

2009

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~ ANNUAL REPORT ~

*South Carolina
ALZHEIMER'S DISEASE REGISTRY*

2009*

ARNOLD SCHOOL OF PUBLIC HEALTH
UNIVERSITY OF SOUTH CAROLINA
COLUMBIA, SC 29208

*Unless otherwise noted, data included in this report cover the period
January 1, 2007 through December 31, 2007,
the most current period with available and comprehensive data.

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~ *Executive Summary* ~

The Office for the Study of Aging (OSA) at the Arnold School of Public Health of the University of South Carolina (USC), in cooperation with the South Carolina (SC) Department of Health and Human Services, the SC Department of Mental Health, the USC School of Medicine, and the SC Office of Budget and Control, maintains a statewide **Registry** of SC residents diagnosed with Alzheimer's disease or related disorders.

This report uses the abbreviation **ADRD** to indicate “Alzheimer's disease or related disorder.” The “related disorders” refer to dementias associated with vascular disease, mixed dementia and with other medical conditions such as Parkinson’s disease. Where we refer specifically to “Alzheimer’s disease” (**AD**), we limit the analysis to individuals with AD only.

Since January 1, 1988, the Registry has identified 150,853 cases of ADRD. During calendar year 2007, the Registry maintained information on 63,834 individuals alive on January 1, 2007.

Registry Goals:

- Maintain the most comprehensive and accurate state registry of ADRD in the nation
- Provide disease prevalence estimates to enable better planning for social and medical services
- Identify differences in disease prevalence among demographic groups
- Help those who care for individuals with ADRD
- Foster research into risk factors for ADRD

Registry Overview:

Of South Carolinians with diagnosed ADRD:

- 65% have Alzheimer's disease
- 16% have a dementia due to stroke
- 19% have a dementia related to other chronic conditions
- 35% live in an institution
- 65% are women
- 32% are African American
- 39% of those with AD are 85 years or older

Population Prevalence of ADRD, South Carolina, 2007:

Based on the Registry and population estimates from the United States Census,

- 10% of South Carolinians age 65 or over have ADRD
- 31% of South Carolinians age 85 or over have ADRD
- Alzheimer's disease prevalence rates vary notably among SC counties.
- African Americans are at notably higher risk of an Alzheimer's disease diagnosis than are non-Hispanic whites. At ages 65 and older, for example, African American South Carolinians are almost twice as likely to have ADRD as are non-Hispanic whites.

South Carolina ADRD Projection:

Based on methods commonly used to estimate prevalence, ***the number of South Carolinians with Alzheimer's disease and related disorders will increase by 150% in the next fifteen years.*** (see Figure 2)

Other Activities of the OSA:

In addition to maintaining the Registry and conducting research using this valuable state resource, the OSA works to provide South Carolina's older persons and their families with access to quality, reliable health and long term care service delivery systems. Specifically, OSA's focus includes the following:

- **Provide education** on ADRD management
- **Develop training** on long term care issues
- **Contribute technical assistance** for programs for older South Carolinians
- **Help to evaluate** programs for older South Carolinians
- **Conduct research** on aging issues

~ *Acknowledgments* ~

The South Carolina Alzheimer's Disease Registry has developed into one of the nation's most important resources for understanding ADRD. The growth and development of the Registry and the related research program in aging at the Office for the Study of Aging has been due to the support of many individuals and organizations. We particularly want to acknowledge the contribution of:

- The **Arnold School of Public Health** at USC, for core support;
- The **Office of Research and Statistics of the State Budget and Control Board**, for its extensive cooperation in maintaining the Registry
- The **USC School of Medicine** (Department of Medicine, Division of Geriatrics), for providing collaboration;
- The **SC Department of Mental Health**, for access to data;
- The **SC Department of Health and Human Services**, for core support and access to data;
- The **SC Department of Health and Environmental Control, Vital Records and Public Health Statistics**; and
- The **Lieutenant Governor's Office, Office on Aging**, for their continued support.

~ Introduction ~

Someone in America develops Alzheimer's every 72 seconds; by mid-century someone will develop Alzheimer's every 33 seconds.¹

In 2000, the U.S. Census Bureau estimated that there were 485,333 people 65 years of age and over living in the State of South Carolina, and the state was ranked 32nd among other states for the highest percentage of persons aged 65 years and older. Since that time, the elderly population in South Carolina has grown at a rapid rate. In fact, by 2030, the U.S. Census Bureau projects that South Carolina will be home to 1.1 million people ages 65 years and older, potentially propelling South Carolina to a ranking of 15th in the nation for the highest percentage of residents over 65 years of age.¹

Alzheimer's disease and related disorders (ADRD) represent an ever-increasing area of concern for the healthcare community and families. Nationwide, an estimated 5.2 million people in the United States are currently living with Alzheimer's disease. By 2030, this estimate is expected to reach 7.7 million; by 2050, the number of persons affect with Alzheimer's disease could be between 11 and 16 million.²

With increasing age as a leading risk factor for Alzheimer's disease, South Carolina's rapidly growing population of persons aged 65 years and older presents a challenge to families, communities and those who plan and deliver services for the state.

ADRD is an umbrella term that encompasses many types of cognitive impairment. The Diagnostic and Statistical Manual of Mental Disorder (Third Edition) (DSM-III-R) defines Alzheimer's disease as an impairment of intellectual abilities such as memory, abstract thinking, judgment, other disturbances of higher cortical functions and behavior and personality change severe enough to interfere significantly with everyday activities. Alzheimer's disease (AD) is a type of ADRD with an insidious onset and a generally progressive deteriorating course for which all other specific causes have been excluded. Other types of ADRD include those related to stroke, mixed dementia (with both Alzheimer's and Vascular dementia), and dementias associated with medical conditions such as Parkinson's Disease, Huntington's Disease, Dementia with Lewy Bodies (DLB), AIDS, and alcohol or drug abuse.

This report covers calendar year 2007 (those alive on Jan 1, 2007), the most recent full year of data available from all reporting sources. Registry cases in this report are defined as Alzheimer's Disease (AD), vascular ADRDs (Vascular), mixed dementias (Mixed) and ADRDs in medical conditions (Other). Registry cases are identified by location of residence, either in a facility (nursing facilities, residential care facilities), in the community (home or adult day care) or in an unknown location. Exclusions of some demographic information are due to the voluntary method of data collection. It should be noted that many cases may be identified at a late stage of the disease rather than at onset. This affects the time from entry into the Registry until death.

¹ The 2006 South Carolina Mature Adults Count Report

² Alzheimer's Association, 2008 Alzheimer's Disease Facts and Figures, published in *Alzheimer's and Dementia* Volume 4, Issue 2.

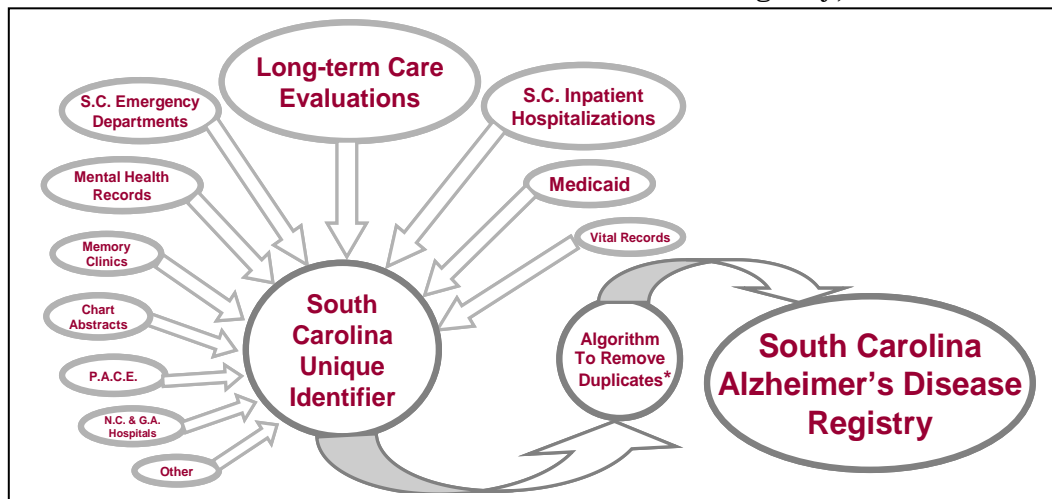
~ *Alzheimer's Disease and Related Disorders* ~ *in South Carolina*

