

Alzheimer's Disease Work Group Meeting Notes

Meeting 3: June 28, 2018

9:00 a.m. – 2:30 p.m.

State Room, Best Western Kelly Inn, 100 4th Avenue South, St. Cloud, MN

Work Group members in attendance:

Darrell Foss (Chairperson), Eric Linn, Jean Nelson, Dan Pakonen, Amanda Mithun, Ed Ratner, Heidi Haley-Franklin, Cheryl Hennen, Gretchen Ulbee, Sherrie Pugh, Terry Barclay, Joe Gaugler (phone participant), Dorothea Harris (phone participant)

Welcome and Introductions

Darrell Foss welcomed the in-person and online attendees with opening comments, summarized below:

- This is the third meeting of the 2018 Alzheimer's Disease Work Group
- The legislature required that two of the five meetings be held outside of the metropolitan area
- This meeting provides an opportunity to reflect on how community needs are the same and different across the state
- Sarah Small, the lead MAD consultant, has left his project to take a different job with the State of Minnesota. Stacy Sjogren has taken over as the lead consultant on the project.

Laura Hood, Aging Services Director for the City of St. Cloud, welcomed the attendees to St. Cloud and provided an overview of central Minnesota's efforts around dementia.

Program Overview

Stacy Sjogren reviewed the Alzheimer's Disease Working Group's legislative charge, summarized the group's progress to date on developing recommendations, and reported on the Conversation in a Box findings.

"Rural" Minnesota & Alzheimer's Disease Panel – Impact and Perspectives

Dr. George Schoepfoerster moderated a panel discussion on the impact of Alzheimer's in rural Minnesota. The panel discussion focused on the following questions and topics:

- What strengths are there in our rural communities and how can they be leveraged or elevated?
- What is happening to support diverse cultural and ethnic communities?
- Public awareness – rural specific
- How can the connection between healthcare providers and community service entities be stronger?
- My "state impact" wishes for what the State of Minnesota could be doing
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Key "rural" takeaways from the panel conversation included:

- Rural areas in Greater Minnesota have the largest proportions of people considered to be geriatric.
- Because patients in rural areas tend to be further away from medical care, helping clinics connect to communities and creating structures will help primary care providers and improve treatment of patients.

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- Doctors that live and work in rural areas see their patients more frequently (at locations other than the clinics) and have more personal connections.
- There's a need to educate communities on how to become more dementia friendly. For example, educating first responders and other community service providers on how to interact with individuals who have dementia. (trained individuals providing virtual dementia tours in northwest Minnesota)
- State investment in dementia cultural consultants (individuals trained in the nuances of dementia).
- Support rural families who have limited access to transportation
- Increased wages for care providers. There are workforce shortages among homecare providers, nursing homes, and care facilities. Turnover is a related issue. For example, many entry-level CNAs are teenagers. Because the work and hours are difficult and the pay is relatively low, they do not return to the profession after high school. Increased wages will attract quality employees.
- Streamlining industry regulation
 - Reduce the amount of time spent on required documentation
 - Look at what regulations must be in place to ensure safety and then investigate what else is necessary. Certain licensing requirements can be overly burdensome for small community organizations.

Committee Presentations of Tentative Recommendations

Diagnosis, Treatment, and Professional Education Committee – Presentation of tentative recommendations

Dr. Ed Ratner, Cheryl Smith, Dr. Pat Zook, Jean Marie Nelson, and Heidi Haley-Franklin presented and discussed the committee's tentative recommendations. Dr. Ratner prefaced their report by explaining that they limited themselves to recommendations that do not conflict with federal guidelines and where the state can have direct or strong indirect influence.

Recommendation #1: The Minnesota Department of Human Services should direct the Senior Linkage Line program to compile and organize a web site that contains links to on-line reliable, non-commercial information about the diagnosis and treatment of dementia for use by Minnesotans.

Questions and comments from the large group discussion included:

- Would there be any way to work in preventative strategies as well? Is there a way to incorporate that into the recommendation?
- The recommendation talks about services, information, and in-person visits. What type of information is the website (Minnesotahelp.info) intended to provide? Lots of people need information resources (more than just dementia patients).

Recommendation #2: The Minnesota Legislature should provide funding for development of a MN State-wide network of community dementia resource centers. This could be through providing grants for specific communities working on this or through direct support through supervision by the University of Minnesota medical school or School of Public Health, similar to what is currently done in Wisconsin.

