



ALZHEIMERS
ASSOCIATION
MINNESOTA-
NORTH DAKOTA

Challenges and Opportunities for Supporting Dementia Caregivers

*Insights from Public Health
Professionals*



BOLD
PUBLIC HEALTH
CENTER OF EXCELLENCE
ON DEMENTIA
CAREGIVING

AUGUST 2021

MESSAGE FROM THE DIRECTOR



Caregiving for people living with dementia is a public health concern. The emotional, financial, social, and health ramifications of providing unpaid help to someone living with dementia is well-documented. Often, the progressive trajectory of care demands also makes helping people living with dementia more challenging than caregiving for other conditions. The complexity of dementia care also affects employers, communities healthcare systems. The U.S. relies heavily on unpaid family members, friends, and others to care for people with dementia, but we are facing an impending "family care gap," where there will be fewer available caregivers for older people in need.

The BOLD Public Health Center of Excellence on Dementia Caregiving aims to partner with and assist public health agencies in their efforts to elevate dementia caregiving as a public health concern, and perhaps more importantly contribute to public health solutions. As a first step, our Center commissioned this report, conducted by the Minnesota-North Dakota Alzheimer's Association office, to learn from public health organizations themselves, to identify how these entities currently support caregivers of people living with dementia, gaps, and how our Center may assist. We hope to rely on this report to frame and develop tools, resources, and information to better support public health agencies across the U.S. in supporting dementia caregivers in all of our communities.

Dr. Gaugler is the Robert L. Kane Endowed Chair in Long-Term Care & Aging and Director of the Center for Healthy Aging and Innovation (CHAI) at the University of Minnesota School of Public Health. Dr. Gaugler's research examines the sources and effectiveness of long-term care for persons with Alzheimer's disease and other chronic conditions.

CONTENT

4

Introduction to PCHOE-DC

5

Project overview

6

Key Themes and Insights

Caregiver "self identification"

Stigma and fears

7

Dementia Awareness

8

Value Proposition/Buy-in
Resources

9

Prioritization
Partnerships & Collaboration

10

Responsiveness

11

Holistic Support
Professional Education &
Workforce Development

12

Feasibility of Best Practices



The Public Health Center of Excellence on Dementia Caregiving (PHCOE-DC)

WHO WE ARE

is one of three national PHCOE's established by the 2018 BOLD Infrastructure for Alzheimer's Act.

The mission of the PHCOE-DC is to help state, local and tribal public health agencies nationwide develop programs and initiatives that support caregivers of people living with dementia in their community. The center does so, by

- identifying and disseminating evidence-based programs and best practices in dementia caregiving,
- providing technical assistance to public health agencies for selecting, implementing and sustaining effective interventions,
- facilitating connections among public health agencies and a wide-range of community partners who serve people with dementia and their caregivers.

To guide its work, the PHCOE-DC actively seeks input from other BOLD-funded public health departments, National Healthy Brain Initiatives and other CDC-funded programs. This report is the summary of our most recent collaboration with the Minnesota-North Dakota Chapter of the Alzheimer's Association.



OVERVIEW

During the summer of 2021, the **Minnesota-North Dakota chapter of the Alzheimer's Association** conducted in-depth **interviews with 12 public health officials** representing county, tribal and state public health agencies and one community-based Health and Human Services organization **across Minnesota and North Dakota.**

The goal of the conversations was to gain a better understanding of the agencies' current work and experience with supporting caregivers of people living with dementia, and the challenges and opportunities they anticipate for implementing dementia caregiving programming in the future, with a special focus on underserved communities.

To ensure a safe space for interviewees to share, the names of the specific interviewees and organizations anonymous. Permission to affiliate names with the quotes below was granted.

