



# THE IHS PRIMARY CARE PROVIDER



*A journal for health professionals working with American Indians and Alaska Natives*

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## Support of Dementia Friendly America

*Olivia Mastry, JD, MPH, Founder Collective Action Lab.  
Correspondence M Ek: mek@collectiveactionlab.com*

### Dementia Friendly Communities

Dementia Friendly America (DFA) is a multi-sector, national collaborative of cross sector organizations and individuals seeking to foster communities across the U.S. that are equipped to support people living with dementia and their caregivers. Dementia friendly communities foster the ability of people living with dementia to remain in community and engage and thrive in day to day living; basic things like going to the store or the bank. The community also buoys the caregiver by adding extra supports such as respite programs.

Every part of the community plays a role and can work together to take steps to create a dementia friendly culture.

- **Businesses**, such as **banks** and **financial and legal services** support customers with dementia and **employers** support employees who are caregivers.
- **Health care systems** promote early diagnosis and options for ongoing care and support.
- **Communities of faith** welcome and engage.
- **Local governments** plan and implement housing, transportation, public spaces, and emergency response that enable people with dementia to thrive in the community.
- **Neighbors and community members** understand and support.
- **Residential care and community based supports** offer a range of services to maximize independence and support ongoing community engagement with a variety of options adapted to cognitive decline.

A dementia friendly community 1) raises awareness of and develops respect and inclusion for people with dementia, 2) has services and resources embedded in all areas of community to ensure meaningful access to community and promote quality of life, 3) supports and educates people with dementia, their care partners and families from diagnosis through disease progression and 4) promotes meaningful engagement in community life.

The Dementia Friendly America initiative provides a system of technical assistance and tools and resources to assist communities and individuals take action to improve community and system capabilities, optimize the health, well-being and involvement of people with dementia and their care partners, and support them to continue in their roles.

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Indicators of success in a dementia friendly community include:

- Increased quality of life for people with dementia and their care partners
- Increased community awareness of dementia
- Increased dementia friendly business and financial practices
- Increased access to and inclusion in community life and meaningful engagement through dementia friendly services and supports

- Increased rates of detection/diagnosis and participation in clinical trials
- Increased rates of advance planning
- Increased options that will help people pay for their care and support needs
- Reduced fraud and abuse
- Increased coordination among sectors / collaboration across sectors to create a synergy of efforts - partnerships between parts of the community that have not traditionally worked together

### **Based upon success in Minnesota**

The Dementia Friendly America initiative is based on ACT on Alzheimer's, a successful statewide, volunteer-driven collaboration of medical, academic, community, government, business and nonprofit stakeholders across Minnesota. Developmental evaluation of these communities has shown an increase in services and resources that are supportive of people living with dementia, an increased awareness of dementia and effective responses from those

living in communities undertaking this effort, and a greater sense of confidence for those living with dementia and/or their care partners.

Since 2011, 43 communities have come together in Minnesota to prepare for the personal, social, and budget impacts of Alzheimer's disease by addressing community needs and increasing support for people impacted by Alzheimer's disease and dementia. The momentum for dementia friendly communities is growing nationally as there are now communities in 20 states actively adopting this work and communities from another 22 states preparing to join the DFA map. Any community can work toward becoming dementia friendly starting with local champions that help organize and coordinate the effort.

Information on the Dementia Friendly America Initiative and resources to help you become a dementia friendly community can be found at <http://www.dfamerica.org>.

For more information about how to work to become a dementia friendly community, please contact Mary Ek at [mek@collectiveactionlab.com](mailto:mek@collectiveactionlab.com).

## **Supporting IHS Providers in Supporting Native American Dementia Caregivers**

*Jennifer Martindale-Adams, Ed.D., Associate Professor and Co-Director Caregiver Center, Department of Preventive Medicine, University of Tennessee Health Science Center and Co-Director Caregiver Center, Veterans Affairs Medical Center Memphis. VAMC (11-H); Memphis, TN; Barbara J. Higgins, M.A., Coach and Trainer, Caregiver Center, Department of Preventive Medicine, University of Tennessee Health Science Center. VAMC (11-H), Memphis, TN; Linda O. Nichols, Ph.D., Co-Director Caregiver Center, Veterans Affairs Medical Center Memphis and Professor and Co-Director Caregiver Center, Department of Preventive Medicine, University of Tennessee Health Science Center. VAMC (11-H), Memphis, TN; Bruce Finke, M.D., Elder Health Consultant, Nashville Area Indian Health Service, Nashville, TN; CAPT Tina Tah, MBA, BSN, RN, Senior Nurse Consultant, Division of Nursing Services, Office of Clinical and Preventive Services, Indian Health*

*Service, Rockville, MD. Corresponding Author B Finke: [bruce.finke@ihs.gov](mailto:bruce.finke@ihs.gov)*

### **Abstract**

Dementia caregivers, including American Indian/Alaskan Native (AI/AN) caregivers, often struggle with the management of disease-related behaviors for their loved one with dementia and their own stress and coping. Resources for Enhancing Alzheimer's Caregivers Health in Tribal Communities (REACH into Indian Country) can help professionals and paraprofessionals effectively support Caregivers in dealing with behavioral problems and their own stress and coping.