Questions and comments from the large group discussion included:

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- How does this differ from BOLD Act? (The BOLD Act is a federal bill that would: define Alzheimer's a public health crisis, create centers of excellence, create partnerships between state, local, and tribal groups)
- This would be a unique opportunity to create a natural experiment. The Minnesota School of Public Health would be very interested in pursuing this recommendation if the legislature got behind it. The research could happen in tandem with service development.
- A model that works in one state does not mean it will necessarily work in MN. Most of what patients need cannot be provided by doctors.

Recommendation #3: The legislature should provide funding for development of a statewide network of community dementia resource centers. This could be done by providing grants to specific communities working in this area or through direct support with supervision by the University of Minnesota medical school or School of Public Health (similar to what is currently done in Wisconsin).

Questions and comments from the large group discussion included:

- There are differences between Native American groups so cultural humility is very important
- Provision of education is important. Are there methods available to see if the strategies are creating changes? For example, people are being trained to screen but are the screenings actually happening?
- Could this recommendation be combined with #2? Could healthcare facilities also serve as resource centers?

Recommendation #4: The Minnesota Department of Veterans Affairs should include in its mission expansion of the workforce able to provide long term care services, including dementia care, through clinical training of medical, nursing, and other health professional trainees.

Questions and comments from the large group discussion included:

- Could the VA's mission also be expanded to mandate targets for training? (e.g., the number of students trained)
- Often the legislature gives that kind of discretion to the commissioners. The Minnesota VA commissioner is supportive of expanding training.
- The Work Group should be more direct about targets in its recommendations
- This is a great idea because it helps answer where training could occur
- Part of the vision could be to build a network of teaching nursing homes

Recommendation #5: The legislature should revise Minnesota Statute 62J.692 Medical Education to remove the exclusion of training in nursing facilities and amend funding formulas for Medical Education and Research Costs (MERC) grants to include sites that serve populations with high prevalence of dementia, such as nursing homes and home health agencies.

Questions and comments from the large group discussion included:

- Would this also include long-term care facilities or assisted living facilities? - Looking at Home Health agencies because they are actually providing the services; very few opportunities to provide dementia diagnosis in homes or at care facilities without dedicated medical staff
- Would it be acceptable to include adult day service providers? - Yes
- There is also a home health agency shortage area designation which allows an RN and LPN to go to a home to provide services and be reimbursed as primary care providers.

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Public Awareness and Risk Reduction Committee – Presentation of tentative recommendations

Dr. Linda Frizzell and Trevor Wichner presented and discussed the committee's tentative recommendations.

Recommendation Area #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.

- Recommendations include:
 - Structured coordination of messaging and awareness campaigns
 - Board on Aging should collaborate with stakeholders to enhance awareness and usage of minnesotahelp.info and the Senior Linkage Line to further build these resources into a centralized hub for Minnesota dementia information and connecting to local resources.
 - Create a work group to break down silos between medical and non-medical systems to increase appropriate referrals and coordinated resource provision for families

Questions and comments from the large group discussion included:

- The language used and the policies developed should be culturally inclusive of every population (the legislation)
- There is a need to address the community stigma of mental health issues (including Alzheimer's, dementia, memory loss)
- "Mental" is not an inclusive term
- In rural America, promising practices must be included with best practices

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

- Recommendations include:
 - Create 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.
 - Reform health systems in Minnesota to enhance upstream interventions for ADAD and incentivize the treatment of ADAD as a chronic disease.
 - 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.

Questions and comments from the large group discussion included:

- Adding more education early in life reduces likelihood of dementia (e.g., getting people access to vision and hearing resources).
- There could be many specific recommendations to reduce risk factors.
- When considering these recommendations, it's important to keep in mind: To whom could the legislature refer the recommendations? What legislative committee would consider these recommendations?

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- One specific barrier is that mental health data from rural communities tends to be based on episodic occurrences – it is helpful to provide decision makers with a quantifiable need.
- It is important to emphasize that the strategies need to be informed by the needs of different ethnic groups and subcultures – recommendations cannot be a blanket application.
- Inclusive language and appropriate terminology
 - Be respectful of culture and mindful of stigma - How do you find balance between being respectful, not increasing fear, and also reducing stigma (e.g., is “dementia” the proper term?)
 - There is a tendency to give complicated names to things versus just talking in simple terms. Maybe it is not about the name but about how things are talked about.
- How do you get word out to people who shy away from technology?
 - The 2011 recommendations said there should be a one-stop information resource, but many groups still have their own information resources.
- How do you leverage the national information resources that exist into recommendations for the state? Dementia-specific resources are already created and managed?
 - There are lots of silos of information and a lot of cross talk between them; but it's hard for the user to actually find something; do we want to trust the state to build a system?
- Public health: there's a stigma among certain groups about using public resources; “public” anything can be problematic; the language used is important.

