could help to inform discussion and planning for services in the U.S. Likewise, the strong role taken by the Alzheimer's Society in advocacy and the provision of information, support, and services for people with early onset dementia and training for service providers could provide a useful template for the development of similar functions in the U.S. Two recent publications of the Alzheimer's Society, *Younger People with Dementia: A Guide to Service Development* (Feb. 2005)⁹⁷ and *Younger People with Dementia: An Approach for the Future* (April 2005)⁹⁸ are valuable for this purpose.

Lastly, responses to the Alzheimer's Association survey and concerns expressed by Alzheimer's Association chapter staff and others identify five types of services that require additional analysis. For each type of service, it will be important to determine whether there are special or unique issues for people with early versus later onset dementia, and if so, how those issues should be addressed in the context of broader efforts to provide appropriate care for people of all ages with dementia.

Ongoing medical care – As noted earlier, the diseases and conditions that cause early onset dementia differ in many ways, such as average survival time and the likelihood that the person will experience psychiatric symptoms, perceptual and language difficulties, and movement and gait

disorders.^{26,63,64,99} These differences are important for various aspects of ongoing medical care, including medication and other treatment recommendations and referrals for specialist evaluation, community services, and residential care. Since early onset dementia is more likely than later onset dementia to be caused by diseases and conditions other than Alzheimer's disease,^{8,9} awareness of these differences is important for doctors who treat people with early onset dementia. On the other hand, it is not clear that treatment needs differ for people with early versus later onset Alzheimer's disease or early versus later onset of any other disease or condition that causes dementia.

Physical rehabilitation services – Often it is assumed that people with dementia cannot benefit from physical rehabilitation services because they cannot learn new behaviors or relearn old behaviors. One recent study that compared improvement in functioning for cognitively impaired and cognitively normal people age 56-95 who received outpatient physical rehabilitation services found no statistically significant differences in outcomes for the two groups.¹⁰⁰ Studies of hip fracture patients who received inpatient physical rehabilitation services have had similar findings.^{101,102} The assumption that people with dementia cannot benefit from these services can result in denial of care that would help to maintain or improve the person's functioning. It is not clear, however, whether people with early onset dementia are more likely than those with later onset dementia to need physical rehabilitation services or to be denied the services because of the assumption that they cannot benefit or for any other reason.

Counseling and support for children – People with early onset dementia, their spouses, and other care partners who responded to the Alzheimer's Association survey expressed strong, shared concerns about the impact of the dementia on their children. The number of children with a parent who has early onset dementia is not known, but young children and teenagers are probably more likely to live in the same household with a person with early versus later onset dementia. These children and teenagers are undoubtedly dealing with difficult feelings, and some are probably assisting with caregiving tasks.¹⁰³ Yet health care and social service professionals who work with people with early onset dementia may not even ask about children, or if they do ask, they may not have time or resources to provide any needed counseling or support.¹⁰⁴ Research should be conducted to clarify the number and service needs of children of people with dementia and to determine what differences, if any, exist between children of people with early versus later onset dementia.

Genetic counseling – It is widely believed that early onset dementia is more likely than later onset dementia to have a genetic cause,¹⁰⁵ and questions about family history of dementia that are asked during the diagnostic process for a younger person with dementia can raise concerns for that person and his or her spouse and siblings about genetic transmission. In the study by Harris and Keady, 7 of the 23

individuals with early onset dementia had a family history of dementia; 11 did not; and 5 were unsure.² Moreover, concerns about genetic transmission were more common in the sample of individuals with early onset dementia than in the comparison sample of individuals with onset of dementia after age 65.⁸⁵ It is not clear whether this difference would also be found in a larger sample of people with early and later onset dementia or whether the best ways to address these concerns differ for the two groups.

Services for people with intellectual disabilities or severe mental illness and early onset dementia – As discussed in Part II, some people with intellectual disabilities or severe mental illness develop dementia before age 65. Specialized services have been created for people with intellectual disabilities and dementia in a few communities. These services include people both under and over age 65. The Alzheimer’s Association is not aware of any specialized services for people with severe mental illness who develop dementia, although such services may exist in some communities. Research is needed to determine how many people with intellectual disabilities or severe mental illness develop dementia, identify their service needs, and find out whether those needs differ by age.

