

## 8: Appendices

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# Appendix A: Needs Assessment Survey

Please take a few minutes to share your experience and suggestions about how to improve the services and resources available in Montana to support persons with Alzheimer's disease or related dementias.

1. What is your year of birth? \_\_\_\_\_
2. What is your zip code? \_\_\_\_\_
3. What is your gender? \_\_\_\_\_ Female \_\_\_\_\_ Male
4. Which of the following best describes you? (please select only one)
  - \_\_\_\_\_ Person with Alzheimer's disease or dementia
  - \_\_\_\_\_ Spouse or partner of person with Alzheimer's disease or dementia
  - \_\_\_\_\_ Son, daughter, or other family member of a person with Alzheimer's disease or dementia
  - \_\_\_\_\_ Non-family caregiver of a person with Alzheimer's disease or dementia
  - \_\_\_\_\_ Health-care provider
  - \_\_\_\_\_ Social service provider
  - \_\_\_\_\_ Public employee or official
  - \_\_\_\_\_ Other, please specify \_\_\_\_\_
5. Do you provide home-based care for someone who has Alzheimer's disease or dementia?
  - \_\_\_\_\_ Yes
  - \_\_\_\_\_ No
  - a. If Yes, how many hours do you care for this individual PER WEEK? \_\_\_\_\_
  - b. If Yes, what type of health insurance does the person you care for currently have? (*check all that apply*)
    - \_\_\_\_\_ Medicare
    - \_\_\_\_\_ Medicaid
    - \_\_\_\_\_ Veteran's benefits
    - \_\_\_\_\_ Private insurance
    - \_\_\_\_\_ They do not have any health insurance
    - \_\_\_\_\_ Other, please specify \_\_\_\_\_

6. Identify the three (3) most pressing needs in Montana for persons impacted by Alzheimer’s disease or other dementia. (Please rank items from 1 to 3 with “1” indicating most pressing.)

- \_\_\_\_\_ Information about the types of services available and how to use them
- \_\_\_\_\_ Access to services
- \_\_\_\_\_ Quality of services
- \_\_\_\_\_ Affordability of service
- \_\_\_\_\_ Support for families and caregivers
- \_\_\_\_\_ Education and training
- \_\_\_\_\_ Other, describe \_\_\_\_\_

Based on your experiences in Montana, please indicate your satisfaction with the following aspects of services and information available to individuals with Alzheimer’s disease or other dementias.

Place an “x” in the appropriate box for each item. 1 = very dissatisfied, 4 = very satisfied

	1	2	3	4	Don’t know
Access to services					
Quality of services					
Affordability of services					
Support for families and caregivers					
Education and training					
Information about the types of services available					
Information about how to use available services					

What recommendations do you have about how to improve the services and resources in Montana that are available to persons with Alzheimer’s disease or dementia? Please be as specific as possible about what you would like to see happen.

## Survey Data Results

### 1. Did you attend a Town Hall meeting?

Yes	204	71%
No	82	29%

### 2. Survey respondents county of residence

<u>County</u>	<u>Number</u>	<u>(%)</u>	<u>County</u>	<u>Number</u>	<u>(%)</u>
* Cascade	46	16.4%	Prairie	3	1.1%
* Yellowstone	41	14.6%	Rosebud	3	1.1%
* Gallatin	35	12.5%	Golden Valley	2	.7%
* Missoula	30	10.7%	Lincoln	2	.7%
Valley	24	8.5%	Musselshell	2	.7%
Flathead	18	6.4%	Park	2	.7%
Pondera	13	4.6%	Beaverhead	1	.4%
Lewis & Clark	9	3.2%	Carbon	1	.4%
Custer	8	2.8%	Deer Lodge	1	.4%
Fergus	5	1.8%	Granite	1	.4%
Jefferson	5	1.8%	Hill	1	.4%
Ravalli	5	1.8%	Natrona	1	.4%
Silver Bow	5	1.8%	Powell	1	.4%
Liberty	4	1.4%	Roosevelt	1	.4%
Dawson	3	1.1%	Stillwater	1	.4%
Lake	3	1.1%	Toole	1	.4%
Phillips	3	1.1%	* Urban		
			Rural		

