

4. Process for Preparing This Plan

A. Process

This plan represents the grassroots effort of several state, local, and national partners interested in improving care and support to Montanans with Alzheimer's disease and related dementias, their families, and caregivers. Work on this plan began in June 2014 and occurred in four phases.

Phase I: Establishing the Montana Alzheimer's/Dementia Work Group

The Montana Alzheimer's/Dementia Work Group was established in June 2014. This state-wide partnership consists of several key national, state, and local partners interested in improving care and support for Montanans with Alzheimer's disease and related dementias, their families, and caregivers.

The Work Group has more than 40 members representing multiple industries and stakeholder groups including:

- The Alzheimer's Association
- The Senior and Long-term Care Division of the Department of Public Health and Human Services
- The Governor's Office
- Other government agencies
- Patient advocacy groups
- Patient advocates and caregivers
- Assisted Living/Long-Term Care facilities
- Senior services agencies
- Regional health care organizations and providers
- The Veteran's Administration
- Educators
- Researchers
- Legislators
- Native Americans
- The LGBT community.

The Work Group recognizes that dementia is one of the most important health care crises of our generation. Dementia is prevalent, underdiagnosed,

and carries significant caregiver burden. It is the costliest disease in America and the sixth leading cause of death in the United States and Montana.

To date there is no effective prevention, cure, or treatment. As the number of individuals with dementia increases over the next decade, their needs and those of their caregivers will increase.

The Work Group concluded that the best way to help our state prepare for the current and future needs of individuals with Alzheimer's disease and related dementias as well as their families and caregivers, was to develop a Montana Alzheimer's and Dementia State Plan.

The Work Group met every other month over the course of two years to begin addressing the needs of individuals and caregivers facing dementia, and creating the state plan.

The goal of the plan is to alert Montanans to this growing health care crisis and identify action steps that will be taken to improve care for individuals with dementia and their caregivers.

To ensure the plan addressed the needs and concerns of all Montanans, Work Group members conducted a state-wide inventory to identify gaps in dementia care resources and services, and held public Town Hall meetings across the state to hear and discuss the challenges, fears, and unmet needs of Montanans caring for individuals with dementia.

Phase II: Conducting a state-wide inventory of existing dementia care resources and services in Montana

To develop a comprehensive action plan, Work Group members identified gaps in dementia care services and resources across the state.

In 2015, the Work Group conducted a state-wide inventory of care and services available for individuals with dementia and their caregivers and families.

The inventory was conducted at a county level, so all Montanans could be represented without regard to where they reside.

Information collected included availability of primary care providers, health care professionals with dementia care expertise, home and community-based providers including residential care, and caregiver resources in each county.

The Work Group members formed several committees to conduct the inventory and used resources provided by the Montana Senior and Long Term Care Division, the Aging Services Bureau, regional health care organizations, professional and advocacy organizations, and Work Group members.

Phase III: Convening Public Town Hall meetings in Montana

For a comprehensive Montana Alzheimer's and Dementia State Plan to be meaningful, it needs to reflect the views, concerns, and recommendations of Montanans from across the state, especially individuals with dementia, their families, caregivers, and advocates.

To ensure this goal was met, in 2015 the Work Group held 13 public Town Hall meetings in 11 urban and rural communities across Montana.

In the same year, public Town Hall meetings were held on seven Native American Reservations and at Indian Health Services centers. Appendix B provides a map of Town Hall meeting locations.

A member of the Work Group facilitated all Town Hall meetings using an open-ended list of questions designed by the Work Group.

Each Town Hall meeting lasted from 60–90 minutes. A total of 428 individuals attended the meetings held in urban and rural communities across Montana.

Town Hall meetings at Native American Reservations and at Indian Health Services Centers drew 153 participants.

Individuals who attended were encouraged to share their views, concerns, challenges and fears about dementia care as well as resources and services available in their communities. They were also 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 care and resources.

A Needs Assessment Survey was developed by the Work Group to help identify the most pressing needs facing Montana families with respect to Alzheimer's disease and related dementias. The survey was given to individuals who attended the Town Hall meetings and they were encouraged to fill it out before leaving the meeting.

The survey was also made available to other individuals who could not attend the Town Hall meetings. Of the 286 people who filled out the survey, 71% had attended a Town Hall meeting. Appendix A provides the Needs Assessment Survey and results.

Phase IV: Writing the Montana Alzheimer's and Dementia State Plan

In preparation for writing the Montana Alzheimer's and Dementia State Plan, the Work Group compiled and analyzed the inventory results and identified gaps in dementia care resources and services across the state. Information obtained from individuals who attended the Town Hall meetings and filled out the Needs Assessment Survey was analyzed to determine common themes.

Based on the findings, Work Group members have recommended and prioritized several action steps for all Montanans, including health care providers, professional organizations, advocacy groups, policy makers, and state officials.

Since this was a "grassroots" effort, several Work Group members' partner organizations helped provide funding to conduct the state wide inventory and Town Hall meetings, offset travel costs and host the Montana State Plan website, www.MTalzplan.org.

Alzheimer's disease is a major health care epidemic in the United States and Montana. Only by working together can we create a dementia-capable state and dementia-friendly communities ready to confront this crisis.

B. Acknowledgements

The following Montana Alzheimer's/Dementia Work Group members contributed significantly to the creation and development of the Montana Alzheimer's and Dementia State Plan. Each has a passion for improving the lives of Montana citizens affected by dementia. We express sincere appreciation to all the Work Group members and partner organizations.

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The Montana Alzheimer's/Dementia Work Group thanks the hundreds of individuals from across Montana who shared their personal stories, concerns, and challenges of Alzheimer's disease and related dementias. Their input was critical to shaping the State Plan.

The Work Group also expresses appreciation to the following elected officials and their staffs, for their participation throughout this process:

- Montana Children, Families, Health, and Human Services Interim Legislative Committee
- Offices and staff of: Governor Bullock, U.S. Representative Ryan Zinke, U.S. Senator Jon Tester, U.S. Senator Steve Daines

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Disclaimer

The statements presented in this publication are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee or other participants in PCORnet.

C. Diversity Inclusion and Cultural Considerations

When considering services for Alzheimer's disease and related dementias in Montana, there are several specific populations requiring special consideration.

To ensure equal access and effectiveness, programs and services must be designed to serve those in rural and frontier communities, racial and ethnic minorities including Native Americans, non-English speaking individuals, veterans, members of the Lesbian, Gay, Bisexual, Transgender (LGBT) community, individuals with younger-onset Alzheimer's disease, individuals with intellectual and developmental disabilities, individuals with traumatic brain injuries including chronic traumatic encephalopathy (CTE), individuals with mobility and/or sensory impairments, and individuals experiencing post-traumatic stress disorder (PTSD) and co-occurring serious mental illness.

The unique barriers, challenges, and issues affecting these special populations should be part of a larger conversation to ensure fair treatment, dignity, respect, and compassionate care for all people experiencing dementia.

Appendix C provides examples of how comfortable environments in health care facilities could be created for all types of individuals.