# Wyoming State Plan To Address Alzheimer's Disease and Related Dementias



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Wyoming Alzheimer's & Dementia Work Group

#### **ACKNOWLEDGEMENTS**

The following Wyoming Alzheimer's and Dementia Work Group members contributed their time and knowledge to the creation and development of the Wyoming State Plan to Address Alzheimer's Disease and Related Dementias. Each has a passion for improving the lives of Wyoming citizens affected by dementia. We express sincere appreciation and gratitude to all of the Work Group members and partner organizations.

#### **Work Group Members**

#### Jane Carlson

Wyoming Department of Family Services, Adult Protective Services

#### Catherine Carrico, PhD

University of Wyoming, College of Health Sciences, Wyoming Center on Aging

#### Linda Chasson, BSW, MS

Wyoming Department of Health, Aging Division, Community Living Section

Wyoming Department of Health, Aging Division, Community Living Section

#### Dirk Dijkstal, JD

Wyoming Department of Health, Aging Division, Community Living Section

#### Rick Geringer

Wyoming Independent Living Rehabilitation

#### Pastor Lynn Howe

Laramie, Wyoming

#### Lindsay Hruby, LCSW

State Long-Term Care Ombudsman

#### **Janet Lewis**

Alzheimer's Association, Wyoming Chapter

#### Christine McKibbin, PhD

University of Wyoming, College of Health Sciences, Wyoming Center on Aging

#### Lisa Osvold, BSW, MBA

Wyoming Department of Health, Aging Division

#### Michelle Panos

Office of Governor Matthew H. Mead

#### <u>Iennifer Rosen</u>

Alzheimer's Association, Senior Associate Director, State Affairs, Washington DC

## Samuel Shumway, JD

American Association of Retired Persons (AARP), Wyoming

### Jennifer Simon

St. John's Hospital Foundation, Jackson, Wyoming

#### Martha Stearn, MD

St. John's Institute for Cognitive Health, St. John's Medical Center, Jackson, Wyoming



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#### **EXECUTIVE SUMMARY**

#### Where We Are Today

Both incurable and fatal, Alzheimer's disease and related dementias (AD/RD) are arguably the most daunting public health challenge of our time. More than five million people in the United States suffer from Alzheimer's disease, the most prevalent type of dementia, and by 2050 this number is projected to rise to 13.8 million<sup>1</sup>. Risk reduction measures and early diagnosis are essential to managing the effects of dementia and reducing health-related costs. The National Alzheimer's Project Act (NAPA) was signed into law by President Obama in 2011 and calls for a comprehensive plan to address Alzheimer's disease and related dementias.<sup>2</sup> Following the passage of NAPA, states around the nation have developed and implemented statewide plans to raise public awareness, provide education, coordinate services, train practitioners, and support the burgeoning needs of communities affected by this public health crisis.

#### **Current Challenges in Wyoming**

- Wyoming is a rural state with a small, geographically dispersed population;
- Wyoming has few specially-trained practitioners, such as geriatric psychiatrists, memory care specialists, and other staff trained to work specifically with people living with Alzheimer's disease and related dementias;
- There is a lack of geriatric mental health care in Wyoming; individuals who do not receive needed geriatric mental health care are at risk of being inappropriately placed, living in more restrictive, more expensive, and less appropriate locations;
- There are limited facilities for people living with AD/RD, particularly those with memory care
- There is no standardized mechanism for patient discharge and caregiver information for those with AD/RD:
  - o When people living with dementia are discharged from the hospital, there is no process by which their caregiver is notified of their course of treatment;
  - When people who might be at risk of dementia are admitted to the hospital, there is no mechanism by which they can be screened for dementia in spite of the existence of reliable screening tools (e.g. the Mini-Cog); and,
- There are little to no resources for individuals with AD/RD, who lack capacity to make healthcare or financial decisions, including limited resources to obtain a professional guardian, conservator, or payee.

#### **Key to Success**

Our success depends on developing a strong coalition of organizations, providers, caregivers, nursing home representatives, and practitioners around the state. With input and materials from surrounding states in the region, the Wyoming State Plan can inform the strategies designed to capitalize on our strengths and minimize our challenges.

<sup>&</sup>lt;sup>1</sup> 2018 Alzheimer's disease Facts and Figures. Alzheimer's Dement 2018;14(3):367-4290

<sup>&</sup>lt;sup>2</sup> https://www.nia.nih.gov/about/nia-and-national-plan-address-alzheimers-disease

#### PROCESS FOR PREPARING THE STATE PLAN

The Wyoming Alzheimer's and Dementia Work Group convened in the Fall of 2015 when Dr. Martha Stearn of the St. John's Institute for Cognitive Health, St. John's Medical Center in Jackson, Jennifer Simon of the St. John's Hospital Foundation, Janet Lewis, Executive Director of the Alzheimer's Association - Wyoming Chapter, and the Wyoming Governor's Office came to together to ascertain various initiatives in Wyoming related to AD/RD, identify stakeholders, and articulate next steps to creating an Alzheimer's State Plan.

The Governor's Office and the Wyoming Department of Health, Aging Division served as the facilitators for monthly group meetings to carry out the process of creating a State Plan for AD/RD



in Wyoming. An important initial step in this process was conducting a statewide needs assessment. The needs assessment process included town hall meetings held across the state to listen to the public's comments to inform the development of the Wyoming State Plan. The town hall meetings provided the opportunity for caregivers, family members, and other community members to share stories and experiences about caring for and providing services to individuals with Alzheimer's disease and related dementias. Individuals with Alzheimer's disease and related dementias were also encouraged to share their experience at these meetings. The University of Wyoming -Wyoming Center on Aging provided consultation and guidance on the needs assessment process and created reports of the findings of this process. These findings are one source of data that have provided guidance during the creation of this plan.

The locations of the town hall meetings were based on the population density of those age 60 and older, relative to the state's 2014 Census Designated Areas. The ten Wyoming communities visited were: Casper, Cheyenne, Cody, Gillette, Guernsey, Jackson, Lander, Rock Springs, the Wind River Indian Reservation (Ethete), and Worland. The meetings were held in March and April of 2017 and were promoted within the communities and held at county libraries and other community centers.

Wyoming Center on Aging staff attended the town hall meetings, provided data transcription and analysis, and created a final report. The Work Group viewed having a Facilitator for the town hall meeting as critical to the function of the information gathering process. The Wyoming Alzheimer's Association recommended Beki Brandborg to be facilitator. Ms. Brandborg served as facilitator for

the Alzheimer's State Plan Town Hall meetings in Montana. The broad topics that surfaced from the listening sessions were: the need for public awareness, information and referral to dementia services, issues related to access to care, the needs of family caregivers, and training and workforce development needs.