The prevalence of ADRD in the United States in 1989, was estimated to be over 10 percent among persons aged 65 and older, and about 47 percent among those aged 85 and older.¹

In 1990, South Carolina residents 75 years and older were 4.3% of the total population; their numbers totaled 151,000. By 2000, there were 215,000 South Carolina residents 75 years and older, representing 5.4% of the total population or a 42% increase.²

We do not know the total number of persons with ADRD in South Carolina with certainty. National estimates of ADRD prevalence vary widely from one study to another. Individuals who have mild forms of the disease, but lack a diagnosis, do not appear in our Registry data. Previous studies suggest that the number of individuals with ADRD may be nearly 50% greater than the number with diagnosed ADRD.³ What we do know is that the South Carolina Alzheimer's Disease Registry is the best population-based Registry of ADRD in the country. There are only two other such registries in existence. One, in New York, is limited to records from in-patient hospital stays.⁴ The second is located in West Virginia and began collecting data in May 2008. Our South Carolina Registry uses data from a wide variety of sources to capture as many diagnoses as possible. These sources are shown in Figure 1.

Figure 1
Registry Data Sources
South Carolina Alzheimer's Disease Registry, 2007



***Duplicates occur because individuals often use more than one name, social security number, or other identifying information when using health or social services.**

1 DA Evans, et al. Prevalence of Alzheimer's disease in a community population of older persons. Higher than previously reported. JAMA 1989;262:2551-6.

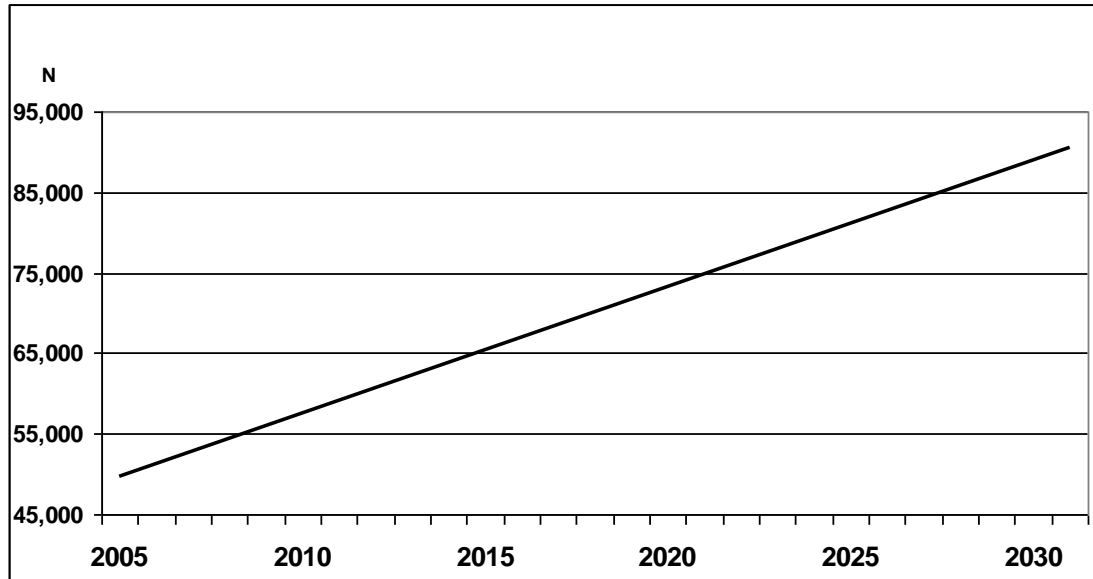
2 South Carolina Mature Adults Count Report.

3 LE Hebert et al. Alzheimer disease in the US population: Prevalence estimates using the 2000 Census. Archives of Neurology, 2003; Vol 60, 1119-1122.

4 PP Lillquist. Challenges in Surveillance of Dementias in New York State. Preventing Chronic Disease: Public Health Research, Practice, and Policy, 2004;Vol. 1, No. 1, 1-9.

~ *Projections of Alzheimer's Disease* ~ *in South Carolina*

Figure 2
Prevalence Projections through 2030
Alzheimer's Disease and Related Disorders in South Carolina, 2007



South Carolina ADRD projections, based on the South Carolina Alzheimer's Disease Registry and Interim State Projections of Population by Single Year of Age and Sex, July 1, 2004 to 2030. Source: U.S. Census Bureau, Population Division, Interim State Population Projections, 2006. Release Date, April 21, 2006.

The projections are based on age- and gender-specific prevalence rate estimates from the Registry. The projections assume a constant ADRD rate over time. This approach is consistent with generally accepted national ADRD projections. However, this approach may over- or under-estimate the actual growth of ADRD in South Carolina. As obesity, hypertension, and diabetes are known risk factors for ADRD, notably increasing rates of these conditions in our population may raise actual rates considerably above those suggested by the projections. Similarly, minorities have higher rates of ADRD; if the proportion of South Carolina seniors who are minorities grows notably, this would also be likely to raise the rates above the projections shown. On the other hand, our state may be enjoying in-migration of relatively highly educated seniors, with relatively high incomes. These individuals would be likely to have lower ADRD risks than the general U.S. population, and considerably lower risks than the SC population. A larger proportion of these individuals with lower ADRD risks in our senior population would tend to moderate the rise in ADRD prevalence.

It should be noted that the prevalence projections are for the Registry. The population prevalence of ADRD will be higher than the projection shown in Figure 2 in any given year, because the Registry includes records only for individuals diagnosed by Registry data sources. The Registry includes records for individuals using health care and social services. Individuals who do not use such services, primarily those with early stages of cognitive impairment, are not represented in the Registry or in the projections.

~ History of the Registry ~

1988

The Alzheimer's Disease Registry, previously the Statewide Alzheimer's Disease and Related Disorders Registry, was established in 1988 to record specific information about South Carolinians who develop Alzheimer's disease and related disorders (ADRDR).

1990

On May 31, 1990, Governor Carroll A. Campbell, Jr., signed a state law authorizing the Registry. This law (R653, H4924) amended Title 44, Code of Laws of South Carolina 1976, relating to health, by adding Chapter 36 establishing a voluntary Statewide Alzheimer's Disease and Related Disorders Registry in the Arnold School of Public Health, University of South Carolina. The law has strict confidentiality requirements but does allow registry staff to contact the families and physicians of persons diagnosed as having Alzheimer's disease or a related disorder to collect relevant data and to provide information about public and private health care resources available to them.

1993

From July 1993 to May 1996, the Registry was located at the James F. Byrnes Center for Geriatric Medicine, Education, and Research, a geriatric research hospital jointly sponsored by the USC School of Medicine and the SC Department of Mental Health.

1997

The registry was moved back to the School of Public Health. The registry is currently maintained by the Office for the Study of Aging, Arnold School of Public Health, USC.

2008

In 2008 the Alzheimer's Disease Registry celebrated its 20th anniversary. It is one of only three statewide registries for Alzheimer's disease and Related Disorders in the United States. It continues to collect and provide prevalence data to public and private entities for planning, advocate for caregivers, and foster research in risk factors for ADRDR and the risk of institutionalization.

This project has received widespread support and interest from the academic community, lay support groups, state agencies, and other public and private organizations as part of a statewide effort to study the growing impact of Alzheimer's disease on the health and welfare of older South Carolinians.

**~CHARACTERISTICS OF ADRD IN SOUTH CAROLINA~
BASED ON 2007 ALZHEIMER’S DISEASE REGISTRY DATA**

Since January 1, 1988, 150,853 cases of Alzheimer’s disease and related disorders (ADRD) have been identified in South Carolina. This report describes demographic characteristics and medical information for the 63,834 cases alive on January 1, 2007, displayed by type of ADRD.

