

Alzheimer's Disease Work Group

Meeting 1: January 8th, 2018

9:00 – 2:30 p.m.

Room 2370, Elmer L. Andersen Building, 540 Cedar Street, St. Paul, MN 55101

Meeting Notes

<input checked="" type="checkbox"/> Darrell Foss, Chair	<input checked="" type="checkbox"/> Amanda Mithun	<input checked="" type="checkbox"/> Mary Manning
<input checked="" type="checkbox"/> Eric John Linn	<input checked="" type="checkbox"/> Dorothea Earlene Harris	<input checked="" type="checkbox"/> Heidi Haley-Franklin
<input checked="" type="checkbox"/> Jean Marie Nelson, RN	<input checked="" type="checkbox"/> Dr. Michael Henry Rosenbloom	<input checked="" type="checkbox"/> Cheryl Hennen
<input checked="" type="checkbox"/> Terry Randy Barclay, PhD	<input checked="" type="checkbox"/> Edward Ratner	<input type="checkbox"/> Gretchen Ulbee
<input checked="" type="checkbox"/> Joseph E. Gaugler	<input type="checkbox"/> Alice Leah Tennis	<input checked="" type="checkbox"/> Sherrie Pugh
<input checked="" type="checkbox"/> Kari Benson		

Meeting started at: 9:08 am

Meeting Facilitated by: Sarah Small and Stacy Sjogren, MAD

Administer oath and explain logistics:

Oath administered and member logistics (e.g. expense reimbursements) explained.

Welcome and introductions:

As members introduced themselves, they were asked to share any post-2011 Report challenges/successes:

- Success: Trained over 2000 docs through Act on Alzheimer's programming
- Success: Partners in Dementia through U of MN and other partners
- Success: Comprehensive Report through Institute of Medicine published last month
- Success: ACT on Alz impact on rural MN
- Success: greater awareness of Alzheimer's Disease in state overall
- Challenge: communicating the other things that can be done to delay the start of dementia
- Expectation: don't want this group to create a report "for a shelf"
- Expectation: harness work already going on nationally and MN-specific
- Expectation: not telling patient their diagnosis continues to be a problem in the medical community
- Expectation: to build on existing work and serve as a catalyst
- Expectation: better diagnosis and care coordination
- Expectation: that we get a lot of work done
- Expectation: cultural navigator/continue to learn more about strengths and needs of diverse communities

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Work Group orientation:

A number of orientation-related subjects were reviewed with Work Group members:

- A Work Group Charter draft was reviewed and members were given an opportunity to suggest changes. Sarah welcomes additional suggestions until Friday, January 12, at which time the Charter will be adopted. No changes were suggested at the meeting.
- A facilitator explained the “spectrum of public participation” and how it will impact Work Group and committee process.
- A tentative Roadmap for the work ahead was reviewed and participants were encouraged to share suggestions of meeting locations outside the metro area. Suggestions generated include:
 - Rochester
 - Mankato
 - Stillwater
 - Alexandria
 - Brainerd Lakes (contact: Amanda Mithun, Lakewood Health System)
 - Moorhead
 - Duluth
 - Hibbing
- A tentative list of meeting Ground Rules was reviewed and discussed. No additions were made.
- Work Group and Committee information will be accessible via a Sharepoint site managed by Sarah and Stacy. Access to the site was explained and members unfamiliar with Sharepoint are encouraged to reach out to Sarah for assistance.
- The tentative committee structure was explained.

Context past and present:

The Working Group's first group activity was a visioning exercise to begin defining what “a Minnesota prepared for Alzheimer's Disease” looks like. Three drawings emerged from this exercise:

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(pictures on next page)

A general debrief generated the following comments:

- We want to encourage dementia friendly communities without “silos”.
- We want the entire state to be dementia-ready, not just Twin Cities.
- There is a serious work-force shortage outside Twin Cities impacting care support.
- Rural communities have growing population diversity.
- Advocacy community needs to be sensitive to use of labels. Hear person-centered voices.
- MN’s next Alzheimer’s model: can we create robust stakeholder engagement for research?
- Workforce not available rurally.
- Challenge of labeling – get tangled up in words (“How do I describe my condition?”).
- How can we foster research that includes stakeholder engagement (we need better identification of those to engage and we need better listening processes to learn from minority groups).
- Need for institution-wide training (“janitor to director”) on interacting with those with memory loss issues.
- Being at a lost after diagnosis. Facilities (i.e. medical community) have limited expertise on guiding patients/families on immediate next steps.
- How can we engage cultural partners to come on board?
- What stakeholders are missing?
 - People who are diagnosed
 - Families of diagnosed
 - Service providers
 - Service receivers
 - Member from memory center to speak to committee?

