Overview

- Dementia basics
- What are the intersections of inclusivity and dementia?
- What we learned from developing the dementia state plan
- How can we build dementia friendly communities?

Why is Alzheimer’s Disease a Public Health Crisis?

Across the Nation…

- More than 5 million Americans are living with Alzheimer’s disease, including an estimated 200,000 individuals under age 65 with younger-onset Alzheimer’s.
- This number is set to reach as many as 16 million by 2050.

People and Families are Unaware

- Underdiagnosed
  – Among individuals with Alzheimer’s disease, only about half have ever been diagnosed.
- Not informed
  – Less than half of seniors diagnosed with Alzheimer’s disease or their caregivers are aware of the diagnosis

Societal Burden is Great

- Most expensive disease in America
- The national cost for caring for those with Alzheimer’s disease in will be about $226 billion in 2015
- Two thirds of this will be paid by Medicare and Medicaid
- Unchecked, by 2050 Alzheimer’s disease will cost over $1.1 trillion (in 2015 dollars)
Alzheimer's is a Deadly Disease

- 6th leading cause of death in the US
- Of the top 10 causes of death, it's the only one that cannot be prevented, cured, or even delayed

It's a Family Affair

Alzheimer's disease has a devastating effect not just on those with the disease but also on their caregivers. In 2014 in the US:

- 15.7 million family and friends provided 17.9 billion hours of unpaid care valued at $217.7 billion

Stakeholders and Experts

What did we learn from the Montana State Plan for Dementia?

Work Group Vision Statements
### Montana Citizens
- Are well aware of the prevalence of Alzheimer’s disease and related dementias
- Understand how to reduce the risk
- Know the early signs and what to expect in the progression of the diseases
- Are aware of the value and importance of the care provided patients and caregivers
- Are comfortable talking about aging and these diseases
- Know where to go for resources – respite, experts, and support
- Live in dementia-friendly communities
- Have first responders, advocates, anyone coming in contact with people who are able to both detect and competently support patients and their families

### Patients
- Are included in making decisions and choices to the best of their ability
- Are treated with dignity
- Receive the care they need for each stage of the disease
- Receive high quality patient-centered treatment
- Remain independent as long as possible
- Receive quality care no matter where they live, what their income is, or what their culture is
- Receive opportunities to participate in research and clinical trials

### Policy Makers
- Understand the crisis Alzheimer’s disease and related dementias present, including the financial impacts and potential burdens to society
- Implement policies and systems to prevent them or reduce risk, and prepare for the impending numbers of people affected
- Consider dementia diseases a public health priority
- Look at the diseases globally, analyze choices, and focus on people’s ability to live independently as long as possible
- Strengthen the quality of care provided, and on ways to reduce costs to the taxpayers, the State, and families/patients
- Support research on early detection, prevention and therapy

### Backbone of the State Plan
- Town Hall Meetings/Surveys
- State Plan contents
- Legislative efforts

### Town Hall Meetings
- Caregivers are on Fire!
- Stigma associated with dementia
- I can do this!
- Guilt vs social acceptance
- Loneliness
- Although most individuals want to remain at home, it can be difficult for caregivers to meet the needs of their loved one with dementia
- A strong public awareness campaign would help with some of these issues

### Town Hall Findings
- Caregivers are on Fire!
- Stigma associated with dementia
- I can do this!
- Guilt vs social acceptance
- Loneliness
- Although most individuals want to remain at home, it can be difficult for caregivers to meet the needs of their loved one with dementia
- A strong public awareness campaign would help with some of these issues
Town Hall Findings

• Montanans need to be prepared to age and understand the nuances of aging services, especially for dementia
  – General information classes from AARP and DPHHS Office on Aging
  – Behavior education
  – Financial/legal concerns
  – Medicare/Medicaid qualifications and coverage
  – Safety concerns

• Caregiver Needs
  – Support groups
  – Care navigators/case managers
  – Respite
  – Accessible resources, and a need for coordination and maintenance of available resources and services listing
  – Make Medicaid process easier

• Participants also felt the healthcare system needed change to better meet the needs of individuals with dementia
  – Early diagnosis
  – Better coordination of care between medical providers
  – Training (and funding) for rural facility staff caregivers and professionals

Inventory Findings

Health Care Providers

• Most counties have no access to specialty services that are important in caring for individuals with dementia
  – Neurologists (82%)
  – Psychiatrists (71%)
  – Psychologists (64%)
  – Counselors (54%)
  – Social workers (54%)

• There are only 7 MDs, NPs, or PAs who have specialized in geriatrics across the state.'