Type of ADRD

Among the 63,834 current Registry cases, 64 percent had a diagnosis of Alzheimer's disease, and 11 percent had a diagnosis of vascular dementia, which is often associated with stroke. In the event of records showing both Alzheimer’s disease and vascular dementia the case was reported in a Mixed dementia category. Six percent of all Registry cases are in the Mixed category. The additional 19%, for the total number of “Other Conditions,” had a dementia related to other medical conditions, such as Parkinson’s disease (see Table 2 for complete listing). The diagnosis shown represents the most current diagnosis in the data received.

Location

More registry cases resided in the community (61%) than in a nursing facility (35%) or unknown locations (3%) (Figure 3). As shown in Figure 4, the distribution of the types of ADRD was similar in the community and in nursing facilities.

**Table 1
Registry Cases by Dementia Type
and Community, Nursing Facility or Unknown Location
South Carolina Alzheimer's Disease Registry, 2007**

Dementia Type	Community		Nursing Facility		Unknown		Total	
	N	%	N	%	N	%	N	%
Alzheimer’s Disease	24,236	62	15,494	69	1,339	61	41,069	64
Vascular dementia	4,205	11	2,317	10	207	10	6,729	11
Mixed dementia	1,592	4	2,043	9	53	2	3,688	6
Other conditions	9,030	23	2,718	12	600	27	12,348	19
Total	39,063	61	22,572	35	2,199	4	63,834	100

~ *Location and ADRD in South Carolina* ~
 (continued)

Figure 3
Registry Cases by Community,
Nursing Facility or Unknown Location
 South Carolina Alzheimer's Disease Registry, 2007

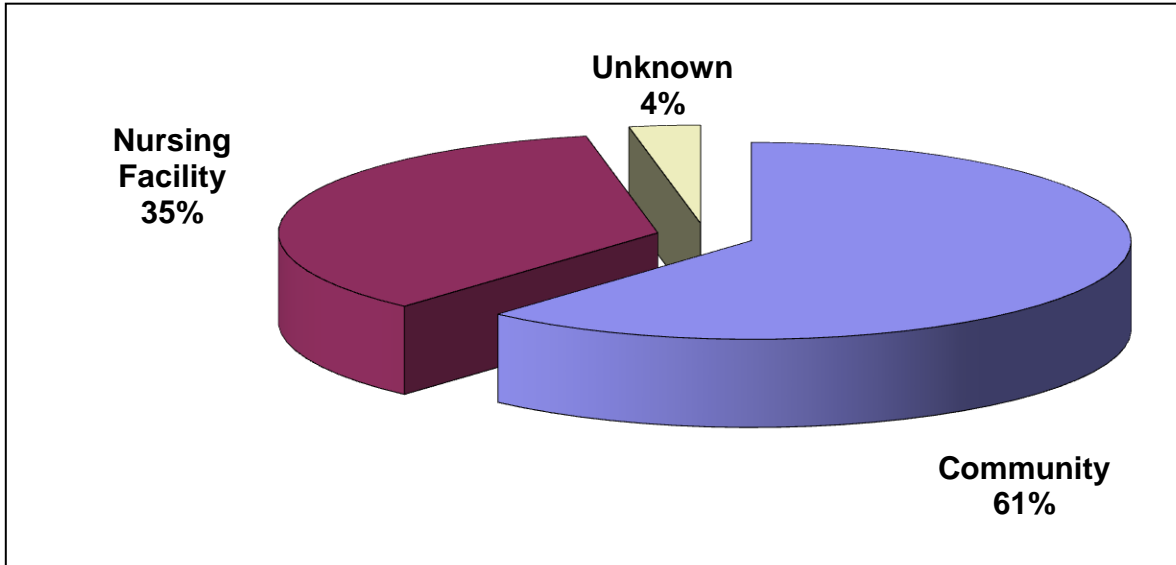
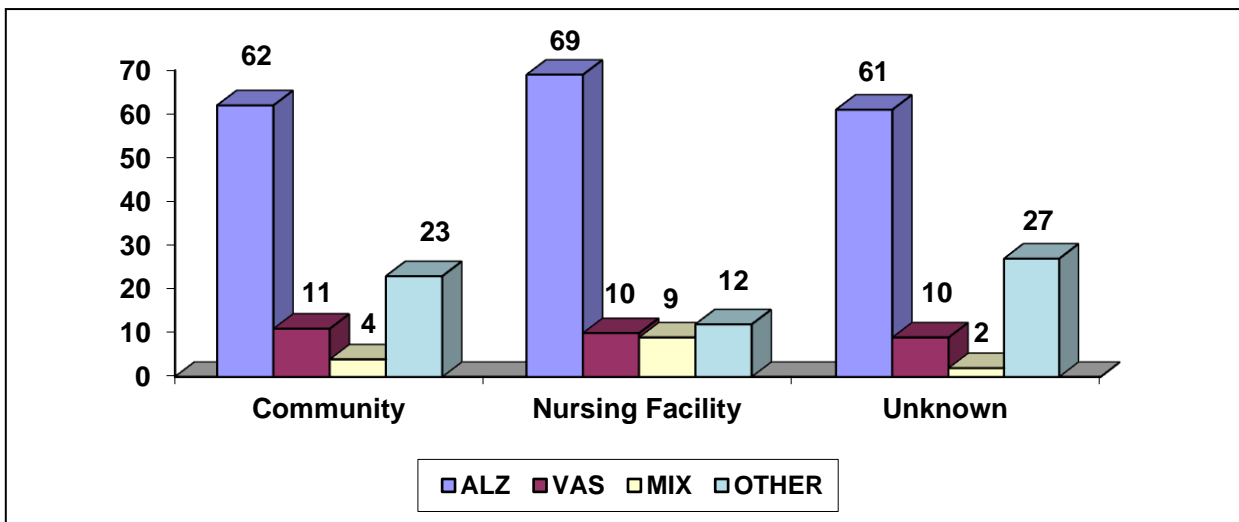


Figure 4
Registry Cases in Community,
Nursing Facility or Unknown Location,
by Dementia Type
 South Carolina Alzheimer's Disease Registry, 2007



~ *Dementia in Other Medical Conditions* ~

In addition to Alzheimer's disease, the Registry tracks dementias that are associated with other medical conditions, such as Parkinson's disease, alcohol and drug abuse, and HIV/AIDS. In the 2007 Registry, there are 11,205 persons with a dementia associated with one of these conditions, who do not also have a diagnosis of Alzheimer's disease or vascular dementia. Six percent of them have dementia associated with Parkinson's disease, and 47% have an indication of dementia associated with some other medical condition (please see Table 2 footnote). The percentages in the table are not mutually exclusive due to the fact that some persons' records indicate that they have more than one medical condition. A few individuals have as many as three such conditions.

Dementia with Lewy Bodies

Dementia with Lewy Bodies (DLB) is a progressive brain disease characterized by abnormal round structures in the areas of the brain that control thinking and movement. Hence, DLB causes symptoms similar to those commonly associated with both Alzheimer's disease and Parkinson's disease. Like Alzheimer's disease, it can cause confusion, memory loss, and depression, while other possible symptoms are slowed movement, rigid muscles, and tremors, symptoms normally found in those with Parkinson's disease. Persons with DLB may also have hallucinations and experience day-to-day changes in their symptoms. Currently, there is no cure for Dementia with Lewy Bodies. Medications used to treat Alzheimer's disease, Parkinson's disease, and depression are typically used to manage DLB symptoms. Dementia with Lewy Bodies (DLB) is the second most common cause of dementia, after Alzheimer's disease. Estimates suggest that DLB accounts for approximately 20% of all dementia cases.¹

Table 2
Dementia in Other Medical Conditions by Age Group
 South Carolina Alzheimer's Disease Registry, 2007*

	Under 65	65-74	75-84	85+	Total	
	%	%	%	%	N	%
Alcohol dementia	19	9	3	2	1,015	8
Drug-induced dementia	1	1	0	0	56	0
Organic brain syndrome	0	0	0	0	12	0
Other cerebral degenerations	40	69	54	42	6,488	54
Parkinson's disease	2	5	8	7	694	6
Huntington's disease	0	0	0	0	8	0
HIV/AIDS dementia	4	0	0	0	139	1
Dementia with Lewy bodies	1	6	10	6	786	7
Frontotemporal dementia	0	0	0	0	7	0
Pick's disease	0	0	0	0	17	0
Dementia with other conditions*	42	36	42	59	5703	47
Total (N)	3,536	3,237	4,620	3,450	14,843	

*Dementia with other conditions includes those with an ICD-9-CM code in 294.1(dementia in conditions classified elsewhere) on their medical record. This code is listed along with the ICD-9-CM code of the dementia-causing condition. However, the dementia-causing condition may not be identifiable from the record, and therefore, may not be in the above table.