#### 2017 ALZHEIMER'S NEEDS ASSESSMENT: BRIEF SUMMARY

To gain insight into the lives of those with or caring for an individual with Alzheimer's disease or a related form of dementia, the task force gathered information from stakeholders statewide through a series of ten town hall listening sessions as well as an online survey. This is a brief summary of the needs assessment process and results. Please see Appendix B for the complete report.

#### **Town Hall Listening Sessions**

#### Methods

A series of ten, 120-minute, town hall meetings were conducted by a professional facilitator across cities and towns throughout Wyoming. Participants in the town hall meetings represented a variety of stakeholders across the continuum of dementia care such as policy makers, health and social services, first responders, caregivers, persons living with dementia, and interested community members. All listening sessions began with participants in



a large group and eventually split into small groups of people with similar roles (e.g. caregivers, healthcare professionals and social service providers, administrators, policy makers).

#### Data Analysis

The Wyoming Center on Aging conducted data analysis. All town hall meetings, both large group and small group discussions, were audio recorded and transcribed. Three researchers trained in qualitative data analysis completed thematic analysis of the transcripts. Thematic analysis revealed overarching themes and subthemes expressed regarding dementia care in Wyoming.

#### **Participants**

Participants included 175 individuals who attended one of the town hall listening sessions. The average age of the participants was 59.32 years old and attendees ranged in age from 14 years to 87 years old. The majority were female (n = 126; 73.7%), non-Hispanic (n = 158; 94%), white (n = 157; 98.1%) with some Native American representation (n = 3; 1.9%). A large percentage of individuals in attendance were caregivers to an individual living with dementia (n = 73; 41.7%). The majority of attendees care for a spouse (n = 26; 35.6%) or parent (n = 23; 31.5%) with Alzheimer's disease or a related dementia.

"Well, as a conduit of [the senior center], my mom has gotten Meals on Wheels. And she hasn't been able to move, which is another set of eyes on her throughout the day. So that has been helpful."

-Caregiver in Gillette

#### Results

Results from the town hall listening sessions revealed available resources for dementia care, as well as needs and areas for improvement. Major concerns coming out of the listening sessions were:

- Awareness/Information & Referral Resources
- Access to Care
- Caregiver Resources
- Workforce Enhancement

these concerns. the Work Group subcommittees to develop suggestions on improving the State's response to these areas.

#### Community Resources

A primary resource for dementia caregivers is the network of senior centers throughout the state. These centers provide a variety of services and supports such as essential transportation and meal/nutrition services. Some communities have local, grass-roots initiatives which support aging in place, such as the Age Friendly Jackson Hole group. Several agencies are already in place in some communities to provide caregiver support services such as support groups, respite care, caregiver programs (e.g. National Family Caregiver Support Program, Wyoming Dementia Care), and in-home support services. These supports were all noted as crucial to caring for an individual living with dementia. Professional resources, such as law enforcement and healthcare professionals, are also available in most communities to provide assistance and support to dementia caregivers. Project Lifesaver was identified as a very valuable program offered through some law enforcement departments; this program aids in locating and identifying an older adult who has become lost. Some communities also have residential care or hospice programs that can be valuable resources for caregivers as the disease progresses. Specifically, facilities that have a person-centered approach to residential care are identified as particularly desirable.

#### Awareness/Information and Referral Themes

Confusion and uncertainty about whom to call for resources and information about Alzheimer's disease is a common problem statewide. Older adults and those caring for a person living with dementia frequently are not aware of what resources are available in their local community, region, or statewide. Information about service quality is also lacking. Town hall attendees had several ideas to improve access to information about



dementia care resources. Attendees suggested the concept of a one-stop shop for information, resources, and referral to services and encouraged that outlets for information access be physically present in places older adults are comfortable going such as the library, grocery store, senior centers, or University of Wyoming extension offices. Additionally, attendees encouraged physicians to provide more information about resources for caregiving at diagnosis. The concept of utilizing local information agents to provide reliable information about Alzheimer's disease and resources was suggested by multiple attendees.

#### Access to Care

Several themes related to access to care for people living with dementia emerged from town hall meetings. One significant issue is difficulty accessing memory care and care continuum facilities in many areas, particularly rural parts of Wyoming. Attendees suggested that regulatory barriers to memory care could be a contributing factor to the low number of memory care facilities in Wyoming. Staffing barriers, most notably, Certified Nursing Assistant shortages, were also described as a reason that several existing long-term care facilities have open beds, but cannot accept new residents. Another challenge to optimal care of people living with dementia is access to geriatric mental health services, particularly access to geriatric psychiatry providers and very limited inpatient geriatric mental health facilities. Additionally, few opportunities for inter-professional geriatric assessment exist to support comprehensive evaluation and recommendations for care. Other support services to assist caregivers can be very challenging to access in rural areas, such as in-home health, respite care, and adult day

services. Adult day services and respite are particularly limited, and attendees reported that these services can be cost prohibitive as there are very few current funding or reimbursement sources. Regulatory barriers to adult day services were suggested as one reason for the possible shortage of this resource. Finally, attendees stated that care coordination services are not readily accessible and this void causes frustrating and uncoordinated trips to the emergency department.

There is consensus among the attendees that improving access to in-home support services, memory care, geriatric mental health, and other important healthcare resources is crucial to the wellbeing of people living with dementia and caregivers in Wyoming.

#### Caregiver Needs

A theme across the state is the need for caregiver support and education as well as respite care. Caregiver support and education is viewed as a way to prevent and reduce some of the strain and emotional burden caregivers naturally experience. Improved access to support groups and educational groups are suggested as a way to improve caregiver wellbeing. Respite care is also cited as a key component of caregiver support.

#### Workforce Issues

Themes related to workforce issues include the need for education about Alzheimer's disease and related dementia for healthcare professionals across the care spectrum -- from primary care physicians to certified nursing and direct care workers. Another prominent workforce issue related to dementia care is the direct care worker shortage. Multiple areas of the state report a Certified Nursing Assistant

shortage. Additionally, attendees identified the need for additional resources for long term care facilities such as increased numbers of direct care workers. There are significant challenges to providing direct care. Direct care workers were reported to burn out easily due to the challenging nature of the work and low wages. Attendees advocated for pay increases and elevating the direct care worker role in order to increase respect for this profession. An innovative idea generated at the town hall meetings is to increase the use of volunteers assisting with dementia care.

