

Summary of Public Awareness and Risk Reduction

Committee Membership

Dr. Linda Bane Frizzell, Co-Chair, (U of M Public Health) and Trevor Wischner (Knutenelson) are presenting.

- Clarissa Dumdei
- Kathleen Dempsey
- Pennie Page
- Lori Vrolson
- Angela Lunde (co-chair)
- Carla Zbacnik
- Peg Gaard
- Kelly Hugunin
- Robyn Birkeland
- PJ Mitchell
- Jenny West
- Cathy Griffin
- Ann Brombach
- Linda Giersdorf
- Lori Paulson
- John Riley McCarten
- Patty Takawira
- Patty Carlson (co-chair)
- Grant Watkins
- Linda Comb
- Lori La Bey

Committee Process

The Public Awareness and Risk Reduction Committee is charged with identifying relevant issues, research, and considerations to the Working Group in the following areas:

- Public awareness, knowledge, and attitudes, including knowledge gaps, stigma, availability of information, and supportive community environments
- Risk reduction, including health education and health promotion on risk factors, safety, and potentially avoidable hospitalizations

Committee Process Overview

The Public Awareness and Risk Reduction Committee met four (4) times between March 29, 2018 and June 28, 2018. In-person meetings with a remote participation option were used to identify key issues, share-out and discuss findings from assigned tasks, and discuss next steps to fulfill the Committee's charge. The Committee made active efforts throughout this process to acknowledge, honor, and leverage each member's various professional lenses and lived experiences to inform the discussions and move towards shared understanding.

The structured meeting time was supplemented with electronic collaboration via e-mail and SharePoint. The Committee used the interim time between meetings to perform and share targeted research, primarily in the form of "environmental scans" on key topic areas. These scans included:

- An inventory of data and research on public awareness and risk reduction since 2011;
- An assessment and benchmarking of website messaging for various organizations and agencies communication about Alzheimer's disease and dementia;
- An overview of resources and tools related to dementia-friendly language and stigma reduction; and
- An inventory of relevant federal and state policy and regulatory changes since 2011.

The group's discussions included the following key themes:

- The need to increase awareness of and connection to medical and non-medical resources

- Developing a consistent, evidence-based and promising practices statewide message that could be tailored to local needs
- New research since the 2011 Alzheimer’s Report regarding modifiable risk factors
- Communication regarding Alzheimer’s Disease, dementia, and memory loss, including:
 - The need to shift to an assets-based approach when working with individuals and families receiving a diagnosis
 - Misunderstandings in the broader public regarding Alzheimer’s, specifically that not all memory loss is related to dementia or Alzheimer’s

Through this process, the Committee assessed the current landscape of public awareness and risk reduction for ADAD and identified emerging considerations for the Working Group to review.

Problem Statement

Currently, Minnesota does not have a collaboratively-led statewide coordinated public awareness campaign for memory impairment. To reduce stigma, an awareness campaign should offer a balanced perspective that includes reducing risk factors, adapting well to a diagnosis of ADAD, and easy access to information. Stigma, that is largely based on perpetuated untruths, has many individual fearful to acknowledge they are experiencing memory issues for fear of a terminal diagnosis, resulting in the loss of valuable time lost to maintain a respectful quality of life. Individuals, families, professionals and communities at large struggle to obtain valid evidence-based education about memory impairment, education regarding ways to reduce modifiable risk factors, and efficient connections to existing support services, despite Minnesota’s vast community resources.

Current Landscape

Public Awareness: Since the Working Group last met in 2011, numerous efforts have been initiated and continued by a broad set of stakeholders to educate and engage communities about Alzheimer’s disease and dementia. Gaps remain around the consistency and clarity of information currently being provided to communities in Minnesota.

Risk Reduction: State and federal strategies have allowed for advancements in research funding and other activities related to Alzheimer’s disease and other dementias. While the search for a cure continues, there is now a better understanding of the importance of early detection and modifiable behaviors that can help reduce the risk and slow the progression of dementia. However, stigma related to memory loss and aging remains a barrier for early detection and risk reduction.

Emerging Recommendations for Working Group

The Committee developed two considerations for review by the Working Group that aim to help harness some of the recent energy and efforts around dementia and memory loss to create a more cohesive strategy for public awareness and risk reduction.

1. Develop a statewide messaging approach with local community influence that encourages consistent language for Alzheimer’s disease and dementia, alongside a statewide awareness campaign built around awareness of and adapting to life with dementia.

