

## Recommendations to the Children and Families Interim Committee From the Alzheimer's and Dementia State Plan Coalition

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- **Establish a State Alzheimer's/Dementia Services Coordinator in Montana**  
Over the next ten years the number of Montanans and their families dealing with the challenges of Alzheimer's disease is expected to increase 42%. Alzheimer's has been determined to be the most costly disease in America<sup>1</sup>. Establishing an Alzheimer's/Dementia Services Coordinator position within DPHHS will ensure that the needs of a growing population with unique challenges, requiring a high level of coordinated care, will be met. The key responsibility of this position is to ensure the coordinated provision of quality dementia services throughout the state. Actions will include increasing concern and awareness; elevating the importance of prevention, early detection and the introduction of appropriate resources and interventions; establishing and maintaining relationships with other state agencies and key stakeholder organizations in the community; identifying gaps in service delivery as well as preventing the duplication of services; elevating best practices of dementia services; and maintaining, implementing and updating Montana's Alzheimer's/Dementia state plan. Working with local services, non-profits and private businesses to improve care of these patients will be key.

Similar state coordinator positions have already been established in Georgia, Hawaii, New Mexico, New York, North Carolina, Texas, Utah, Virginia, Washington, with many other states currently working towards establishing this kind of position, as a result of their state plan implementation efforts.

- **Provide more opportunity for people with Alzheimer's and related dementia to stay in their homes and local assisted living through the Medicaid waiver program** – In order to maintain quality of life and keep down costs, Alzheimer's and related dementia (ARD) patients should be supported to live at home or in assisted living facilities with appropriate services for as long as possible. Currently, the state Medicaid program pays about twice as much for a day in a nursing home compared to a day in an assisted living facility and even less on average for home care. Although nursing home care is an entitlement, care at home or in assisted living is limited to available "slots" through the Big Sky Medicaid waiver program. The 2015 legislature did not increase available waiver "slots" for the current biennium, so as of January '16 there is a waiting list of 426 people for these services.

First, we recommend that the Big Sky Medicaid waiver program be expanded to accommodate many of the people on the waiting list so that people with ARD have a better chance of receiving care in their home or assisted living. However, just expanding this waiver program does not deal with a critical issue of available placement in assisted living memory care units or settings that provide care to people with more complex needs. Currently the waiver program pays a maximum rate of \$74.58/day for care in assisted living. The cost of memory care units is significantly more resulting in many facilities refusing to take Medicaid waiver patients who

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<sup>1</sup> New England Journal Medicine, April 2013

need high levels of care. We recommend that the waiver program be directed to establish a tier of rates that consider the cost of providing care to patients with complex needs, like those in later stages of Alzheimer's or dementia. Additional funding for the waiver program will be needed to accomplish both goals of increasing available slots and re-structuring the rates for assisted living care for people with complex needs.

The 2015 legislature left the issue of patients with ADRD at the Montana State Hospital unresolved. As an alternative to building out the Lewistown nursing home to accommodate some of these people, we recommend community-based care. Caring for ADRD patients in the Spratt unit of the State hospital costs an average of \$516/day, all general fund. If these individuals could be served through a Medicaid waiver in community settings, federal Medicaid funds would be leveraged.

- **Give family caregivers a break from the stress of caregiving by increasing respite services** – The demands of caregiving for a family member with Alzheimer's or dementia are very taxing, long-term and often burn out family caregivers. In the AARP fall 2015 survey, 89% of Montanans support providing respite care so family caregivers can take a break. Caregivers also ranked respite high on their list of important services they need. In a national scorecard of long-term care services and supports,<sup>i</sup> Montana ranked 49<sup>th</sup> in support of family caregivers. Providing more respite care will be step in the right direction.

Currently a limited amount of respite care is provided through the Area Agencies on Aging (AAAs) and the LifeSpan Respite program. A proposal from AAAs to increase respite and other services related to the care of people with Alzheimer's and dementia is attached. Montana Lifespan Respite which provides respite to many populations will run out of their federal grant in 2017. State funding could also be allocated to continue the Lifespan program.

- **Alzheimer's and dementia services and supports for the non-Medicaid population** – Area Agencies on Aging (AAAs) are our front line and primary source of services for seniors and their families regardless of income. We recommend funding the AAAs to more adequately meet the needs of the ADRD population through more information and assistance, public awareness of early detection, and direct services to help family caregivers. See attached proposal from the AAAs. In serving the non-Medicaid population, the AAAs are able to prevent or delay people from spending down their assets until they qualify for Medicaid. Investing in AAA services is a good deal for the state.
- **Creating a statewide guardianship system** – Improving Montana's guardianship is very important to people who have become incapacitated in later stages of Alzheimer's and dementia and may need a guardian appointed. We support the work of the interim committee to create a statewide system of standards, training and accountability of guardianships. Funding for public guardianship services should be considered, as well.

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<sup>i</sup> Raising Expectations 2014: A State Scorecard on Long-Term Services and Supports. [www.longtermscorecard.org](http://www.longtermscorecard.org).