"You're paying \$10 an hour to do the hardest work of your life."

-23 yr old CNA, Jackson

#### **Needs Assessment Survey**

#### Methods and Participants

To gather input from individuals who may not have been able to attend a town hall listening session or who had additional feedback, the Wyoming Center on Aging conducted a needs assessment survey. Data were collected through either paper/pen or online survey. The survey was completed by 43 individuals who have a role in caring for a person living with dementia. Participants represent 18 out of 23 Wyoming counties. Respondents were largely female (n=35; 81.4%), in their late middle-ages (median birth year=1955), and were spouses (n=11; 25.6%) or adult children (n=18; 41.9%) of individuals with Alzheimer's disease or a related dementia. On average, respondents provided nearly 60 hours of direct care per week (M=58.71; SD=68.84).

#### Results

Participants reported the highest satisfaction with availability of generalized healthcare providers and quality of services. Participants were least satisfied with support in rural areas, both in-person and delivered via telehealth and electronic means. The areas of highest priority for dementia caregivers include access to services and information about available services. Of lowest priority are telehealth and electronic support in rural areas.

#### Conclusion

While the town hall meetings and needs assessment survey are useful for identifying the resources and needs in communities throughout Wyoming, these data may not reflect the comprehensive need or resources throughout the state. Continued exploration of needs and resources is encouraged. Both the survey and town hall meetings highlight the need for increased education for healthcare professionals of all disciplines; improved caregiver support and services including respite care; improved access to services including clear pathways and systematic dissemination of information; and a focus on the direct care worker shortage that appears to be impacting the long term care of people living with dementia. Wyoming has many strengths to celebrate and build upon which are highlighted in this report. Future exploration of innovative community resources and programs which meet Wyoming needs could improve dementia care and strengthen the aging network statewide.



#### **CHANGING DEMOGRAPHICS**

#### **Current Population and Projections**

Wyoming's entire population is expected to increase by approximately 12% by 2030. Figure 1, below details how four different age groups: 0-19 year olds, 20-64 year olds, 65-79 year olds, and 80 years old and up, are projected to change by 2030.

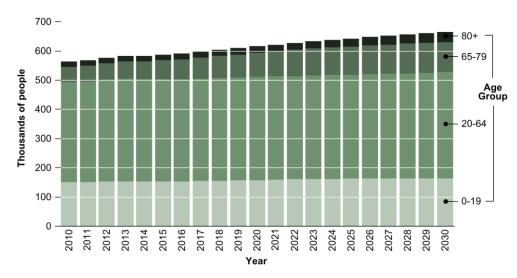


Figure 1. Demographic projections for Wyoming, 2010 - 2030<sup>3</sup>

Wyoming's population age 65 and older is expected to increase from 90,000 people in 2016 to 138,000 people in 2030, a 54% increase. As you can see in Figure 1, the 65-79 and 80 and older demographics will increase at a faster rate than the younger demographics. Figure 2, below, provides a closer look as to how the two older demographics will expand from 12% and 3.5% of Wyoming's population in 2017, to 15.3% and 5.4% of Wyoming's population in 2030, respectively.

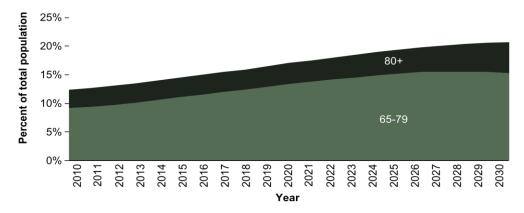


Figure 2. Elderly Residents as a Percentage of Total Projected State Population, 2010 – 2030<sup>4</sup>

The Wyoming Department of Health, Aging Division, State Plan for Aging Services delves further into the issue of Wyoming's growing aging population by discussing the aged dependency ratio, the changes it will endure, and what that means for Wyoming. Essentially, the ratio of working-age adults

<sup>&</sup>lt;sup>3</sup> https://health.wyo.gov/aging/communityliving/agingstateplan/

<sup>&</sup>lt;sup>4</sup> https://health.wyo.gov/aging/communityliving/agingstateplan/

to individuals over the age of 80 will decrease. This means there will be fewer individuals working and paying into systems like Social Security, Medicare, and other safety net programs, and there will also be fewer adults available to provide care to the elderly.<sup>2</sup>

As the general population age 65 and older in Wyoming rapidly increases, so will the instances of AD/RD within that expanding population. The Alzheimer's Association estimates that the number of people aged 65 and older with Alzheimer's disease in Wyoming will increase from 9,700 in 2018 to 13,000 in 2025. The Alzheimer's Association also states that there are currently 28,000 dementia caregivers in Wyoming; as the aged dependency ratio decreases, the need for these caregivers will increase over the next 15 years. Alzheimer's disease is currently the sixth leading cause of death in Wyoming, among all age groups, with 151 deaths attributed to the disease in 2015. Refer to Figures 3, below and Figure 4, on the next page, for statistics on mortality rates and deaths per year by age range.

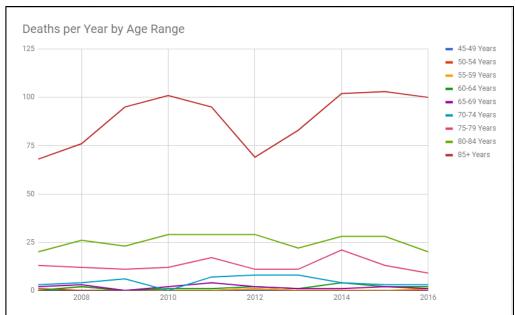


Figure 3. Wyoming Deaths per Year by Age Range

<sup>&</sup>lt;sup>5</sup> www.alz.org/facts/overview.asp



Figure 4. Wyoming Alzheimer's Mortality Rate

#### Cost of AD/RD in Wyoming

There are many costs for individuals with AD/RD and the care associated with these conditions. As far as settings in which individuals with AD/RD receive their care, costs vary. There is a spectrum of care beginning with informal family caregivers progressing up to 24-hour nursing facility care. The Alzheimer's Association estimates the total value of unpaid care received from these 28,000 unpaid caregivers for 32,000,000 hours of unpaid care provided to be \$400,000,000 in 2016.<sup>3</sup> Figure 4, below, compares the 2017 costs of formal care such as home health care, adult day health care, assisted living facility care, and nursing home care along with a projection of what those respective costs/settings will be in 2030. Costs for long-term care are rapidly rising.

