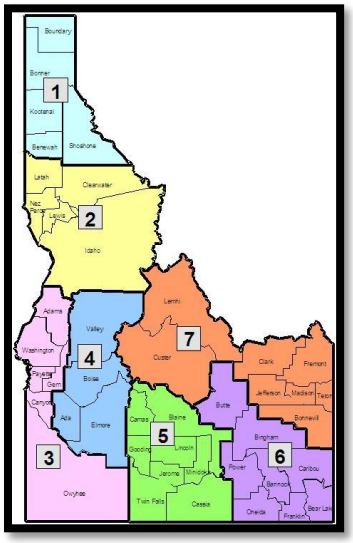
A State Plan for Alzheimer's Disease and Related Dementias

Addressing the needs of Idahoans with ADRD, their caregivers and family members

(Released March 2013)



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Executive Summary

With the unanimous passage of Senate Concurrent Resolution 112, the 2012 Idaho legislature acknowledged the rising influence of Alzheimer's disease and related dementias (ADRD) on the citizens of our state, and the advisability of a state plan to effectively meet the needs of those impacted by the disease. Furthermore, it endorsed the efforts of the Idaho Alzheimer's Planning Group (IAPG), a grass roots organization of professionals and lay people dedicated to helping the ADRD population in Idaho, in the development of a statewide plan. Such a plan will address the rising costs of ADRD to the state (primarily through Medicaid outlays) and seek ways to mitigate those costs through programs and services that keep individuals with ADRD at home longer, which is also where they want to be.

At no cost to the taxpayers, the IAPG conducted a year-long, statewide community needs assessment, using a variety of research methods, to determine how a state plan could best serve individuals with ADRD, their caregivers and family members. The results of that assessment were analyzed and prioritized into five major recommendations which form the core of the state plan:

#1 Increase public awareness about ADRD and provide comprehensive, practical and timely information related to the disease

#2 Provide ADRD-specific education and training for current and future health care providers, institutional caregivers and family caregivers

#3 Coordinate support services for ADRD patients, family members and caregivers throughout the state

#4 Create a positive regulatory and financial environment for addressing dementia-related issues

#5 Develop an ongoing source of data collection with regard to the needs of Idaho's ADRD patients, families and caregivers

The following plan provides complete background information on ADRD, the IAPG and the Statewide Community Needs Assessment, including research methodologies, data and data analysis. For each recommendation listed above, the plan also contains a discussion of one or more initiatives, as well as ideas for future consideration.

Alzheimer's Disease and Related Dementias: An Overview

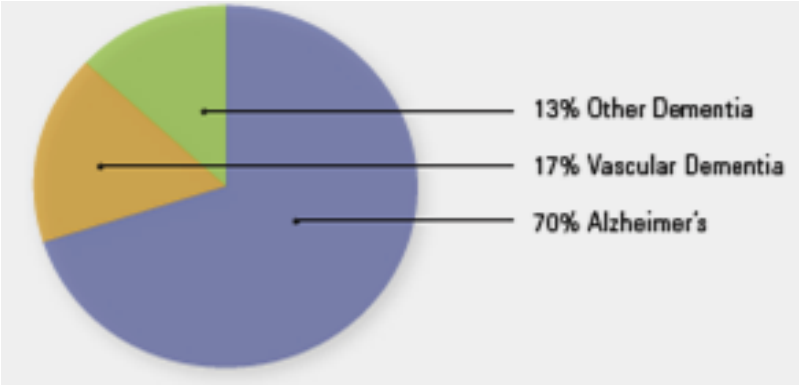
Defining Alzheimer's Disease

A person who suffers from Alzheimer's disease will at some point experience dementia, which is characterized by, among other things, a loss of short term memory. However, not everyone who has dementia has Alzheimer's disease. That is why the Idaho state plan refers to "Alzheimer's disease and related dementias," or ADRD. The following discussion will explain the similarities and distinctions between Alzheimer's disease and other dementias.

Alzheimer's disease (AD) is classified as a neurodegenerative disorder affecting neurons of the brain that are responsible for memory and higher cognitive functions. The brain consists of more than 100 billion neurons that specialize in the ability to transmit information to other cells, and thus constitute the basic working unit of the brain. Because these neurons lack capacity to regenerate, once they are lost and symptoms appear, the process is essentially irreversible.

Alzheimer's is a progressive disorder that can take from 5-20 years to run its course. The loss of neurons during that time is significant: affected individuals can lose up to 50% brain mass over the trajectory of the disease. Such loss leads to symptoms including memory impairments, difficulties with language, inability to

execute motor activities and an overall decline in cognitive skills [1]. “Dementia” is the umbrella term often used to describe the symptoms of Alzheimer’s, and Alzheimer’s is by far the leading cause of dementia in the United States, accounting for more than 70% of all known cases of dementia.



Causes of Dementia in People Aged 71 and older. Source: [2]

Although Alzheimer’s is the leading type of dementia, other forms exist, such as vascular dementia (often caused by mini strokes) as well as rarer forms of neurodegenerative diseases. The latter include dementia with Lewy bodies, Frontotemporal lobar degeneration and Parkinson’s disease. In each case, although the pathway to cell death may be different, the common denominator is the loss of neurons in areas of the brain responsible for memory and cognitive function. This leads to a great deal of overlap between the symptoms of the various dementias; however, different types of dementia are associated with distinct symptom patterns and brain abnormalities [1].

COMMON TYPES OF DEMENTIA

There is a great deal of overlap between the symptoms of various dementias.

Dementia type	Symptoms	Neuropathology	Proportion of dementia cases
Alzheimer's disease	Impaired memory, depression, poor judgement and confusion	Amyloid plaques and neurofibrillary tangles	50–80%
Vascular dementia	Similar to Alzheimer's disease, but memory less affected	Decreased blood flow to the brain owing to a series of small strokes	20–30%
Frontotemporal dementia	Changes in personality and mood, and difficulties with language	Damage limited to frontal and temporal lobes	5–10%
Dementia with Lewy bodies	Similar to Alzheimer's disease, also hallucinations, tremors	Cortical Lewy bodies (of the protein α-synuclein) inside neurons	<5%

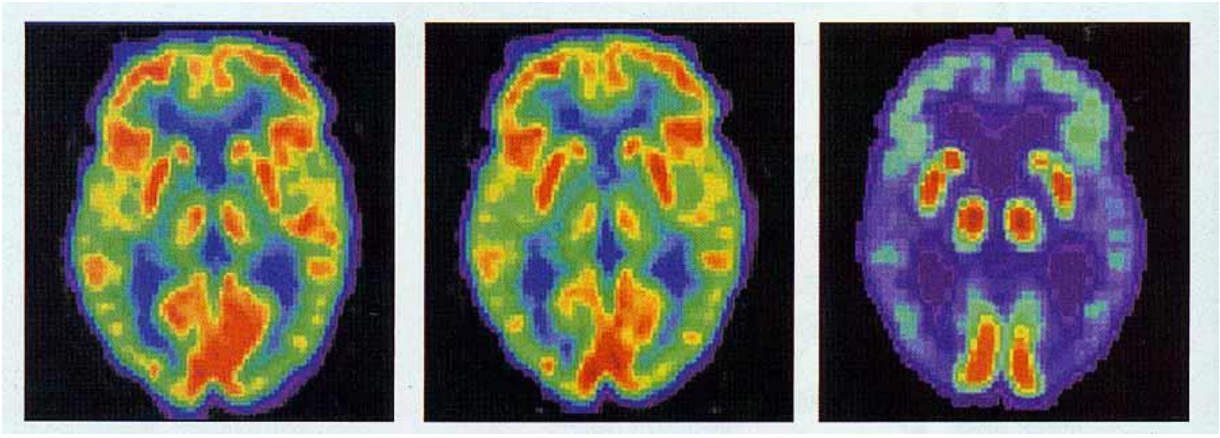
When making a diagnosis of dementia, physicians use the guidelines set forth in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*. To meet *DSM-IV* criteria for dementia, symptoms must include a decline in memory and in at least one of the following cognitive abilities [1]:

- Ability to generate coherent speech or understand spoken or written language
- Ability to recognize or identify objects, assuming intact sensory function
- Ability to execute motor activities, assuming intact motor abilities and sensory function and comprehension of the required task
- Ability to think abstractly, make sound judgments and plan and carry out complex tasks

Importantly, the decline in cognitive skills must be severe enough to interfere with daily life. In addition, to make a definitive diagnosis of dementia or more specifically Alzheimer's, a physician must rule out reversible forms of dementia

that include treatable conditions such as depression, side effects from medications, thyroid problems, certain vitamin deficiencies and excessive use of alcohol.

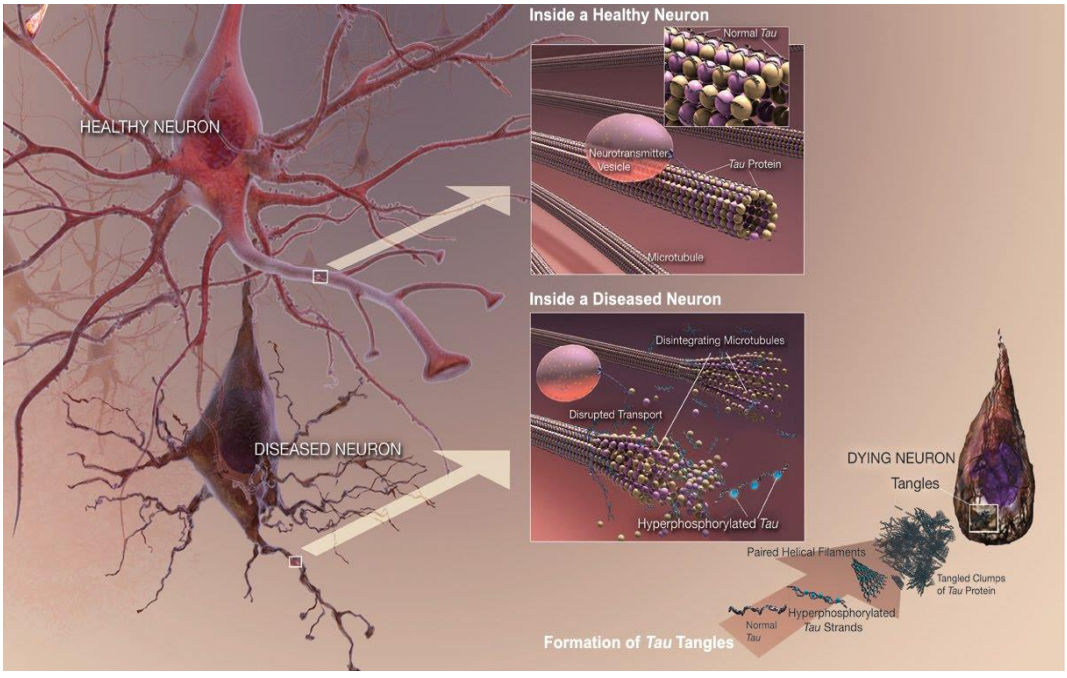
Alzheimer's causes functional and structural changes in the brain that lead to the symptoms of dementia. The two areas of the brain that are greatly impacted during the course of the disease are the hippocampus and the cerebral cortex. The hippocampus is important for memory while the cerebral cortex carries out higher cognitive functions. The loss of neurons in both regions leads to a concomitant reduction of brain activity as reflected in brain images.



Positron-emission tomographic (PET) scans from a 20-year-old (top row, left), a normal 80-year-old (middle) and an Alzheimer's patient (right) show that the diseased brain has a reduction in brain activity, indicative of cognitive decline. Source: Alzheimer's Disease Education and Referral Center/National Institute of Aging.

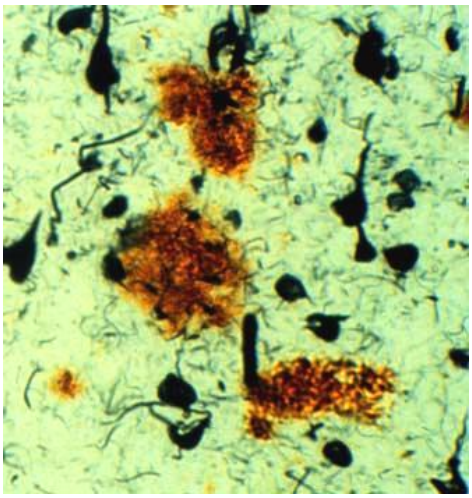
The Pathology of Alzheimer's Disease

Scientists regard the presence of two abnormal microscopic structures called "tangles" and "plaques" as a requirement for a definitive diagnosis of Alzheimer's disease. Tangles are twisted strands of a protein named "tau" that normally plays a critical function in maintaining the structural integrity of the neuron by helping assemble proteins called microtubules that support the framework of the nerve cell. In this regard, tau normally stabilizes the internal scaffolding of the neuron and acts similarly to a railroad tie. During the course of the disease, tau no longer works properly, leading to the breakdown of the framework of the neuron. This may affect neuronal function and lead to neuronal cell death.