¹ Lewy Body Dementia Association. www.lewybodydementia.org. Accessed March 7, 2008

~ *Pick's disease: A frontotemporal dementia* ~

Frequently misdiagnosed as Alzheimer's disease or as a psychiatric disorder, Pick's disease is a form of dementia affecting the frontal and temporal lobes of the brain¹. These areas of the brain are associated with personality, behavior, and language. Because of the affected brain areas, Pick's disease is classified as a frontotemporal dementia (FTD). Onset of Pick's disease and other FTDs are characterized by changes in personality, behavior, and/or impaired speech or writing.

Five characteristics are used in the early stages of Pick's disease to distinguish it from Alzheimer's disease. If three or more are present, then an individual is more likely to have Pick's disease rather than Alzheimer's disease. They are:

1. Onset before age 65
2. Initial personality changes
3. Loss of normal controls, e.g., gluttony, hypersexuality
4. Lack of inhibition
5. Roaming behavior.²

*Frontotemporal dementia ...
The second most common cause
of early onset dementia after
Alzheimer's disease*

The onset of Pick's disease is usually more rapid than that of Alzheimer's disease. Onset may begin as early as age 40.

Primary progressive aphasia (PPA) and semantic dementia (SD) are also classified as FTDs. Unlike Alzheimer's disease, the memory of an individual with PPA remains largely intact for

the initial years of the condition. Instead, the initial years of PPA typically involve increasing dysfunction in the areas of word choice, object naming, syntax, and/or word comprehension. Semantic dementia also causes deficits in the areas of word comprehension, as well as in the recognition of faces and objects.^{3,4}

While the exact cause is unknown, FTDs exhibit a strong genetic component, and they often run in families.^{2,5} The standard prognosis for individuals with FTDs is poor. The dementias often progress rapidly, and individuals may succumb to the disease within 2 – 10 years of diagnosis.⁵ Median survival time is 7 years.⁶

At this time, the FDA has not approved any medications for the treatment of Pick's disease or any of the other frontotemporal dementias. Medications may be used to manage behavioral problems, but currently no developed drugs are effective at treating the disease.

1 Frontotemporal dementia. Retrieved June 24, 2010, from <http://www.mayoclinic.com/health/frontotemporal-dementia/ds00874>.

2 Rose, A, Russell D. Pick's disease: signs, symptoms, treatment, and support. Retrieved June 24, 2010, from http://helpguide.org/elder/picks_disease.htm.

3 Mesulam, M-3 Lewy Body Dementia Association. www.lewybodydementia.org. Accessed March 7, 2008M. Primary progressive aphasia – a language-based dementia. N Engl J Med 2003; 349: 1535-42.

4 Hodges, JR, Patterson K. Semantic dementia: a unique clinicopathological syndrome. Lancet Neurol 2007; 6: 1004-14.

5 NINDS frontotemporal dementia information page. Retrieved June 24, 2010, from <http://www.ninds.nih.gov/disorders/picks/picks.htm>.

6 Haberland, C. Frontotemporal dementia or frontotemporal lobar degeneration – overview of a group of proteinopathies. [Idegyogy Sz.](http://www.elsevier.com/locate/S096999611000087) 2010 Mar 30;63(3-4):87-93.

~ Age and ADRD in South Carolina ~

Table 3 shows that 40% of persons with Alzheimer’s disease are 85 years of age or older. Figure 5 shows this information graphically for all dementias included in ADRD, with 36% of persons over 85 years of age. Figure 6 indicates that for people with ADRD, over 60% of those 75 to 85 years of age are being cared for in the community. Living in the community is the location of choice for the individual and family. However, as Figure 6 indicates, with age comes an increase in movement to nursing facilities.

Table 3
Registry Cases by Age Group and Dementia Type

South Carolina Alzheimer's Disease Registry, 2007*

AGE	AD		VASCULAR		MIXED		OTHER		TOTAL	
	N	%	N	%	N	%	N	%	N	%
Under 65	2,671	7	979	15	219	6	2,489	21	6,358	10
65 – 74	6,869	17	1,417	22	638	17	2,759	24	11,683	19
75 – 84	14,475	36	2,200	34	1,412	39	3,460	30	21,547	35
85 +	15,917	40	1,908	29	1,386	38	2,881	25	22,029	36
Total	38,625	65	6,385	11	3,252	6	10,421	18	58,673	100

*2,154 records for individuals have missing values for the variables required for inclusion in this table or have ages either less than 50 or greater than 110.

AD=Alzheimer’s disease or senile dementia; VASCULAR=Vascular dementia; MIXED=both Alzheimer’s disease and Vascular dementia; OTHER=dementia in other medical conditions.

Figure 5
Registry Cases by Age Group
South Carolina Alzheimer’s Disease Registry, 2007

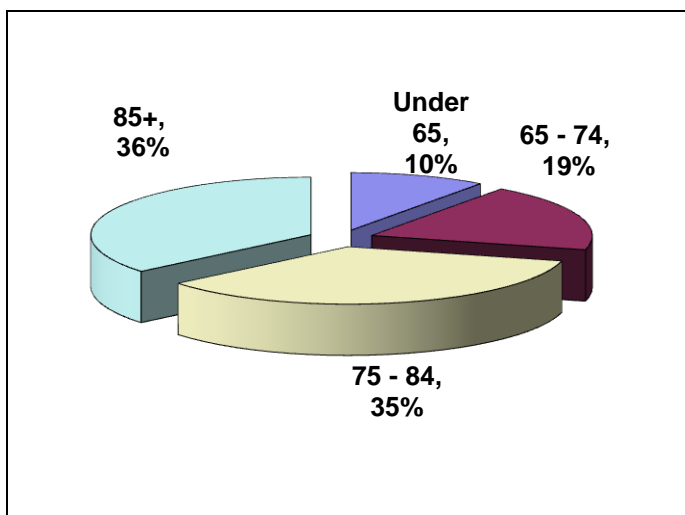
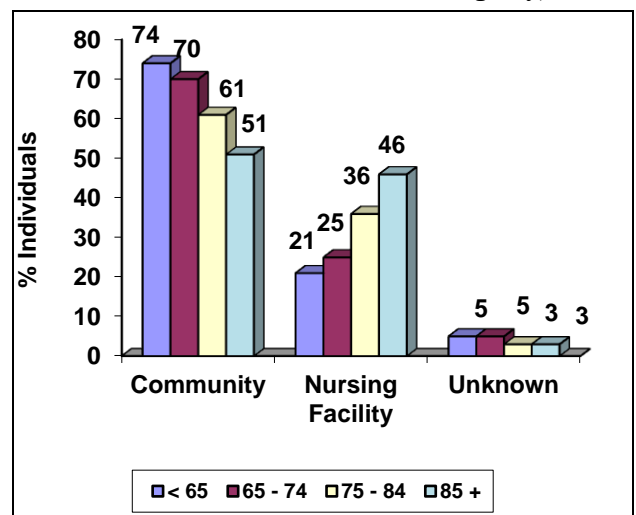


Figure 6
Registry Cases by Age Group in Community, Nursing Facility or Unknown Location

South Carolina Alzheimer’s Disease Registry, 2007



~ Gender and ADRD in South Carolina ~

Table 4 shows Registry cases by gender, dementia type, and age group. For each dementia type, the number of women is notably larger than the number of men in all but the youngest age category. In particular, among those age 85 or over, the number of women with ADRD is 3.5 times the number of men with ADRD.

