Idaho Needs Assessment:
Alzheimer’s Disease and Related Dementias

August 2012

Conducted by:
Idaho Alzheimer’s Planning Group

A Project of the
Center for the Study of Aging
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Acknowledgements

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Executive Summary

The 2012 Idaho Legislature recognized the importance of developing a statewide plan for Alzheimer's disease and related dementias (ADRD) with its support of Concurrent Resolution 112. This legislation acknowledged the seriousness of the impact of ADRD and endorsed the efforts of the Idaho Alzheimer’s Planning Group (IAPG) to develop a state plan. The following report describes the findings of assessment activities conducted to inform IAPG and others of the needs of patients and their caregivers and families.

A total of 444 individuals representing all regions of the state participated in the needs assessment. 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.

One of the consistent messages received from all 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 as a backdrop, the most pressing needs of persons impacted by ADRD were:

- access to training and information on how to care for individuals with ADRD
- more timely and comprehensive information from primary care providers (PCP)
- 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 caregivers

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

Challenges of providing care for individuals with ADRD noted by administrators from assisted living and skilled nursing facilities also reflected a need for more support from PCPs and training opportunities for staff. Other common concerns from this population were:

- lack of parity between reimbursement rates and the level of care required for an individual with dementia
- lack of coordination between service providers to assure that residents are receiving the most appropriate level of care, i.e., ability to transfer a resident from an ALF to a SNF and visa-versa or to a behavioral health facility
- regulatory standards and review processes that do not recognize the specific needs of individuals with ADRD

The results of this assessment provide the foundation of a state plan. The full report provides a comprehensive review of findings and includes specific recommendations for an Idaho plan identified by participants directly impacted by ADRD.
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 Concurrent Resolution (CR) 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. See Figure 1 for recognition of the passage of CR 112 by Governor Otter.

![Recognition of Concurrent Resolution 112 by Governor Otter, March 2012.](image)

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.
Methods

A mixed methods research design was used 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, phone 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

<table>
<thead>
<tr>
<th>Population Groups of Interest</th>
<th>Data Collection Strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>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)</td>
<td>Survey</td>
</tr>
<tr>
<td>Family members providing full-time care for individuals with ADRD. (n=8)</td>
<td>Phone Interviews</td>
</tr>
<tr>
<td>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)</td>
<td>Focus Groups</td>
</tr>
<tr>
<td>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)</td>
<td>Focus Groups and Phone Interviews</td>
</tr>
</tbody>
</table>
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)

<table>
<thead>
<tr>
<th>Public Health District</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (Panhandle)</td>
<td>78</td>
</tr>
<tr>
<td>2 (North Central)</td>
<td>30</td>
</tr>
<tr>
<td>3 (Southwest)</td>
<td>32</td>
</tr>
<tr>
<td>4 (Central)</td>
<td>99</td>
</tr>
<tr>
<td>5 (South Central)</td>
<td>117</td>
</tr>
<tr>
<td>6 (Southeastern)</td>
<td>57</td>
</tr>
<tr>
<td>7 (Eastern)</td>
<td>28</td>
</tr>
<tr>
<td>Unknown</td>
<td>3</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Demographic Characteristics (n=325)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average Age =56, Age Range = 22-89</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>71</td>
<td>21.8</td>
</tr>
<tr>
<td>Female</td>
<td>254</td>
<td>78.2</td>
</tr>
<tr>
<td>Residence by Public Health District</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Region 1 (Panhandle)</td>
<td>40</td>
<td>12.3</td>
</tr>
<tr>
<td>Region 2 (North Central)</td>
<td>21</td>
<td>6.5</td>
</tr>
<tr>
<td>Region 3 (Southwest)</td>
<td>21</td>
<td>6.5</td>
</tr>
<tr>
<td>Region 4 (Central)</td>
<td>85</td>
<td>26.2</td>
</tr>
<tr>
<td>Region 5 (South Central)</td>
<td>86</td>
<td>26.5</td>
</tr>
<tr>
<td>Region 6 (Southeastern)</td>
<td>43</td>
<td>13.2</td>
</tr>
<tr>
<td>Region 7 (Eastern)</td>
<td>26</td>
<td>8.0</td>
</tr>
<tr>
<td>Unknown</td>
<td>3</td>
<td>0.9</td>
</tr>
</tbody>
</table>
Demographic Characteristics (n=325) | n | %
---|---|---
**Relationship to Person with ADRD**
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

<table>
<thead>
<tr>
<th>Demographic Characteristics of Caregivers (n=129)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average Age</strong> = 59, <strong>Age Range</strong> = 22-88</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| 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

<table>
<thead>
<tr>
<th>Insurance Coverage</th>
<th>n*</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare</td>
<td>97</td>
<td>74.0</td>
</tr>
<tr>
<td>Medicaid</td>
<td>28</td>
<td>21.4</td>
</tr>
<tr>
<td>Veteran’s Benefits</td>
<td>25</td>
<td>19.1</td>
</tr>
<tr>
<td>Private Insurance</td>
<td>57</td>
<td>43.5</td>
</tr>
</tbody>
</table>
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.