Planning for recommendation review and synthesis

Work Group members were given opportunities throughout the meeting period to write down specific thoughts on posters set up around the room related to each of the recommendations shared by both committees that shared their reports. Those comments were added to the written reports each committee shared and are included as separate attachments to these meeting notes.

Stacy Sjogren described the next steps for summarizing and synthesizing the tentative recommendations proposed by the committees. She presented the following questions to help guide the Work Group discussion.

- What are the common themes? What are the supporting strategies?
- What can be synthesized from the recommendations?
- How can the Work Group incorporate the recommendations into connected themes for the report?

Possible themes – or report categories – identified included:

- There seem to be three major themes developing:
 - 1. Need for data collection
 - 2. Effective knowledge transfer (includes communication and education plans)
 - 3. Innovation (i.e., process improvement, dementia grants, support of local innovation)
- Another possible framework: Who are the recommendations aimed at?
 - Some recommendations currently do not have an audience

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- Another possible themes framework:
 - Community needs
 - Clinicians' needs
 - Individual/family needs

Several strategies emerged as the Work Group was exploring themes:

- The need for early detection: Early detection is very important, but there are several factors that create roadblocks. It does save a lot of money over the long term if disease can be detected earlier. Early detection overlaps with screening: Could the phrase "early detection" be reworded as "early management?" Early management implies that something is being done.
- Frequency of feedback to the legislature: Other states' plans have ongoing Alzheimer's work groups. They meet annually rather than once every seven years (strategy rather than theme?)
- Feedback infrastructure: There is a lack of infrastructure in Minnesota to develop and implement recommendations on an annual basis.
 - If the state identifies Alzheimer's as a public health problem, resources can be assigned and coordinated (needs leadership)
 - Need an infrastructure to begin tracking implementation of recommendations
- Identifying and combining the information resources available
- Hesitancy with cost-effectiveness strategy: Do not want to say something because it is going to save money. The costs do need be considered, but efforts should be about saving lives and saving families first.

Regarding the report tone, members shared the following thoughts:

- Person-centered: The use of stories are central
- Positioning strategy: There's a need to justify why the recommendations are important (e.g., early detection saves money)
- Seek guidance/input from a person involved in the Minnesota legislative process
- Is there a need for a person could provide realistic feedback about what is possible? The Work Group should decide what is important to them, but then have outside input on what could actually be accomplished.
- The Work Group is not expected to be experts so it does not need to know which recommendations are actionable and which are not. Considering what is actionable should not bog the group down. It is the state's role to decide what can be implemented.

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Numerous comments were shared as part of this discussion but aren't clearly themes or strategies for the report:

- Do any lists of recommendations from other states exist? Because they have already been proposed, they are not necessarily controversial.
- Frontline/first responders theme: training the clinicians through professional education to increase cultural competency (need for training specific to cultural communities)
- Referrals following initial interventions: culturally competent care-coordination and care-coordinators
- The problems talked about today fall under community-based dementia resources and services. There will never be enough specialists so primary care providers need to be incentivized.
- There's a need to clarify about language: a "screening" is an asymptomatic assessment (i.e. using a tool to uncover an issue when the patient has not symptoms).
 - Objective assessment tools should be used when problems are recognized. A current problem is that even when symptoms are identified, the healthcare system does not objectively measure. Using tools objectively will lead to earlier detection.
 - Needs to be a call out recommendation in report about early detection (could fall under knowledge transfer themes)
- Develop a profile of "high risk"? (cardiovascular research uses this approach)
- Cognitive assessments (do not tell patients it's a "test")
 - "I want to see how your brain is working today" and then give patients the results
- Get more providers to conduct assessments.
 - It is not a reimbursed activity for many insurance plans.

Next steps

- Stacy has made the Conversation in a Box report available on the Work Group's section of SharePoint.
- Stacy Sjogren asked for volunteers from among the Work Group to assist in preparing a process for reviewing and synthesizing the emerging for the Work Groups as well as developing the report. That group; Darrell, Heidi, Sherrie, Cheryl, and Amanda, will meet at least once before the August 14 meeting.