> **Table 1**. 2017 and 2030 Wyoming State Median Annual (Private Pay) Price for Long-Term Care Options<sup>6</sup>

Year	Home	Home	Adult Day	Assisted	Nursing	Nursing
	Health	Health	Health	Living	Facility	Facility
	Homemaker	Homemaker	Care	Facility	(Semi-	(Private
	Services	Aide		(Private,	Private	Room)
				One-	Room)	ŕ
				Bedroom)		
2017	\$59,488	\$61,776	\$22,100	\$40,974	\$84,939	\$96,725
2030	\$87,360	\$90,720	\$32,455	\$60,172	\$124,736	\$142,044

<sup>&</sup>lt;sup>6</sup> 2017 Genworth Cost of Care Survey (https://www.genworth.com/about-us/industry-expertise/cost-of-care.html)

Many individuals will be unable to afford the astronomical costs of receiving care in the various aforementioned settings. Many will be eligible for and receive Medicaid benefits in order to cover the cost of this care.

> "There's a CNA that will go in and stay overnight with somebody but charges like \$20 an hour or \$40 an hour or something. Most people can't afford that. You can't. There is no way." - Caregiver in Ethete.

The Wyoming Community Choices Medicaid waiver is an option for individuals who require a nursing home level of care but choose to receive that care and support in an assisted living facility or in a home setting and qualify for the program based on income limits. In 2016, 2,372 Wyoming residents received Wyoming Community Choices waiver services. The total cost of those services to the State of Wyoming was \$39,439,729.00, approximately \$1,775 per member per month for these Medicaid services. Individuals can choose to receive these Medicaid waiver services in an assisted living facility or in their home. In 2016, 12% of the Wyoming Community Choices waiver recipients received services in an assisted living facility and 88% of the recipients received services in their home.

There is also the option to receive services in a nursing care facility with Wyoming Medicaid coverage for those who qualify based on income limits. In 2016, 62.8% of total nursing home residents in Wyoming were enrolled in Medicaid. The Medicaid payment for a nursing home resident, in 2016, was \$10,390.00 per member per month. Wyoming Medicaid's total nursing home expenditures, for 2016, were \$85,795,802.00.

The Wyoming Department of Health, Aging Division, State Plan for Aging Services provides a chart, reproduced in Figure 5, on the next page, of projected Medicaid members requiring long-term care until 2030. These projections would include nursing care facilities, assisted living facilities, and care provided in the recipients' home. Considering the previously stated current and projected costs of care in these settings the State of Wyoming will also incur increasing costs for Medicaid members requiring long-term care in the years to come.

6000 Medicaid long-term care population Total (projection) 5000 4000 3000 Long-Term Care (LTC) and Assisted Living Facility (ALF) waivers 2000 1000 Skilled nursing facilities (SNF) 2013 2015 2016 2012 2014 2017 2018 2019 2020 2025 2026 2011 2024 2027 Year

Figure 5. Projected Medicaid Members Requiring Long-Term Care<sup>7</sup>

Alternatives to private pay and Medicaid coverage are limited, leaving long-term care insurance. The Wyoming Department of Health, Aging Division's State Plan on Aging describes Wyoming's longterm care insurance market as "neither large nor robust". 5 The plan goes on to detail that purchasing of long-term care insurance in Wyoming has plateaued since the mid-2000s, as shown in Figure 6. Seemingly, this is not a dependable source of coverage for many individuals who currently, or may in the future, require long-term care.

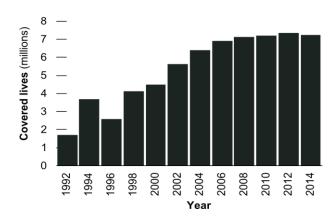


Figure 6. Total Covered Lives, Long-Term Care Insurance<sup>8</sup>

#### Availability of Medical Professionals in Wyoming

As of 2017, Wyoming ranks 48th nationwide in terms of primary care physicians per capita with 105.7 physicians per 100,000 residents. Wyoming's rural and frontier communities present a unique problem in that physicians are even fewer in these areas and more frequently located in larger communities.

<sup>&</sup>lt;sup>7</sup> https://health.wyo.gov/aging/communityliving/agingstateplan/

<sup>&</sup>lt;sup>8</sup> Center for Insurance Policy and Research. The State of Long-Term Care Insurance. May 2016.

http://www.naic.org/documents/cipr\_current\_study\_160519\_ltc\_insurance.pdf

<sup>9</sup> https://www.americashealthrankings.org/explore/2017-annual-report/measure/clinical\_care/state/WY

As of 2016 there are seven Board Certified Geriatricians in the state of Wyoming. To meet the needs of Wyoming's older adults, there need to be 38 geriatricians in the state. This deficit will only increase

in the coming years, as the American Geriatrics Society estimates the need for 59 geriatricians in Wyoming in 2030. 10 United Health Foundation states that "Geriatricians are specially trained to meet the unique needs of older adults in both outpatient and inpatient settings. Diseases and medications may affect older adults differently than younger adults. In inpatient settings, seniors receiving care in special geriatric units have better function at the time of discharge, and inpatient rehabilitative services involving geriatricians result in lower nursing home admissions and improved function at follow-up compared with standard care."8

"If they diagnose you or your family member, what do they tell you after that? If they diagnose you with cancer, they're gonna say, "Well, you need to go here, or there, or do this or that." But what about Alzheimer's?" -Healthcare Professional, Ethete

For Wyoming, these low rankings in primary care physicians and high need to have more specialized care means that the entire aging population does not have the appropriate level of medical care, let alone individuals with AD/RD.

#### **Existing Long-Term Care Structure in Wyoming**

Wyoming has many levels of care available to individuals requiring long-term care. Table 3, below, details the care types, services provided, coverage options, and limitations.

**Table 3.** Types of Care in Wyoming

Care Type	Services Provided	Coverage Options	Limitations
		Coverage Options	
Independent Senior Housing	Housing complexes, units, buildings that are specifically for seniors. Often times this type of housing offers communal dining and activities.	<ul> <li>Private pay</li> <li>Some may accept housing authority or section 8 payment</li> </ul>	No medical care is provided.
Non-Skilled In-Home Care	These services offer in-home, non-skilled care at an hourly rate. Services may include companionship, meals, transportation, respite care, etc.	<ul><li>Private pay</li><li>Some long-term care insurance</li></ul>	Does not include skilled care, such as skilled nursing, physical therapy, occupational therapy, or certified nursing assistant services.
National Family Caregiver Support Program	This program provides assistance to caregivers, 18 years and older, caring for persons who are 60 years and older or of any age with AD/RD.	This is a grant funded, Older Americans Act, program and all payment for services, by recipients, is donation.	Funding is limited, the program is not located in all counties in Wyoming.