<table>
<thead>
<tr>
<th>Insurance Coverage</th>
<th>10</th>
<th>7.6</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>16</td>
<td>12.2</td>
</tr>
</tbody>
</table>

*Respondents were instructed to check all that apply.

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

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

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

<table>
<thead>
<tr>
<th>Theme</th>
<th>Suggestions and Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to Information</td>
<td>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</td>
</tr>
<tr>
<td></td>
<td>How about a central information source to direct caregivers to resources services, and available support?</td>
</tr>
<tr>
<td></td>
<td>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).</td>
</tr>
<tr>
<td>Access to Services</td>
<td>There is a huge problem connecting the patient and family and services available.</td>
</tr>
<tr>
<td></td>
<td>Affordable care and help for families with caregiving. Respite care services for families. Legal resources for caregivers -- for guardianships for their loved ones.</td>
</tr>
<tr>
<td>Education of Providers</td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td>More training for providers -- how to communicate with client. How to approach client in different situations.</td>
</tr>
<tr>
<td></td>
<td>Increased education to the general public and to law enforcement and other responsive organizations.</td>
</tr>
<tr>
<td></td>
<td>I feel the medical profession hasn't been much help- It makes one feel pretty hopeless</td>
</tr>
<tr>
<td>Family Support</td>
<td>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 &quot;middle,&quot; where we can’t afford full time care, but we make too much money to qualify for assistance.</td>
</tr>
<tr>
<td></td>
<td>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-</td>
</tr>
<tr>
<td>Theme</td>
<td>Suggestions and Quotes</td>
</tr>
<tr>
<td>------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Need for Statewide Initiative | *anger-showers*  
Legislative support to help care agencies provide cost effective care. Support Alzheimer’s/ Dementia care - needs are continually increasing for Idaho families.  
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 National Alzheimer’s Association, Friends in Action (an Idaho-based nonprofit organization), seminars, the local Office on Aging, and their healthcare 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

<table>
<thead>
<tr>
<th>Demographic Characteristics (n=63)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>8</td>
<td>12.7</td>
</tr>
<tr>
<td>Female</td>
<td>55</td>
<td>87.3</td>
</tr>
<tr>
<td>Residence by Public Health District</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Region 1 (Panhandle)</td>
<td>29</td>
<td>46.0</td>
</tr>
<tr>
<td>Region 2 (North Central)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Region 3 and 4 (Southwest/Central)</td>
<td>5</td>
<td>7.9</td>
</tr>
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<tr>
<td>Relationship to ADRD</td>
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<td>1.6</td>
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<tr>
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<td>19.0</td>
</tr>
<tr>
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<td>23.8</td>
</tr>
<tr>
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<tr>
<td>Health-care provider</td>
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<tr>
<td>Social service provider</td>
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<td>20.6</td>
</tr>
<tr>
<td>Public employee or official</td>
<td>7</td>
<td>11.1</td>
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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, such as how to get someone to eat, what diapers to buy, how to assure a safe environment, were 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 to maintaining 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 and 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 navigators – “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
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
- Local and National 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**

Participant responses 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)

<table>
<thead>
<tr>
<th>Idaho Public Health District</th>
<th>Number of Participants</th>
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<tr>
<td>1 (Panhandle)</td>
<td>8</td>
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<tr>
<td>2 (North Central)</td>
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<tr>
<td>7 (Eastern)</td>
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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
  o Mandate increased staffing ratios on units caring for people with ADRD
  o Mandate staff education that focuses on patients with ADRD.
  o 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
  o Revise the state regulations that govern LTC facilities to reflect consideration for the unique needs of patients with ADRD
  o 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.
  o Increase public awareness, recognition and understanding of ADRD.
  o Provide standardized curriculum for:
    ▪ family caregivers
    ▪ students pursuing health careers
    ▪ facility staff members
  o Increase understanding of ADRD among primary care physicians to facilitate early diagnosis and treatment.
  o Increase access to educational opportunities for facilities in rural areas (ex: through community colleges, community-based extension offices, online offerings, etc.)
  o Support specialized education and training in care and treatment of individuals with neurological conditions for physicians, nurses, and social workers.