IV. A Call to Action

A growing number of men and women with early onset dementia are speaking out about their experiences and service needs. Families are also speaking out, along with the person with dementia or in his or her place, if necessary.*

John Mauro is a devoted caregiver and strong advocate for his wife Deborah, who is no longer able to speak out for herself, and for all people with early onset dementia. He meets with state and local legislators, raises concerns about early onset dementia at every opportunity, and works with the Maine Alzheimer's Association Chapter to increase awareness of and services for people with dementia and their families.

Gerald Michalak is an active member of the Western New York Alzheimer's Association Chapter, committed to learning more about Alzheimer's disease and helping others with the disease, including authoring an article about telling friends and family about an Alzheimer's diagnosis for the chapter newsletter. He has volunteered to participate in the Alzheimer's Disease Neuroimaging Initiative sponsored by the National Institutes of Health in the hope of finding a cure for this disease. On March 7, 2006, Jerry traveled to Albany to participate in the Alzheimer's Association New York state lobby day, where he met with his state senator and his assemblyman. He and his wife Janet, who retired from teaching in 2004 to spend more time with Jerry, have two grown sons, Nathan and Justin

Woody Hoffman was an active member of the Northern California and Nevada Alzheimer's Association Chapter before his injury in late 2005. He captained a Memory Walk team; spearheaded many programs for early onset dementia; testified in Sacramento on Alzheimer's legislation; and was honored as an "Outstanding Advocate for Alzheimer's." He continues to inspire and defy the odds as he regains physical and cognitive function following his injury. Cathy Dodd is a highly regarded Chapter volunteer and committee member. Since Woody's injury, she has scaled back her job responsibilities in the University of California, Berkeley's MBA programs to be at Woody's side and advocate for rehabilitation for him and other people with dementia.

* Individuals named in this report are not HRS respondents.

Darlene Ryan is an active member of the national board of the Association for Frontotemporal Dementias. She is a strong advocate for her husband, Dick, and other people with frontotemporal and other dementias. She continues to run her pharmaceutical manufacturing business, raise their son, and visit and bring Dick home for family dinners on weekends whenever possible.

Tracy Mobley has written a second book with the help of her 11-year old son; it is an interactive storybook for children to explain Alzheimer's disease and dementia and suggest ways that children can help. Tracy continues to volunteer as an advocate with the Southwest Missouri Alzheimer's Association Chapter and the Dementia Advocacy and Support Network International (DASNI). She has also led a national project to create a Dementia Memory Quilt which will be displayed in the Alzheimer's Association national office in Chicago.

The Alzheimer's Association congratulates these individuals and the many others who are working to increase awareness of and concern about early onset dementia and those affected by it. We encourage others to join us in ongoing efforts to resolve problems and improve available services for people with early onset dementia and their families.

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Appendix A: The Health and Retirement Study

The Health and Retirement Study (HRS) is a large-scale, longitudinal survey of a nationally representative sample of people age 50 and older in the United States, including people living in the community, nursing homes, and other institutions. The survey is conducted by the University of Michigan's Institute for Social Research and Survey Research Center, under a cooperative agreement with the National Institute on Aging. The HRS has been conducted every two years since 1992. (More information, including the HRS survey instruments, is available at <http://hrsonline.isr.umich.edu>.)

The 2000 Survey - In 2000, the HRS sample consisted of more than 19,000 people age 50 and older, including 6,513 people age 55-64. The HRS interviews were conducted both by telephone and in person.

Raw data from HRS interviews are weighted to make them representative of the U.S. population. This report uses these weighted data. With weighting, the 6,513 people age 55-64 in the 2000 survey represent 23,859,596 people age 55-64.

Decision Not To Include People Age 50-54 in this Report - In 2000, the HRS included people age 50-54, but the sample in that age group was not nationally representative due to the timing of enrollment of people age 50-52. Therefore, it was decided not to include people age 50-54 in this report.

Self and Proxy Respondents - If an HRS sample member was not able to respond to the interview, a proxy (usually a spouse or adult child) responded for him or her. In 2000, 91% of the HRS sample members age 55-64 responded for themselves, and 9% had a proxy respondent. As noted below, these proportions differed for people with different levels of cognitive functioning.