<sup>10</sup> https://www.americangeriatrics.org/geriatrics-profession/about-geriatrics/geriatrics-workforce-numbers

Care Type	Services Provided	Coverage Options	Limitations
Wyoming Home Services	A program typically provided through senior centers or home health agencies. May provide services like care coordination, homemaking, personal care, nursing, respite care, personal emergency	Services are provided on a sliding scale basis.	Funding is limited, not all services are provided in all counties.
Licensed Home Health Care	response systems, etc.  An agency that provides skilled services, such as nursing, physical and occupational therapy, speech therapy, and certified nursing assistant services.	<ul><li>Medicare</li><li>Medicaid</li><li>Private Insurance</li><li>Private Pay</li></ul>	Could be fairly short term, depending on how much the pay source will cover.
Program of All-Inclusive Care for the Elderly (PACE)	For individuals who meet nursing home level of care, but would like to remain in their home. Services include onsite physician and medical personnel, nursing and social work, physical, occupational, and speech therapies, hospital and emergency care, prescription drug coverage and management, testing and diagnostics, meals, personal care, home care, adult day care, and transportation.	<ul> <li>Medicare (cost may vary)</li> <li>Medicaid</li> <li>Private Insurance</li> <li>Private Pay</li> </ul>	Coverage options are limited. Those who take part in PACE must use PACE physicians and medical services. Currently only available in Cheyenne.
Adult Day Care	A facility licensed by the Wy Department of Health, providing activities of daily living support and supervision services.	<ul><li>Medicaid Waiver Programs</li><li>Private Pay</li><li>Some private insurances</li></ul>	There are only 4 licensed adult day care facilities in Wyoming.
Community Choices Waiver	An option for individuals who meet nursing home level of care but wish to remain in their home or live in an assisted living facility. Services include personal care, skilled nursing, meals, assisted living care services, etc.	Medicaid Waiver Program	Must be Medicaid eligible.
Boarding Homes	Licensed by the Wyoming Department of Health. A house operated by a person or organization to provide rooms for rent and provide meals and personal daily living care, but not habilitative or nursing care.	<ul><li>Private pay for room</li><li>Medicaid</li></ul>	Care provided is limited. There are only 8 licensed boarding homes in Wyoming.

Care Type	Services Provided	Coverage Options	Limitations
Assisted Living Facilities	Licensed by the Wyoming Department of Health. Services provided include limited nursing care, personal care, meals, activities, and transportation. Some may have a level 2 secure unit for ADRD.	<ul><li>Medicaid Waiver Programs</li><li>Private Pay</li><li>Some private insurances</li></ul>	Care is limited. There are only 5 assisted living facilities that have a level 2 secure unit.
Skilled Nursing Facility	Licensed according to state and federal rules and regulations. Services include 24 hour care, nursing, therapies, certified nursing assistants, activities, laundry, etc. Some skilled nursing facilities have secure units for individuals with ADRD.	<ul><li>Medicare</li><li>Medicaid</li><li>Private Pay</li><li>Private insurances</li></ul>	There are 14 skilled nursing facilities in Wyoming that have secure units.
Hospitals	Licensed by the Wyoming Department of Health. Providing inpatient acute care, emergency care, rehabilitation, psychiatric care, swing beds.	<ul><li>Medicare</li><li>Medicaid</li><li>Private Pay</li><li>Private insurances</li></ul>	Not a long-term option.
Hospice	A program that may provide in-home or institutional care for individuals that are terminally ill and their families. Services include medical, palliative, psychological, spiritual, and supportive care and treatment.	<ul><li>Medicare</li><li>Medicaid</li><li>Private Pay</li><li>Private insurances</li></ul>	Must be terminally ill.

While Table 3 shows many types of care, pay sources and other limitations continue to be a barrier for individuals to access these types of care. As stated in the previous section regarding population projections, it may be correct to assume that these current options may not be able to accommodate the rapidly increasing long-term care needs of Wyoming's residents.

#### Guardianship and Legal Representation in Wyoming

Many Wyoming residents with Alzheimer's disease or a related dementia have been determined to not have decision making capacity by their primary care physician and have in place an acting power of attorney or a court appointed guardian. Some Wyoming residents have family or friends that serve in this capacity. Approximately 200 Wyoming residents receive professional guardianship services through Wyoming Guardianship Corporation; of these, 93 live in nursing homes or assisted living facilities. At times a Wyoming resident may not have friends or family available to serve as a legal representative, which is when a professional guardian would facilitate care. Wyoming currently has one non-profit entity offering professional guardianship services for all of Wyoming, Wyoming Guardianship Corporation. Unfortunately, Wyoming Guardianship Corporation has reached their maximum level of people who can be served. They are currently holding a waiting list of 25 people;

56% of those on the waiting list are adults over the age of 60, and 36% of those on the waiting list live in a nursing home or assisted living facility.

Individuals with AD/RD will lose decision-making capacity at some point. If there is no one to serve these individuals in making important life decisions for them, they may go without needed services, like: medical services, social services, and advocacy services; services that every person deserves in order to live a dignified life. With the aged dependency ratio, explained above, decreasing, there will also be a likely increase in the need for professional guardianship services.

#### Current Initiatives and Resources in Wyoming

There are multiple AD/RD initiatives currently happening in Wyoming, these are summarized below:

#### Dementia Friendly Wyoming

The Hub, Sheridan's Senior Center, received a grant in 2016 to work towards a Dementia Friendly Community, and to eventually spread this information across Wyoming. The history of Dementia Friendly Wyoming is explained below:

"...through the development of Green House Living for Sheridan, the community showed its commitment to elders, creating a nurturing environment where elders continue to live with hope and social engagement. This vision is now evolving to our neighborhoods and public places where 60% to 70% of those living with dementia still live at home. The Center for Vital Community took this to the next step by hosting the Dementia Circles which invited citizens to participate in developing initiatives in moving forward. Due to the effort and time of many caring people to write a grant proposal representing these initiatives, The Hub, Sheridan's Senior Center, became the recipient of a three-year federal grant to strengthen Sheridan's community support for those living with dementia and their care partners.

For the next three years and beyond, Sheridan will create innovative opportunities in community settings and organizations for those living with dementia and their care partners and then share it with communities across Wyoming."<sup>11</sup>

Currently, the project is based in one county in Wyoming, Sheridan County. In the future, the information and experience the project has gained will be shared with the remainder of Wyoming. The Alzheimer's State Plan has identified Dementia Friendly Wyoming as a key partner in working on recommendations and meeting future goals of the plan.