More women than men in this population were diagnosed with ADRD (Fig. 7). This is likely due to the larger number of women alive after age 75. The differences in the ADRD diagnoses by gender are shown graphically in Figure 8.

Table 4
Registry Cases by Gender, Age Group and ADRD Type
 South Carolina Alzheimer's Disease Registry, 2007*

	<i>AD</i>		<i>VASCULAR</i>		<i>MIXED</i>		<i>OTHER</i>		TOTAL	
	N	%	N	%	N	%	N	%	N	%
MEN										
Under 65	1,212	10	541	21	117	10	1,505	29	3,375	16
65 – 74	2,791	23	667	26	312	27	1,443	28	5,213	25
75 – 84	4,485	38	872	34	463	39	1,428	27	7,248	35
85 +	3,499	29	478	19	287	24	828	16	5,092	24
WOMEN										
Under 65	1,449	5	433	11	100	4	923	15	2,966	7
65 – 74	4,065	15	742	19	326	13	1,315	21	6,448	16
75 – 84	9,951	36	1,324	34	941	39	2,028	32	14,244	35
85 +	12,339	44	1,423	36	1,092	44	2,046	32	16,900	42

*Records for 2,154 individuals have missing values for gender or age.

AD=Alzheimer's disease or senile dementia; VASCULAR=Vascular dementia; MIXED=both Alzheimer's disease and Vascular dementia; OTHER=dementia in other medical conditions.

Figure 7
Registry Cases by Gender

South Carolina Alzheimer's Disease Registry, 2007

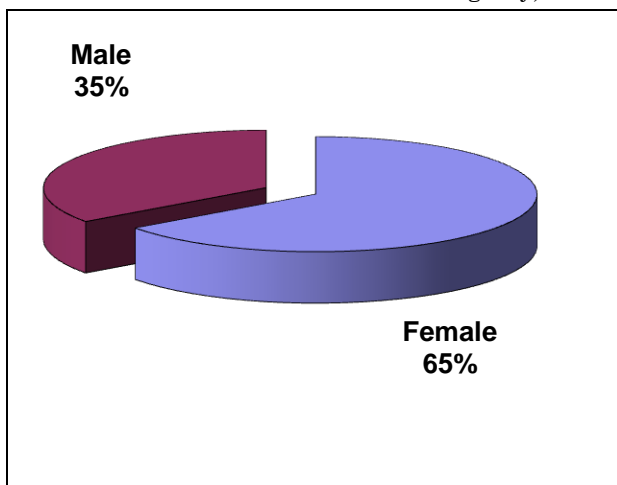
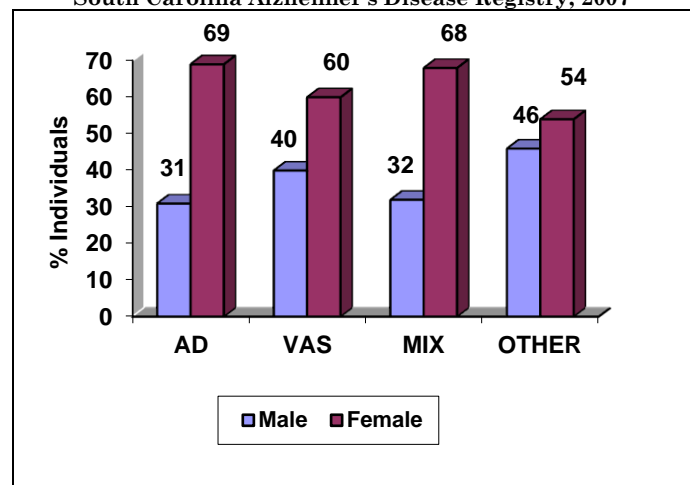


Figure 8
Registry Cases by Gender and ADRD Type

South Carolina Alzheimer's Disease Registry, 2007



~ Race and ADRD in South Carolina ~

Compared with whites, African Americans, who comprise nearly 21% of the adult South Carolina population 65 years and older, were over-represented in Vascular dementia (41%) and in the overall Alzheimer's Disease Registry with 32% (Table 5). Sixty-six percent of African Americans with ADRD reside in the community, compared to 58% of whites living in the community (Figure 10).

Table 5
Registry Cases by Race and ADRD Type
South Carolina Alzheimer's Disease Registry, 2007*

RACE	AD		VASCULAR		MIXED		OTHER		TOTAL	
	N	%	N	%	N	%	N	%	N	%
White	27,596	67	3,759	56	2,260	61	7,619	62	39,093	65
African-American	12,340	31	2,792	41	1,355	37	4,232	34	19,917	32
Hispanic	191	<1	39	1	8	<1	61	1	275	1
All Others	942	2	139	2	65	2	436	3	1,477	2
Total	41,069		6,729		3,688		12,348		63,834	

*AD=Alzheimer's disease or senile dementia; VASCULAR=Vascular dementia; MIXED=both Alzheimer's disease and Vascular dementia; OTHER=dementia in other medical conditions.

Figure 9
Registry Cases by Race
South Carolina Alzheimer's Disease Registry, 2007

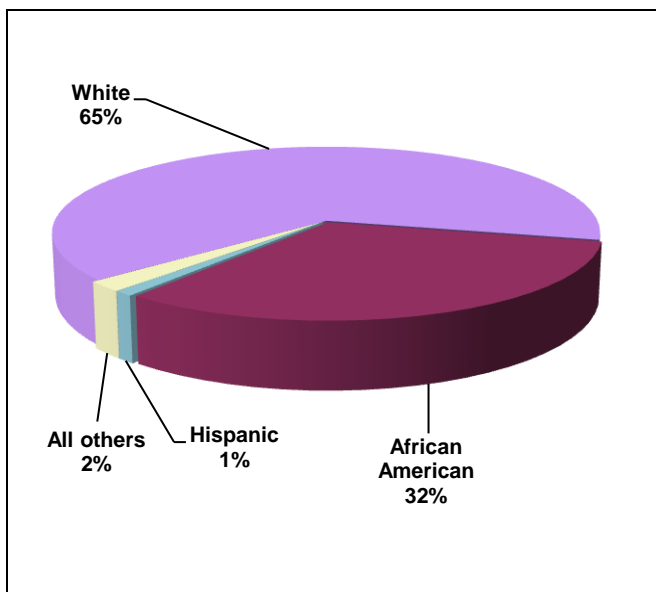
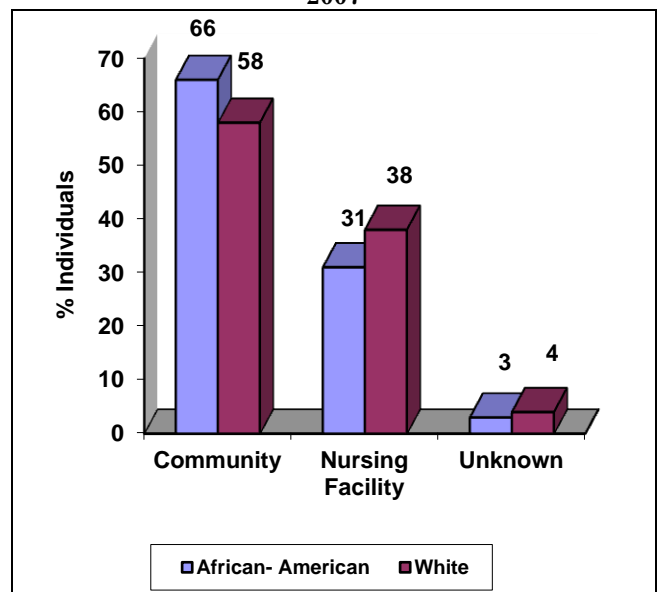


Figure 10
Registry Cases by Race in Community, Nursing Facility or Unknown Location
South Carolina Alzheimer's Disease Registry, 2007



~ Deaths among Individuals in the Registry ~

The Alzheimer's Disease Registry data are linked with death certificates to summarize the deaths occurring among persons in the Registry. Of those people identified with ADRD since 1988, 87,019 have died. The individual's first date of diagnosis may not be known to the Registry in every instance. For example, if an individual is first diagnosed during a physician office visit, then that diagnosis is not available to the Registry. We use the first date that a person entered one of the systems reporting to us as their entry date (Table 6).