A collaboration of Indian Health Service (IHS), Administration on Community Living (ACL), and University of Tennessee Health Science Center (UTHSC), funded by the Rx Foundation, is implementing REACH into

Indian Country in partnership with Tribal communities, organizations, and health programs. This article discusses how the use of the REACH Program can also help maximize staff interactions with Caregivers and the progress of the Program over the last year.

Caregivers of family members with dementia are faced with challenges in managing illness-related behavioral difficulties and their own stress and coping associated with caregiving. Primary care health providers are generally the main medical resource for dementia caregivers and Tribal Senior Center programs funded by Title VI of the Older Americans Act are the main social resources. The evidence-based behavioral intervention for dementia caregivers, Resources for Enhancing Alzheimer’s Caregivers Health in Tribal Communities (REACH into Indian Country) can help professionals and paraprofessionals effectively support caregivers in dealing with behavioral problems and their own stress and coping.

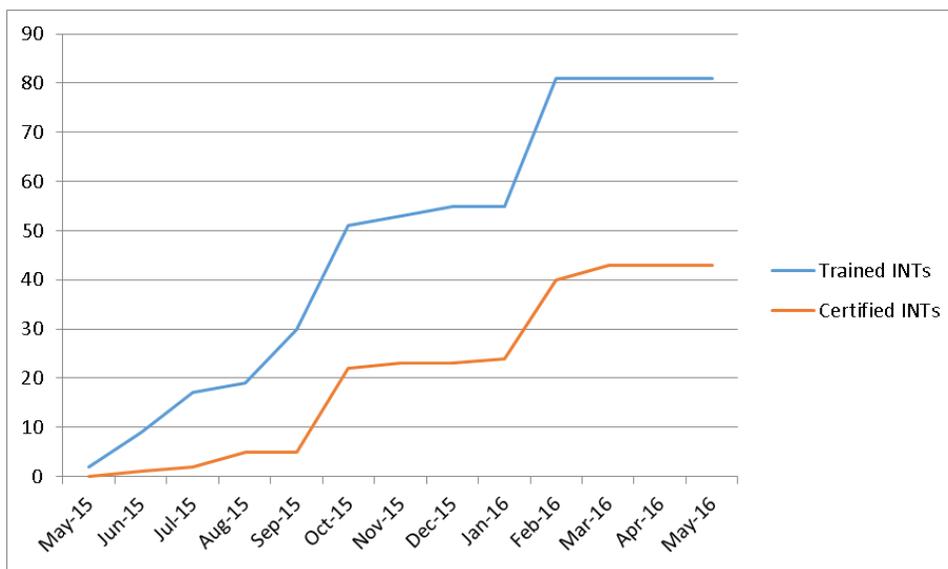
As previously reported in 2015, the University of Tennessee Health Science Center (UTHSC) was funded for three years by the Rx Foundation to implement REACH into Indian Country and UTHSC has been working in partnership with the Indian Health Service (IHS), Administration on

Community Living (ACL) in this initiative. This further expands the collaboration among these partners and the Department of Veterans Affairs, which implemented REACH VA into Indian Country.

REACH is a program of simple-to-learn skills that is targeted to the specific needs of the caregiver and the patient and produces excellent outcomes. There are four core sessions with the option for additional sessions if needed and a Caregiver Notebook written at a fifth grade reading level with practical strategies to help caregivers manage patient behavioral concerns and their own stress. The REACH Program can be offered in the home, in facility or clinic, or by telephone or telehealth modalities.

Training of staff to function as REACH Coaches, predominantly IHS and Tribal public health nurses who serve caregivers of American Indian/Alaskan Native (AI/AN) individuals with dementia as well as caregiver support staff from Tribal Senior Center programs, was initially virtual. Based on staff requests, face-to-face trainings have been implemented. These REACH Coaches are then certified at the training or through a telephone or video role play (Figure 1).

**Figure 1. Trained and Certified REACH Coaches**



Use of the REACH Program can help maximize staff interactions with caregivers. REACH Coaches work with family members to empower the family caregivers to feel confident that they are providing the highest quality of care possible to their loved one while maintaining their own physical health and a positive mood. For clinical and Senior Center staff, REACH offers these benefits.

Develops a working relationship quickly. The use of a Risk Assessment encourages the caregiver to identify problems and concerns and “tell the caregiving story.” This provides an opportunity for therapeutic rapport between caregiver and Coach, as the caregiver’s issues and concerns are heard.