### 3. Which characteristic best describes you?

	<u>Number</u>	<u>(%)</u>
One with Alzheimer's	8	3%
Family of One with Alzheimer's	142	50%
Caregiver of One with Alzheimer's	16	6%
Professional Service Provider	86	31%
Public Employee or Official	26	9%
Not Specified	4	1%

### 4. Do you provide home-based care for someone with Alzheimer's or dementia?

Yes	71	25%
No	213	75%

**5. If yes, what type of health insurance does the person you care for have?**

<b>Health Insurance</b>	<b>Number</b>	<b>(%)</b>
Medicare	57	80%
Medicaid	9	13%
Veteran's Benefits	13	18%
Private Insurance	36	55%
They do not have insurance	3	4%
Other	9	13%

**6. What are the most pressing needs in Montana?**

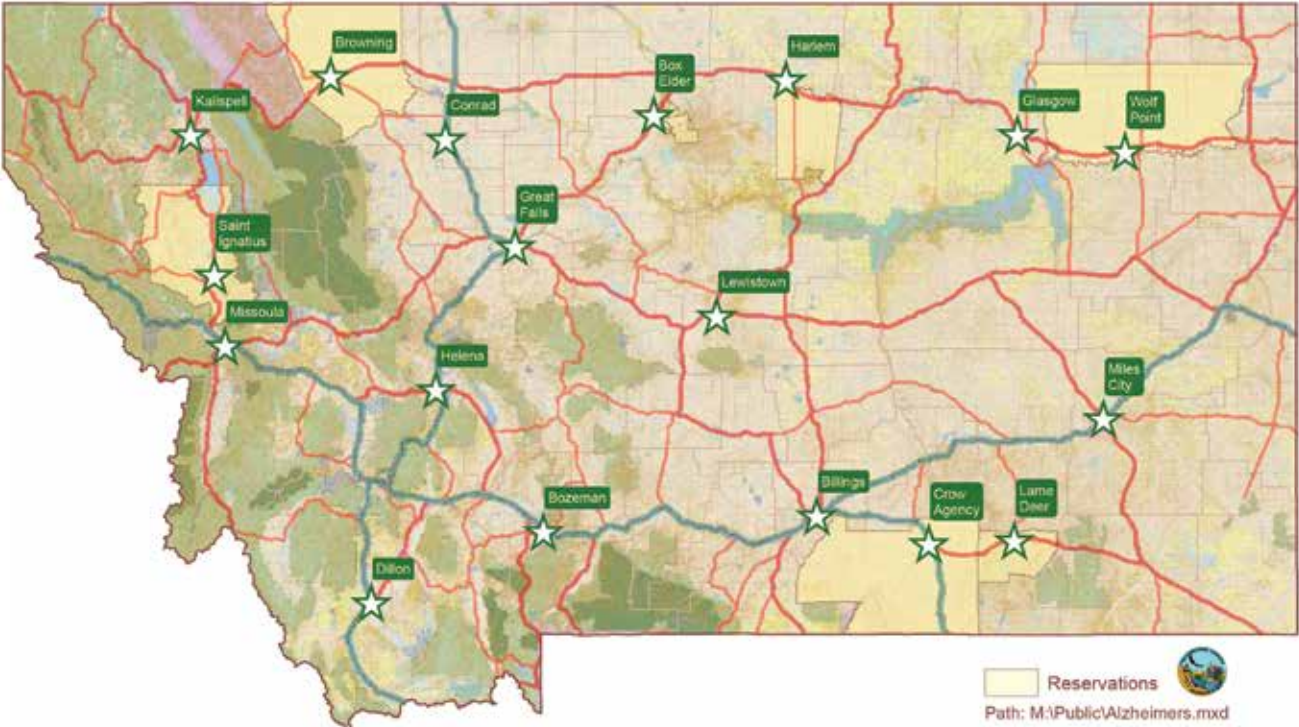
<b>Needs</b>	<b>% of 1st</b>	<b>% of 2nd</b>	<b>% of 3rd</b>	<b># Prioritized (1, 2, or 3)</b>
Information about types of services available and how to use them	40%	13%	6%	171
Access to services	29%	12%	14%	154
Quality of services	19%	10%	6%	98
<b>Affordability of services</b>	37%	13%	12%	178
Support for families and caregivers	29%	18%	13%	172
Education and training	25%	11%	11%	133