#### Alzheimer's Association--Wyoming Chapter

The Alzheimer's Association--Wyoming Chapter, provides a comprehensive continuum of community-based programs and services to meet the increasing need for Alzheimer's disease care and support throughout Wyoming. Through the Alzheimer's Association's cost-free 24/7 Helpline, people can call toll-free to speak with a trained care consultant who can help with decision-making support, information & referral services, crisis assistance, and education on issues that families face every day. Also available are 24/7 online services with help for any aspect of the disease.

<sup>11</sup> http://www.dfwsheridan.org/history-dementia-friendly-wyoming

Local care consultations are also free and comprise an assessment of a person's situation and creation of an action plan for managing life with the disease. Delivered by telephone or in-person, care consultations help families to better manage care and make informed decisions. Throughout Wyoming, Support Groups are conducted by volunteers trained and supported by the Alzheimer's Association. Participants learn more about dementia and discuss their feelings and concerns in a confidential and supportive environment. Community education programs covering all aspects of the disease for people with dementia are also provided.

To further enhance the quality of life for many more American families who are living with Alzheimer's, the Alzheimer's Association leverages the power of federal and state governments by motivating policymakers to take action.

The Alzheimer's Association is proud to be the largest private, non-profit funder of Alzheimer's science in the world. They are dedicated to stepping up research in dramatic ways that will lead to earlier diagnosis, improved treatment and, one day, realization of their vision of a world without Alzheimer's.

#### Wyoming Center on Aging

The University of Wyoming Center on Aging (WyCOA) creates and delivers education and community-based programs to provide healthcare professionals, older adults, families, and caregivers with the knowledge and skills to improve the health and quality of care of older adults in Wyoming. Alzheimer's disease and related dementias are a specific focus of WyCOA. WyCOA has two evidencebased programs for dementia caregivers, Our Family Journey and SHARE, offered in various locations statewide. Education opportunities include On-the-Road Alzheimer's disease workshops, the Rocky Mountain Alzheimer's Summit, an annual Dementia Caregiver Webinar Series, the online Dementia Care Certificate program, and the UW ECHO in Geriatrics for healthcare professionals. ECHO (Extension for Community Healthcare Outcomes) is an online platform for case consultation and comanagement of challenging cases, to build provider expertise in a specific condition. The UW ECHO in Geriatrics provides Wyoming healthcare professionals with access to an interprofessional team of geriatric specialists including a geriatrician, geriatric psychiatrist, geriatric pharmacist, neurologist, social worker, physical therapist, and speech therapist. Providers who present cases are provided with evidence-based recommendations to inform their care of the presented individual. WyCOA has also created regional Dementia Resource Guides to assist caregivers, friends, and healthcare professionals. To download a Resource Guide or learn more about the education and programs available through WyCOA please visit www.uwyo.edu/wycoa or call (307) 766-2829.

#### **AARP Wyoming**

AARP has been involved in a number of initiatives and activities to support, protect, educate, and advocate on behalf of those with Alzheimer's and related dementias and their families and caregivers.

#### **CARE ACT** communications

In March of 2016, Wyoming became the 21st state in the nation to pass the Caregiver Advise, Record, Enable (CARE) Act. House Enrolled Act 27 – The Designated Caregiver Act, requires hospitals to:

- Record a caregiver's name on the medical record of their loved one;
- Inform caregivers when their loved one is to be discharged to another facility or back home; and,

Give caregivers education and instruction of the medical tasks they will need to perform at home, like managing medication or giving injections.

In 2018, AARP partnered with the Wyoming Hospital Association, the Wyoming Department of Health, and others to promote the requirements of the CARE Act to caregivers, healthcare providers, and those who work in admissions and discharges in Wyoming hospitals and clinics.

#### Radio Partnership

Starting in the fourth quarter of 2017, AARP Wyoming and the Alzheimer's Association--Wyoming Chapter began a partnership in which the two organizations share a 30-minute segment on KFBC Radio in Cheyenne twice-a-month. The focus of these programs is issues important to older Wyomingites such as tips for caregivers. AARP Wyoming, which pays for the airtime, also takes that subject matter on radio stations in Sweetwater and Campbell Counties once-a-month.

#### Elder and Vulnerable Adult Task Force

The Governor's Task Force on Elder and Vulnerable Adult Abuse, formed in February of 2016, released a list of seven recommendations to help curb elder abuse on January 20, 2017. In the 2017 Legislative session, the Task Force recommended passage of the Uniform Power of Attorney Act. This law, aimed at protecting vulnerable individuals from exploitation, updated Wyoming's laws and provided clarity, a comprehensive set of guidelines, and heightened protections. In the 2018 Legislative session, the Task Force asked the legislature to update the statutory definition of "vulnerable adult." Ultimately the bill failed, but will be brought again next session and be a possible interim study topic.

#### **Caregiving Resources**

AARP's national website offers several pages and programs devoted to caregivers of those suffering from a number of ailments, including Alzheimer's. Among the resources are financial and legal help, such as information about advanced directives, care cost calculators; caregiver basics; and tips for taking care of a loved one at home. Those resources can https://www.aarp.org/caregiving/.

#### Wyoming Dementia Care

Wyoming Dementia Care provides support through free direct services to caregivers of those with a dementia diagnosis. The tasks of caregiving can feel overwhelming, and the staff at Wyoming Dementia Care can help. By seeking solutions together to improve the quality of life for caregivers, the lives of care-receivers are improved as well. Wyoming Dementia Care focuses on supportive services to educate caregivers and connect them to valuable resources in the Natrona County area.

Wyoming Dementia Care offers immediate care planning services and disease education from the initial diagnosis and then a continuum of care support through end-of-life decisions. Services include care planning, counseling, support groups, outreach in the community, and a dementia-focused art class. All services are free to caregivers because the founders, board of directors, and staff of Wyoming Dementia Care believe the burden of caregiving should be eased without the burden of additional costs to the dedicated family members and spouses who spend their days and nights caring for loved ones with a dementia diagnosis.

#### GOALS AND RECOMMENDATIONS

The town hall meetings informed the Work Group of primary themes. Four subcommittees convened and developed goals and recommendations based upon these themes, as well as additional research and expert advice. These goals, recommendations, and action steps are stated below. Each recommendation has been identified to be a short-term, intermediate, or long-term recommendation for the workgroup.