HRS Measures of Cognitive Status, Classification of Cognitive Status, and Use of the Term *Disabling Cognitive Impairment* - The HRS uses several methods to measure cognitive status.¹ For each method used for this report, an approach was developed to classify cognitive status as normal, borderline cognitive impairment, or disabling cognitive impairment. As noted throughout the report, the HRS does not provide information about the number or proportion of sample members who have dementia. The term *disabling cognitive impairment* is used in this report to refer to a level of cognitive impairment severe enough to cause functional limitation for the person, as required for a diagnosis of dementia.

1. For sample members age 55-64 who were able to complete their own telephone interview: the 2000 survey used a shortened version of the Telephone Interview for Cognitive Status (TICS), a validated cognitive assessment instrument.²⁻⁴ The test is scored on a 27-point scale and includes: 1) an immediate and delayed 10-noun free recall test; 2) a serial sevens subtraction test; and 3) a counting backwards test. If a sample member did not respond to a test item, the item was scored as incorrect.

There is no prior research based on the shortened version of the TICS that can be used to select or validate cut-points for the three categories, normal cognitive status, borderline cognitive impairment, and disabling cognitive impairment. To select cut-points for this report, HRS researchers examined the distribution of test scores on the 27-point scale for the entire 2000 sample, including sample members age 65 and older, and selected cut-points based on clinical judgment and a comparison of the proportions of HRS sample members age 65 and older that would be in each category given alternate cut-points and the proportions of people age 65 and older that have been found to have various levels of cognitive impairment in other studies. Table A-1 shows the cut points that were selected.*

* In comparison, Herzog and Wallace (1997) recommended a score range of 0-8 to classify HRS sample members as having dementia based on their scores on the 35-point version of the TICS that is used for sample members age 65 and older.⁵

Table A-1. Cut Points for Cognitive Test Scores That are Used To Classify Cognitive Status for This Report

Cognitive Status	Cognitive Test Scores
Normal	8 – 27
Borderline cognitive impairment	6 – 7
Disabling cognitive impairment	0 – 5

2. For sample members age 55-64 who were not able to respond to a telephone interview: a proxy respondent was asked a single question about the person’s memory, “How would you rate [the person’s] memory at the present time? Would you say it is excellent, very good, good, fair, or poor?”
3. For sample members age 55-64 with a proxy respondent: the interviewer was asked, “Do you have reason to think the person would have difficulty completing this interview because of cognitive limitations?” Possible responses were:
 - a. no reason to think the subject has any cognitive limitations;
 - b. the subject may have some cognitive limitations but could probably do the interview;
 - c. the subject has cognitive limitations that prevent him/her from being interviewed; or
 - d. the subject started to do an interview but received a very low score, so a proxy respondent was substituted. (This response was chosen for less than 1% of the proxy interviews in 2000).

To classify levels of cognitive impairment for sample members with a proxy respondent, HRS researchers combined the proxy and interviewer responses as shown in table A-2.

Table A-2. Proxy and Interviewer Responses Combined To Classify Cognitive Status

Cognitive Status	Proxy Rating of Memory	Interviewer Rating of Cognitive Impairment (CI)
Normal	Excellent or very good	& No CI or may have CI
Normal	Good	& No CI
Borderline	Excellent	& Has CI
Borderline	Good	& May have CI
Borderline	Fair or Poor	& No CI
Disabling cognitive impairment	Fair or Poor	& Has CI or may have CI

Decision Not to Include Findings for People with Borderline Cognitive Impairment in the Report Text - Sample members with borderline cognitive impairment as defined for this report appear to represent a middle group with characteristics between those with normal cognitive status and those with disabling cognitive impairment. They are included in the report tables in Appendix B for information purposes. It is not clear how many or what proportion of them have diseases or conditions that might progress to

disabling cognitive impairment. Because of this uncertainty, data on their characteristics are not discussed in the report.

Self and Proxy Respondents by Cognitive Status - Among HRS sample members with normal cognitive status as defined by the approaches used to classify cognitive status for this report, 93% responded for themselves, and 7% had a proxy respondent. Among those with borderline cognitive impairment, 62% responded for themselves, and 38% had a proxy respondent. Among those with disabling cognitive impairment, 57% responded for themselves, and 43% had a proxy respondent.