Tangles are one of the two major pathological features associated with Alzheimer's disease. Source: Alzheimer's Association, www.alz.org

The other major pathological finding in Alzheimer's disease is senile plaques that are composed principally of the molecule called "beta-amyloid." Beta-amyloid is a toxic protein fragment that accumulates into the characteristic amyloid plaques that distinguish the brains of people who die from Alzheimer's disease.



Plaques are the other major pathological feature associated with Alzheimer's Disease. The figure shows circular plaques in brown surrounded by numerous tangles in black. Source: Laboratory of Dr. Troy Rohn, Department of Biological Sciences, Boise State University.

Scientists have not yet determined the exact role that plaques and tangles may play, but most believe that these proteins are key to disrupting the normal processes of neurons, including the ability to repair themselves; communication; and metabolism.

Alzheimer's disease is a multifactorial disorder, whose causes remain largely unknown. Despite extensive research on genetic factors, the vast majority of Alzheimer's cases (>90%) are not directly linked to them [3]. Aging is by far the most well established risk factor for the development of sporadic Alzheimer's disease with incidence rates showing an exponential growth between the ages of 65

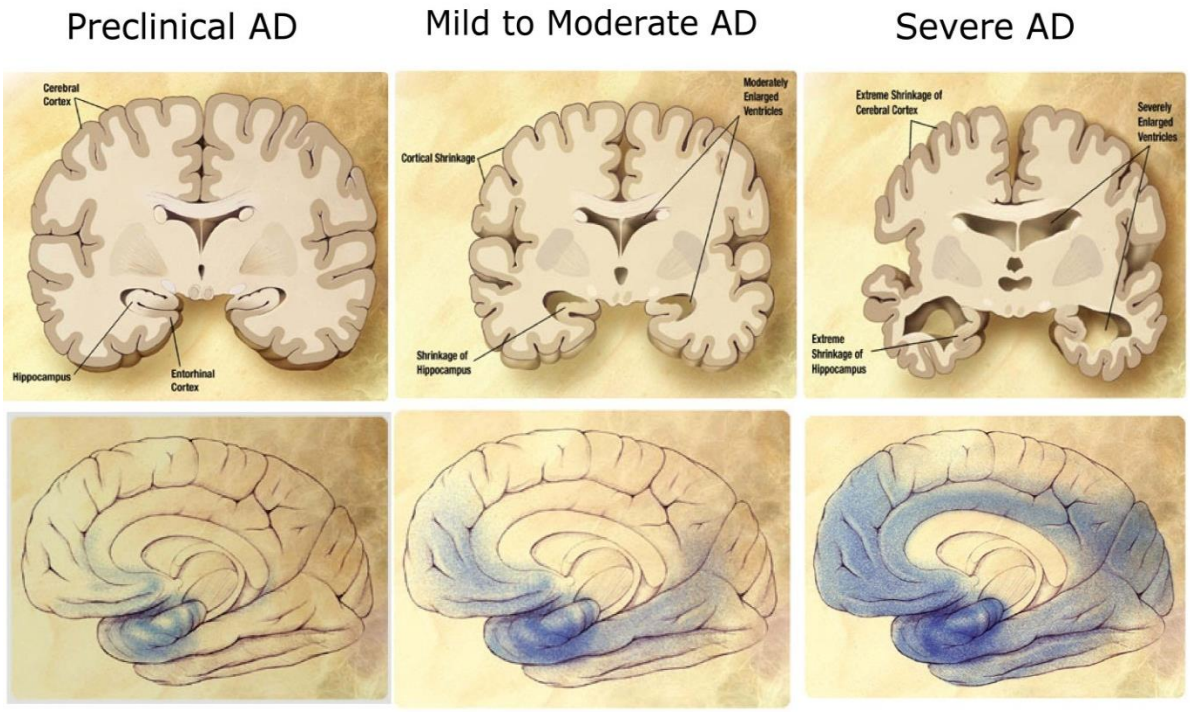
and 85 years, doubling every 5 years [3]. Thus, most Americans with Alzheimer's disease are age 65 or older.

A small percentage of Alzheimer's cases are caused by rare genetic variations found in a few hundred families worldwide. In these inherited forms of Alzheimer's, the disease tends to strike younger individuals. When Alzheimer's is first recognized in a person under the age of 65, it is referred to as "early-onset" Alzheimer's. It's estimated that approximately 1% of Americans are currently living with early-onset Alzheimer's as a result of genetic mutations that lead to the early-onset form of the disease [1]. Modifiable risk factors including high blood pressure, high levels of cholesterol, smoking, diabetes and obesity are also associated with higher risks of developing Alzheimer's and other dementias [1].

Progression of the Disease

In general, the symptoms of Alzheimer's disease reflect the presence of plaques and tangles in the hippocampus and cerebral cortex areas of the brain. For example, because plaques and tangles first appear in the hippocampus, a structure critical for memory, patients first present with memory impairments. From the hippocampus, the plaques and tangles eventually invade the cerebral cortex and in addition to memory loss, symptoms of confusion, poor judgment, mood changes and increased anxiety begin to manifest. Additional symptoms during the moderate

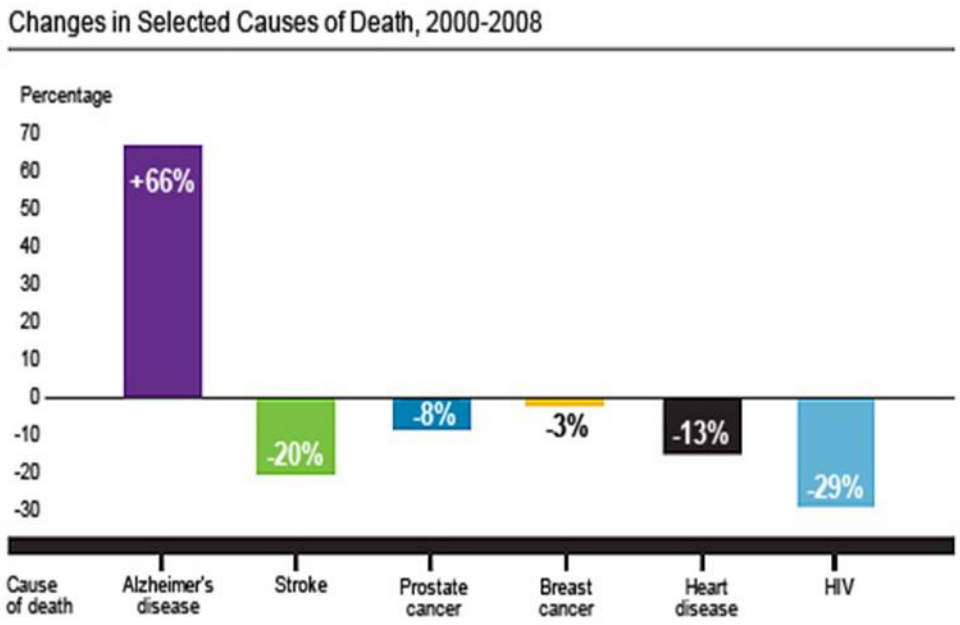
stage of Alzheimer's include problems recognizing people, difficulty with language and thoughts, restlessness, agitation, wandering and repetitive statements. Finally, during the severe stage of Alzheimer's disease, patients are completely dependent on others for care. Symptoms include weight loss, seizures, skin infections, increased sleeping and loss of bladder and bowel control. Death usually occurs from aspiration pneumonia or other infections. Caregivers often turn to a hospice program for help and palliative care. It's important to note that of all the stages of Alzheimer's, patients will generally spend the most amount of time (40%) in the last stage of the disease, which is often the most difficult to manage.



Progression of Alzheimer's disease. Bottom panels display the presence of plaques and tangles in blue and the spread of the pathology from the hippocampus to cerebral cortex. The top panels are the reflective brain changes as the disease progresses. Source: www.alz.org

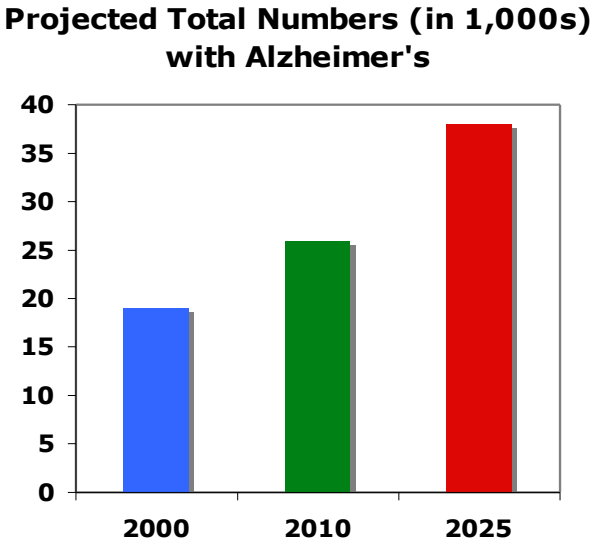
AD Prevalence and Demographic Trends

The national numbers on Alzheimer's disease are alarming: currently one in eight older Americans has Alzheimer's disease, making it the sixth-leading cause of death in the United States. An estimated 5.4 million Americans have Alzheimer's, a figure that includes 5.2 million people age 65 and older [1]. Of those with the disease, an estimated 4 percent are under the age 65; 6 percent are 64 to 74; 44 percent are 75 to 84; and 46 percent are 85 or older [1]. Of all of the major causes of death in the United States, including stroke, cancer and heart disease, only Alzheimer's disease has shown a significant increase in mortality during the same time frame (2000-2008).



Mortality and Alzheimer's disease. Source: Alzheimer's Association 2012 Alzheimer's Disease Facts and Figures.

In Idaho, because of our rising older population, we are projected to see some of the largest increases across the nation in the proportion of individuals diagnosed with Alzheimer's disease: an estimated 81% - 127% percent increase between the year 2000 and 2025.



Projected numbers of Alzheimer's cases in Idaho. Source: Alzheimer's Association 2012 Alzheimer's Disease Facts and Figures.

Financial Impact

According to the Alzheimer's Association, the number of Idahoans with Alzheimer's reached 26,000 in 2010, a number that has no doubt increased in the past three years. When considering the effect of Alzheimer's on a population, however, it's not just the number of people who are diagnosed with the disease, but also those who provide care. Many of these caregivers are in fact family members who devote a significant amount of their time, energy and resources over the course of the disease. Idaho currently has more than 75,000 such caregivers for ADRD patients, providing unpaid care valued at over one billion dollars [1].

Caring for a person with Alzheimer's disease poses special challenges. Although caregivers report positive feelings about caregiving, they also report high levels of stress and may become "secondary patients" because of the negative impact that providing care may have on their general health, risk for chronic disease, and even death. Such factors contribute to an estimated $35 million in higher health care costs for caregivers in Idaho [1].

Over time, the numerous costs of ADRD become prohibitive and in most cases are absorbed by state and federal government programs. Medicare covers many of the expenses for Idahoans over 65 who are living with ADRD in the community, and those individuals contribute a significant portion toward their own health care costs. However, that percentage decreases once the ADRD patient moves to a residential care setting such as assisted living or a skilled nursing facility. When that happens, an individual with ADRD will incur nearly three times as much in health care costs as he or she did while living at home, and that cost will be born almost completely by both Medicare and Medicaid [1]. The Statewide Community Needs Assessment discussed below revealed that most patients and their caregivers want to be able to remain independent and stay in their homes as long as possible. That, it turns out, is in the financial best interest of the state as well.

New Directions in Alzheimer's Research

Recently, new Alzheimer's guidelines were established to stress the importance of early diagnosis [4]. These new guidelines are in stark contrast to the last set of recommendations, published in 1984, which only recognized the full-blown dementia phase of the disease. The current shift encourages early screening for Alzheimer's as well as continued research into drugs that could halt early brain changes. Part of the reason for this shift is the realization by scientists that the pathology surrounding the accumulation of beta-amyloid plaques may take years or decades to take hold before the first irreversible symptoms appear. Therefore, the new guidelines have been designed to identify people who would most benefit from disease-modifying treatments when such drugs become available. The new Alzheimer's guidelines now recognize three stages:

- *Preclinical Alzheimer's disease*. The new guidelines recognize that the Alzheimer's disease process begins well before there are any symptoms. But for now, tests aren't accurate enough to determine whether or not a person has this stage of Alzheimer's.
- *Mild cognitive impairment*. The new category includes patients with changes in memory and thinking ability that do not keep them from performing everyday functions, but which strongly suggest that a patient will develop Alzheimer's-related dementia.
- *Dementia*, including mental impairments not as severe as those previously required for an Alzheimer's diagnosis

Currently there is no FDA approved disease-modifying treatments that would significantly impact the course of Alzheimer's disease. Until such treatments are discovered, there are still many possible benefits of early detection and diagnosis. For example, early awareness allows for the prompt evaluation of non-Alzheimer's related cognitive impairment that may be treatable or reversible. Early diagnosis can also lead to better management of cognitive and behavioral symptoms with medications or other interventions as well as help prevent the use of medications for coexisting conditions that might worsen cognitive function. Finally, early awareness helps reduce anxiety for the affected person and his or her family about the cause of their distress, and most importantly, enables patients and family members to plan for the future [1].