Table 6
Length of Time from Entry to Death by ADRD Type
South Carolina Alzheimer's Disease Registry, 2007*

	AD		VASCULAR		MIXED		OTHER		TOTAL	
	N	%	N	%	N	%	N	%	N	%
ENTRY to DEATH										
< 2 years	36,212	63	7,668	67	3,175	61	9,493	72	56,548	65
2-5 years	14,437	25	2,570	23	1,510	29	2,523	19	21,040	24
5 + years	6,505	12	1,172	10	533	10	1,221	9	9,431	11
Total	57,154	66	11,410	13	5,218	6	13,237	15	87,019	100

AD=Alzheimer's disease or senile dementia; VASCULAR=Vascular dementia; MIXED=both Alzheimer's disease and Vascular dementia; OTHER=dementia in other medical conditions.

Table 7 lists the top 10 underlying causes of death for persons 65 years of age or older in the South Carolina Alzheimer's Disease Registry who died during 2007. The #1 underlying cause of death for these persons was attributed to senility and organic mental disorders. This category includes Alzheimer's Disease and many other dementing illnesses. Nationally, the leading causes of death for persons ages 65 years and older were: heart disease, cancer, stroke, chronic lower respiratory diseases, influenza and pneumonia, Alzheimer's disease, diabetes, nephritis, accidents, and septicemia.¹ Except for nephritis, accidents, and septicemia, the underlying causes of death for those with ADRD in the Registry nearly mirror the national trend.

Table 7
Top 10 Underlying Causes of Death Among Those 65 Years or Older
South Carolina Alzheimer's Disease Registry, 2007*

Rank	
1	Senility and Organic Mental Disorders
2	Acute Cerebrovascular Disease
3	Coronary Atherosclerosis and Other Heart Disease
4	Acute Myocardial Infarction
5	Chronic Obstructive Pulmonary Disease
6	Pneumonia**
7	Congestive Heart Failure; Non-hypertensive
8	Diabetes Mellitus without Complication
9	Cancer of Bronchus; Lung
10	Hypertension with Complications and Secondary Hypertension

*Only includes persons who died during the 2007 calendar year.

**Except pneumonia caused by tuberculosis or sexually transmitted disease.

¹ Gorina Y, Hoyert D, Lentzner H, Goulding M. Trends in causes of death among older persons in the United States. Aging Trends, No 6. Hyattsville, Maryland: National Center for Health Statistics. 2006.

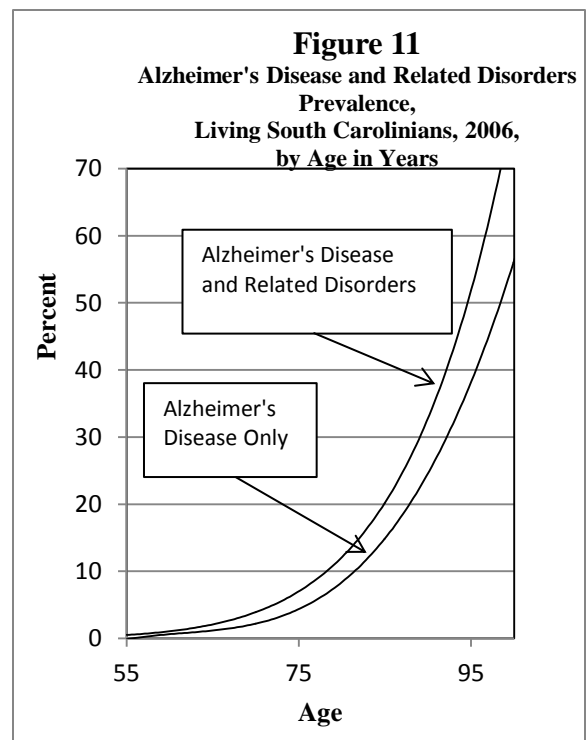
~ Population-based ADRD Rates in South Carolina ~

These population-based ADRD rates are estimates among South Carolinians. These rates are calculated using the 2007 Registry information linked with the 2007 United States Census Estimates. Among our findings from these data:

- **9.7% of South Carolinians over the age of 65 have ADRD.** 6.5% of South Carolina residents have a diagnosis of Alzheimer's disease. Previous research suggests that the number of individuals with some cognitive impairment may be nearly 50% greater than this estimate, because diagnosed cases do not include individuals with Mild Cognitive Impairment, a condition that can develop into Alzheimer's disease.
- **31% of South Carolina residents age 85 or older have ADRD.**

- Figure 11 shows how the prevalence of Alzheimer's disease increases with age. Although about 22 % of those at ages 85 or older have Alzheimer's disease (not including related memory disorders), the risk for individuals in their 80s is considerable smaller than this summary number suggests. At age 85, the prevalence of Alzheimer's disease is about 21%. By age 90, it is about 31%. **As the figure illustrates, the greatest risk comes at much older ages.**

- The figure also shows the prevalence of ADRD. Related disorders include vascular dementia and dementias associated with medical diseases such as Parkinson's disease. **The prevalence of these related disorders also rises with age. About 54% of those who reach age 100 have at least one type of dementia.**



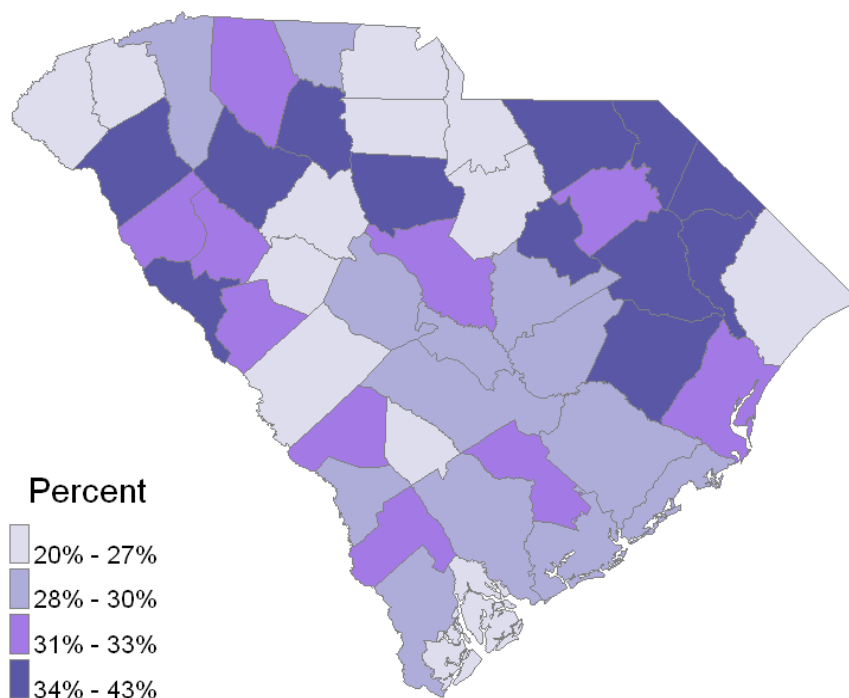
- **The figure provides the nation's first look at an age distribution of Alzheimer's disease and related disorders that is not based merely on projections from small samples. No other data source in the United States enables researchers to accurately calculate the age distribution of Alzheimer's disease.**

~ *Population-based ADRD Rates in South Carolina* ~
(continued)