#### Goal #1: Maximize awareness and understanding of AD/RD.

#### Short-Term

- Create public service announcements about AD/RD and the Alzheimer's State Plan that can be shared with news media around Wyoming.
- Coordinate with organizations that are currently working to reduce risk factors for other chronic diseases, to incorporate similar work for AD/RD.

#### Intermediate

Educate the faith-based community and public and private organizations to better recognize and have an increased understanding of AD/RD.

#### Long-Term

- Create, publicize, and maintain support groups and evidence-based interventions for people living with dementia and their caregivers.
- Engage community partners in distributing information about the differences between normal aging-related memory changes and early signs of a possible dementia.

Key Partners: AARP Wyoming, Alzheimer's Association, Wyoming Center on Aging, Dementia Friendly Wyoming, Wyoming Department of Health Public Health, and Wyoming Senior Centers.

#### Goal #2: Create a central point of access for information and referral.

#### **Short-Term**

- Educate the public on the www.ADRCWyoming.org website as a resource for services and supports for those with AD/RD and their caregivers.
- Maintain, promote, and distribute the Wyoming Center on Aging Dementia Resource Guides.
- Educate health providers, social services providers, and first responders on the www.ADRCWyoming.org website as a resource for services and supports for those with AD/RD and their caregivers.
- Work with the Wyoming Department of Health, Aging Division to enhance their website to include a section referring individuals with AD/RD, their families, caregivers, and interested parties to the www.ADRCWyoming.org website.

Key Partners: Wyoming 211, Alzheimer's Association, Wyoming Center on Aging, Wyoming Department of Health Aging Division, and Wyoming Senior Centers

#### Goal #3: Improve coordination among providers across care settings in which individuals with AD/RD take part.

#### **Short-Term**

Promote and educate individuals with AD/RD, their caregivers, and medical professionals across the state regarding the CARE Act.

#### Intermediate

Research and implement evidence-based methods to improve communication among providers across care settings in which individuals with AD/RD take part.

#### Long-Term

Research and offer evidence-based educational activities regarding dementia care for primary care providers.

Key Partners: Wyoming Department of Health Public health, Alzheimer's Association, Wyoming Primary Care Association, Wyoming Center on Aging, Wyoming Senior Centers, Wyoming Law Enforcement, Emergency Responders, Wyoming Long-Term Care Ombudsman Program, Leading Age Wyoming, Wyoming Health Care Association.

#### Goal #4: Improve access to long-term care residential facilities, which specialize in care for those with AD/RD.

#### Long-Term

- Increase the number of long-term residential care communities and the capacity and competency of existing facilities in rural areas through recruitment of facilities.
- Increase the number of long-term residential care communities and the capacity and competency of existing facilities in rural areas through reduction of regulatory barriers to business operations and staffing.

The workgroup has identified this goal and both recommendations as long-term steps.

Key Partners: Department of Health Aging Division, Department of Health Healthcare Financing Division, Leading Age Wyoming, Wyoming Health Care Association, Wyoming legislature, Wyoming Business Council, AARP, professional nursing and medical societies, medical professional boards, University of Wyoming, Wyoming community colleges, Climb Wyoming.

#### Goal #5: Increase access to funding, to expand services that individuals with AD/RD use.

#### Intermediate

Inform decision makers/policy makers as to the current and future status of Wyoming's increasing aging population and needs for individuals with AD/RD.

#### Long-Term

Explore the feasibility of the Wyoming Community Choices Waiver to allow greater flexibility in coverage of adult daycare and group respite services.

Using the Alzheimer's State Plan, as well as the Wyoming State Plan on Aging, education of the Wyoming Legislature is an intermediate goal. Changes in the Wyoming Community Choices waiver is a long-term goal, as the work group does not have immediate control over this system.

Key Partners: Wyoming Department of Health Aging Division, Wyoming Department of Health Division of Healthcare Financing, Wyoming Governor's Office, Wyoming Legislature.

#### Goal #6: Expand Wyoming's ability to provide individuals with AD/RD, who are near the end-of-life, with high-quality, palliative focused care.

#### Intermediate

- Partner with the Governor's Council on Palliative Care to identify and implement palliative care policies and practices that will benefit individuals with AD/RD and their caregivers/families.
- Educate health care providers on the importance of having open, honest, and compassionate conversations with individuals, family members, and caregivers regarding prognosis and treatment options in the later stages of AD/RD.

#### Long-Term

Launch a public awareness campaign regarding the importance of discussing advanced directives and end-of-life wishes early in the AD/RD disease process to involve the individual with AD/RD in the decision-making process.

Key Partners: Department of Health Aging Division, Governor's Council on Palliative Care, Wyoming Primary Care Association, Dementia Friendly Wyoming, Wyoming Medical Society, AARP Wyoming, Wyoming Center on Aging.

Goal #7: Ensure that Wyomingites with AD/RD, their families, and caregivers are aware of, and have access to, Wyoming-specific materials regarding legal and financial resources for decision-making upon incapacity.

#### **Short-Term**

- Work with Legal Aid of Wyoming to develop a legal and financial awareness packet for individuals with AD/RD and their caregivers and include information to access to a recorded webinar in this packet.
- Provide access to this legal and financial awareness packet on the www.ADRCWyoming.org website.

#### Intermediate

- Distribute this legal and financial awareness packet to healthcare providers throughout Wyoming to provide to their patients with AD/RD and their caregivers.
- Research and allocate resources to expand the option for public professional guardianship for individuals with AD/RD, for those who do not have access to a family member or friend who can serve as a legal representative.

Legal Aid of Wyoming has expertise in these areas; the recommendation begins by contacting and working with them in the short-term, in order to create the stated resource. Providing access to the packet via the web takes place in the short-term. Distributing this information statewide requires a more intermediate timeframe. Researching and allocating viable resources in order to expand the option of professional guardianship for those who need it will take more time, and has therefore been identified as an intermediate recommendation.

Key Partners: Legal Aid of Wyoming, Wyoming Bar Association, Elder Justice Wyoming, AARP Wyoming, Alzheimer's Association, Wyoming Center on Aging, Department of Health Aging Division, Association of Elder Law Attorneys, Wyoming Guardianship Corporation.

Goal #8: Develop and maintain a professional workforce that has the awareness, knowledge, and skills to care competently for persons living with AD/RD and their caregivers.

