Testimony to the North Dakota Long Term Care Committee
Submitted by Brad Gibbens, Associate Director
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September 28, 2010

Good morning, Chairman Kreidt and members of the committee. My name is Brad Gibbens and I am the Associate Director of the Center for Rural Health at the University of North Dakota School of Medicine and Health Sciences. Thank you for allowing me to appear before you today.

In 2009, the North Dakota Legislature passed the Dementia Care Services bill (House Bill 1043) to provide resources, assistance, and support for citizens across the state of North Dakota, including all geographic areas, large and small, urban, and rural.

The Aging Services Division of the North Dakota Department of Human Services issued a Request for Proposal (RFP) for these services and awarded the contract to the Alzheimer's Association of MN/ND.

The Alzheimer's Association selected the Center for Rural Health to conduct the study and report the outcomes of the dementia care services program; including estimated long-term care, and health care costs avoided, and the improvement in disease management and caregiver assistance. The Center's research staff led by Dr Marilyn Klug, Dr. Kyle Muus, and Dr. Boris Volkov are responsible for the research.

Implementation of the Dementia Care Services project began in January 2010 and we now have preliminary data to share here today. From the perspective of the Alzheimer's Association and the Center for Rural Health, I must emphasize this program is still in the early stages of its implementation; however, the data is indicative of an overall positive trend.

As you see from Slide 1, the number of citizens completing intake into the program continues to grow larger with each successive month. With Slide 2, we are able to confirm services in every geographical area, including 25% of services provided to caregivers living in isolated rural areas. (Slide 3)The caregiver is most generally the adult child (40%) which is usually a daughter or the wife (20%).

Slide 4 shows where persons with Alzheimer's disease who have received services currently reside. The Alzheimer's Association provides service delivery in all 8 DHS regional service areas. The DHS region that has the highest number of Alzheimer cases seeking care is Region V, the Southeast with 33%. This includes the counties of Steele, Trail, Cass, Ransom, Sargent, and Richland. This followed by Region VII. The West Central with 23% and includes the counties of McLean, Sheridan, Mercer, Oliver, Burleigh, Kidder, Morton, Grant, Sioux, and Emmons. The region most challenging at the moment is found in the Devils Lake area (Region 3), where cultural barriers may exist requiring a longer time to build tribal relationships and develop trust.

Slide 5 demonstrates that most of those living with Alzheimer's disease remain in their own home, as do national statistics that show up to 70% of those with dementia in the U.S. continue to live at home. In North Dakota we are seeing a majority, 56%, are residing in their home setting, The next closest living arrangements are LTC (11%), family (11%) and simply unknown (11%).

Slides 6-9 provide a breakout of veterans who have received services from the Alzheimer's Association. The veteran population is a distinct group and an important part of our society. This is particularly true in a rural state like North Dakota. Nationally, about 36% of veterans come from rural areas when only about 20% of the entire U.S. population is rural. In North Dakota, about 48% of our veterans are rural so access to health services are compounded by geographical factors. For a rural veteran and his or her family dealing with Alzheimer's, access to important services can be a struggle. To date, our study shows (slide 6) that 14% of those served to date have been veterans. Those veterans served thus far are more likely to live in the country (slide 7). By country, we mean rural but outside of the city limits. There is also a greater percentage of veterans than non-veteran with Alzheimer's living in urban and large rural. Slide 8 shows the living arrangement for veteran's with Alzheimer's and we see that they tend to remain in their own home (over 50%) although the rate of non-veterans living in their own home is slightly greater. This slide also shows that the veteran is more likely than the non-veteran to live with family or live in a group home or live in a long term care setting. The part of the state with the highest percentage of people with Alzheimer's and to be a veteran is in the southeastern region (Region V and shown in slide 9).

Slide 10 is included to indicate the geographical breakdown of multiple service users. The highest number of users is in the urban centers, where awareness of the disease may be higher, and in the isolated rural area, where access may be more difficult leading to multiple requests to assist the same family.

Slide 11 confirms our supposition that families caring for the family member in their own home remain the families needing the greatest assistance.

Slide 12 provides a visual demonstrating multiple requests for services leads to families putting in place important legal planning such as power of attorney and health care directives. In a way this data is likely evidence that as time goes by, as the complexity of the health and family situation builds, and as the stress mounts families contend with more extensive and formal decision making.

The final slide (Slide 13) proves the importance of services delivery provided in person versus on the telephone and demonstrates a decrease in the family's likelihood to place their loved one in long term care after receiving Alzheimer's Association services delivered in person.