- **African Americans are at notably higher risk of an Alzheimer's disease diagnosis than are whites.** At ages 55 through 64, African Americans are about 2.2 times as likely to have Alzheimer's disease, and 3 times as likely to have ADRD. The risk is particularly great for African American men at these ages, who are 3.5 times as likely to have ADRD as are white men. At ages 65 through 84, African Americans are about 1.8 times as likely to have Alzheimer's disease and twice as likely to have ADRD. However, at ages 85 and over, African Americans are only about 1.8 times as likely to have ADRD. The declining difference with age may be due to earlier onset or diagnosis of Alzheimer's disease for African Americans, combined with earlier death for African Americans with the disease. **No previous research has had access to a sufficiently large sample to reveal this phenomenon. These findings illustrate the rich research capabilities of the South Carolina Alzheimer's Disease Registry.**
- According to the U.S. Census, there were an estimated 6,049 Hispanics age 65 or over in South Carolina in 2007. This group is of interest because of the state's growing Hispanic population. The 2007 Registry indicates ADRD prevalence for these Hispanics was 4.1%, compared with 9.7% for the total population at those ages. The average age of Hispanics in the Registry was significantly lower than the average for whites; whites were on average 3.9 years older. The mean ages of Hispanics and African Americans were not notably different. However, among those without ADRD, the age profile of older Hispanics and others may differ. This could account for the prevalence difference. Also, if many older Hispanic South Carolinians are immigrants, they may represent a relatively healthy population, as immigrants generally come to this country in good health.

- **The prevalence of Alzheimer’s disease and related disorders may vary notably among SC counties.** For example, Figure 12 shows the percentage of individuals age 85 or over with ADRD in 2006. The county prevalence rates vary from a low of about 20%, to a high of about 43%. We examined the possibility that rates for border counties might be affected by South Carolina residents obtaining hospital care in North Carolina or Georgia; however, few older South Carolinians with an ADRD diagnosis use hospital services in bordering states. **This county variation provides an important starting point for epidemiological studies of Alzheimer’s disease and related disorders.**

Figure 12
Percentage of Living Persons Age 85 and Over
With a Diagnosis of Alzheimer's Disease or Related Disorders,
by County, South Carolina, 2006



It should be noted that counties where residents enjoy particularly long lives are likely to have greater percentages of individuals with ADRD. This is so because the risks of ADRD rise dramatically at older ages. Thus, the map should not be interpreted to suggest that the incidence of ADRD is higher in counties with higher prevalence. However, **the map is useful because it illustrates where the greatest service needs are for the oldest old, who are more likely than others to require institutional care.**

~ Registry Procedures ~

A definitive diagnosis of ADRD is difficult, especially in the early stages. The registry staff is not directly involved in diagnosis; the physician's diagnosis is collected from the individual's medical records through codes using the International Classification of Diseases, 9th revision, Clinical Modification (ICD-9-CM, 1980). An individual is then classified into four general categories for reporting purposes as shown in Table 8.

Individuals with ADRD are usually identified, as they (or their family members) require provider services. Since no single system identifies all newly diagnosed patients with ADRD, cases are collected from several sources: the SC Department of Mental Health, the Community Mental Health Centers, the Medical University of South Carolina, Community Long-Term Care, Nursing Homes and Residential Care Facilities, the SC Department of Health and Environmental Control, and the SC Budget and Control Board.

Table 8
Classification of ADRD by ICD-9-CM Codes
South Carolina Alzheimer's Disease Registry, 2007

ALZHEIMER'S DISEASE	
290.0 - 290.3	Senile or presenile dementia
290.8 - 290.9	
331.0	Alzheimer's disease
VASCULAR DEMENTIA	
290.4 - 290.43	Arteriosclerotic dementia
435 - 438	Cerebrovascular disease (with a dementia code*)
MIXED DEMENTIA	
Both Alzheimer's disease and Vascular dementia	
DEMENTIA IN OTHER MEDICAL CONDITIONS (see note below)	
291.2	Alcohol dementia
292.82	Drug-induced dementia
294.1	Dementia with other conditions
331.82	Dementia with Lewy bodies
(the same code is used for dementia with Parkinsonism)	
The following conditions are included with a dementia code*:	
310.1	Organic brain syndrome
331.1 - 331.9	Other cerebral degeneration
332.0 - 332.1	Parkinson's disease
333.4	Huntington's disease
042	HIV

NOTE: In the case where a person's record contains multiple indicators of the above categories, Alzheimer's disease and vascular dementia take precedence, except in the case where there are indications of both Alzheimer's disease and vascular dementia. In this case, the person is classified as having mixed dementia. Those classified with dementia in other medical conditions have no indications of Alzheimer's disease or vascular dementia.

*One of the following dementia codes must also be present: 290.0-290.3, 290.8-290.9, 331.0, 290.4-290.43, 291.2, 292.82, 294.1, 331.82.

~ *Registry Core Data Items* ~

The registry core data set (Table 9) consists of case-identifying data and diagnostic data (ICD-9-CM codes), and the place from which the records were obtained. Other information collected, *if available*, includes other medical diagnoses, educational status, caregiver contact data for follow-up and marital status.

Table 9
Registry Core Data Items
South Carolina Alzheimer's Disease Registry, 2007

Identification of case (for matching purposes only)
Location of case (for follow-up)
Name and location of caregiver/contact person (*if available*)
Sociodemographic data (education, marital status, gender, race, age)
Diagnosis (current dementia diagnosis and other medical diagnoses)

~ *Research Projects & Other Activities* ~

In addition to registering and tracking individuals with ADRD, the staff of the Alzheimer's Disease Registry and Office for the Study of Aging (OSA) also conduct other activities focused on aging issues of older individuals.

Research

Association between Behavioral Disturbances and Nursing Home Admission in Patients with Alzheimer's disease

Caregivers of individuals with Alzheimer's disease are being interviewed to identify specific behavioral disturbances of the individual with Alzheimer's disease that are associated with nursing home admission. In addition caregiver burden is being assessed to understand if caregiver factors mediate association between behavioral disturbances and home admissions.

Faith and Health

The USC Faith and Health Project explores the complex patterns related to social capital, aspects of faith, and health through in-depth interviews and brief survey instruments. Study groups included United Methodist members who had participated in a holistic health program, regular attendees of United Methodist churches (not part of the holistic health program) and infrequent /non-attendees of religious services, with each category stratified by race (AA and Caucasian). Based on findings and existing literature, a survey instrument has been developed to assess social capital, health outcomes, and multiple dimensions of faith and practice.

Training

Dementia Dialogues

"Dementia Dialogues" consists of 5 parts, each approximately 1.5 hours in length, which allows participants to integrate new ideas with information they already possess. Part 1 consists of **"The Basic Facts"**, an overview of ADRD, Part 2 **"Keeping the Dialogue Going"**, strategies for effective communication, Part 3 **"It's a Different World"**, understanding the impact of the environment and ways to promote independence in activities of daily living, Part 4 **"It's Nothing Personal"**, addressing challenging behaviors and Part 5 **"Now What Do I Do"**, creative problem solving. Each participant receives a certificate of participation for each unit and a Dementia Specialist Certificate upon completing all five Units. This program is offered at no cost to participants and is held regionally. **Over 13,000 professional, non-professional and family caregivers in South Carolina have received this training.** For further information please contact: Jan Merling, MA, Office for the Study of Aging, Arnold School of Public Health, University of South Carolina, 803-318-1601, jmerling@sc.edu or www.sph.sc.edu/OSA/programs_dementia.html

Dementia Dialogues Train-The-Trainer

A “Train-The-Trainer” curriculum for “Dementia Dialogues” has been developed and implemented for those who have completed Dementia Dialogues and wish to conduct these trainings in their facilities and agencies. For further information please contact: Jan Merling, MA, Office for the Study of Aging, Arnold School of Public Health, University of South Carolina, 803-318-1601, jmerling@sc.edu.

Elder Mistreatment Prevention Training

The OSA, in collaboration with the Center for Child and Family Studies in the College of Social Work and with the support of the SC Department of Health and Human Services has developed an Elder Mistreatment Prevention Training ***We Each Have a Story*** for nursing home management and direct care staff. For further information please contact: Jan Merling, MA, Office for the Study of Aging, Arnold School of Public Health, University of South Carolina, 803-318-1601, jmerling@sc.edu.