This approach will:

- Reduce stigma by offering a new face for dementia and acknowledgement that not all memory issues are the result of dementias.
- Provide coordinated messaging and education across Minnesota tailored for local community needs
 - Increase public understanding of aging normally vs aging abnormally
 - Thoughtfully and intentionally acknowledge the experiences of those who have not had the experience of “living well” with dementia
 - Enhance the awareness of medical professionals for how to connect to non-medical community supports

Working Group Poster Comments:

- Need more specific recommendations for legislature to address risk factor reduction – as a public health issue.
- Fantastic that there are work groups to help improve the quality of life for people with memory loss
- Entity must use cultural consultants to ensure all of the diverse cultures are included to understand stakeholder comments.
- Good idea – similar to “Make it OK”?
- Do not shy away from using “Alzheimer’s disease”
- How could public radio and TV collaborate?
- We need to tell story and use personal language not technical eg. Use the basic term memory loss to improve understanding and reduce stigma.

In order to do this, the Working Group could:

- Recommend structured coordination of messaging and awareness campaigns, including:
 - Designating an entity to collaboratively develop statewide language that is evidence-based or a promising practices and allows for local customization for cultural traditions and understanding.
 - Empowering the designee to develop a strategy to implement shared language across stakeholders in Minnesota
 - Community communication, messaging, and access to valid resources needs to be available in multiple formats to ensure every community member can access regardless of computer capabilities, e.g. local newspapers, PSAs on radio, tribal newspapers, religious communications
- Recommend the Board on Aging collaborate with stakeholders to enhance awareness and usage of mnhelp.info and the Senior Linkage Line to further build these resources into a centralized hub for Minnesota dementia and memory loss information and connecting to local resources.

Work Group Poster Comments:

- Yes!
- Common vessel/medium for transfer of information
- Make Senior Linkage more information as well as referral source.

- Recommend a work group to break down silos between medical and non-medical systems to increase appropriate referrals and coordinated resource provision for individuals and families, including:
 - Pilot programs that leverage mentors in every day interactions (medical community, employers, community organizations, and individuals with experience living with or caring for those with memory impairment) to provide hope and practical skills for individuals, family caregivers, and professional caregivers Pilots should be diverse to learn from racial, ethnical, and sub-cultures (e.g. various types of rural areas) populations.
 - Considering innovative funding incentives for medical professionals to incentivize effective referrals to non-medical supports in the community, such as reimbursement for referrals, as well establishing communications channels to evaluate outcomes.

Work Group Poster Comments:

- Seems like language could be incorporated into language in dementia grants
- Dementia Resource Center could be such pilots

2. The Working Group should explore upstream interventions to reduce risk and understand possible ways to slow the progression of dementia.

This approach will:

- Leverage new understanding about modifiable risk factors related to dementia.

In order to do this, the Working Group could:

- Recommend a work group to further define the modifiable risk factors, then explore strategies to increase public understanding and education of the known causes and risk factors for memory impairment.

Work Group Poster Comments:

- Multiple government studies have looked at risk factors. Likely that cardiovascular approaches most promising (diet and exercise)
- Modifiable risk factors currently being researched by Federal programs – use of public health to disseminate information?

- Reform health systems in Minnesota to enhance upstream interventions for ADAD and incentivize the treatment of ADAD as a chronic disease, such as: including education and screening for ADAD and modifiable risk factors into annual visit standards alongside improving first experiences with diagnosis through asset-based messaging and effective resource provision.

Work Group Poster Comments:

- Increase education about lifestyle choices that influence / are correlated with AD.
- Unclear how state can affect this. Already have Health Care Homes. Medicare controls reimbursement.
 - Increase awareness of this? More incentives??
- Too vague – need to drill down to actionable recommendation

- Recommend that state and local health departments assess and enhance their involvement in treating ADAD as a chronic disease, including upstream interventions for modifiable risk factors and public health programming.

Work Group Poster Comments:

- Similar to treatment of high blood pressure, cancer, diabetes. Would think about investments made in control of infectious diseases.
- Too vague – need to narrow to actionable items. How would you measure if goal was accomplished?

Work Group DISCUSSION QUESTIONS – use after buckets 1 and 2:

- Are there any recommendations that the committee should revisit conceptually? Why?
- Do any recommendations connect to recommendations emerging from other committees that we should be aware of in terms of shaping the final report?
- What recommendations are missing?
- Collectively, are these recommendations “pitched” at the right level?
- *Comment added by Linda post meeting: We should establish a work group that can develop legislative language that specifically includes the term “memory loss” since current legislation only states: Alzheimers and other dementias. This change would certainly reduce stigma for accessing professional services, as well as being more culturally accepted.*