INTERVIEW QUESTIONS

- 01 *Does your agency play a role in supporting caregivers? If yes, tell us about it.*
- 02 *Does your agency play a role in supporting caregivers of people with dementia? If yes, tell us about it. What are the challenges and successes? What gets in the way of this work?*
- 03 *As you think about what your agency could do (or hopes to do) in the future to support caregivers of people with dementia: What challenges do you anticipate? What might support you and your agency in this work?*
- 04 *As your agency works to disseminate best practices, strategies, tools and materials to support caregivers of people with dementia: What would help? What would be valuable to you?*
- 05 *What are the challenges and successes? What makes it easier to do this work?*

KEY THEMES & INSIGHTS

Self-identification as a "caregiver"

People who care for a family member or a friend (even those who provide significant direct care) don't necessarily self-identify as "caregivers". While they may identify as 'caring for/about' their loved one, they may consider it a moral responsibility but not "caregiving". This may especially be the case amongst some cultural communities that are disproportionately impacted by dementia. For example, one tribal community created a screening tool to help one determine if they are a 'caregiver'.



Stigma and fear

Some people “*don't want to talk about it*”, and it can be difficult for them to take the first step and seek help. Public health agencies can help make it easier for people to share and talk about dementia more openly. One agency reported that it raises awareness about dementia by providing resources in ways that are fun, creative and interactive. This not only helps make the resources more accessible but also reduces stigma and hesitancy people feel when it comes to talking about dementia. Another public health official shared that their agency has had a lot of success educating and engaging the community through “virtual dementia tours” in which community members get to hear first-hand from caregivers and people with dementia what it is like to live with the disease.

Appropriate framing of the topic is crucial. One of the tribal public health agencies interviewed recommended taking a strengths-based approach and focusing on assets and solutions, rather than presenting dementia as another health equity issue.

KEY THEMES & INSIGHTS



Awareness

Dementia is often erroneously perceived as a normal part of aging. There is a need to educate the public about dementia as a brain disease and to elevate it as a public health priority among community leaders.

Communities all over the country are doing great work to raise awareness and educate the public about dementia, through grants, partnerships and innovative communication approaches. Public Health agencies can promote and highlight this work as part their outreach and education efforts.

Caregivers also need more information and guidance about care options, and when to transition a person dementia to a higher level of care. There are resources and programming available to guide care partners in this decision making and public health agencies can make this information more accessible.

Finally, public education and awareness can support earlier detection and diagnosis. Public health agencies should encourage healthcare providers to integrate cognitive assessments as part of regular primary care screening (e.g. add the question(s) “have you noticed any changes in your memory/cognition?” or “do you have any concerns about your memory/cognition?”).

Increase response from the first point of caregiver/patient contact with medical care by including a memory question as part of the intake process and offer immediate resources: Alzheimer's 24/7, 10 Warning Signs card, a first step resource list.

KEY THEMES & INSIGHTS

Value proposition

Clearly communicating to policy-makers the importance and benefits of prioritizing dementia caregiving is key to securing funding for caregiver support programs. A strong value proposition should clearly articulate why dementia caregiving should be treated as a public health issue by the legislature. Specifically,

- historic data can be used to tell the story and quantify the economic benefits (ROI) of caregiver support programs,
- the data should be local (county-level and state level), and
- dementia should be presented along with other chronic diseases and community priorities.



Resources

Public Health agencies often lack dedicated staff for dementia support and caregiving. Dedicated resources, including funding, people, tools and materials are needed to support public health agencies in developing and sustaining their dementia caregiving efforts.



At the same time, families and communities might also lack a ‘sandwich generation’ to provide care support. In some communities, grandparents are increasing having to take on the caregiver role to care for their school-age grandchildren. Their work is further complicated by the fragmented system of care where locating and accessing resources is often challenging.

KEY THEMES & INSIGHTS

Prioritization

Other chronic conditions, such as cancer, diabetes and obesity, or COVID19, often overshadow dementia in healthcare. As a complex, long-term debilitating disease, dementia deserves focused attention as a chronic condition and should be seamlessly integrated as part of regular care.

One agency suggested encouraging providers to pair cognitive screening with other regular screenings (e.g. colorectal cancer screenings and immunizations) in order to elevate and normalize it as a regular and expected part of care. Currently, other health and living issues (e.g. homelessness) take precedence over dementia, and also act as a confounder to diagnosis and care to dementia.



Partnerships and Collaboration

Partnering and collaborating internally (across departments) and externally (with other community-based organizations) is a strength. There is continued opportunity to

- 1) **elevate** dementia as a focus area for the community,
- 2) support and **expand** these partnerships and collaborations
- 3) collaborate with **diverse** partners who are deeply embedded in diverse communities and doing this work well already.