#### Long-Term

- Research, identify, and select strategies to increase and maintain the number of Certified Nursing Assistants working in long-term care in Wyoming.
- Develop tuition assistance for rural-based dementia care providers.
- Investigate and recommend AD/RD specific evidence-based programming for medical providers, first responders, law enforcement, financial services, pharmacies, and other businesses in communities to support individuals with AD/RD and their caregivers.

Wyoming Department of Health, Wyoming Hospital Association, Wyoming Department of Workforce Services, Wyoming Department of Health Aging Division, Wyoming Center on Aging.

#### PLANNING FOR THE FUTURE

The Wyoming State Plan to Address AD/RD is a living document. Activities completed by the work group and identified stakeholders will be structured according to the short, intermediate, and long term timeframes assigned to recommendations. These timeframes have not been assigned specific dates or lengths of time, they are arranged so the work group and stakeholders can begin with the short-term and progress through the intermediate and long-term. The work group will produce periodic, and as needed reports to inform interested parties as to any new information on the subject Reports will include any work that has been accomplished in the previous year.

Appendix A

Glossary of Terms

#### **GLOSSARY OF TERMS**

Alzheimer's Disease Initiative Supportive Services: The Sheridan Senior Center in Sheridan, Wyoming was one of eleven national recipients of the AoA/ACL Alzheimer's Disease initiative grants. The Center was awarded a \$1.1 million dollar grant over three years and plans to expand and significantly strengthen Sheridan County's capability for individuals with dementia and their caregivers by improving awareness, providing early diagnosis and access to services, and improved quality of life. The Center plans to focus on the following objectives: creating communities where people living with dementia feel accepted and understood; encouraging meaningful activity and social interaction while reducing risks and providing quiet, safe spaces; assuring integration of care across health and social services; people living with dementia and their families can receive initial and ongoing support; and involving, including, and caring for those living with dementia.

Caregiver: Anyone who provides care to a person with Alzheimer's disease or related dementias. Caregivers can be family members, friends, or paid professional caregivers. Caregivers may provide full or part-time help to the individual with dementia.

Chronic disease: According to the U.S. National Center for Health Statistics, a chronic disease is one persisting for a long time (usually three months or more) and generally cannot be prevented by vaccines or cured by medications, nor do the symptoms disappear on their own. Health-damaging behaviors, particularly tobacco use, lack of physical activity, and poor eating habits, are major contributors to chronic disease.<sup>12</sup>

**Dementia:** Dementia is not a specific disease. Instead, dementia describes a group of symptoms associated with a decline in memory, thinking, and social abilities severe enough to reduce an individual's ability to perform everyday activities. Alzheimer's disease is the most common type of progressive dementia in older adults, yet there are a number of types of dementia.<sup>13</sup>

Do Not Resuscitate (DNR) Order: A DNR order, signed by a health care provider based on a patient's wishes, instructs medical personnel not to perform life-saving CPR or other procedures to restart the heart or breathing once they have ceased. Once signed, the DNR directive must be placed in the patient's chart. This sometimes takes the form of a Physician Order for Life Sustaining Treatment (POLST). The POLST form is often more detailed than a DNR order and also includes an individual's wishes regarding how aggressive to be with care (ICU or not, for example) and use of feeding tubes.

Geriatric Assessment Clinic: A clinic dedicated solely to the evaluation and management of medical conditions in older adults, including dementia. These clinics usually help develop a comprehensive plan of care that addresses the individual's medical, cognitive, and functional needs.

Geriatricians: Physicians concerned with the diagnosis, treatment, and prevention of disease in older adults. They specialize in managing conditions specific to aging, including dementia.

Guardian: Guardianship is established by a court order. The court grants the guardian authority and responsibility to act on behalf of another person. The relationship is fiduciary, which means that the guardian is obliged to act in the best interest of the individual for whom he/she is a guardian.

<sup>&</sup>lt;sup>12</sup> https://www.medicinenet.com/script/main/art.asp?articlekey=33490

<sup>13</sup> https://www.alz.org/what-is-dementia.asp

**Hospice:** A hospice program offers support for dying individuals to live as fully and comfortably as possible. Hospice care is generally provided to individuals with a life expectancy of six months or less. Rather than seeking a cure, hospice care aims to make an individual's remaining time as comfortable and as meaningful as possible. Hospice is a Medicare benefit.

Long-term care facility: A long-term care facility is a nursing home or assisted living center designed to provide a variety of services, including both medical and personal care, to individuals who are unable to manage independently in the community. Many residents in long-term care facilities have dementia.

Medicaid: Medicaid is a joint federal and state program that helps with medical costs for qualified individuals with limited income and resources. Medicaid can also provide benefits not normally covered by Medicare, including long-term nursing home care and personal care services.

**Medicaid waiver:** States can use the waiver process to test new or existing ways to deliver and pay for healthcare services in Medicaid and the Children's Health Insurance Program (CHIP). There are four primary types of waivers and demonstration projects, one of which is the Section 1915(c) Home and Community-Based Services Waiver.

Medicare: Medicare is a federally-funded government health insurance program for people aged 65 and older and for certain younger individuals with disabilities.

**PACE:** The Program of All-Inclusive Care for the Elderly (PACE) provides comprehensive medical and social services to certain frail, community dwelling elderly individuals, most of whom are eligible for both Medicare and Medicaid benefits. An interdisciplinary team of health professionals provides PACE participants with coordinated care. For most participants, the comprehensive service package enables them to remain in the community rather than receive care in a nursing home.

Palliative care: Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.<sup>14</sup>

Person-centered care: This term refers to health care and social services designed to reflect the individual's unique preferences, values, and needs, identified and agreed upon in partnership with the medical providers, the patient, and other family members, when appropriate. The goal is for people to be treated as individuals and to receive appropriate and timely care that meets their needs.

**Power-of-attorney form:** A power of attorney form is a legal document designating someone to act on someone's behalf when making major decisions such as medical and financial decisions when the individual is unable to make those decisions him/herself.

Respite care: Respite care provides a caregiver temporary relief from the responsibility and stress of caring for individuals with chronic physical or mental disabilities. Examples of respite care include inhome assistance, a short or long-term care facility stay, or day care programs for adults.

<sup>&</sup>lt;sup>14</sup> http://www.who.int/mediacentre/factsheets/fs402/en/

Rural communities: For the purposes of this plan, rural communities in Wyoming were those with a total population of less than 25,000.

Urban communities: For the purposes of this plan, urban communities in Wyoming were those with a total population of more than 25,000.

# Appendix B

Wyoming Alzheimer's State Plan Task Force Needs Assessment Results

Please contact the Wyoming Center on Aging for Needs Assessment results at www.uwyo.edu/wycoa