The committee will continue to refine their vision knowing that part of their job is to reinforce that vision through committee process and incorporate vision into final report.

Alzheimer's Disease Work Group

Meeting 1: January 8th, 2018

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Activity to discuss legislative report elements

The next Work Group activity was to analyze the elements required in legislation of the 2019 report and begin to assess:

- What has been accomplished and what work is underway since the 2011 report?
- What information should we review collectively to inform our recommendations?
- What are the gaps?

Analysis and assessment of public health and health care data to accurately determine trends and disparities in cognitive decline

- ▶ What has been accomplished in this area or what work is currently underway?
 - MDH-increased data collection, analysis of dementia progress modest – limited data collection, if any rely mostly on behavioral risk factor surveillance system (BRFSS)
- ▶ What information should we review collectively to inform our recommendations on this element?
 - Review current MDH effort, ID gaps, ID steps, falls/injury prevention
 - Can MN implement a survey strategy? MDH SHIP data?
 - Itself national survey modes
 - Is Alzheimer part report or nursing report card?
 - Evaluate cognitive screenings that are pertinent to diverse clients
 - Environmental scan of what is being done in other states.
 - Chronic disease sot report – review 2017
- ▶ What are the known gaps for this element in Minnesota
 - Public health registry for AD? Like cancer?
 - Standardize mortality data for Alzheimer's/dementia
 - Need more info on cultural groups
 - Implement health care organization reporting of quality metrics
 - Data not only on patient But also caregiver – BKFSS
 - Data from wellness visit cog. Screening – how well are minorities represented in data?

Alzheimer's Disease Work Group

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Public awareness, knowledge, and attitudes, including knowledge gaps, stigma, availability of information, and supportive community environments

- ▶ What has been accomplished in this area or what work is currently underway?
 - Dementia cultural consultants. All CNA's – 8 hrs on dementia (training) cultural cognitive screening in CC training (meaning?) Alz. Assoc. working with federal qualified H.C. clinics establishment of divers act on Alzheimer dementia friendly.
 - MBA dementia grants alz. Assoc. cultural diversity grant - Hmong, Spanish?
- ▶ What information should we review collectively to inform our recommendations on this element?
 - cultural competent consultation caller
 - Review health equity findings from previous group
 - Review /explore geographical gaps to HQ dementia care
 - Review new/revised dementia care practice recom. (Alz. Assoc.)
 - How can systems become culturally competent in memory care?
 - MBA dementia grants
 - Disparities could also include social economics, IDD, geography, linguistic
 - Obtain insight from representatives on gaps.
- ▶ What are the known gaps for this element in Minnesota?
 - Access participation in Alz related research –diverse community
 - Utilization/awareness dementia cultural consultants – more info more access
 - Education/understand of need etc. for all caregivers.
 - Rural access and technology challenges
 - Change: what can we learn from diverse families?
 - Diversity in the direct care work force- you get the best WF when you recruit from that community
- Health care organizations are unaware of cult. Consultants.

Alzheimer's Disease Work Group

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Risk reduction, including health education and health promotion on risk factors, safety, and potentially avoidable hospitalizations

- ▶ What has been accomplished in this area or what works is currently underway?
 - Home community based services – fed. Reg. –person centered focus
 - Nursing home/assisted living
 - Hours of dementia training – legislation (2016 start)
 - Community living specialist and sr. linkage line
 - More options now
 - Gov. elder abuse work group
- ▶ What information should we review collectively to inform our recommendations on this element?
 - Disclosure of services, costs, why/when increase
 - Cost to families we need more info
 - How do different cultural groups define “residential services” and family understand of care/traditions
 - “report card” “VA” – with training received
 - Training – what it is? Moving from person centered to family centered.
 - Are there best practice? How to access trainings? I.D. disseminate? Service appropriate for young onset and atypical.
- ▶ What are the known gaps for this element in Minnesota?
 - Gaps on vulnerability –honoring caregivers role and care needs
 - Proper consumer protections – due process, e.g. protecting patients from other residents and staff.
 - Rural vs. urban divide
 - Gaps in funding – transparent cost information for families
 - Defining of residential services – can we standardize? Educate?
 - Standardized training for all staff – deconstructing “Presidential”
 - Work force - \$- People

Alzheimer's Disease Work Group

Meeting 1: January 8th, 2018

9:00 – 2:30 p.m.

