

6. Findings from Montana Alzheimer's/Dementias Work Group

The following information is the result of work conducted by the Montana Alzheimer's/Dementia Work Group from 2014–2016.

This includes an inventory of health care professionals, home and community-based services including residential care, and the summary of information obtained from discussions with Montanans during public Town Hall meetings held across the state.

The meetings also included conversations with Native American populations conducted on Native American Reservations and Indian Health Services Centers. The concerns, fears, and hopes expressed by Montana citizens echo the challenges outlined previously.

A. Inventory

1. Health Care Professionals

Montana has a shortage of health care professionals, particularly in rural and frontier areas. Eleven Montana counties (21%) do not have access to a primary care physician and another 9% do not have access to a nurse practitioner or physician assistant. Montana currently ranks 41st out of 50 states for primary care providers per capita, with 99.7 physicians per 100,000 residents, as compared to the national average of 120 physicians per 100,000 residents.¹⁵

Further, Montana has a significant shortage of providers specializing in care of older adults and Alzheimer's disease and related dementias, even in urban communities. A noteworthy percentage of counties have no access to specialty providers for this demographic sector, such as neurologists (82%), psychiatrists (71%), psychologists (64%), counselors (54%), and social workers (54%). Although geriatricians have proven to be beneficial when involved in the care of individuals with dementia, there is a shortage nationwide. This is particularly evident in Montana where there are currently only seven physicians, nurse practitioners, and physician assistants specifically trained in geriatric care across the state for a population of just under 160,000 adults 65 and older.

No concrete data are available, but anecdotally, health care organizations across the state are

concerned about a shortage of direct-care workers, especially nurses. Current vacancy rates are concerning, given the aging of the state's population. At the same time, the working-age population is stagnating and even decreasing in some areas of Montana. This may lead to inadequate staffing and a disruption of health care services, particularly as current employees are themselves aging and retiring in higher numbers.

2. Home and Community-Based Services

While dementia services are severely lacking throughout the state, even when services are available, a lack of knowledge persists about availability of community resources among individuals with Alzheimer's disease and related dementias and their caregivers, health care professionals, and service-providing organizations.

Montana citizens indicated during Town Hall meetings that programs offered through Medicaid are very limited and difficult to navigate. The system of long-term-care support services involves numerous funding streams and is administered by a variety of federal, state, and local agencies using fragmented and complex intake, assessment, and eligibility processes.

Town Hall participants also reported frustration with the seeming lack of knowledge and comfort level in diagnosing and managing dementia by medical providers.

Disparities exist between urban and rural and

frontier communities in Montana. Three rural counties have no access to health care providers, in-home services, long-term care facilities, or a hospital. The Area Agencies on Aging (AAAs) admit to a lack of services statewide due to funding levels that have not kept pace with increased demands of an aging population.³¹ The rising cost of providing care coupled with an increased demand for services as the population ages compounds this situation.

The following services are particularly lacking in Montana:

- Dementia case management services—there is only one known case-management organization specializing in Alzheimer’s disease and related dementias in the state.
- Geriatric assessment clinics—there are only five in the state.
- A majority of Montana counties do not have critical dementia care services
 - 63% of counties do not have respite services
 - 67% of counties have one or no organization offering adult day-care
 - 52% of counties have one or no organization offering non-skilled home health service
 - 48% of counties have no hospice services

3. Residential Care

Community housing options for older adults in Montana include low-income senior housing (for persons able to live on their own), assisted living facilities, and nursing home facilities.

Finding these types of housing options in rural and frontier communities, particularly facilities that specialize in memory care, can be difficult.

Thirty-four percent of Montana counties have no access to low-income senior housing.

Twenty-one percent 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.

“[We need] education, someone to call when presented with unexpected situations, similar to a crisis hotline for the newly diagnosed and caregivers.”

~ Townhall Participant

Availability of residential care across Montana as of February 2015 is outlined in Appendix G.

B. Town Hall Meeting Themes

Thirteen public Town Hall meetings were held in 11 urban and rural communities as well as seven Indian Reservations and Indian Health Services centers to address the current and future needs of people with Alzheimer’s disease and related dementia.