Sources Cited:

1. 2012 Alzheimer's disease facts and figures. Alzheimers Dement 8:131-168

2. Plassman BL, Langa KM, Fisher GG, Heeringa SG, Weir DR, Ofstedal MB, Burke JR, Hurd MD, Potter GG, Rodgers WL, Steffens DC, Willis RJ, Wallace RB (2007) Prevalence of dementia in the United States: the aging, demographics, and memory study. Neuroepidemiology 29:125-132
3. Alves L, Correia AS, Miguel R, Alegria P, Bugalho P Alzheimer's disease: a clinical practice-oriented review. Front Neurol 3:63
4. Jack CR, Jr., Albert MS, Knopman DS, McKhann GM, Sperling RA, Carrillo MC, Thies B, Phelps CH Introduction to the recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. Alzheimers Dement 7:257-262

Note: This overview was prepared by Dr. Troy Rohn, professor of biology, Boise State University.

Developing the Idaho State Plan

Origins of the Idaho Alzheimer's Planning Group (IAPG)

In September 2011, the *Idaho Statesman* ran a front-page headline: "Frantic Families Demand Help with Alzheimer's." While the Associated Press (AP) article dealt with the disease and its growing impact on our nation as a whole, an equally urgent story could be told about the challenge facing the citizens of Idaho.

Today, Alzheimer's patients throughout our state would fill Bronco stadium, and because Baby Boomers are now reaching their mid-sixties, that number is on track to double in a generation. For every dementia patient, there's a family whose physical, emotional and financial resources are being stretched to the limit. Once those limits are reached, the state must step in to help and as the number of patients grows, the strain on government resources will increase as well. Meeting this challenge requires a concerted effort on the part of individuals, communities and the state – a partnership best guided by a state plan, one that reflects the unique needs of Idahoans.

A year before the publication of the AP article, the push for a plan had already begun. In the fall of 2010, a group of dedicated individuals formed a grass roots organization called the Idaho Alzheimer's Planning Group, known as IAPG. Comprised of educators, researchers, administrators, advocates and lay people, the IAPG became a project of Boise State University's Center for the Study of Aging. Its steering committee grew to incorporate a wide range of stakeholders, including representatives from the Idaho Commission on Aging (ICOA), Idaho AARP and the Alzheimer's Association (see Appendix). Its stated mission is "to improve the spectrum of prevention, diagnosis, treatment and caregiver support services for people with Alzheimer's disease and other dementias." From the beginning, IAPG members have been dedicated to making Alzheimer's and other dementias a public policy priority for our state.

A comprehensive approach. The steering committee of the IAPG agreed that its efforts should fall into three main areas: communication, research and advocacy. The group immediately began educating the public about the rising challenge of Alzheimer's disease in Idaho and the need for a state plan. This effort included the creation of a speaker's bureau, online newsletters and a website, which may be accessed at http://hs.boisestate.edu/csa/iapg.

Determining the needs of individuals with ADRD, their families and caregivers throughout the state was another priority; IAPG researchers began preparing a data collection plan that would eventually comprise several methodologies (see below). Finally, with the help of professionals in the area of state government, IAPG began its quest for the endorsement of state-level government agencies, the Idaho legislature and the governor.

Senate Concurrent Resolution 112

The majority of states that have developed plans for a specific health issue have worked from the top down – that is, the legislature passes a bill (usually with funding) that empowers a panel of experts (often appointed by the governor) to study a problem and create a plan to address it. The Idaho Alzheimer's Planning Group chose a different path. With the help of respected professional stakeholders and lay people willing to donate their time and expertise, IAPG developed a fact-based presentation for appropriate members of the state legislature. After a brief explanation of the disease by noted local biologist and AD researcher Dr. Troy Rohn, the talk centered around the growing impact of ADRD on our population and the need for policies and programs that will deliver services cost effectively throughout the state.

In the spring of 2011, the group made a brief presentation to the House and Senate Health and Welfare committees, followed by another presentation later in the year to the state's Health Care Task Force, a bipartisan committee of elected officials that advises Idaho's full legislature on issues related to health care. As a result of those meetings, state senator Joyce Broadsword agreed to help "champion" the work of the IAPG by sponsoring a concurrent resolution. With the co-sponsorship of legislators from both sides of the political aisle, Senate Concurrent Resolution (SCR) 112 was passed through the Senate and House Health and Welfare Committees and eventually voted on by the full legislature, passing unanimously in both houses. In March of 2012, the resolution was signed by Governor Butch Otter (see Appendix for the text of the resolution).

Recognition of Senate Concurrent Resolution 112 by Governor Otter, March 2012. **Photo by Adam Berlin**

The purpose of SCR112 was not to raise money for Alzheimer's-related issues. Instead it gave ADRD a much higher visibility within the government and public realms. The legislature announced for the record that the increasing prevalence of ADRD must be examined, and a state plan should be developed to address the needs of the ADRD population. Furthermore, it sanctioned the work of the IAPG to delve into the matter more deeply – to find out just what we can, should and must do to meet the challenge that ADRD poses for our state.

The IAPG would like to thank the following individuals in particular for their role in bringing the issue of Alzheimer's disease before the Idaho Legislature during the 2011 and 2012 sessions:

Senator Joyce Broadsword

Representative Dr. Fred Wood	Senator Dan Schmidt
Representative Dr. John Rusche	Representative Carlos Bilbao
Teresa Molitor	Bruce Newcomb
Ryan Bush	Amy Johnson

The Statewide Community Needs Assessment

With the support of the Idaho state legislature, IAPG called upon charter member Dr. Sarah Toevs, director of Boise State University's Center for the Study of Aging, to collect data related to the needs of Idahoans with ADRD, their caregivers and family members. AARP Idaho generously provided a grant of $10,000 to fund the statewide research effort. Dr. Toevs' charge was to find the answers to questions such as whether or not the state has the right type and number

of facilities and services to help those afflicted with ADRD...if caregivers have the educational and respite services they need...and can limited taxpayer dollars be used in better ways to serve the ADRD population.

The needs assessment used several research methodologies involving a total of 444 individuals representing all regions of the state (see Appendix). Participants included individuals with ADRD, their family members, community-based health care and social service professionals, and administrators of assisted living (ALF) and skilled nursing (SNF) facilities. Information was gathered through the use of surveys, focus groups, and telephone and in-person interviews. The data collection took place over several months, and data analysis followed.

One of the consistent messages expressed by the participants was the desire to "manage on their own" as long as possible. Caregivers and family members are not looking for a hand-out, but rather for a supportive hand as they navigate the often unpredictable landscape of ADRD. With that in mind, the most pressing needs of Idahoans impacted by ADRD were:

- Access to training and information on caring for individuals with ADRD
- More timely and comprehensive information from primary care providers (PCP's)
- The need for a central point of contact for information about available services and guidance on how to navigate the system
- Additional support for family members, especially caregivers

Community-based caregivers also reported high levels of dissatisfaction with the cost of services and are concerned about the lack of awareness and stigma associated with the disease.

Administrators from assisted living and skilled nursing facilities focused on the challenges of providing care for individuals with ADRD and indicated a need for more support from primary care physicians (PCP's) along with training opportunities for staff members. Other common concerns:

- lack of parity between reimbursement rates and the level of care required for an individual with dementia
- lack of coordination between service providers to ensure that residents are receiving the most appropriate level of care, e.g. the ability to transfer a resident from an ALF to a SNF and vice-versa, or to a more appropriate behavioral health facility
- regulatory standards, review processes and reimbursement policies that don't recognize the specific needs of individuals with ADRD

Availability and cost of services was a concern for many respondents; however in general they were happy with the quality of ADRD-related care they or their loved ones received. Our state can take pride in the fact that our caregivers (professional, volunteer and familial) are dedicated to helping those with Alzheimer's disease and other dementias. That is an excellent foundation upon which to strengthen our state's response to the needs of the ADRD population.

Findings, Recommendations and Initiatives

Guiding principles. Before translating the results of the Statewide Community Needs Assessment into recommendations for a state plan, IAPG members developed a set of guiding principles to help direct their efforts. The full list can be found in the Appendix, but briefly, all agreed that recommendations should be based on the identified needs (using the Assessment) of people with ADRD, their family members, and professional and volunteer caregivers. They should accommodate residents from all areas of the state, and should be based on best practices of existing services and systems in order to be as cost effective as possible. Finally, they should include measurable initiatives whose effectiveness can be quantified.

Based on those guidelines, IAPG established five major recommendations, each of which has one or more specific, actionable, measurable initiatives attached to it. These initiatives are not attached to a timeline or a phased implementation schedule. Because virtually any of them could, under the right circumstances, be worked into an existing government or private enterprise program, they lend themselves to moments of opportunity. A case in point: as of January 2013, the

2-1-1 Idaho CareLine, an already existing toll-free statewide health information referral service, has become a portal for resources regarding Alzheimer's disease, thus fulfilling the initiative for Recommendation #1.

Following the recommendations and initiatives below, a list of "Ideas for Future Consideration" can be found, which includes additional concepts gleaned from a review of other state plans. These ideas provide a valuable resource material for further actions related to ADRD challenges in Idaho.

Finding #1: *Need for Improved Access to Information*

One of the most pressing needs of people with ADRD, their caregivers and family members was identified as more comprehensive, practical and timely information about the disease and resources available to address those impacted by it.

Recommendation: Increase public awareness about Alzheimer's disease and related dementias and provide comprehensive, practical and timely information related to the disease as well as the resources that are available to help address it.

Initiative: Develop and promote a centralized, statewide information portal about ADRD.

Based on the above finding from the Statewide Community Needs Assessment, IAPG will help to put in place a mechanism which can educate and relay information to family and informal/formal caregivers about dementia, the caregiving process and local resources. This will be accomplished through coordination with the Alzheimer's Association, Area Agencies on Aging, and similar organizations and agencies. This conduit will provide caregivers with facts about dementia as well as information on how caregivers can stay healthy; information on the various legal issues associated with a loved one's dementia diagnosis (e.g. Advanced Medical Directives, Power of Attorney); and resources such as local respite care services. This will be accomplished through a statewide information portal that will be routinely promoted so that Idahoans will know how to access it. ADRD-related call volume will be tracked and reported on annually.

Finding #2: *Need for Improved Education of Care Providers*

Health care professionals often do not have enough education or information about ADRD to make a proper diagnosis and provide a treatment plan to meet the needs of people with the disease. Similarly, professional and lay caregivers do not have enough training or information to meet the needs of people with ADRD.

Recommendation: Provide ADRD-specific education and training for current and future health care providers, institutional caregivers and family caregivers.

Initiative #1: Develop and implement a statewide ADRD education program using continuing education credits for health care professionals, including physicians, nurses, social workers, pharmacists, etc.

Based on the finding above from the Statewide Community Needs Assessment, IAPG will initiate a program to educate health care professionals using the State's most notable people in the field of ADRD research, medicine and gerontology. These experts will educate physicians, nurses, social workers and other allied health professionals throughout the state. Continuing education units (CEU's) will be provided as an incentive to participate in these seminars about ADRD. Statistics will be kept on the numbers of professionals trained; subsequent surveys will determine if ADRD-impacted individuals feel they in turn are receiving better quality diagnoses and information from their health care providers.

Initiative #2: Promote existing professional and lay caregiver training programs.

Based on the finding above from the Statewide Community Needs Assessment, IAPG will incorporate information about family caregiver training programs in the initiative related to Finding #1. This will be accomplished by incorporating information about existing family caregiver trainings in the new statewide information portal. A special effort will be made to reach out to rural areas of the state to inform them of these programs and to promote increased caregiver training. Effectiveness will be measured through call volume data as well as program participation rates.

Initiative #3: Develop and promote geriatric-centered curricula for students pursuing health care careers.

Based on the finding above, IAPG will work with the state's higher education institutions to help them develop curricula related to gerontological studies in their health care related academic programs. Success in this endeavor will be measured by added course material as well as applicable additional course options.

Initiative #4: Work with industry trade groups to provide additional, standardized ADRD training for institutional and home-based professional caregivers.

Based on the finding above from the Statewide Community Needs Assessment, IAPG will work with organizations like the Idaho Health Care Association /Idaho Center for Assisted Living (IHCA/ICAL) as well as community-based caregiver organizations to develop additional training for institutional and home-based professional caregivers. Participation rates in such trainings as well as ADRD-impacted individual feedback will be used to determine the effectiveness of the initiative.