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Diagnosis and treatment, including early detection, access to diagnosis, quality of dementia care, and cost of treatment

- ▶ What has been accomplished in this area or what works is currently underway?
 - Assisted living dementia training required
 - U of M partners in dementia elective
 - Increased medical student geriatrics curriculum time
 - Legislature gave to U of M for geriatrics – no reporting on how spent.
 - ACT curriculum development, 10 care training in screening
 - VA medical centers
 - Dementia friends
 - Education for all = schools grade school and up all community outlets and churches
- ▶ What information should we review collectively to inform our recommendations on this element?
 - What did U of M do with money
 - What is training for EMS /law enforcement/ APS re: dementia
 - Curriculum in higher education health professions across school and profession
 - DHS workforce development/training efforts
 - Ethics/language barriers (demography) in dementia care.
 - Existing elementary, middle, high school, dementia education/curriculum – create d-f generation
 - Impact of increasing minimum wage?
 - The stigma of direct care work
 - Review residency match choices (aging/neuro/psyc/geriatrics) for medical students
- ▶ What are the known gaps for this element in Minnesota?
 - Wide variation in dementia training across settings/more education geared to population of colors
 - More coverage in legal education and other professionals
 - More direct care workers, more colleges offering courses, emphasis on other professional (ex. Librarians) mandated training for first responders/law enforcement/pharmacist- what are statewide association for these sectors?
 - Legislative/state funding line for UMN center on aging

Alzheimer's Disease Work Group

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- UMN – geriatrics of memory care clinic

Professional education and training, including geriatric education for licensed health care professionals and dementia-specific training for direct care workers, first responders, and other professionals in communities

▶ What has been accomplished in this area or what works is currently underway?

- Dementia care best practices identified, avail on act website, update coming soon in journal of gerontology.
- Annual wellness was created (Medicare) and include cognitive screen- all systems have options to use it. More education on the availability of this.
- Economic modeling completed – early detect and cger support = found cost savings. US preventative services task force reconvening to update screening recommendations.
- MNHCH model – care coordinators trained in dementia – training embedded in states in hire learning MY UCI implanted but challenges with sustainability.
- Trained 2,000 providers in dementia care best practice around MN.

▶ What information should we review collectively to inform our recommendations on this element?

- NAPA, ACT, USPS task force report
- New dementia care best practice recs., MBA dementia grant legislative report
- Evaluation from these annual screenings (trends, stats)
- QI in dementia working /report

▶ What are the known gaps for this element in Minnesota?

- Lack of money to support appropriate level of funding for AD research – in MN?
- Limited access to specialist in outstate, and underserved communities
- Limited adoption of providers and institution of screen, DX and management. How to deliver the diagnosis?
- Care coordination, once diagnosed seamless communication.
- Educate physicians/providers on annual wellness and to implement co screens!
- Need to get c-suite health care systems to buy in dementia
- Need psychoeducation support for all patents and families is organizing principle to holistic care.
- Identify apparent reimbursement streams –fueling models
- Empowerment of primary care does dementia mgmt.

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Meeting 1: January 8th, 2018

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Residential services, including cost to families as well as regulation and licensing gaps

- ▶ What has been accomplished in this area or what works is currently underway?
 - ACT managing mid-late stage dementia practice tool (safety and available hospitalizations)
 - Chronic disease self-management “living well with chronic conditions”
 - Increase in education provide by vol. on risk reduction (know 10 signs)
 - Smaller community educational opportunities (i.e. UAMAA forum/twin ports)
- ▶ What information should we review collectively to inform our recommendations on this element?
 - incorporate safety as a research /clinical outcome.
 - Inst. Of medicine recent report on risk reduction and prevention CDC healthy brain initiative(MDH grant with Alz Assn)
 - MN's evidence based health promotion programs
 - What is happening in MN's SHIP (dementia focus)
 - Respite for caregivers to prevent hospitalization for patients and caregivers.
 - What is the gap of Medicare/Medicaid coverage US private care quality of coverage? Native Elders – wisdom steps has health improved.
- ▶ What are the known gaps for this element in Minnesota?
 - This entire topic!!
 - Central /diversity disparities – more culturally sensitive training environments i.e. Characters
 - Moving from a medical model to a more person-centered care plan. Finley centered (NASEM report)
 - Aging effects, standardized guideline for driving in Alzheimer's care.
 - Understanding of resources available to promote safety .
 - Disease education i.e. “behaviors”