**7. What is your level of satisfaction with the following aspects of services and care?**

<b>Cell Percentages</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>Don't know</b>
Quality of services	13%	28%	25%	4%	30%
Affordability of services	7%	21%	29%	12%	32%
Support for families and caregivers	26%	25%	16%	2%	30%
Education and training	16%	30%	20%	4%	30%
Information about the types of services available	12%	38%	17%	5%	28%
Information about how to use available services	14%	37%	16%	3%	30%

# Appendix B: Map of Montana Town Hall Meetings

Montana Cities Served



# Appendix C: Cultural Considerations in Residential Care Facilities

The following areas are examples of how to create comfortable environments for inclusion of all types of individuals.

**Intake Forms and Documentation**—Because the intake process and forms are often a first encounter for individuals and families, they can be powerful tools in creating a safe and affirming space.

In a safe and confidential space, make sure to ask the individual of their race and cultural preferences as well as sexual orientation and gender identity. If they prefer not to disclose, be respectful. In lieu of terminology such as “husband” or “wife,” use “partner,” “significant other,” and/or “domestic partner” in addition to the traditional “husband” and “wife.”

In lieu of terminology for gender restricted to “male” or “female,” also have a box/line dedicated to “they,” “FTM (female to male),” “MTF (male to female),” as well as a blank line for individuals to self-identify. Transgender and gender non-conforming clients should feel that their gender identity is respected. Ask a client’s gender pronoun and make sure to respect the response. Mis-gendering someone can have devastating impacts.

Modify the definition of “family” to extend to non-biological family and allows clients to assign who their family is. This could be a domestic partner, significant other, and/or friends who have been a significant support in their lives.

**Training**—Provide a welcoming and affirming environment by offering culturally competent training to employees to ensure respectful and dignified care is being delivered.

There are many resources available for training programs for specific populations such as lesbian, gay, bisexual, or transgender (LGBT).

**Facility Accommodations**—Policies and practices written into a facility’s by-laws can shape an individual’s sense of safety, and the overall care.

Establish a Non-Discrimination Policy within the facility that declares protections for individuals based on their sexual orientation, gender identity and gender expression, as well as race and other defining characteristics. This can extend to both employees and residents. This sets a precedent for quality care and reaffirms a safe space.

Consider allocating a “Cultural Liaison” to ensure policies are being followed and culturally-appropriate programs are offered.

Consider a cultural support group for residents to come together and feel safe.

Specifically for LGBT residents, consider inclusive signage posted on the door/window to signify the facility is LGBT-inclusive and affirming.

Also, gender neutral restrooms for transgender and some gender non-conforming individuals, including the clients and family and friends who may be visiting them provides a safer and more welcoming accommodation.

Allow residents to dress and accessorize in accordance with their gender or race identity. Assess whether a transgender patient is using hormone replacement therapy, and ensure that staff is informed on how to administer it as needed.

Practices should be in place to ensure partners, friends, or family members in minority populations can visit without the fear of discrimination or mistreatment.

Assure that all staff and caregivers understand the modified definition of family and understand that all are welcome to visit patients.

# Appendix D: Stages of Dementia

Developed by the Montana Alzheimer's/Dementias Work Group

## Dementia Stages and Characteristics

## Needs

### Stage 1: Normal Aging

- No deficits
- May be more inclined for workup/prevention if there is a strong family history of dementia.

### Clinical Stage: Normal/Preclinical

Wellness and risk-reduction

General wellness and brain health

Advance Planning with help from experts in:

- Legal documents
- Financial (long term care insurance)
- Plan for aging/long term care planning
- End of life wishes

### Stage 2: Possible Mild Cognitive Impairment

- Personal awareness of cognitive decline that may be affecting daily life.
- Self-reported symptoms may not be recognizable by friends/family/coworkers or evident on medical exam.