Finding #3: *Need for Increased Family Support*

Family members of people with ADRD often do not know, nor are they told, where to begin to seek assistance once their loved one receives a diagnosis of ADRD.

Recommendation: Coordinate support services for ADRD patients, family members and caregivers throughout the state.

Initiative #1: Promote and/or develop a community-based "resource counselor" or "care coach" program using trained lay people to shepherd newcomers through the ADRD landscape.

Based on the finding above from the Statewide Community Needs Assessment, IAPG will work with community organizations, the Alzheimer's Association and the Area Agency on Aging/Idaho Commission on Aging to promote an existing resource counselor program and/or help develop a program to train lay resource counselors for families of people with ADRD. These individuals will provide families with local care options and resources available to help them address the needs of their loved ones with ADRD. The effectiveness of this program will be measured by participation rates by both counselors and end users.

<u>Initiative #2</u>: Link current ADRD support groups and respite care services into a vetted caregiver support network and provide viable options for areas of the state not presently served (i.e., rural areas).

Based on the finding above, IAPG will work with the Idaho Commission on Aging/Area Agencies on Aging, Alzheimer's Association and other stakeholders to develop and promote (through the Idaho 211 CareLine) a statewide caregiver support network database, made up of professional, volunteer and community organizations (e.g. churches and service clubs). The mandate of this working group will be to explore any and all legitimate caregiver support options in both rural and urban areas. The group will establish its own measurement of success based on such factors as database usage. It will also report on areas of the state where viable caregiver support is needed and may not exist.

<u>Finding #4: *Regulatory/Financial Reform*</u>

Facilities state that the reimbursement rates between care settings (e.g., Assisted Living vs. Skilled Nursing) for dementia care are not equitable. This differential represents an unsustainable business model for Assisted Living facilities and they state it may cause them to discontinue dementia care services. Furthermore, stringent regulations in some cases keep both Assisted Living and Skilled Nursing facilities from providing the most appropriate care setting for residents with behavioral issues associated with ADRD.

Individual caregivers also feel the financial burden of lost productivity and wages as they struggle to care for loved ones with ADRD.

<u>Recommendation</u>: Create a positive regulatory and financial environment for treatment of dementia-related issues.

<u>Initiative #1</u>: Establish a consortium of institutional care providers and ADRD advocates to propose viable regulatory reforms regarding such matters as staffing ratios, training standards and Medicare/Medicaid reimbursement rates related to the treatment of ADRD.

Based on the finding above, IAPG will facilitate a group of institutional care providers, relevant government agency representatives and ADRD advocates to further evaluate and address regulations related to providing care for people with ADRD. The group will establish its own measurement of success based on its specific findings and recommendations.

<u>Initiative #2</u>: Provide financial incentives (e.g. tax credits or deductions) to help family members keep loved ones with ADRD at home longer before institutionalizing them and thus reducing Medicaid outlays.

Based on the finding above, IAPG will work with university researchers and other stakeholders to conduct further evaluation of the financial burden on family caregivers of people with ADRD and make recommendations that will help them defray caregiving costs. Effectiveness will be measured based on future recommendations and implementation.

Finding #5: *Need for Improved Data Collection*

Idaho needs a mechanism for collecting periodic and/or ongoing information about the incidence and prevalence of Idahoans with ADRD.

Recommendation: Institute an ongoing source of data collection with regard to the needs of Idahoans with ADRD, their families and caregivers.

Initiative #1: Work with the Department of Health and Welfare to incorporate questions about cognitive health in their annual Behavioral Risk Factor Surveillance System (BRFSS).

Based on the above finding, the most effective mechanism for data collection is the state's annual Behavioral Risk Factor Surveillance System, known as BRFSS. Thanks to a grant from the Alzheimer's Association, the cognitive impairment module has been included in the BRFSS for 2013. Steps should be taken to ensure that this module is included often enough to provide accurate and salient data regarding the cognitive health of Idahoans.

Initiative #2: Create an annual mechanism for reporting progress to the legislative and/or executive branch of the state government.

Working with the legislature to develop a process by which an annual report is submitted to, reviewed by and feedback derived from the legislature, an annual report would include information gleaned from ongoing surveys like the BRFSS and other data collection efforts, as well as a review of the effectiveness of programs instituted by this plan.

Ideas for Future Consideration

The participants in the Statewide Community Needs Assessment made many excellent recommendations aimed at helping the ADRD community in Idaho, the most critical of which were incorporated into the recommendations and initiatives of our state plan. A review of ADRD-related plans from several other states revealed a plethora of good ideas as well. The following suggestions, listed under the goals to which they pertain, provide ample "food for thought" as Idahoans aspire to achieve goals beyond those listed in our state plan.

Finding #1: Increase public awareness about Alzheimer's disease and related dementias (ADRD) and provide comprehensive, practical and timely information related to the disease.

- Find and use resources to reach out to rural communities, racial and ethnic minorities, and faith-based communities. May or may not include a combined effort with the Alzheimer's Association in order to increase availability and use of education materials tailored to these groups.
- Disseminate public education campaign messages through accessible websites, mobile apps, libraries, senior centers, and physician offices with standardized Alzheimer's disease and related dementia content. Use positive and realistic images of people with ADRD and their caregivers to overcome existing public stigma and misperception.
- Ensure information and educational materials are offered at appropriate literacy, language, and legibility (font-size) for a diverse population.
- Develop dementia volunteer programs that engage a diverse group of stakeholders to increase awareness and understanding of dementia and to expand supports to people with dementia and their families.

Finding #2: Provide ADRD-specific education and training for current and future health care providers, institutional caregivers and family caregivers

- Institute training modules for professional first responders (police, fire, EMS, search and rescue) and emergency personnel, including protocols for dealing with missing adults with ADRD.
- Ensure that specific needs of applicable minority populations with dementia are included in training modules.
- Require a standard level of dementia sensitivity and disease education for all trainees in health-related fields at the student and residency levels. Include signs of younger-onset as well as early stage dementia.
- Educate providers on the use of Medicare coding to reimburse physicians and allied health professionals for family conferences and care consultation that educate and support family caregivers, guide future decisions, and enhance the quality of medical care and support services.
- Establish standards for dementia-specific training for staff of any state-licensed entity that provides for care of individuals with Alzheimer's disease and other dementias, including, but not limited to, nursing homes, community residential care facilities, home health agencies, hospice, or adult day care centers. Require periodic re-certification through "refresher" courses.
- Create a flexible curriculum for caregiver education based on existing best practices, which can be applied in multiple settings and formats for both paid and unpaid caregivers; include information about home safety modifications and record-keeping; make such a program accessible throughout all areas of the state.

Finding #3: Coordinate support services for ADRD patients, family members and caregivers throughout the state

- Revise regulations, to the extent permitted by federal law, to simplify short-stay admission to any residential facility for respite care.
- Identify opportunities for Idaho to secure federal and non-federal funding to advance home- and community-based options for those with ADRD.

- Develop state policies regarding subsidies for adult day services, similar to those for child care settings, which support, enable, and supplement active caregiving by families and friends.
- Eliminate barriers, if any, to providing adult day care in adult residential care communities.
- Preserve, restore, and increase established home- and community-based programs that effectively serve people with dementia and support their caregivers, including Alzheimer's Day Care Resource Centers, Adult Day Health Care, In-Home Supportive Services, and the Programs for All-Inclusive Care for the Elderly (PACE).
- Consider working through state associations of social workers and nurses to train these professionals as resource counselors
- Ensure that Idahoans in all areas of the state have affordable transportation options in order to take advantage of adult day programs

Finding #4: Create a positive regulatory and financial environment for treatment of dementia-related issues

- Create an integrated state long-term care financing approach that provides incentives for people to receive care in home- and community-based settings, and enables Idaho to retain and reinvest cost savings back into the state's long-term care infrastructure.
- Explore Medicaid waivers as an option to help address the many needs of Idahoans with ADRD including adult day services, assisted living, respite care, occupational and speech therapy, social work services, dieticians and affordable transportation
- Support federal legislation for a caregiver tax credit for providing in-home care for dependent relatives who have little to no income, and have been diagnosed with ADRD.
- Explore state policies to provide financial incentives for family caregivers, including cash or tax benefits (deductions and/or credits); health care coverage; deferred income incentives (retirement) as well as non-monetary incentives such as counseling eligibility. Analyze cost/benefits of such measures in relation to state outlays for institutional care.

- Create incentives (such as cash benefits and/or income tax credits) for caregivers to get the training, group support, respite care and other services needed to help them keep their loved ones with ADRD in the most homelike (and therefore most cost effective) setting for as long as possible.

Finding #5: Develop an ongoing source of data collection with regard to the needs of Idaho's ADRD patients, families and caregivers

- Mandate that the death certificate data include information obtained through the postmortem diagnostic examinations.
- Use the new cognitive assessment that is part of the Medicare Annual Wellness Visit as a means of developing better statewide prevalence data on cognitive impairment by reporting the data to the Idaho Community Measurement for further research, validation, and development of estimates.
- Work with service providers to create a coordinated and systematic way of collecting ADRD date in Idaho's Medicaid and Medicare programs.
- Promote common and uniform data collection using publicly funded disability programs
- Collect ongoing data (e.g. ADRD prevalence, number of inpatient geriatric psychiatry beds, availability of geriatric specialists, number of caregivers) through Office of Public Health.

Closing Thoughts

Many aspects of Alzheimer's disease remain a mystery to us. We do not know how to prevent it, who it will strike, how long it will linger, or how it will affect the person who has it.

One thing we do know is that the number of Idahoans impacted by ADRD is growing. Soon virtually all of us will lay claim to some connection to the disease, either directly or through someone we know and love. Those struggling in the midst of it need our ongoing support. By implementing the recommendations and initiatives of our state plan, as well as considering many of the additional ideas listed above, we can meet the challenge that ADRD has placed before us. There's work to do, now and in the future.

Acknowledgements

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The Idaho Commission on Aging, Sam Haws, Administrator
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We would like to offer a special thanks to all the people across the state of Idaho who are affected by Alzheimer's disease and related dementias, who provided input into this plan.

Appendices

Senate Concurrent Resolution 112

LEGISLATURE OF THE STATE OF IDAHO
Sixty-first Legislature Second Regular Session - 2012
IN THE SENATE
SENATE CONCURRENT RESOLUTION NO. 112
BY HEALTH AND WELFARE COMMITTEE

A CONCURRENT RESOLUTION
STATING FINDINGS OF THE LEGISLATURE AND ACKNOWLEDGING THE SERIOUSNESS OF
ALZHEIMER'S DISEASE AND OTHER DEMENTIAS IN IDAHO BY ENDORSING THE IDAHO
ALZHEIMER'S PLANNING GROUP AND SUPPORTING SAID PLANNING GROUP'S COM
PREHENSIVE APPROACH TO THE DEVELOPMENT OF A STATEWIDE PLAN TO ADDRESS
THE NEEDS OF PEOPLE WITH ALZHEIMER'S DISEASE AND OTHER DEMENTIAS, THEIR
FAMILY MEMBERS AND CAREGIVERS.
Be It Resolved by the Legislature of the State of Idaho:
WHEREAS, some 26,000 Idahoans are currently diagnosed with Alzheimer's
disease, and the number is projected to increase significantly through 2025;
and
WHEREAS, Idaho is projected to have the fifth highest increase in people
suffering from Alzheimer's disease among all of the United States over the
next several years; and
WHEREAS, Alzheimer's disease is the only major cause of death that has a
mortality rate that continues to increase; and
WHEREAS, Idaho's mortality rate from Alzheimer's disease is consis
tently higher than the national average; and
WHEREAS, 41% of Idahoans living in nursing homes have moderate to severe
dementia; and
WHEREAS, the Idaho Alzheimer's Planning Group is developing a plan to
address the problem of Alzheimer's disease and other dementias throughout
the state; and
WHEREAS, the Idaho State Plan for Alzheimer's disease and other demen
tias will help agencies, organizations and individuals develop specific
programs and strategies to meet the needs of Alzheimer's patients, their
families and caregivers at the state, regional and local levels.
NOW, THEREFORE, BE IT RESOLVED by the members of the Second Regular Ses
sion of the Sixty-first Idaho Legislature, the Senate and the House of Repre
sentatives concurring therein, that the State of Idaho acknowledges the se
riousness of the impact of Alzheimer's disease and other dementias upon the
state by endorsing the Idaho Alzheimer's Planning Group's community aware
ness, data collection and resulting statewide plan development and imple

mentation efforts to address the issue.
BE IT FURTHER RESOLVED that the members of the Second Regular Session of the Sixty-first Idaho Legislature, the Senate and the House of Represen tatives concurring therein, support the Idaho Alzheimer's Planning Group's comprehensive approach toward educating the public about Alzheimer's dis ease and other dementias; collecting and analyzing statewide data related to current and future needs for Alzheimer's patients, families and caregivers; and recommending programs and strategies for addressing those needs.