Partnering with cultural communities requires building trust. Connecting and knowing one another is essential.

“The biggest opportunity to advance support is to encourage cross-sector collaboration. When organizations with shared goals collaborate to pool their knowledge and resources, it can lead to innovative and progressive work that improves support for dementia caregivers.”

KEY THEMES & INSIGHTS

Responsiveness

It is crucial to develop materials and content that are culturally-responsive to underserved and disproportionately impacted communities (e.g. BIPOC, LGBTQ, rural, veterans).

Both content and approaches have to be adapted in order to be useful and meaningful for diverse communities. For example, in some communities “dementia” isn’t even a word. To address this issue, one service provider created a culturally-sensitive screening tool that would help with diagnosis of dementia in the community.

It is also important to diversify the workforce so that the staff reflects the cultural, ethnic and linguistic diversity of the community it serves.

Finally, the amount and complexity of the information provided to caregivers should be according to their needs and abilities. Public health and health care providers should strive to adapt their communication and materials to the individual learning abilities of the caregivers. Spacing out the information can help avoid overwhelming the caregivers



Increase funding for education and awareness. For example: 10 warning signs for all medical personnel.. or promote opportunities for caregivers such as REACH Community (Resources for Enhancing Alzheimer’s Caregiver’s Health) Indian Country, Savvy Caregiver in Indian Country, and materials (posters, info sheets, media campaign..) with a focus on Native American people.

KEY THEMES & INSIGHTS

Holistic support

There is a need to address caregivers' needs from an integrated, holistic perspective -including social, mental, physical, legal, spiritual and financial wellbeing.

Caregiver support programs should include mental health support, respite care and suicide prevention.

Some families and certain cultural communities prefer to care for their loved ones with dementia at home, yet our system does not compensate informal caregivers for the care they provide.

Professional Education & Workforce development

Compensation and education of professionals are barriers to making dementia caregiving better. There is a lack of training and opportunities to learn how to recognize and care for someone living with dementia within the educational system.



Promote “Healthy Brain Initiative – Roadmap for Indian Country” to be available and offered as training and source of information for all service providers in tribal nations.

-Fran King,
Supportive Services Coordinator, MN Indian Area Agency on Aging, MN
Chippewa Tribe

KEY THEMES & INSIGHTS

Feasibility of best practices

While evidence-based interventions are of great value, they are not utilized by the community nearly as much as they could be. There is often a gap between evidence based best practices and the ability to implement them in the real-world.

It can often be time-intensive for caregivers to participate in programs and for staff to get trained in interventions and to deliver them. This gap may also include cultural practices and approaches to caregiving that are not necessarily reflected in evidence based interventions.



Evidence-based programs also need to be culturally responsive, and reflect individual communities' preferences and cultural values in order to be meaningful, adopted and sustained in diverse communities. The Association interviewed representatives from **Native American communities and those working with Black and African American persons**. Additional interviews may find similarities in views around caregiving (e.g., family, moral, or cultural obligation), approaches to elder engagement (needs to be “fun” and less education focused), and perceptions around dementia itself (some languages do not have a word for “dementia” and may use derogatory terms to describe the condition) across many underserved communities.

CONCLUSION

What did we learn from these interviews?



Center dementia as a public health issue and reduce stigma

- *Encourage caregiver education and identification*
- *Reduce dementia stigma, especially in tribal communities*
- *Create public health awareness and increase dementia care resources*

Articulate the need for supporting dementia caregivers

- *Communicate the value to policymakers and align dementia with other chronic diseases*
- *Increase resources and staff at public health agencies*
- *Prioritize dementia in healthcare and integrate it in regular health screenings*
- *Build partnerships, internally and externally*



Increase dementia education reach by diversifying materials and approaches

- *Develop culturally responsive content tailored to LGBTQ+, BIPOC, rural and veteran caregivers*
- *Advocate for and provide more holistic support*
- *Encourage professional and workplace education*
- *Adapt best practices to reflect the values and preferences of diverse communities*