### Clinical Stage: Mild Cognitive Impairment

### Above needs as well as:

- Wellness and risk-reduction
- Public awareness/Education
- Knowledge of early signs of dementia and what to expect
- Community members are comfortable talking about aging and dementia
- Knowledge of community resources
- Begin building dementia-friendly communities so citizens are comfortable and competent to support individuals with dementia and their families and everyone knows where to go for resources
- Advance Planning/Long-term care planning
- Aging in place plan including accessibility, safety, and security issues
- Personal wishes for aging
- Review of unpaid and paid caregiver options
- Skilled medical provider cognitive examination to evaluate potential causes of memory loss
- Consider joining a memory loss registry



### Stage 3: Mild Dementia

- Friends/family/coworkers may begin to notice deficits.
- Problems may be measurable with cognitive testing
- Social and work performance issues
- Decline in ability to plan/organize
- Word-finding difficulty

### Clinical Stage: Mild Dementia

### Above needs as well as:

#### *Public awareness/dementia friendly communities*

- Protocols in place for employees who may have concerns about a coworker's cognitive ability
- Employers support employees in caregiving roles

#### *Medical care*

- Skilled medical provider cognitive examination to diagnose dementia
- Diagnosis discussion includes individual and caregiver/family
- Educate on trajectory of disease
- Education regarding appropriate community resources
- Develop pathways for diagnosis and post-diagnosis care individualized to each patient
- Referral to a neurologist or other specialist if warranted

#### *Caregivers*

- Caregiver support groups
- Knowledgeable about available resources
- Training in managing dementia at home
- Home and community-based services
- Services provided in a consistent and coordinated fashion
- Adult day care
- Advance planning/Long-term care planning

#### *Research*

- Public is knowledgeable about available research studies
- Support ongoing research studies
- Encourage more dementia studies in Montana

#### *Training*

- Offer continuing education/certification option for direct-care workers
- Offer training for first responders on how to best handle individuals with ADRD

#### *Policy implications*

- Collect public health surveillance data on dementia through BRFSS
- Create policies to support caregivers
- Conduct a formal needs assessment to fully assess the financial impact and burden of disease in communities to effectively develop appropriate policies and determine workforce shortages
- Support incentives for health care workers to pursue careers in geriatrics

### Stage 4: Moderate Dementia

- Clear cognitive deficits
- Impaired short term memory
- Difficulty with simple math
- Decreased capacity to perform complex tasks i.e. cooking, cleaning, managing finances, driving
- Reduced memory of personal history
- Possible personality changes
  - More subdued and withdrawn
  - Agitated in challenging situations

### Clinical stage: Moderate Dementia

### *Public awareness/dementia friendly communities*

- Improve public safety of individuals with dementia who wander
- Review of driving safety issues

### *Medical care*

- Skilled medical provider cognitive examination to make diagnosis of dementia, if not already done

### *Caregivers*

- Support groups
- Respite care
- Advance planning/Long-term care planning
- Consider legal protective actions such as payee and guardianship/conservatorship roles with help for legal services
- Re-review plan for aging and initiate long term care planning, if not already done

### *Home and community-based services*

- Adult day care
- Meals on Wheels
- Senior center meal sites
- Personal care assistance through in-home care including; dressing, bathing, medication administration, housekeeping, laundry, grocery shopping, and meal preparation
- Transportation
- Assisted living

### *Policy implications*

- Provide affordable assisted living options by increasing reimbursement through Medicaid waiver and increasing the number of Medicaid waiver slots
- Improve wages for direct care workers

### Stage 5: Moderately Severe Dementia

- Major gaps in memory
- Confused about time/date and place
- May need assistance with some activities of daily living, i.e. dressing

### Clinical stage: Moderate Dementia

- Diagnosis of dementia made if not done already
- Whether at home or in a facility, care is provided by an interdisciplinary team of medical providers i.e. social workers, occupational therapists, physical therapists, speech therapists, nursing

### *Caregivers*

- Advance planning/Long-term care planning
- Review end of life wishes
- Re-review long term care plan
- Consider increased home and community-based services
- Consider placement in a memory care assisted living or nursing home

### Stage 6: Severe Cognitive Impairment

#### (Moderately severe dementia)

- Worsening memory
- May begin to forget names of family and friends
- Significant personality changes
  - May become suspicious
  - May have hallucinations (seeing or hearing things that are not there)
  - May have compulsive or repetitive behaviors
- May wander and become lost
- May need extensive help with activities of daily living
- May need help with toileting and may experience bladder and/or bowel incontinence
- May need help with bathing
- May experience disruption of sleep/wake cycle