Idaho Needs Assessment of Alzheimer's Disease and Related Dementias Conducted by the Idaho Alzheimer's Planning Group

Introduction

The following report describes the findings of assessment activities conducted to inform the Idaho Alzheimer's Planning Group (IAPG) and others of the needs of patients and their caregivers and families. This information will be used to develop a comprehensive state plan. The 2012 Idaho Legislature recognized the importance of this effort with its unanimous support of Senate Concurrent Resolution (SCR) 112 which acknowledged the seriousness of the impact of Alzheimer's disease and related dementias (ADRD) and endorsed the efforts of the IAPG to develop an Alzheimer's state plan.

This document provides an overview of the research methods and results of the needs assessment. The results are organized as separate appendices detailing the findings from the following populations:

- Appendix A: Information from individuals impacted by ADRD. Participants were recruited during informational presentations on ADRD sponsored by the Idaho Area Agencies on Aging and local groups.
- Appendix B: Findings from family members providing full-time care for individuals with ADRD
- Appendix C: Information from individuals participating in statewide Brain Health seminars sponsored by the Idaho AARP. Participants included caregivers, family members, and community-based health care and social service professionals.
- Appendix D: Results from administrators and directors of nursing/memory care units of assisted living (ALF) and skilled nursing (SNF) facilities.

Research Methods

A mixed methods research design was use to gather information about the challenges of providing care for individuals with ADRD and their caregivers and families. Data collection strategies included a survey, facilitated focus groups, and telephone and in-person interviews.

Standardization of data collection procedures was established through training sessions, regular debriefings and pilot testing of the survey and interview questions. Approval from the Institutional Review Board (IRB) at Boise State University was also obtained for data collection activities involving home-based family members providing full-time care for an individual with dementia. All data analysis was performed by staff at the Boise State University Center for the Study of Aging.

Participant Recruitment

Recruiting of participants for this needs assessment was conducted through mailings, emails and phone messages distributed between October 2011 and August 2012. The message provided a brief overview of the project, an explanation of how the information being gathered would be used, and an introduction to the IAPG.

Individuals from multiple sectors of the population impacted by ADRD were recruited to participate in the needs assessment. Table 1 describes the populations of interest and primary strategies used to gather information from each group.

Table 1. Population groups recruited and methods used to gather data

Population Groups of Interest	**Data Collection Strategy**
Individuals impacted by ADRD recruited during informational presentations on ADRD sponsored by the Idaho Area Agencies on Aging and local groups. Participants included caregivers, health care and social service providers and the general public. (n=325)	Survey
Family members providing full-time care for individuals with ADRD. (n=8)	Phone Interviews
Community-based individuals, health care and social service providers impacted by ADRD. Participants were recruited in conjunction with the statewide Idaho AARP Brain Health events. (n=63)	Focus Groups
Administrators of assisted living facilities (ALF) and skilled nursing homes (SNF). This population included executive directors, directors of nursing and memory care units. (n=48)	Focus Groups and Phone Interviews

A total of 444 individuals representing all regions of the state participated in the needs assessment. The distribution of participants by public health region is reported in Table 2. See Figure 2 for geographic location of the public health regions in Idaho.

Table 2. Distribution of participants by region of state (n=444)

Public Health District	Number of Participants
1 (Panhandle)	78
2 (North Central)	30
3 (Southwest)	32
4 (Central)	99
5 (South Central)	117
6 (Southeastern)	57
7 (Eastern)	28
Unknown	3

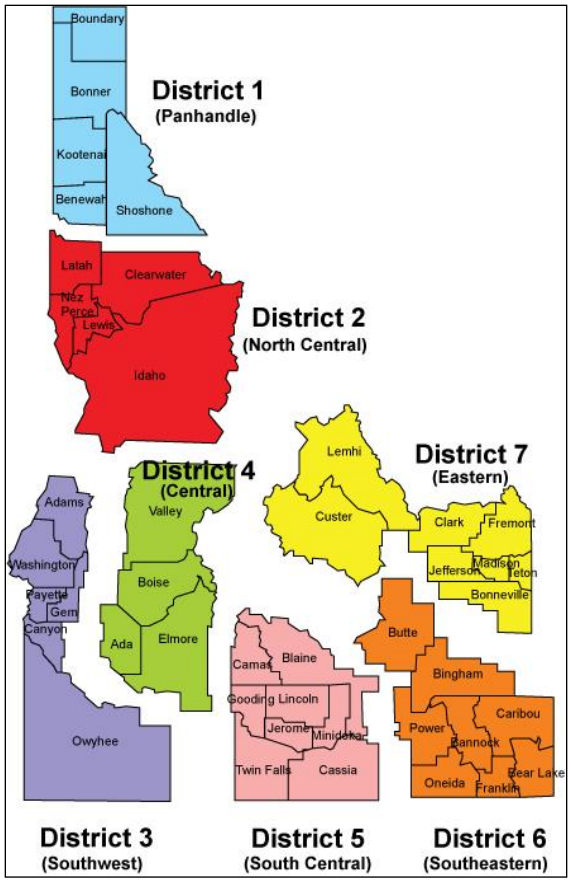

Figure 2. Idaho Public Health Districts

Appendix A: Quantitative Findings from Individuals Impacted by ADRD

The purpose of this assessment was to describe the needs and experiences of individuals impacted by Alzheimer's disease and related dementias (ADRD) in Idaho. The target audience of interest was individuals with ADRD and their family members and caregivers. Information was collected primarily through a survey distributed to individuals attending conferences on Alzheimer's disease sponsored by Area Agencies on Aging and other groups throughout the state. A link to the survey was also available on the Boise State University Center for the Study of Aging website.

The survey collected information about needs of persons impacted by ADRD, satisfaction with services and information, and recommendations for how to improve services and access to resources. In addition, basic demographic information and the names and contact information for individuals interested in being contacted for more information were collected. The questionnaire was adapted from existing needs assessment tools used in other states and pilot tested prior to distribution.

Data entry and analysis was performed by staff at the Boise State University Center for the Study of Aging. All analysis was conducted using the statistical software SPSS v.19.

Results

Characteristics of Participants

The findings presented in this report are based on responses from 325 individuals, representing all areas of Idaho. The average age of participants was 56 years old and ranged from 22-89 years old. Approximately half, 53% (n=173), of the respondents indicated they were a spouse, partner, son, daughter, or other family member of a person with ADRD. The demographic characteristics of the participants are reported in Table A.1.

Table A.1. Demographic characteristics of survey participants

Demographic Characteristics (n=325)		n	%
Average Age =56, Age Range = 22-89			
Gender	Male	71	21.8
	Female	254	78.2
Residence by Public Health District	Region 1 (Panhandle)	40	12.3
	Region 2 (North Central)	21	6.5
	Region 3 (Southwest)	21	6.5
	Region 4 (Central)	85	26.2
	Region 5 (South Central)	86	26.5
	Region 6 (Southeastern)	43	13.2
	Region 7 (Eastern)	26	8.0
	Unknown	3	0.9

Demographic Characteristics (n=325)		n	%
Relationship to ADRD	Person with ADRD	9	2.8
	Spouse or partner of person with ADRD	49	15.1
	Other family member of a person with ADRD	124	38.2
	Non-family caregiver of a person with ADRD	31	9.5
	Health-care provider	56	17.2
	Social service provider	28	8.6
	Public employee or official	4	1.2
	Other	23	7.1

Characteristics of Individuals Providing Home-based Care

Forty percent (n=129) of the participants reported providing home-based care for someone with ADRD, providing an average of 81 hours of care per week. One-third (n=43) of those providing care indicated they provided 168 hours of care per week (24 hours a day, 7 days a week). Additional demographic characteristics of caregivers are reported in Table A.2.

Table A.2. Demographic characteristics of participants providing home-based care

Demographic Characteristics of Caregivers (n=129)		n	%
Average Age = 59, Age Range = 22-88			
Gender	Male	26	19.8
	Female	105	80.2
Location of Residence (Public Health District)*	Region 1 and 2 (Northern Idaho)	24	18.3
	Region 3 and 4 (Southwestern/Central Idaho)	48	36.6
	Region 5 (South Central Idaho)	36	27.5
	Region 6 and 7 (Southeastern/Eastern Idaho)	22	16.8
Number of Hours/Week of Home-based Care	20 hours or less	37	24.8
	21 – 39 hours	12	11.0
	40 – 168 hours	60	55.0

*Regions combined to allow for statistical analysis

Those providing care were asked to identify the type of health insurance the person they were caring for had. Almost 75% (n=97) of the respondents indicated the use of Medicare benefits followed by private insurance, Medicaid and Veteran's benefits, see Table A.3.

Table A.3. Type of insurance coverage of participants receiving home-based care

Insurance Coverage		
Type	n*	%
Medicare	97	74.0
Medicaid	28	21.4
Veteran's Benefits	25	19.1
Private Insurance	57	43.5
None	10	7.6
Other	16	12.2

*Respondents were instructed to check all that apply.

Approximately 30% (n=27) of the caregivers indicated that the person they were providing care for received both Medicare and Medicaid benefits. Analysis of the demographic characteristics of these caregivers revealed the following differences: caregivers were younger (average age of 50, range = 22-77) and slightly less likely to provide 40 or more hours per week of care (48% versus 55% among all caregivers.)

Most Pressing Needs

Respondents were asked to identify the three (3) most pressing needs in Idaho for persons impacted by ADRD. Participants could select from a list and/or describe additional needs not included on the survey form. Regardless of where they live in the state, their caregiver status (providing home-based care or not), or their level or type of insurance coverage, the respondents' most commonly identified need was for "information about the types of services available and how to use them" followed by "affordability of services," and "support for family and caregivers." See Figure A.1.

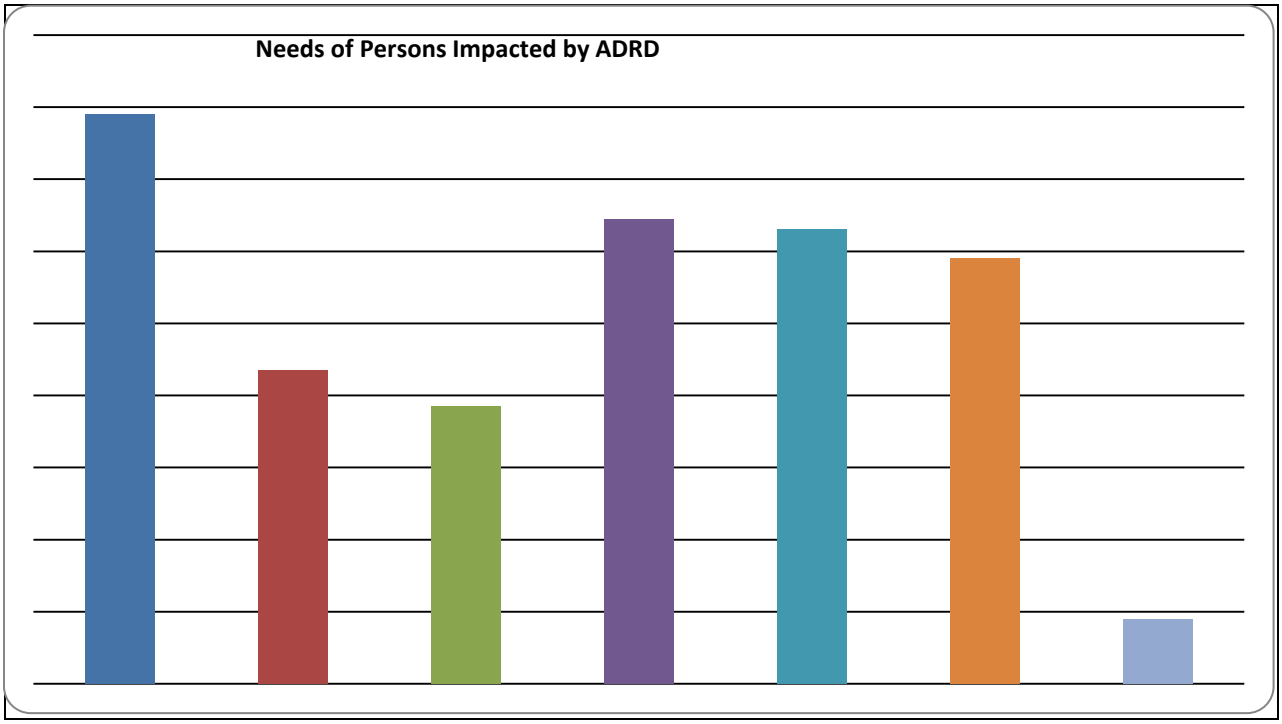

Figure A.1. Most Pressing Needs for Persons Impacted by ADRD

Level of Satisfaction with Services and Information

The survey also asked participants to indicate their level of satisfaction with the following aspects of service and information: Access; Quality; Affordability; Support for Families and Caregivers; Education and Training; Information about the Types of Services Available; and Information about How to Use Available Services. Low levels of satisfaction were noted for all items with Affordability of Services and Access to Information about Available Services identified as the areas of greatest dissatisfaction. These results again hold true regardless of location of residence, caregiver status or availability/type of insurance. Additional information about satisfaction with services and information is reported in Table A.4.