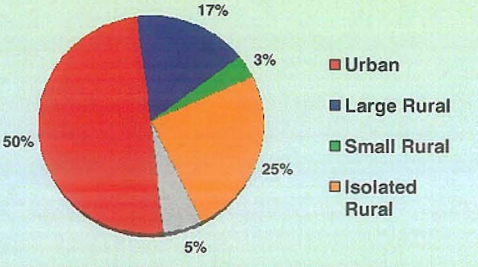
This project continues through June 30, 2011 and the data collected by that time will provide additional valuable information.

I am happy to respond to any questions and I am also joined by Alzheimer's Association staff to assist in providing clarity to this presentation.

Number of Intake Forms Completed During January to July, 2010

1

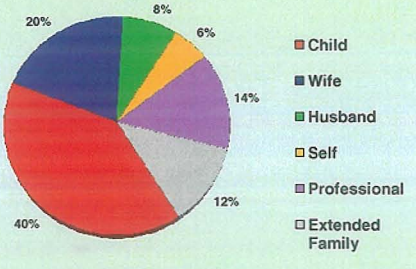
Rurality of Caregivers



Urban - cities with populations of 50,000 or more and those places with strong work commuting relationships to them;
Large Rural – towns with populations of 10,000-49,999 and those places with strong commuting relationships to them;
Small Rural - towns with populations of 2,500-9,999 and those places with strong commuting relationships to them;
Isolated Rural – towns with populations of less than 2,500 and no primary commuting flow of more than 5% to an urban cluster.

2

Role/Relationship of Caregivers to Person with Alzheimer's



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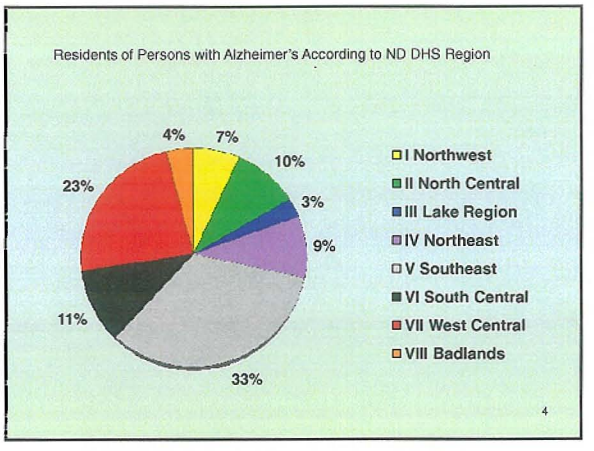
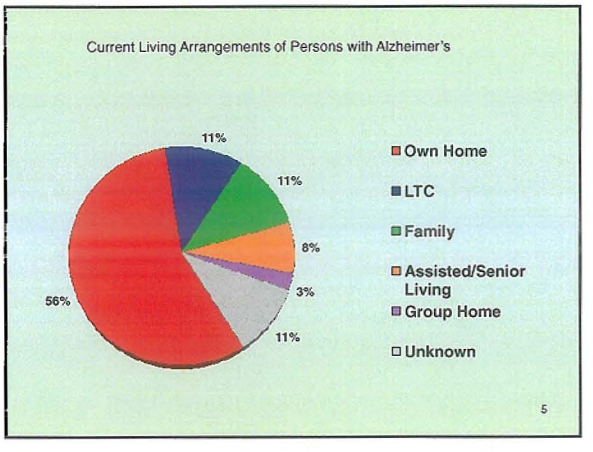
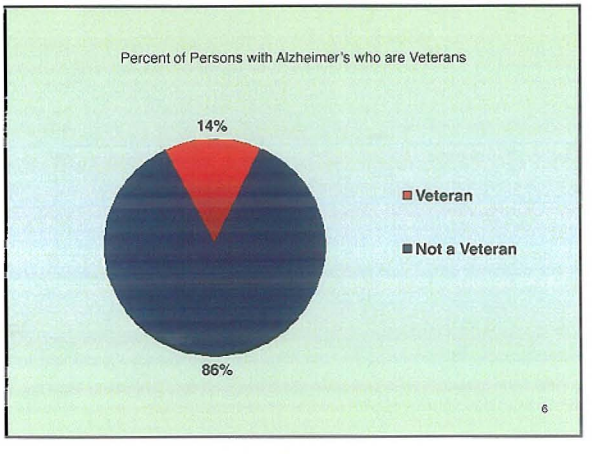
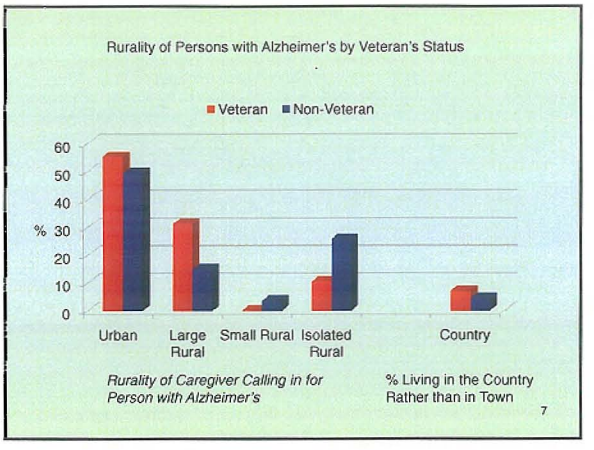
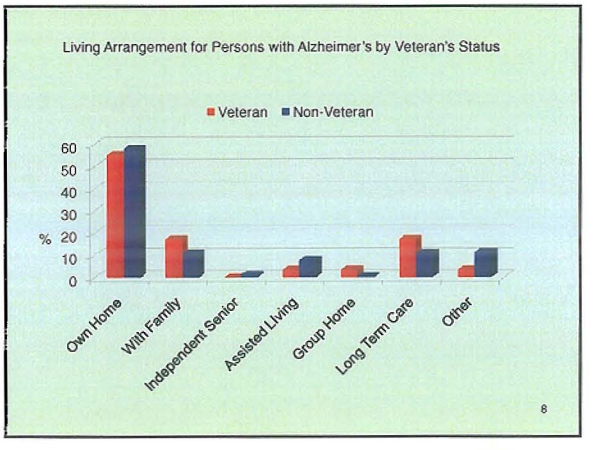
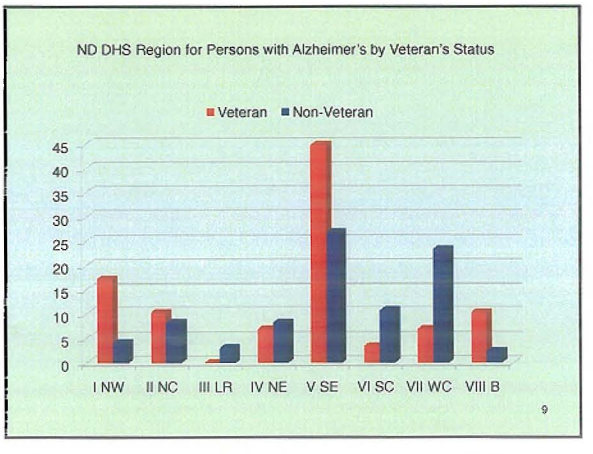