#### Clinical stage: Moderate dementia

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### Stage 7: Very Severe Dementia

- Loss of ability to respond to the environment
- May lose ability to speak
- May lose functional ability
- Muscles may grow rigid
- May have difficulty walking, sitting up independently
- More extensive help with activities of daily living needed (eating and toileting)
- Swallowing may be impaired

#### Clinical Stage: Severe Dementia

#### Above needs as well as:

- Diagnosis of dementia made if not done already
- Provide education on how to manage behavior changes at home
- Improve facilities' abilities to manage behavioral issues to avoid transfer to the state mental hospital

#### Above needs as well as:

- Diagnosis of dementia made if not done already
- More emphasis on palliative care
- Consider hospice care
- Increase availability of hospice providers, particularly in rural areas

# Appendix E: Montana Workforce Training Programs

The **Montana Geriatric Education Center** (MTGEC) provides a multitude of educational topics to various professional disciplines and some support for training for direct care workers and caregivers.

The Center was recently awarded a Geriatric Workforce Enhancement Program (GWEP) grant that provides geriatric education and training to health care workers in order to improve health outcomes for older adults.

Programming will be provided for patients, families, caregivers, direct care workers, health professionals, students, family medicine residents, and faculty in a variety of settings.

**Mountain Pacific Quality Health** is currently working with nursing home facilities on several training projects including:

- Dementia topics
- Staffing stability to help facilities attract, train, empower, and retain quality help.
- Quality Assessment and Performance Improvement (QAPI) and quality measures to enhance quality of care addressing antipsychotics, activities of daily living, incontinence, pain, depression, falls, pressure ulcers, urinary tract infections, catheters, weight loss, physical restraints, and vaccinations.

Training is provided through webinars, in-services, and/or handouts.

Through the Affordable Care Act, direct care workers in long-term care facilities need to show proof of annual education in the management of dementia. However, dementia training programs are still not routinely done in many facilities.

There are many examples of effective, tested, and validated training programs, including **Staff Training in Assisted-living Residences (STAR)**. This program allowed for improved staff satisfaction and knowledge while improving resident behavior<sup>8</sup>.

The **Hand in Hand training** is another example of this type of training.

The **HealthCARE Montana** grant is a new program in Montana that is revising the curriculum for nursing education and other health professional curriculum in the state. MTGEC is working with this program on the geriatric component.

The HealthCARE Montana program goal is to improve health care training opportunities in Montana at the two-year college level, while enhancing pathways to baccalaureate degrees, and provide successful employment for students with attention to adult learners and veterans, particularly in rural locations.

**Montana Area Health Education Centers and the Montana Office of Rural Health** have created many programs and committees to support Montana communities and the state's health care workforce, such as the training of Community Health Workers.

The **Montana Hospital Association** (MHA) and the **Montana Health Care Association** (MHCA) also offer training programs on dementia care on a regular basis.

**Montana Gerontology Society** holds an annual conference providing professional development and continuing education in the field of aging for multiple health care and social service disciplines.

The **National Association of Mental Illness** (NAMI) offers training programs specifically for managing behavioral issues.

The **Alzheimer's Association** offers many training toolkits.

# Appendix F: Goals and Guidelines for Residential Care from the Alzheimer's Association

## Alzheimer's Association Goals of Care and Clinical Practice Guidelines for Residents with Dementia Living in Residential Care

### Goals of Care

Staff and families will act as care partners with residents with dementia to achieve optimal functioning and quality of life.

Staff will use flexible approaches to care to help anticipate needs and prevent problems in order to meet the changing needs of residents with dementia.

Staff will use a person-centered approach to care in managing residents with dementia with an emphasis on consistent care approach throughout all shifts.

Staff will assist residents with dementia to maintain cognitive and functional abilities as long as possible.

### Clinical Practice Guidelines

Complete comprehensive and holistic assessments and care plans.

Ensure staffing patterns allow for residents with dementia to have sufficient assistance so their needs are met.

Screen for appropriate nutritional care.

Encourage consistent staff assignments to promote quality relationships between staff and residents.

Promote proper nutrition and hydration given resident preferences and life circumstances.