Table A.4. Satisfaction with available services and information

Satisfaction with Services and Information Available to Persons Impacted by ADRD					
Item	Very Dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied
Access to Services	12.3% (n=30)	25.9% (n=63)	**39.1% (n=95)**	17.3% (n=42)	5.3% (n=13)
Quality of Services	10.1% (n=24)	24.9% (n=59)	**32.9% (n=78)**	24.1% (n=57)	8.0% (n=19)
Affordability of Services	29.0% (n=64)	**33.9% (n=75)**	25.3% (n=56)	9.5% (n=21)	2.3% (n=5)
Support for Families and Caregivers	14.2% (n=36)	25.7% (n=65)	**36.8% (n=93)**	15.8% (n=40)	7.5% (n=19)
Education and Training	15.9% (n=39)	29.3% (n=72)	**34.1% (n=84)**	12.2% (n=30)	8.5% (n=21)
Information about Types of Services Available	17.1% (n=43)	**31.5% (n=79)**	28.7% (n=72)	15.5% (n=39)	7.2% (n=18)
Information about How to Use Available Services	17.9% (n=44)	32.5% (n=80)	**33.3% (n=82)**	11.8% (n=29)	4.5% (n=11)

Note: Most frequent response has been highlighted.

Further analysis of participant satisfaction was conducted to explore findings based on caregiver status, i.e., providing home-based care or not, and location of residence in Idaho. Prior to this analysis the results were collapsed into three (3) categories to create an adequate sample size for each rating. The three categories were:

- Dissatisfied = combination of "very dissatisfied" and "dissatisfied"
- Neutral = "neutral"
- Satisfied = combination of "satisfied" and "very satisfied"

The highest levels of concern for participants providing home-based care were related to affordability of services and support for families and caregivers. See Figure A.2. Satisfaction related to information about the types of services available and how to use available services is reported in Figure A.3.

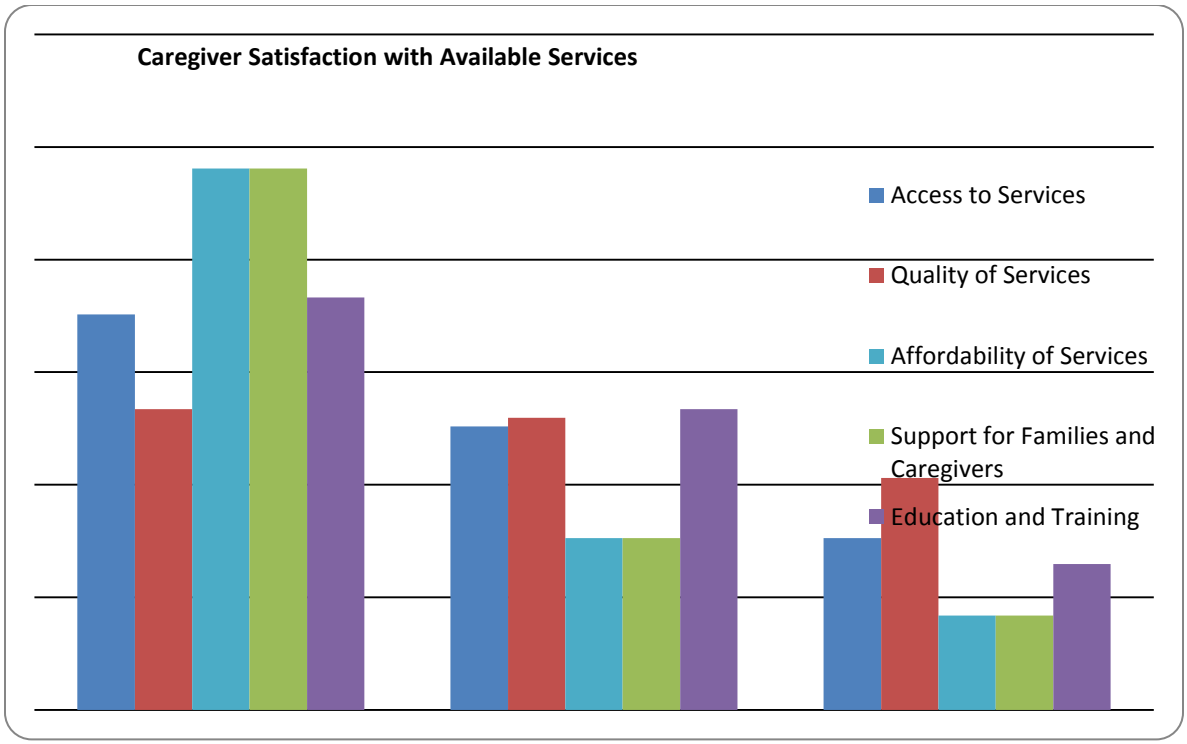

Figure A.2. Satisfaction with Available Services Reported by Caregivers

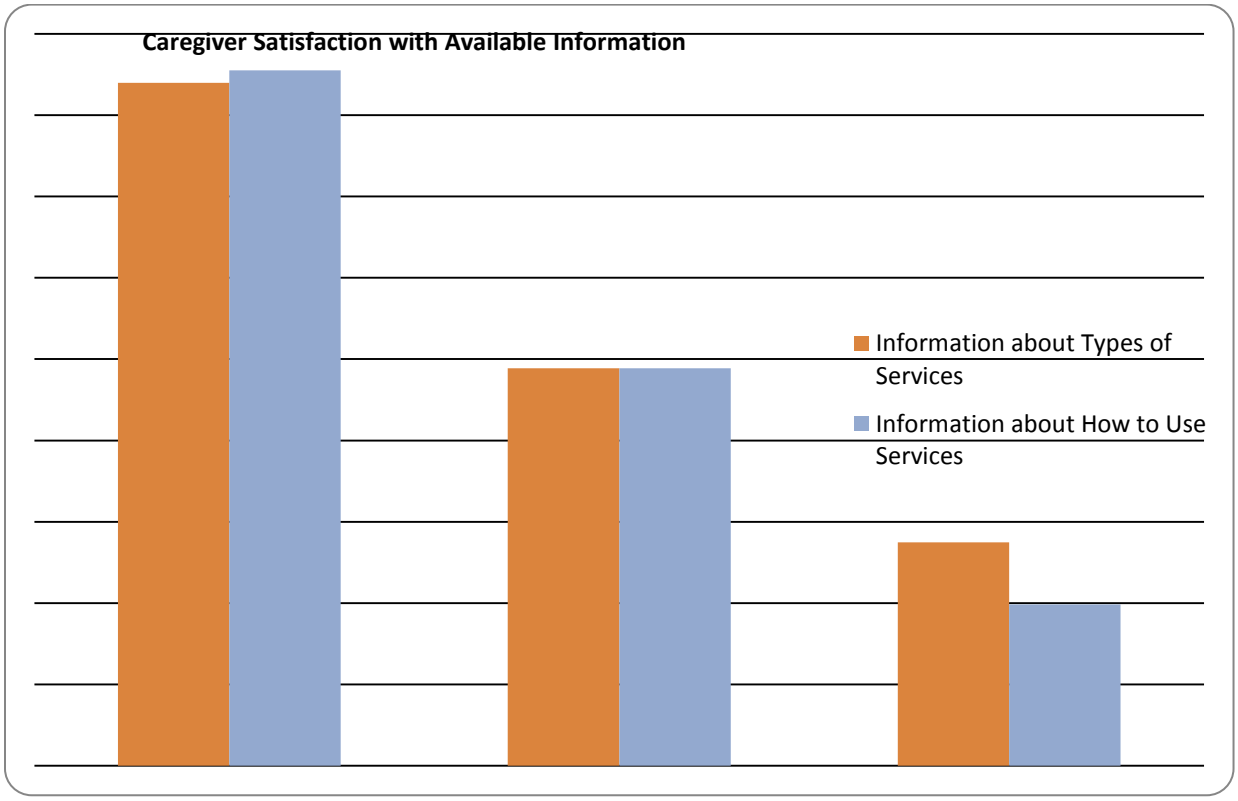

Figure A.3. Satisfaction with Available Information as Reported by Caregivers

Finally, a comparison of satisfaction scores between regions was conducted. No statistically significant differences were found between regions, indicating that satisfaction with services and/or access to information was not associated with where a person lives in Idaho.

Recommendations for State Plan

Many participants provided suggestions on how to improve the services and resources available to person with ADRD. Major themes and representative quotes are reported in Table A.5.

Table A.5. Major themes, suggestions, and quotes

Theme	Suggestions and Quotes
Access to Information	*The types of resources available and to whom they are directed toward is confusing. Can some type of directory be developed so individuals can better discern for themselves what is available*
	How about a central information source to direct caregivers to resources services, and available support?
	After acknowledging someone with a need [it would help to] provide more information personally (by visit or phone call) instead of giving something to read (don't know the last time I could sit down and read).
Access to Services	*There is a huge problem connecting the patient and family and services available.*
	Affordable care and help for families with caregiving. Respite care services for families. Legal resources for caregivers -- for guardianships for their loved ones.
Education of Providers	*I think that anyone who works with AD patients they should be required to receive proper training on the disease. So many caregivers do not have a clue what people with AD are going through and get frustrated. They need to understand.*
	More training for providers -- how to communicate with client. How to approach client in different situations.
	Increased education to the general public and to law enforcement and other responsive organizations.
	I feel the medical profession hasn't been much help- It makes one feel pretty hopeless
Family Support	*My family's frustration has been that you can go to ten different people and get ten different answers. So far the whole process has been extremely frustrating for my family. We appear to be in the "middle," where we can't afford full time care, but we make too much money to qualify for assistance.*
	More support groups for caregivers with people with Alzheimer's/dementia. Husband and I go to 1 hour twice a month but very few people attend. So hard to get ideas as what to do when [we]have concern or [need]help with issues-bedwetting-anger-showers
Need for Statewide Initiative	*Legislative support to help care agencies provide cost effective care. Support Alzheimer's/ Dementia care - needs are continually increasing for Idaho families.*

Theme	Suggestions and Quotes
	support on the Alzheimer's Association education/ support groups in N Idaho. State sponsorship or visibility to inform and educate
	The state needs geriatric physicians and medical centers designed around Alz patients needs! Website (non govt) for families to comment on area care facilities.
Support for Rural Areas	*I lived in a rural area. Was forced to sell home and move to Boise for services.*
	more of the services we are privileged to have available here in Coeur d'Alene should be available in the more remote counties of Idaho

Appendix B: Qualitative findings from family members providing full-time care for individuals with ADRD

Telephone interviews were conducted with family members providing full-time care in order to assess their current situation and frame of mind; determine which resources they are currently using and identify their needs, resources they are currently using, and resources that would help them in their role as a caregiver. Approval for all research procedures was obtained from the Institutional Review Board at Boise State University prior to data collection.

The names and telephone contact information for potential participants were obtained from the Directors of the six regional Area Agencies on Aging in Idaho. These individuals were then contacted by phone and provided with a description of the project and an introduction to the Idaho Alzheimer's Planning Group. Telephone interviews with interested participants were then scheduled. The interviews took approximately 30 minutes to complete, and were recorded with the permission of each participant, for note taking purposes. The interviews were conducted in October and November 2011 and June and July 2012.

Eleven (11) participants (caregivers) were contacted and eight (8) agreed to participate in the needs assessment. A scripted interview was used to guide the conversation, with follow-up questions and/or prompts included as needed. Questions included three demographic items and seven questions about access to resources, their experiences as a caregiver, and recommendations they would make to other caregivers.

Results

Characteristics of Participants

Participants represented both urban and rural areas and were from the northern, southeastern and southwestern regions of the state. They reported involvement as caregivers for an average of 5 years with a range from 3-8 years. All of the respondents indicated they were primarily "on their own" with care-giving responsibilities. Four reported getting minimal help and four received some support from family and friends.

Access to Information and Assistance

All of the respondents indicated that they had access to information from sources including the internet, the Alzheimer's Association, Friends in Action (an Idaho-based nonprofit organization), seminars, the local Office on Aging, and their health care provider. Seven of the participants indicated they had a computer with access to the internet in their home.