Impact of the Approaches Used to Classify Cognitive Status for this Report - If the scores used to classify results from the cognitive test (Table A-1) or the approach for combining proxy and interviewer responses (Table A-2) were changed, the number and proportion of HRS sample members identified as having normal cognitive status, borderline cognitive impairment, and disabling cognitive impairment would also change. The resulting numbers and proportions could be either higher or lower. The classification approaches used in this report reflect an informed judgment about the best approaches.

Functional Status of HRS Sample Members by Cognitive Category - The HRS collects information about the functional status of sample members, including their ability to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Table A-3 shows the mean number of limitations in ability to perform ADLs and IADLs for sample members for each cognitive category. The six ADLs used for this analysis are eating, transferring, toileting, dressing, bathing, and walking across a room. The five IADLs are cooking, grocery shopping, making phone calls, taking medication, and managing money. The table shows mean number of limitations in ability to perform ADLs and IADLs for sample members at three levels of cognitive impairment within the category, disabling cognitive impairment.

As shown in Table A-3, the mean number of limitations in ADLs is at least 5 times higher for sample members with disabling cognitive impairment as defined for this report than for sample members with normal cognitive status. Likewise, the mean number of limitations in IADLs is at least 8 times higher for sample members with “disabling cognitive impairment” as defined for the report than for sample members with normal cognitive status. These figures support the classification process used in the report by showing that increasing levels of cognitive impairment are associated, as would be expected, with greater ADL and IADL limitations, although it is also likely possible that some subjects’ ADL and IADL limitations are due in whole or in part to co-existing physical conditions, such as stroke.

Table A-3. Mean Number of ADL and IADL Limitations by Cognitive Status for People Age 55-64, Health and Retirement Study, 2000, N=6,513.*

Cognitive Status	ADL and IADL Limitations	
	Mean Number of ADL Limitations**	Mean Number of IADL Limitations**
Normal	.24 (.22 – .26)	.11 (.10 – .13)
Borderline cognitive impairment	.68 (.49 – .87)	.42 (.30 – .54)
Disabling cognitive impairment		
Cognitive test scores 0 = 5	1.28 (.81 – 1.76)	.89 (.49 – 1.31)
Cognitive test scores 3 – 4	2.03 (.93 – 3.14)	1.79 (1.04 – 2.55)
Cognitive test scores 0 – 2	1.68 (1.01 – 2.34)	1.85 (1.17 – 2.52)

*The intervals in parentheses are the 95% confidence intervals for the weighted means for ADL and IADL limitations.

**P< 0.001 for comparison of mean functional limitations across cognitive status categories by F test.

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Appendix B: Tables

Table 1. Proportion of People age 55-64 by Cognitive Status, Health and Retirement Study, 2000, (N=6,513)

Age	Cognitive Status		
	Normal n (%)	Borderline Cognitive Impairment n (%)	Disabling Cognitive Impairment n (%)
55-64 years	6,163 (95.5)	193 (2.5)	157 (2.0)
55-59 years	2,655 (96.0)	55 (2.1)	59 (1.9)
60-64 years	3,508 (94.8)	138 (3.1)	98 (2.2)

Table 2. Proportion of People Age 55-64 by Cognitive Status and Specified Medical Conditions, Health and Retirement Study, 2000 (N=6,513)

Medical condition	Cognitive Status			
	Normal (N=6,163)	Borderline Cognitive Impairment (N=193)	Disabling Cognitive Impairment (N=157)	All Levels N=6,513)
Hypertension*	41 %	55 %	64 %	42 %
Heart disease*	14 %	21 %	34 %	15 %
Stroke*	3 %	10 %	24 %	4 %
Diabetes*	12 %	16 %	28 %	13 %
Cancer	8 %	9 %	8 %	8 %
Lung disease*	8 %	12 %	11 %	8 %
Arthritis	47 %	56 %	55 %	47 %

* $P \leq 0.05$ for comparison of indicated variable across cognitive status categories by chi-square test

Table 3. Proportion of People Age 55-64 by Cognitive Status, Employment, and Annual Income, Health and Retirement Study 2000, (N=6,513)

	Cognitive Status			
	Normal (N=6,163)	Borderline Cognitive Impairment (N=193)	Disabling Cognitive Impairment (N=157)	All Levels (N=6,513)
Currently employed*	65 %	38 %	22 %	64%
Yearly income^a				
Less than \$11,000	15 %	45 %	62 %	17 %
\$11,001 – \$20,000	17 %	22 %	13 %	17 %
\$20,001 – \$36,000	29 %	20 %	14 %	28 %
More than \$36,000	40 %	13 %	11 %	39 %
Average income**	\$42,852	\$18,178	\$17,840	

*P≤ 0.05 for comparison of indicated variable across cognitive status categories by chi-square test.