• 3 rural counties have no local access to medical providers, in-home services, long-term care facilities, or hospitals
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

The 11 major goals of the Montana Alzheimer’s and Dementia State Plan are to:
1. Promote public awareness and understanding about Alzheimer’s and related dementia diseases.
2. Encourage all health care providers to recognize and diagnosis dementia early in the process and appropriately refer individuals and families to community resources.
3. Ensure that Montanans with Alzheimer’s disease and related dementias and their caregivers are aware of, and have access to, Montana-specific materials regarding legal and financial planning.
4. Promote person-centered care, ensuring that Montanans with Alzheimer’s disease and related dementias are able to age in place in the least-restrictive setting while maintaining a high quality of life.
5. Maintain adequate numbers of health care workers who are trained to meet the needs of the population experiencing Alzheimer’s disease and related dementias.
6. Promote dementia-friendly communities in Montana where individuals and their caregivers are treated respectfully and have opportunities to actively participate in community life.
7. Reduce caregiver burden and stress by promoting systemic changes in medical, social system, and employment practices that will support and empower caregivers.
8. Expand the availability of high-quality, affordable home and community-based services that meet the needs of individuals living with Alzheimer’s and related dementias, allowing them to live in the most appropriate and least-restrictive setting.
9. Promote wellness and maintenance of cognitive function at residential care facilities through activities tailored to each individual, and employ staff trained in person-centered interventions and models of care.
10. Provide high quality palliative and hospice care for individuals with Alzheimer’s disease and related dementias during the end of life and support for their families and loved ones.
11. Improve Alzheimer’s disease and related dementia data collection and research efforts in Montana.

Goals and Recommendations

Resources

- MTAzPlan.org
  - Executive summary
  - Calendar
  - Downloadable version of full state plan

What are the Issues of Inclusivity in Dementia Care?

- Difficult to attract nurses to care for individuals with dementia
  - CNAs, LPNs, RNs often not interested in this type of work
  - Can be “looked down on” by peers
  - Not well compensated in assisted living, nursing home, and home health settings compared to hospital and clinic settings
  - Shortage of nursing staff more acutely affects these settings and will likely get worse
  - Little to no education on dementia

Nursing Care

- Proper dementia care requires a multidisciplinary approach from a variety of care partners including:
  - Nurses
  - Social Workers
  - Therapists
  - Primary Care (MDs, NPs, PAs)
  - Dietitians
  - Activity Therapists
  - Neurologists/Psychiatrists
  - Volunteers

Multidisciplinary Care

- Required to appropriately treat and rule-out reversible causes
- Allows for future planning and the individual to be involved in decision making
- Without a diagnosis, individuals and families are left to fend for themselves to seek out education and community resources
- Family members can wait an average of 18 months for a definitive diagnosis of dementia
- Even when a diagnosis is made, individuals may not be told of the diagnosis and are not provided education or proper referrals
  - One study found fewer than 50% of individuals with dementia were aware of their diagnosis

Accurate Diagnosis
Accurate Diagnosis

- Many barriers
  - Lack of education
  - Don’t want to be “bearer of bad news” particularly in smaller communities where the provider likely knows the patient
  - Diagnosis considered futile as there is virtually no treatment options
  - Complexity of subject matter and time constraints
  - Patient wishes not to know or is not truthful about memory loss

Person-centered Care

- When you meet someone with dementia, you’ve met one person with dementia. Each individual is affected differently and has different needs

Caregivers

- Appropriate dementia care requires the inclusion of caregivers in care-planning
- Dementia can be a very isolating disease for both individuals with dementia as well as their caregivers

Communities

- We need communities who support, accept, and invite individuals with dementia and their caregivers to remain active in their home community.

What are dementia friendly communities?

Dementia-friendly Communities/State

Designed or all stages of Alzheimer's disease and other related dementia
What is a Dementia-friendly community?

- Dementia friendly communities in the UK

Dementia Friendly Nursing Homes

- Allows residents to feel like they are still part of society
- Netherlands dementia village

Questions?