Residents of Persons with Alzheimer's According to ND DHS Region
4%
7%
10%
3%
9%
33%
11%
23%
I Northwest
II North Central
III Lake Region
IV Northeast
V Southeast
VI South Central
VII West Central
VIII Badlands
4

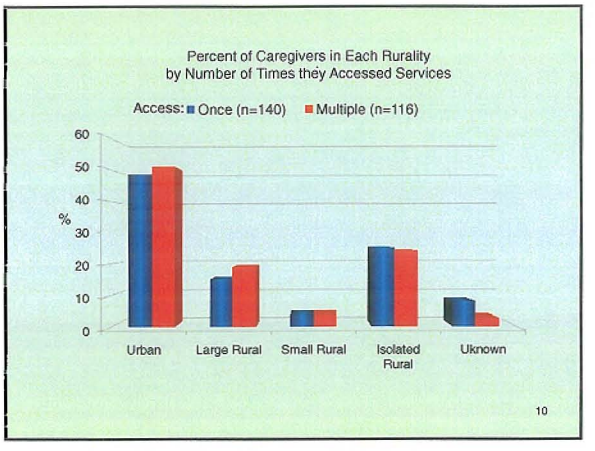

Current Living Arrangements of Persons with Alzheimer's
11%
11%
8%
3%
11%
56%
Own Home
LTC
Family
Assisted/Senior Living
Group Home
Unknown
5