Reduce risk of falls by assessing underlying causes of falls for the individual.

Assure mealtime is pleasant and enjoyable with ample staff to observe and interact with residents.

Avoid physical restraints by addressing underlying problems that prompt the use of restraints.

Assess pain routinely using a systematic approach to ease distress associated with pain and improve quality of life.

Encourage and support residents with dementia mobility choices, enabling him/her to move about safely and independently. However, unsafe wandering and successful exit seeking should be avoided.

Tailor pain management to each resident's needs and risk profile.

Maintain open communication with family members.

Offer many opportunities for social engagement, respecting resident's preferences, even if that preference is solitude.

Promote a physical environment that is comfortable and inviting, encouraging and supporting independence while encouraging safety.

# Appendix G: Availability of Residential Care in Montana as of February 2015

## **Low-income senior housing**

- 159 low-income senior housing facilities across Montana.
- Ratio is roughly one low-income senior housing complex for every 1,000 Montanans age 65 and older.
- 34% of counties do not have a low-income senior housing complex.

## **Assisted living facilities**

- 201 assisted living facilities with a total of 5,643 beds.
- 60 facilities have Category C (memory care) designation for a total of 1,265 beds.
- 123 assisted living facilities accept Medicaid waiver recipients.
- Ratio is one assisted living facility for every 796 Montanans age 65 and older, and only one designated memory care bed for every 126 Montanans 65 and older.

## **Nursing homes**

- 83 nursing facilities in the state with a total of 6,588 beds.
- Ratio is one nursing home for every 1,925 Montanans age 65 and older, and one nursing home bed for every 24 Montanans 65 and older.
- 21% of counties have no access to a nursing home facility and three counties (Petroleum, Judith Basin, and Treasure) have no access to either an assisted living or nursing home.
- 81 out of 83 facilities accept Medicaid.
- 31 nursing home facilities have secure dementia units.
- 35 facilities have a contract with Veterans Affairs (VA) to provide nursing home care to an average of 120 veterans a month.
- The Montana Veterans Home in Columbia Falls and the Eastern Montana Veterans Home in Glendive provide long-term residential care and are operated by the State of Montana. The total operation cost in 2014 for the Columbia Falls facility was \$10.38 million with one-third of the costs covered by federal funding. Total operation cost for the Eastern Montana Veterans Home in 2014 was \$2.9 million with the majority covered by federal funds.

- The average length of stay in a nursing home is 1.92 years. However, the length of stay varies by payer source, as do resident demographics:

#### **Medicaid**

- Average length of stay is 2.45 years.
- Average age is 77.
- Medicaid accounts for 60% of nursing home costs.
- Nursing home costs are the largest portion of Montana's long-term-care budget with expenditure of almost \$162 million in 2014.

#### **Medicare**

- Medicare only covers short-term skilled stays usually for rehabilitation following a hospital stay.
- Average length of stay is 88 days.
- Average age of individuals covered by Medicare in these facilities is 88.
- Medicare accounts for 12% of nursing home costs.

#### **Private insurance**

- Average length of stay is 1.27 years.
- Average age is 85.
- Accounts for 28% of nursing home costs.







# Appendix I: Proposed Dementia Navigator System



- Appropriate Referral to initiate discussions, educate, inform, provide resources, establish goals based on current needs (dementia specialist vs. designated agency)
- In-home assessment by licensed practitioner (e.g., RN, LCSW)
- Identify support person or point of contact early on
- Obtain authorizations as indicated for collaboration of the health care team



- Utilize systematic approach to discussing issues and addressing needs
- Perform Medication Review & Education and set standards for routine review of medications and chronic condition status
- Make appropriate referrals based on findings: Physical and or Occupational Therapy, Geriatrician, Pharmacist, Neurologist, Financial Counselor, etc.
- Development of Care Plan
- Completion of immediate goals (Advance Directives, Legal Proxy decision-maker)



- Establish home health plan using non-paid and/or paid services, as appropriate
- Designate point of contact for assisting with on-going management and trouble shooting
- Provide framework for routine review of care plan and additional in-home assessments for detection of problems
- Resource sharing for further assistance, as needed. (hot line vs. direct call to agency)
- Review long-term goals

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