There was a wide range of response to the question of whether they were actively seeking help for themselves. Several felt mentally burned out while one reported teaching classes for other caregivers. When asked specifically about participating in a support group, two of the caregivers were currently attending; two used to attend, but were currently not doing so; one stated being unable to do so as she did not want to take time away from being with her husband; and one did not see a need to attend a support group.

Impact of Caregiving

All of the respondents had experienced significant changes in their lives since taking on care-giving responsibilities. These included their friends not coming around; their loved one's friends not coming around; and not being able to go out for dinner or other social activities. One caregiver described the impact on his life in this way: ". . . number one is frustration, anxiety and the loss of freedom, and that is pretty basic." When asked what their biggest challenge had been, several noted the change in role in the household (paying bills, yard work, etc.) and others mentioned wandering, incontinence, and watching their loved one struggle to find the words they were looking for.

Suggestions for Other Caregivers

Finally, participants were asked about the advice they would give to someone who was just beginning in the role as a caregiver. Common responses included:

- "take classes, join support groups, and contact the Alzheimer's Association"
- "Take care of yourself, eat right, get plenty of sleep, and get away for a couple of hours"
- "Do not argue with them, if they say they are Santa Claus do not argue with them because it gets them frustrated and angry. Just agree with them and walk away. . . Do not try to drag them into your reality, because it does not work. Just let them do what come natural to them because they are going to do it anyway, as long as they do not hurt themselves"
- "always remember that the action and behaviors are the disease and not the person"
- "be patient and maintain the ability to 'step back' from the situation when feeling stressed"

The findings from these interviews reveal some of the challenges of providing full-time care giving for an individual with Alzheimer's disease. Caregivers were quite frank in their discussion of the amount of energy the responsibility required and most expressed a desire for more help and/or support.

Appendix C: Qualitative findings from individuals participating in statewide Brain Health seminars sponsored by the Idaho AARP

The purpose of this assessment was to describe the needs and experiences of individuals impacted by Alzheimer's disease and related dementias (ADRD) in Idaho. The target audience of interest was individuals with ADRD, their caregivers and family members and members of the local communities impacted by the disease.

Contact with potential participants was made by the AARP Idaho and focus groups were held in conjunction with the following AARP Idaho Brain Health events:

- Sandpoint, July 20
- Couer d' Alene, July 21
- Twin Falls, August 1
- Ketchum, August 2
- Meridian, August 23
- Pocatello, August 24

Participant Characteristics

Table C.1. Demographic characteristics of Brain Health related focus group participants

Demographic Characteristics (n=63)		n	%
Gender	Male	8	12.7
	Female	55	87.3
Residence by Public Health District	Region 1 (Panhandle)	29	46.0
	Region 2 (North Central)	0	0
	Region 3 and 4 (Southwest/Central)	5	7.9
	Region 5 (South Central)	22	34.9
	Region 6 (Southeastern)	7	11.1
	Region 7 (Eastern)	0	0
Relationship to ADRD	Person with ADRD	1	1.6
	Spouse or partner of person with ADRD	12	19.0
	Other family member of a person with ADRD	15	23.8
	Non-family caregiver of a person with ADRD	2	3.2
	Health-care provider	11	17.5
	Social service provider	13	20.6
	Public employee or official	7	11.1

Participants were asked to respond to a series of questions that identified and prioritized the challenges associated with caring for individuals with ADRD and were then asked to suggest changes/solutions that would address the issues. Information was analyzed to identify patterns and the findings were then organized using an ecological perspective, see Figure C.1. The ecological model recognizes the complex interplay between the individual, the environment (community and systems), and society (policies and norms) and the impact these influences have on the well-being of an individual and their family.

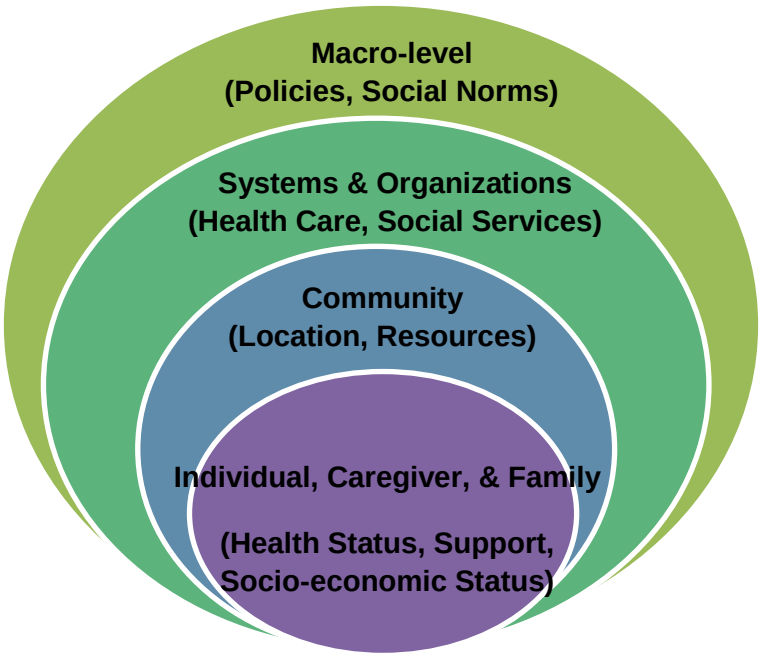

Figure C.1. Ecological Model

Results

The four interdependent systems used to organize information gathered through the focus groups were:

- Individual, Caregiver, and Family,
- Community,
- Systems and Organizations, and
- Macro Level (social norms and policies)

Individual and Caregiver/Family Level Challenges

All participants noted that the needs of individuals with ADRD and their caregiver/family support systems varied widely. However, three categories of types of support generally needed were identified. These included: Basic needs, Planning needs, and Personal support needs.

Basic Needs

Individuals, caregivers, and families impacted by ADRD are faced with the management of a chronic disease that alters a person's ability to think and process information. As stated by several of the caregivers, "it's like having your spouse turn into a 3-year old." This reality makes the support of basic needs (e.g. how to get someone to eat, what diapers to buy, how to assure a safe environment) particularly important.

Concerns expressed during the focus groups regarding these needs included:

- Information about how to:
    - communicate with someone who has lost their ability to reason
    - deal with difficult or aggressive behavior
    - get someone to eat, i.e., use catsup or chocolate on food
    - manage incontinence (how to buy and change diapers)
    - manage personal hygiene (prevention of urinary-tract infections, bathing strategies)
    - manage wandering and assure safety at home
    - handle loss of ability to drive
- Information about resources
- Who to call - "Point of contact is unclear"
- Getting the right information at the right time
- "I didn't know what I didn't know"
- "Most people don't know the 10 basic signs of dementia"
- Getting the family educated about ADRD
- Poverty
- Literacy issues with written materials

Planning Needs

Planning needs expressed during the discussions included:

- Education about what to expect through the course of the illness; "Patients and families need to know what comes next"
- "No easy, clear-cut answers, can't just Google a solution, each case is different"
- New information all the time – "new cure, new meds, etc."
- "Should I put my loved on in clinical trials?"
- The need for guidance on when to make changes like no more driving or when/how to decide if it's time to move someone to a care facility
- Help with personal finances and planning for future expenses
- Need more education about end-of-life choices
- "ADRD can cause financial devastation and people need to be prepared."

Personal Support Needs

As with Basic and Planning needs, numerous challenges related to the need for Personal Support were identified.

- People become isolated and they lose their informal support networks; "ADRD drives people away"
- Denial by patient, by caregivers, by other family members adds to caregiver burden
- Guilt, depression, mood swings; "Am I doing enough?"
- Need help with managing anger, frustration, and loss
- Caregivers overwhelmed by all the aspects of care and the system

- "People don't know how to ask for help and it is unclear if families will help."
- Caregiver tendency not to ask for help; sometimes due to wanting to avoid family conflicts
- "Families often become fractured and conflicts about proper treatment and next steps are common"
- "Sometimes adult children who aren't close to the situation impose their opinions and ideas. . . they need to walk in the local family caregiver's footsteps"
- "[Family members often have] no idea how the situation really is"
- "Caregivers need to know they aren't alone"
- "Getting people to attend a caregiver group because of stigma and the fact that it's hard to ask for help."
- Frustration with the system that can lead to inaction
- Reluctance to put people in facilities
- Need a person to talk to who can help the family
- "Helps to talk in person-emails can be problematic."
- "Families and caregivers need more emotional care and support. Dementia affects everybody, not just the patient."

Community Level Needs

The discussions highlighted the importance of community supports in order to maintain a "healthy" environment for individuals with ADRD and their caregivers. Members of the immediate neighborhood and larger community need to understand the unique challenges related to the disease, as well as the programs and services that are available. Many of the items included here also apply to the individual, caregiver and family; this reflects the interdependent nature of the support network. Community level support needs included:

- Advocates from the community to build awareness/serve as a champion
- Support groups
- Access to reliable and trustworthy respite support
- "Volunteers that are trained on ADRD, how know what to look for and how to offer assistance"
- "need a coordinated volunteer or stipend program to offer caregivers informal support"
- Information network to create awareness of available services; use a variety of outlets – mailings, churches, senior centers, meals on wheels, extension offices
- Need community-based resource counselors – "someone to guide them through the process"
- Need individuals with the skills and resources to create low cost local support programs. Examples include respite services provided by Sandpoint's Senior Center and Hailey's community support program
- Access to resource list that is up-to-date and includes a contact name and phone number

System and Organization Level Needs

In discussing challenges related to providing care at home for a person with ADRD, three major system and organization-related themes emerged from the discussions:

- Capacity limitations exist, in terms of the level of support received from primary health care providers (PCP). Participants most frequently mentioned physicians as their PCP, but concerns may also apply to primary care providers.
    - Health care providers not diagnosing, treating or educating effectively
    - Medical community not cooperative with ADRD: need more than just a pill, need education and assistance with connecting with resources
    - Referrals to hospice come too late and the caregiver can't cope
    - Lack of follow-through after diagnosis.
    - Physicians not accepting Medicare patients
    - Need appropriate referrals to neurologist, etc.
    - Didn't advise me
    - Didn't follow-up with condition nor give referrals
    - Doctors need to be educated and willing to refer with ADRD
    - Doctor didn't know how to follow-up on disease with family
    - Doctors only know the surface of ADRD and its implications
    - Doctors only give meds and stop testing
    - "Difficult because when you break a foot you leave with care instructions. Get an ADRD diagnosis and you leave empty handed."
    - "Doctors are not making community resource referrals. They see it as someone else's job."
    - Only want to handle the problem with services that don't help like PT, OT, speech therapy etc.
    - Skirt around the issue about the reality of the situation
    - Dance around the diagnosis; "Wouldn't be honest with me about what I needed to deal with or expect with ADRD."
    - Difficult to get proper diagnosis – local PCP's are often helpful, but not necessarily very involved in ongoing care.
    - PCP's don't always know or remember enough to make referrals to non-emergent programs, like adult day care.
    - Services are not coordinated
- Capacity limitations exist, in terms of available services
    - Lack of respite
    - Lack of availability of resources in rural communities
    - Managing difficult behaviors – no local facility for these patients; they have to go to Twin Falls
    - Affordable long term care (LTC) housing options are limited
- Systems and organizations designed to assist individuals are difficult to navigate, not coordinated, and not meeting needs.
    - Need help with VA paperwork
    - "Medications, doctor appointments and money are not managed and this costs the state a lot of money."
    - Services are not coordinated

- Care transitions are good at hospital to community but lacking with LTC
- Need more training on Medicaid applications and eligibility
- Must protect individual data and quality control of records
- Reduce the red tape to apply for Medicaid
- [Individuals working for Medicaid] need more training on Medicaid applications and eligibility
- Not empowered to give comprehensive information or advice on different avenues for eligibility
- Accurate information on Medicaid not provided
- Medicaid should include respite without pre-qualifying caregivers for Medicaid
- State doesn't see how respite is cost-effective
- Need for policy makers to understand challenges
- Alzheimer's Associations seem to have focus on raising money
- Groups like the IAPG not working to meet basic needs of caregiver – too focused on policy and data collection

Macro-level Needs

Participants also addressed factors at the macro level that impact quality of life and the ability to sustain caregiver responsibilities. These included:

- Social stigma related to ADRD
- Social stigma related to planning for end-of-life
- Lack of funding for and acknowledgement of the value of informal caregivers
- Difficulty of implementing systemic change – no point person/agency taking the lead

Recommendations for a State Plan

Solutions suggested by the participants addressed a broad array of issues with the need for family, community, and systems/organizations to work together in support of the informal caregiver as a consistent theme.

Recommendations addressing individual/family level factors included awareness, education, and the need to "stay plugged in." For example, individuals from several groups suggested that a state plan should address the need for caregiver training. As proposed, the training would be prescribed by an individual's primary care provider (PCP) and cover basic caregiving skills, strategies for how to maintain their own health, information on respite and other available resources, financial and end-of-life planning, and other pertinent topics.