** P< 0.001 for comparison of average yearly income across cognitive status categories by F test.

^a Household income was converted to per capita income by dividing the value for 2-person households in half.

Table 4. Proportion of People Age 55-64 by Cognitive Status and Receipt of Social Security Disability Insurance (SSDI), Health and Retirement Study, 2000 (N=6,513)

	Cognitive Status			
	Normal (N=6,163)	Borderline Cognitive Impairment (N=193)	Disabling Cognitive Impairment ^a (N=157)	All Levels (N=6,513)
SSDI				
Receiving*	8 %	23 %	29 %	9 %
Applying*	1 %	2 %	3 %	1 %
None*	91 %	75 %	69 %	90 %

* P≤ 0.05 for comparison of indicated variable across cognitive status categories by chi-square test

^a Column does not total 100 % because of rounding.

Table 5. Proportion of People Age 55-64 by Cognitive Status and Receipt of Supplemental Security Income (SSI), Health and Retirement Study, 2000 (N=6,513)

	Cognitive Status			
	Normal (N=6,163)	Borderline Cognitive Impairment (N=193)	Disabling Cognitive Impairment (N=157)	All Levels (N=6,513)
SSI				
Receiving*	3 %	12 %	18 %	4 %
Applying*	1 %	5 %	12 %	1 %
None*	96 %	83 %	70 %	95 %

* P≤ 0.05 for comparison of indicated variable across cognitive status categories by chi-square test

Table 6. — Proportion of People Age 55-64 by Cognitive Status and Health Insurance Coverage, Health and Retirement Study, 2000 (N=6,513)

	Cognitive Status			
	Normal (N=6,163)	Borderline Cognitive Impairment (N=193)	Disabling Cognitive Impairment (N=157)	All Levels (N=6,513)
Health insurance				
Medicare*	7 %	22 %	26 %	8 %
Medicaid*	4 %	15 %	29 %	5 %
Dual eligible ^{a*}	1 %	6 %	11 %	2 %
Employer provided ^{b*}	70 %	53%	35 %	69 %
No health insurance	22 %	22 %	29 %	22 %

* P≤ 0.05 for comparison of indicated variable across cognitive status categories by chi-square test

^a Dual eligible persons have both Medicare and Medicaid. These dual eligible persons are included in the Medicare and Medicaid rows above.

^b HRS question about employer provided insurance: “Not including Medicare, Medicaid, or CHAMPUS/CHAMP-VA insurance, are you covered by any employer-provided health insurance, through either your or your spouse’s current or past employer?”

Table 7. Proportion of People Age 55-64 who used Specified Services by Cognitive Status, Health and Retirement Study, 2000 (N=6,513)

	Cognitive Status			
	Normal (N=6,163)	Borderline Cognitive Impairment (N=193)	Disabling Cognitive Impairment (N=157)	All Levels (N=6,513)
Service use in the last 2 years				
Hospital*	18 %	24 %	42 %	19 %
Home health care ^{a*}	5 %	7 %	11 %	5 %
Doctor visit	93 %	85 %	93 %	93 %
Nursing home*	>1 %	1 %	8 %	>1 %
Other paid in-home care ^b	>1 %	1 %	6 %	1 %

* P≤0.05 for comparison of indicated variable across cognitive status categories by chi-square test.

^a HRS question to identify use of home health care: “In the last 2 years, has any medically-trained person come to your home to help you, yourself? Medically-trained persons include professional nurses, visiting nurse’s aides, physical or occupational therapists, chemotherapists, and respiratory oxygen therapists.” This question was not asked of sample members who were in a nursing home at the time of the interview.