Cultural competence and responsiveness to reduce health disparities and improve access to high-quality dementia care

- ▶ What has been accomplished in this area or what works is currently underway?
 - Act on Alzheimer web site w/links – D.F. communities tool kit
 - Act dementia friendly communities
 - Alz association website (consumers, family members)

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- Dementia friends MN
 - MBA dementia grants
 - Increase in volunteers creating awareness
 - Wilder “I am a caregiver”
- ▶ What information should we review collectively to inform our recommendations on this element?
- Research on social isolation
 - Outcomes related to health care homes? Ways to share research with community
 - World health organization –dementia NAPA report
 - BRFSS data on subject cog. Decline and caregivers
 - Recognizing various “trusted advisors” in communities (regional cultural)
- ▶ What are the known gaps for this element in Minnesota?
- Making it easy to participate in research/of supportive communities
 - I.e. Education on truths/myths signee reduction
 - Advance care planning
 - Working closely with diverse communities
 - Resource for community health workers \$\$
 - No statewide public awareness campaign
 - Coalition of PWD and families let your voice be heard – community engaged research model (UR) PPI program

The Group Shared Ah-Has from the discussion related to the legislative report elements:

Analysis and assessment

- A lot of information – but hidden, not easy to access
- Minnesota could take the lead in this area

Cultural Competence

- Minorities will call help lines but information people aren't always providing culturally appropriate answers.

Residential services

- Transparency is lacking re: cost of care facilities. We are more aware this is an issue evidenced by the fact the issue is listed in three different areas of this activity.

Professional education and training

- Amount of work accomplished since '11 is impressive. However, we haven't seen primary care sites demonstrate improvements.

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Diagnosis and treatment

- Biomarkers are coming. Work Group needs to be mindful of its impact.
- Best practices are available but service providers haven't figured out "what is in it for them" to embrace them.

Risk reduction

- What are the "correct" set of evidence measures?
- Stigma related to aging issues is still a problem.

"Big Worries"

- Are people and organizations using the great '11-resulting tools?
- Resources need to be more assessable to more people.
- Getting buy-in to fill gaps to a dementia-friendly community (i.e. fire department).
- Standardized training is missing.
- Families know there is a problem with their loved one. When they don't get the right help once they ask enter the system (visit the doctor), they get frustrated.
- Doctors don't know enough about memory issues or about various service providers.
- We need to better hear the voice of those with Alzheimer's. Is there a productive role within committee structure?
- Our final report needs to be shorter and "tighter".

"Common Threads"

- Cultural communities impacted differently within each of the seven areas.
- Education needed to speak same language across cultures and disciplines and be understood.
- Need to come up with the *most important* items for next report and not an exhaustive list.
- Wondering what really happened as consequence of '11 report.
- There is a need for standardization (e.g. when license is revoked, different data collection points)
 - The flip side is the need to personalize services to meet individual situations.

What's missing?

- More work on caregiving aspect
- Focus on trauma situations
- Research success and failure

Reflection

Regarding Committee Structure:

- Cultural competence will be its own committee and incorporated as a cross-cutting topic across all committees
- Caregiver/care person will be another cross-cutting topic

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- Potentially combine data-intensive categories.

Wrap up and next steps:

- Work group members should use sharepoint to nominate individuals (including themselves) to serve on committees by 1/26
 - Please do indicate which topic(s) individuals are interested in. If committee topics are combined/streamlined, we will still use this information.
 - Individuals can be nominated to serve on more than one committee.
- Work group members should review the legislative report elements and send ideas for streamlining/combining committee topics to Sarah Small (sarah.small@state.mn.us) by Jan 16th, 2018.

Open Forum (Public Comment)

No citizens requested opportunity to speak to the Work Group.

Meeting Adjourned at: 2:15 p.m.

Next Work Group Meeting: April 24, 2018