Other suggestions related to building awareness included:

- Statewide campaign about common signs of dementia with the goal of early identification and diagnosis.
- Statewide effort to de-stigmatize the disease; "More people should see videos about cool people with dementia, as well as talk to early stage patients. This lessens the stigma, since people see they aren't alone, and that patients are people just like them."

- A state plan that funds the distribution of information using "natural destinations" such as, churches, grocery stores, medical offices, libraries, senior centers, county extension offices, and web sites. This information could also be distributed through existing portals such as the 211 CareLine, the Aging and Disability Resource Network (ADRC), but participants emphatically stated that it must be current and include local contacts and services.

Several participants suggested establishing a "care manager" entity in the state. The role of this position would be to work with the patient, caregiver and family members throughout the course of the disease to help connect people with the "right" resources at the "right" time. In addition, this person could also serve as a sounding board in the decision-making process. As with the caregiver training, it was suggested that a care manager would be "prescribed" by the PCP as an essential component of the treatment plan for an individual diagnosed with dementia. Participants noted that the care manager could be a trained lay-person and that it would be important to follow evidenced-based protocols and implement quality assurance measures.

The importance of the PCP was highlighted in all discussions and the need for additional training and guidance for providers was noted. Participants recommended that professional schools, i.e., medical, nursing, social work, include more training on ADRD in the curriculum. Others suggested that conferences for physicians, nurses, social workers, and public health professionals include instruction on ADRD and that PCP's have the tools needed to diagnosis and communicate a comprehensive treatment plan readily available.

A state plan that directs multiple stakeholders to work together was another common theme. Suggestions included:

- Work with social workers at hospitals
- Form partnerships with adult protective services, law enforcement, the Veteran's Administration, and other state agencies
- Work with the legal profession and those involved with establishing guardianships to assure they have an understanding of the disease process and available support
- Expand existing Idaho-based programs such as the Fit and Fall Proof Program and Living Well in Idaho to reach individuals/caregivers
- Expand the use of telemedicine for diagnosis and follow-up

Finally, the elimination of barriers that limit capacity to provide care at home should be a desired outcome of a state plan. Suggestions included:

- Allow spouses to qualify as certified family care providers
- Reimburse caregivers who are unemployed
- Implement a tracking system that would monitor return on investment (ROI) of home-based care versus status quo
- Divert funding from Medicaid long-term care services to caregivers to allow people to provide needed care
- Develop a statewide coordinated volunteer program or stipend program to offer caregivers informal support
- Create structure for a volunteer coalition that would assure appropriate training and support for caregivers and individuals provide respite services

Appendix D: Findings from administrators and directors of nursing/memory care units in assisted living (ALF) and skilled nursing (SNF) facilities

The purpose of this assessment was to gather information about the challenges of providing care for individuals with ADRD and their caregivers and families from the perspective of administrators and directors of nursing/memory care units of assisted living (ALF) and skilled nursing facilities (SNF). Contact information for participants was obtained from the Idaho Health Care Association/Idaho Center for Assisted Living.

Standardization of the data collection procedures was established through a training session, regular debriefings, and use of a common introductory message and interview questions.

Data collection occurred between February and July 2012 with phone interviews conducted in April and May 2012. The focus groups were held in conjunction with the following events:

- Idaho Health Care Association and Idaho Center for Assisted Living (IHCA/ICAL)
    - Winter Workshop, February 7
    - Convention and Trade Show, July 31

Results

The findings gathered through the focus groups and interviews are presented in aggregate.

Participant Characteristics

A total of 49 individuals representing all regions of the state participated in the administrator focus groups and phone interviews. The distribution of participants by public health regions are reported in Table D.1.

Table D.1. Distribution of participants by public health district (n=48)

Idaho Public Health District	Number of Participants
1 (Panhandle)	8
2 (North Central)	8
3 (Southwest)	7
4 (Central)	9
5 (South Central)	8
6 (Southeastern)	6
7 (Eastern)	2

Participants were asked to respond to a series of questions that identified and prioritized the challenges associated with working with individuals with ADRD and their families and were then asked to suggest changes/solutions that would address the issues.

Challenges

Challenge: The complexity of care required by individuals with dementia.

- Requires higher staffing ratios than facilities can afford
    - Patients with dementia require close supervision and frequent redirection.
    - The reimbursement system for LTC facilities is based on a medical model and there is no way to capture the acuity of patients with behavioral issues who do not have medical issues. As a result there is a disparity between the number of staff hours needed to provide appropriate care for these patients and the rate of reimbursement the facility receives.
    - There is no difference in the reimbursement for memory care vs. assisted living.
    - It takes a great deal of time to properly care for an Alzheimer's resident and Medicaid funds could be more effectively used if there was a mid-level category for residents with dementia.
    - Assisted living facilities and skilled nursing facilities are not always focused on the complex needs of residents with dementia.
- Providing the most basic of daily care is time consuming and difficult with individuals who are confused
    - Staff caring for patients with ADRD needs specialized training in order to provide appropriate care for these individuals.
    - Access to appropriate training in rural areas is difficult.
    - Staff providing care in Assisted Living Facilities, which often have memory care units, are not required to be a licensed Certified Nursing Assistants (CNA).
    - Caring for people with progressive dementia takes an emotional toll on staff members
- Need for skilled and licensed caregivers
    - There is traditionally a high rate of staff turnover in nursing facilities.
- Safety concerns such as wandering and falls and/or endangering others
- The need for appropriate activities to decrease behaviors and enhance the quality of life for individuals with dementia and their families
- It is extremely difficult to transfer an individual whose condition has deteriorated
    - Reimbursement is not available for behavioral/ mental health facilities that accept patients with a primary diagnosis of dementia
    - Changes in reimbursement have forced facilities to close dedicated units
    - There are few specialized units in facilities in rural areas
- Facilities often have only enough time to meet the basic needs of the patient and are unable to provide ongoing support for the families

Challenge: Regulatory system fails to recognize the unique requirements of working with individuals with dementia

- The regulatory system for LTC is very punitive in nature
- The state regulatory system for LTC facilities has no provisions for the special needs of patients with ADRD.
- Facilities may be willing to accept the challenge of caring for persons with ADRD, but are discouraged from doing so for fear of being unable to meet state standards

Challenge: The complexity of support needed in the community to assure safety and quality of life for individuals with ADRD, their family members and caregivers

- Family members may not have adequate education to provide the type of care their loved ones need to keep them safe
    - Families may be in denial and have unrealistic expectations of the facility
- Services are not coordinated
- Families don't have the type of support they need during the grieving process
- The resources needed to support family caregivers such as respite care and support groups are not always available, especially in rural areas
    - Lack of support for planning (medical, legal, financial) and end-of-life care
- There is no access to geriatric neurologists or geriatric psychiatrists in rural areas.
- Placement in an appropriate facility may not be an option because of lack of finances or availability

Challenge: Lack of knowledge about prevalence, recognition, and management of ADRD

- Lack of early diagnosis and treatment
- Literacy issues with written materials
- Need more education on end-of-life choices
- More training on ADRD for physicians, nurses, social workers and other providers
- Guardianships/Advance Directives

Recommendations for State Plan

- Address funding challenges
    - Provide incentives for facilities to provide environments that are appropriate for the care of persons with ADRD.
    - Provide support for appropriate activity programs to improve the quality of life for people with ADRD.
    - Provide resources for diagnostic testing and treatments such as approved medications
    - Provide financial reimbursement for family members to encourage them to care for loved ones with ADRD at home rather than institutionalizing them.
    - Expand care options other than LTC placement for patients with ADRD
- Review and revise facility regulations and regulatory processes
    - Mandate increased staffing ratios on units caring for people with ADRD
    - Mandate staff education that focuses on patients with ADRD.

    - Change the current Preadmission Screening and Resident Review (PASRR) and reimbursement system to facilitate transfer of patients to appropriate care environments when the need arises
    - Revise the state regulations that govern LTC facilities to reflect consideration for the unique needs of patients with ADRD
    - Involve professionals working in LTC in the process of revising the state survey procedures
- Implement educational programs for the public, families and health and social service providers.
    - Increase public awareness, recognition and understanding of ADRD.
    - Provide standardized curriculum for:
        - family caregivers
        - students pursing health careers
        - facility staff members
    - Increase understanding of ADRD among primary care physicians to facilitate early diagnosis and treatment.
    - Increase access to educational opportunities for facilities in rural areas (ex: through community colleges, community-based extension offices, online offerings, etc.)
- Support specialized education and training in care and treatment of individuals with neurological conditions for physicians, nurses, and social workers.

IAPG State Plan

Guiding Principles

The Idaho Alzheimer's Planning Group (IAPG) has been endorsed by the Idaho State legislature to develop a statewide plan to address the urgent and growing needs of people impacted by Alzheimer's disease and related dementias (ADRD). IAPG will use the following guiding principles to develop the plan:

1. The planning process will be used to increase awareness about ADRD and its impact on families, communities and the state.

2. Plan recommendations will be based on:

    a. Input from people self-identified as concerned about Alzheimer's disease and related dementias (ADRD);
    b. Input from people representing all regions within the state.

3. Plan recommendations will be based on the specific needs of:

    a. People with ADRD;

    b. Family members of people with ADRD;

    c. Professional and volunteer caregivers of people with ADRD;

    d. Professionals working in the ADRD field.

4. Plan recommendations will emphasize public-private ventures when possible and will not allow conflicts of interests among plan participants.

5. Plan recommendations will build on best practices of existing services and systems.

6. Plan recommendations will be cost-effective.

7. Plan recommendations will include specific, measurable objectives.

Mission

To improve the spectrum of prevention, diagnosis, treatment, and caregiver support services for people with Alzheimer's disease and other dementias.

Vision

Alzheimer's disease and other dementias will be identified as a public policy priority in Idaho. We will take a leadership role in educating legislators and the public about this growing health care issue and advocate for a statewide strategic plan to address it.

ADRD Resources
In Idaho

Alzheimer's Association:

Greater Idaho Chapter
6126 W. State St., Suite 305
Boise, ID 83703
Direct Line: (208) 206-0041 – please use the area code
Email: mackenzie.rodgers@alz.org

Inland Northwest Chapter
Coeur d'Alene
1042 W. Mill Ave., Ste. 205
Coeur d'Alene, ID 83814
Phone 208.666.2996
Website: www.alz.org
E-mail: InlandNW@alz.org

Utah Chapter (serving southeastern Idaho)
Salt Lake County
855 East 4800 South, Suite 100
SLC, UT 84107
801.265.1944

Idaho Department of Health and Welfare
Telephone: Idaho CareLine dial 2-1-1 or 1-800-926-2588
Website: http://www.211.idaho.gov
http://www.healthandwelfare.idaho.gov/

Area Agencies on Aging:

Area 1 – North Idaho – serving counties - Benewah, Boundary, Bonner, Kootenai, Shoshone
Telephone: 1-208-667-3179 or 1-800-786-5536
Website - http://www.aaani.org/

Area 2 – North Central Idaho – serving counties - Clearwater, Idaho, Latah, Lewis, Nez Perce

Telephone: 1-208-798-4192 or 1-800-877-3206
Website - http://www.cap4action.org/PSAgencyOnAging.html

Area 3 – Southwest Idaho – serving counties Ada, Adams, Boise, Canyon, Elmore, Gem, Owyhee, Payette, Valley, Washington
Telephone: 1-800-859-0321 or 1-208-908-4990
Website - http://seniors.idahocog.com

Area 4 – South Central Idaho – serving counties Blaine, Camas, Cassia, Gooding, Jerome, Lincoln, Minidoka, Twin Falls

Telephone: 1-208-736-2122 or 1-800-574-8656
Website - http://officeonaging.csi.edu/

Area 5 - Southeast Idaho – serving counties Bannock, Bear Lake, Bingham, Caribou, Franklin, Oneida, Power

Telephone: 1-208-233-4032 or 1-800-526-8129
Website- http://www.sicog.org/AgingAgency/AreaAgingAgency.html

Area 6 – Eastern Idaho – serving counties Bonneville, Butte, Clark, Custer, Fremont, Jefferson, Lemhi, Madison, Teton

Telephone: 208-522-5391 or 1-800-632-4813
Website - http://www.eastidahoaging.com or
http://www.eicap.org/programs/senior

Idaho's Aging and Disability Resource Center

Telephone: 2-1-1or 1-800-926-2588
Website: icoa@aging.idaho.gov

Idaho Commission on Aging

Telephone: (208) 334-3833 or 1-800-926-2588
Website: www.idahoaging.com

AARP Idaho

Telephone: (208) 288-2277
Website: http://states.aarp.org/category/idaho/

BSU Center for the Study of Aging

Telephone: (208)
Website: http:/hs.boisestate.edu/csa/IAPG