Increases clinical skills in promoting dementia education. Caregivers may be reluctant to self-identify difficulties and stress related to the care of their loved one. AI/AN caregivers are particularly sensitive to cultural influences that define the psychological and emotional posture concerning caregiving duties. The primary emphasis on education and support provided by the REACH Program allows the staff to lessen caregiver barriers to access of needed resources. While the REACH Program is designed for one-on-one interactions, it encourages participation of extended family support. Staff working in AI/AN communities are able to utilize education and support to provide increased awareness of dementia related issues for the primary caregiver as well as the extended family unit. In addition, trained and certified REACH staff are multi-disciplinary and reflect diverse job assignments. As implemented in Indian Country, REACH Coaches have utilized effective intercommunication to identify potential caregivers that could benefit from the REACH Program.

Maximizes staff time and interaction with the caregiver. The Risk Assessment allows the REACH Coach and caregiver to work on the problems that are the most difficult or distressing based on the caregiver's responses to the risk based questions. Staff trained in other caregiver interventions have reported that REACH is a valuable program, by enabling expansion of current resources and providing direct educational support for identified caregivers needing a more targeted intervention.

Gives staff a structure for interaction. The REACH Program is structured in that, as with most successful caregiver programs, it targets education about safety issues, health of the caregiver and patient, well-being of the caregiver, and the many problem behavior challenges that can come with a diagnosis of dementia. A Staff Manual provides guidelines and scripts for each session making the Program "grab and go." As one staff member said, "Looking back at the training, especially the first day, I could not imagine implementing the Program. As I re-read the material in different sections, it becomes easier to 'digest' and the applicability is actually easy."

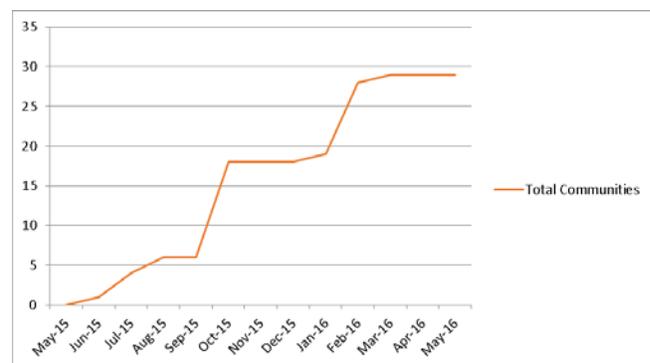
Gives the caregiver exactly what he/she needs. The REACH Coach reviews basic problem solving skills to work with the family caregiver in identifying a problem, breaking it down into when and where it happens, and, using the Caregiver Notebook, deciding on strategies that can be tried. One staff member reported, "The REACH Program was a method to help the caregiver to deal with complex problems in a structured way. Our caregivers changed from viewing the issues with their loved ones as huge problems into thinking

proactively by addressing small parts of the issues. The book helped them to break things down into a doable level. The program in our experience was very user friendly."

Lessens caregiver dependence on staff. Staff are not always available to help caregivers deal with the ongoing and changing challenges of dementia care. With REACH training, caregivers are empowered to identify what they need and work toward their goals, instead of not knowing what will help them. "... I was in the clinic just yesterday and had a chat with a patient who shared she was a caregiver and was looking for assistance and resources. We chatted for quite some time and she was very grateful just to have a sympathetic ear which made me again realize how important the REACH training will be to our unit."

Currently, REACH into Indian Country is in 29 communities (Figure 2) and the UTHSC Caregiver Center continues to train and certify REACH Coaches and provide staff manuals and Caregiver Notebooks. Any individual working with AI/AN dementia caregivers can have the REACH into Indian Country program as part of their tool kit to help caregivers. For more information, please visit the REACH into Indian Country website:

**Figure 2. Communities Reached**



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## Uniting Nursing Homes in Tribal Excellence

*Deborah J Dyjak RN, BSN, MS, Education Coordinator, Archie Hendricks Sr. Skilled Nursing Facility Tohono O'odham Nursing Care Authority, Sells, AZ. Corresponding Author D Dyjak: [ddyjak@toltc.org](mailto:ddyjak@toltc.org)*

Over 15 nursing homes across Indian country are meeting monthly as the UNITE (Uniting Nursing Homes in Tribal Excellence) collaborative to share resources and experience and to work toward changing the environment of long term care to better reflect our Elders' cultural choices. UNITE has

over 30 members and is collaborating with CMS, IHS, Administration on Community Living, state agencies, Geriatric Workforce Enhancement Programs (GWEPs), NCAI, NICOA, and Quality Improvement Organizations in Alaska and Arizona. We presented our work on "Traditional Foods, Traditional Lives" on a CMS LTSS webinar May 25th, 2016 and will be presenting at the National Congress for American Indian's mid year conference June 29th, 2016, in Spokane Washington. Any questions may be addressed to Debbie Dyjak RN at [ddyjak@toltc.org](mailto:ddyjak@toltc.org).

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