In an article published in *The Missoulian* on June 2, 2015, Kavan Peterson wrote that the Montana Alzheimer’s/Dementia Work Group’s community meetings are “about how we can transform our communities to embrace people living with dementia,” a sentiment that fully applies to both Native American and non-Native American communities.

Conversations were generated from open-ended questions asked to the participants. Participants were given the opportunity to share—in writing—the point they found the most compelling or important for the Montana Alzheimer’s/Dementia Work Group to consider or understand related to dementia services.

A Needs Assessment Survey was also given to participants during Town Hall meetings with encouragement to complete the survey before leaving.

Individuals who completed the survey were asked to identify the most pressing needs facing Montana families with respect to Alzheimer’s disease and related dementias.

The most important issues identified by this

group were the need for information about the types of services available and how to access these services, affordability of services and support for families and caregivers.

Respondents were also

asked an open-ended question at the end of the survey regarding recommendations they might have to improve the care of Montanans with Alzheimer’s disease and related dementias.

The themes of increased service availability, increased education, and increased funding were

continuously reflected in the responses. Inherent in the Town Hall discussions were the differences in level and availability of services facing rural communities.

During several of the Town Hall meetings, participants expressed lack of awareness of existing legal and financial educational resources, while others voiced concern that some resources are only available online. Online access to information has become more common as entities attempt to control their costs. However, families without computers and printers are at a disadvantage. Also, in rural areas, Internet service is intermittent, unreliable, or very slow, which inhibits the downloading of materials.

Another concern was that while the Alzheimer's Association provides a wealth of information on a national level, state-specific materials about legal and financial information are largely unavailable. Individuals may believe they have prepared directives, only to find that these documents may not meet state legal standards.

Native American

Group interviews about Alzheimer's disease and related dementias and its challenges were conducted on all seven Native American Reservations in Montana and at several urban Indian centers with large Native American populations.

Though some national research exists about American, Alaskan, and Canadian Natives on the subject of dementia, much more work must be done to better understand the needs, challenges, and solutions for Native communities.

The findings of the group interviews point out a stark reality, yet attendees also expressed tremendous hope and ideas for the future. Many of the needs expressed reiterated the themes and points made at the urban/rural Town Hall meetings.

However, several issues were unique to Native American communities.

Issues of particular relevance to Native American communities in Montana include:

- Nursing homes and assisted living facilities are present on some Reservations or in geographic areas with large populations. Other more remote Reservations have either very limited beds available, which are not considered a good choice, or alternatives that are many hours away. Placing a loved one in a nursing home or assisted living facility hours away is not a realistic option because of the challenge of not being able to visit regularly. Based on values of interdependence and reciprocity, there is a strong tradition of family members caring for their elders. Having a loved one in a long-term care facility that is hours away can cause significant family distress.
- Financial issues (particularly because of high poverty levels) are also a barrier to placement in facilities, even when it is obviously needed. The requirements and constraints of Medicare and Medicaid spend down guidelines, and the services available through Indian Health Service are both confusing and limit people's access. One urban health care service provider explained that more than 200 people on their client list are eligible and had been pre-qualified for enrollment through Medicaid expansion, yet only a handful had gone through the process to enroll. Furthermore, the cost of between \$4,000 and \$8,000 a month of institutional care, regardless of the source to pay for it, is prohibitive. In addition, program regulations may make offered services incongruent with cultural values.
- Concern was expressed in some communities about instances of observed elder mistreatment and exploitation, with elders who have dementia being most vulnerable. This was particularly troubling to Town Hall participants who indicated their elders should be honored as carriers of tradition and teachers of wisdom.

The Montana service inventory demonstrates that our current resources are woefully inadequate to face increasing demands. At the same time, Montanans across the state have stated loud and clear that we need to prepare ourselves to deal with all facets associated with dementia, so that affected individuals and families can transition through the inevitable phases with dignity and compassion.

Preparing for the years to come will require commitment and courage. Solutions are not simple, but with collective efforts we can begin to address the impending challenges. The following section, Goals and Recommended Action Steps, outlines 11 major issue areas and proposes specific goals and action steps for each. In effect, the plan is a recommended blueprint for the future.