Recruitment and Retention Training

Practical solutions and tools are included in a series of courses on issues surrounding recruitment and retention of direct care staff in long term care have been developed and are available. This training and technical assistance are available to assist administrators and managers to maintain a quality staff to provide services to the aging and disabled population. For course descriptions: http://www.sph.sc.edu/osa/programs_recruitment.html.

Technical Assistance & Evaluation

Person- Centered Hospital Discharge Planning Model

Consumer direction is a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive. In collaboration with the Lt. Governor’s Office on Aging, staff is involved in a Center for Medicare and Medicaid grant to identify and evaluate a person-centered hospital discharge planning model. Activities include being members of the core planning team, providing training in person-centered planning and outcome evaluation.

Caregiver Coaching Service

The Office for the Study of Aging staff are working in collaboration with Community Long Term Care (CLTC) staff to pilot a caregiver Coaching Service to provide training to family caregivers of CLTC participants in order to improve the caregivers’ competence in topics, that include Dementia care, Incontinence care, Assistance with Activities of Daily Living and a Wellness module to promote resilience and empowerment of the caregivers.

~ Research Projects and Other Activities ~ *(continued)*

Evaluation of SC Department of Health and Human Services Grants

The South Carolina Department of Health and Human Services offers funds to nursing homes in the form of grants to improve the quality of life for nursing home residents. This past year facilities were required to select from the following items: My InnerView, Bladder Scanner or development funding for an Electronic Record System. OSA evaluates the facilities use of these grants through a series of surveys and site visits.

Exercise

Move for Life

OSA in collaboration with a Duke Endowment Grant and other Arnold School of Public Health Departments has developed an exercise DVD designed to increase physical activity. These exercises are for adults who are 50 years and older and younger people who haven't been exercising regularly or who have limitations. The DVD contains exercise instructions, deep breathing and stretching, strength and balance exercises and a cardio routine in 10 minute segments or a full routine of 28 minutes. Further information can be found at www.sph.sc.edu/osa.

Placemat Strength Training Program

Training home care workers to assist clients in maintaining independence by improving physical functioning through strength training has resulted in the Placemat Strength Training Program (PSTP). This exercise program has been specifically designed for the person who has met nursing home level of care and has chosen to remain at home. This program is being implemented through Community Long-Term Care and is also available to anyone. See www.sph.sc.edu/OSA/programs_placemat.html.

Community Outreach

The staff of the Office for the Study of Aging provides expertise and technical assistance to the community through the involvement on committees that include: Alzheimer's Resource Coordination Center, Caregiver Coalition of the Midlands, Advisory Committee for Nurse Aide Training, Nurse Aide Training Coordinator's & Instructors Annual Workshop, and the South Carolina Emergency Preparedness Committee on Special Populations.

The Purple Ribbon Task Force was created by a concurrent resolution adopted by the General Assembly to study the current and future impact of Alzheimer's disease in South Carolina and assess the resources for the needs of persons with Alzheimer's disease and related disorders so as to develop a state strategy to address this health issue. An OSA staff member was appointed to this task force and participated in the development of recommendations. A final report entitled "Conquering the Specter of Alzheimer's Disease in South Carolina" was submitted to the General Assembly. Report can be found at <http://aging.sc.gov>

~ Registry Staff ~

Carol B. Cornman, B.S., R.N., P.A., **Director** of the Alzheimer's Disease Registry and related projects. She handles all requests for information from the registry. Her research interests include ethnic differences in ADRD, incorporating wellness activities that maintain independence in the elderly, consumer directed care and elder mistreatment prevention.

Courtney Davis, M.H.A., **Research Associate**, provides technical assistance and program evaluation for activities related to the office for the Study of Aging and conducts research and training in the area of long term care. Her interests include consumer-directed care, disaster preparedness for vulnerable adults, elder mistreatment, and quality improvement in facility and community-based health services.

Dorothy Davis, B.A., serves as **Data Manager** for the Alzheimer's Disease Registry, including Community Long Term Care (CLTC), vital records, Department of Mental Health, and other registry databases.

Marcia J. Lane, M.P.H., **Associate Director** of the Alzheimer's Disease Registry, provides program coordination and evaluation. Her research interests include older women's health issues, physical activity, ADRD, medication adherence, elder mistreatment, quality of life in long-term care, and consumer directed care.

Jan Merling, M.A., CTRS, **Education Coordinator**, is the trainer for "Dementia Dialogues" Prevention of Elder Mistreatment and the Placemat Strength Training Program. Her interests include adult learning and quality of life for older persons.

Dale Morris, A.S., **Administrative Assistant**, coordinates administrative activity and data entry for all projects.

Candace N. Porter, M.S., **Statistical Research Associate** for the Alzheimer's Disease Registry and related projects. Her research interests include AIDS dementia, Alzheimer's disease and related disorders as causes of death, survival analysis, and count data models. She is a Ph.D. candidate in Epidemiology and Biostatistics.

Alicia Best, M.P.H., Graduate Research Assistant, is a Ph.D. candidate in Health Promotion, Education and Behavior. Her research interests involve understanding the role of spirituality and/or faith in chronic disease management among African American women, as well as developing effective health communication strategies for urban African American populations.

Maggi Miller, M.P.H., **Graduate Research Assistant**, is a Ph.D. candidate in Epidemiology and Biostatistics. Her research interests are in aging, exercise and holistic health.

~ *Affiliated Professionals* ~

Cheryl Addy, Ph.D., is Executive Associate Dean, Arnold School of Public Health.

Sam Baker, Ph.D., is an Associate Professor, Department of Health Services Policy and Management, Arnold School of Public Health.

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Natalie Colabianchi, PhD., is an Assistant Professor, Department of Epidemiology and Biostatistics, Arnold School of Public Health.

Shawn Chillag, M.D., is Chairman and Professor, USC School of Medicine, Department of Internal Medicine, Division of Geriatrics.

Sara Corwin, Ph.D., is an Assistant Professor and Interim Director, Office of Public Health Practice, Arnold School of Public Health.

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Jan Probst, Ph.D., is Interim Chairman, Department of Health Services and Policy Management, Arnold School of Public Health.

Robert McKeown, Ph.D., is Professor and Chairman, Department of Epidemiology and Biostatistics, Arnold School of Public Health.

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Donna Ray, M.D., is Assistant Professor, USC School of Medicine, Department of Internal Medicine.

Nancy Richeson, M.D., is Professor, USC School of Medicine, Department of Internal Medicine.

Richard M. Schulz, Ph.D., is Professor in the USC College of Pharmacy.

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Myriam Torres, Ph.D., is a Clinical Instructor, Assistant Professor, Department of Epidemiology and Biostatistics, Arnold School of Public Health.

Kenneth Watkins, Ph.D., is an Associate Professor, Department of Health Promotion, Education and Behavior, Arnold School of Public Health.

Darryl Wieland, Ph.D., M.P.H., is Professor, Division of Geriatrics, Department of Medicine, USC School of Medicine.

Sara Wilcox, Ph.D., is an Associate Professor, Department of Exercise Science, Arnold School of Public Health.

Sudha Xirasagar, Ph.D., is Research Assistant Professor, Department of Health Services and Policy Management, Arnold School of Public Health.

~ Office Publications ~

The following is a list of the manuscripts and reports generated by the OSA staff. Reprints of these articles can be obtained from the registry office.

- Williams HG, Ullmann G, Gossard JL, Hussey JR, Brotherton SS, Laditka JN, Cornman CB. Functional Status Assessment for Community Long-Term Care: Preliminary Observations. *Home Health Care Services Quarterly* 28:4, 141-171, 2009.
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~ *Further Information* ~

This Annual Report is online at http://osa.sph.sc.edu/alzheimers_registry.html.

Any state or local agency may request the registry staff to provide specific data summaries (without identifiers). These requests are handled on an individual basis and will be provided free of charge, as time allows. Contact the registry staff at (803) 777-5337 for further information, or e-mail Carol Cornman at: ccornman@sc.edu.