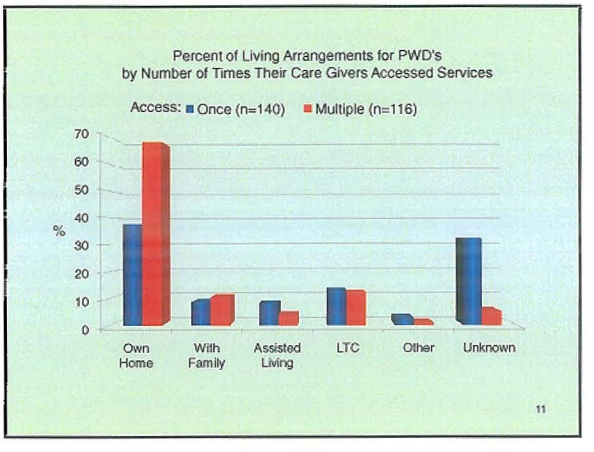

Percent of Persons with Alzheimer's who are Veterans
14%
86%
Veteran
Not a Veteran
6

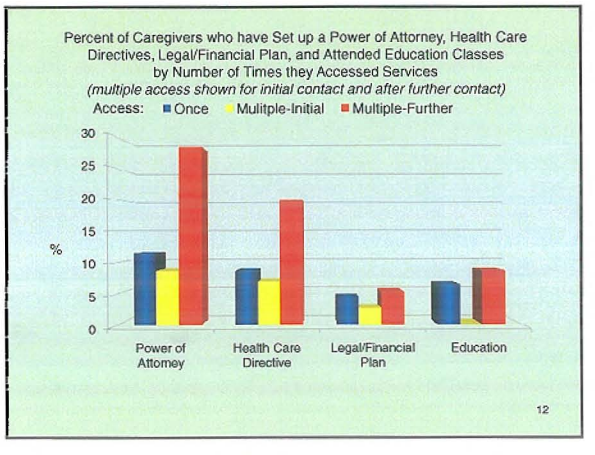

Rurality of Persons with Alzheimer's by Veteran's Status
Veteran
Non-Veteran
60
50
40
% 30
20
10
0
Urban
Large Rural
Small Rural
Isolated Rural
Country
Rurality of Caregiver Calling in for Person with Alzheimer's
% Living in the Country Rather than in Town
7

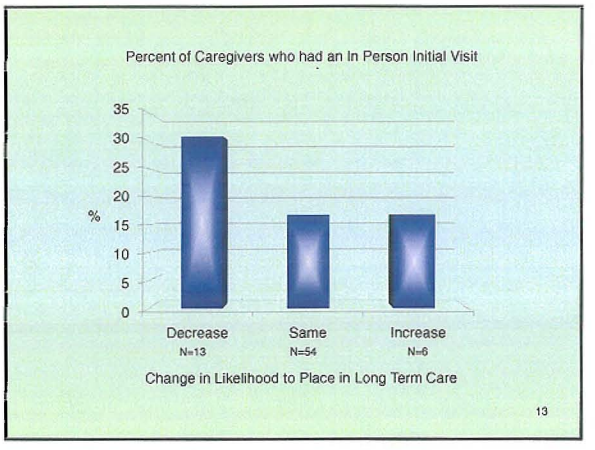

Living Arrangement for Persons with Alzheimer's by Veteran's Status
Veteran
Non-Veteran
60
50
40
30
% 20
10
0
Own Home
With Family
Independent Senior
Assisted Living
Group Home
Long Term Care
Other
8


ND DHS Region for Persons with Alzheimer's by Veteran's Status
Veteran
Non-Veteran
45
40
35
30
25
20
15
10
5
0
I NW
II NC
III LR
IV NE
V SE
VI SC
VII WC
VIII B
9


Percent of Caregivers in Each Rurality
by Number of Times they Accessed Services
Access: Once (n=140) Multiple (n=116)
%
60
50
40
30
20
10
0
Urban
Large Rural
Small Rural
Isolated Rural
Uknown
10


Percent of Living Arrangements for PWD's
by Number of Times Their Care Givers Accessed Services
Access: Once (n=140) Multiple (n=116)
%
70
60
50
40
30
20
10
0
Own Home
With Family
Assisted Living
LTC
Other
Unknown
11


Percent of Caregivers who have Set up a Power of Attorney, Health Care Directives, Legal/Financial Plan, and Attended Education Classes
by Number of Times they Accessed Services
(multiple access shown for initial contact and after further contact)
Access: Once Mulitple-Initial Multiple-Further
%
30
25
20
15
10
5
0
Power of Attorney
Health Care Directive
Legal/Financial Plan
Education
12


Percent of Caregivers who had an In Person Initial Visit
35
30
25
20
15
10
5
0
%
Decrease
N=13
Same
N=54
Increase
N=6
Change in Likelihood to Place in Long Term Care
13