^b HRS questions to identify “other paid in-home care:” HRS respondents who reported difficulties or receiving help with ADLs (eating, transferring, toileting, dressing, bathing, and walking across a room) or IADLs (cooking, grocery shopping, making phone calls, taking medication, and managing money), were then asked to identify: 1) who helps them with these activities; 2) how many hours per week they receive help; and 3) whether the person who helps them is paid. “Other paid in-home care” is identified by responses to these questions.

Table 8. Proportion of People age 55-64 by Cognitive Status, Out-of-Pocket Health Care Expenditures (OOPE) and Mean Monthly OOPE, Health and Retirement Study, 2000 (N=6,513)

	Cognitive Status			
	Normal (N=6,163)	Borderline Cognitive Impairment (N=193)	Disabling Cognitive Impairment (N=157)	All Levels (N=6,513)
Average total monthly OOPE^{1*}				
\$0	10 %	25 %	30 %	11 %
\$1 – \$20	25 %	21 %	17 %	25 %
\$21 – \$50	26 %	21 %	12 %	25 %
\$51 – \$114	21 %	14 %	10 %	20 %
More than \$114	18 %	20 %	31 %	19 %
Mean monthly OOPE (SE)	\$79 (3.1)	\$85 (19.8)	\$205 (103.7)	

* P≤ 0.05 for comparison of average total monthly OOPE across cognitive status categories by chi-square test.

¹ Includes OOPE for hospital, nursing home, medical and other paid in-home care, outpatient visits, and prescription drugs.

Table 9: Proportion of People age 55-64 with Out-of-Pocket Expenditures (OOPE) for Prescription Drugs by Cognitive Status and Average Monthly OOPE, Health and Retirement Study, 2000 (N=6,513)

	Cognitive Status			
	Normal (N=6,163)	Borderline Cognitive Impairment (N=193)	Disabling Cognitive Impairment (N=157)	All Levels (N=6,513)
Taking prescription drugs	70 %	73 %	79 %	70 %
Average monthly OOPE for prescription drugs*				
\$0	38 %	47%	47 %	38 %
\$1 – \$15	22 %	19 %	8 %	21 %
\$16 – \$40	21 %	16 %	15 %	21 %
\$41 – \$100	14 %	11 %	12 %	14 %
More than \$100	5 %	7 %	18 %	6 %
Average monthly OOPE (SE)	\$33 (1.6)	\$49 (18.8)	\$141 (80.3)	

* P<0.05 for comparison of average total monthly OOPE for prescription drugs across cognitive status categories by chi-square test.

Table 10. Proportion of People Age 55-64 by Marital Status, Living Arrangements, and Cognitive Status, Health and Retirement Study, 2000, N=6513)

	Cognitive Status			
	Normal (N=6,163)	Borderline Cognitive Impairment (N=193)	Disabling Cognitive Impairment (N=157)	All Levels (N=6,513)
Marital status and living arrangements*				
Married, living with spouse	70 %	67 %	48 %	70 %
Unmarried, living with others	12 %	17 %	21 %	12 %
Unmarried, living alone	18 %	16 %	31 %	18 %

* $P \leq 0.05$ for comparison of indicated variable across cognitive status categories by chi-square test.

Table 11. Proportion of People Age 55-64 with Children Living at Home by Cognitive Status, Health and Retirement Study, 2000 (N=6,513)

	Cognitive Status			
	Normal (N=6,163)	Borderline Cognitive Impairment (N=193)	Disabling Cognitive Impairment (N=157)	All Levels (N=6,513)
Has children living at home	27 %	35 %	31 %	27 %

Table 12. —Proportion of People Age 55-64 by Cognitive Status and Self- or Proxy-Reported Health Status, Health and Retirement Study, 2000 (N=6,510^a)

	Cognitive Status			
	Normal (N=6,161)	Borderline Cognitive Impairment (N=193)	Disabling Cognitive Impairment (N=156)	All Levels (N=6,510)
Health status				
Excellent*	18 %	4 %	7 %	17 %
Very Good*	34 %	16 %	12 %	33 %
Good*	29 %	27 %	16 %	29 %
Fair*	14 %	31 %	18 %	14 %
Poor*	6 %	23 %	48 %	7 %

* $P \leq 0.05$ for comparison of indicated variable across cognitive status categories by chi-square test

^a There were 3 missing values for self-reported health status.