Addressing Dementia Caregiving Service and Support Needs Across the Indian Health System

Prepared by Cardea for the:

Indian Health Service (IHS) Alzheimer's Program

Contents

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Workgroup members:

Michelle Archuleta, MA, MS
Indian Health Service

Laurai Atcitty
Inter Tribal Council of Arizona, Inc.

Alberta Becenti, MPH
Indian Health Service

Brandi Bell
Kenaitze Indian Tribe

Dan Calac, MD
Indian Health Council, Inc.

Addison Carey
Cherokee Nation

Rebecca Carrillo, MSN, ACM-RN, Acting BH/PHN SCN
Phoenix Indian Medical Center

Derrell Cox
Integrated Research Institute

Shawnell Damon, MPH, MSc
Indian Health Service

Shaylynn DeMarrias
Spirit Lake Tribe

Bruce Finke, MD
Indian Health Service

Jane Ferril
Thrive Alliance

Atheda Fletcher
Absentee Shawnee Tribal Health System

Jessica Ford
Nimiipuu Health

Andrea Grove
Northern Valley Indian Health

Cammie Hayward, RN
Norton Sound Health Corporation

Lindsay Hernandez
Absentee Shawnee Tribal Health System

Loretta Heuer, PhD, RN, FAAN
North Dakota State University

Amber Hoon
Great Lakes Inter-Tribal Council, Inc.

Diane Hugar, CDP
Wichita and Affiliated Tribes

Lexie Jackson, PhD, RDN, CDCES
Pacific University

John Keller, RN
Indian Health Council, Inc.

Jordan P. Lewis, PhD, MSW, CPG
University of Alaska, Anchorage

Lucia Lee
Hualapai Tribe

Alexis Lichty
Confederated Tribes of Grand Ronde

Erin Long, MSW
Administration on Aging/Administration for Community Living

Jodi Lyons
CareBrains

Arisha McAllister
Absentee Shawnee Tribal Health System

Rema Metts
San Carlos Apache Tribe

Dominique Nault
Seattle Indian Health Board

Shayna Padilla Gomez
Nimiipuu Health

Hadyn K Paternite, PhD, MSN, RN
Absentee Shawnee Tribal Health System

Megan Russell
Indian Health Service

Anna Sampley, MPH
Alzheimer's Association

Christine Schultz, LCSW
Norton Sound Health Corporation

Christina Svec
Kenaitze Indian Tribe

Tina Tah, RN, BSN, MBA, CAPT, USPHS
Indian Health Service

Emily Tahy-Ceballos, EdD, MPH
Indian Health Service

Kimber Tower
Televeda

Tonya Tyler, RN
Northern Valley Indian Health

Jenny Walker
McMaster Institute for Research on Aging

Iris Walking Eagle
Spirit Lake Tribe

Mary Weston
Inter Tribal Council of Arizona, Inc.

Amy Whisler, PharmD, MA, NCPS, CDR, USPHS
Indian Health Service

Amanda Whitesinger
Gila River Health Care

Hailey Wilson, MD
Nimiipuu Health

Mary Wolf
Inter Tribal Council of Arizona

D. Richard Wright
Indian Health Board of Minneapolis

Cerrie Watson
Indian Health Council

Interview Participants

Fawn Cothran, PhD, RN, GCNS-BC, FGSA
National Alliance for Caregiving

Jordan P Lewis, PhD, MSW, CPG
University of Alaska Anchorage

Bruce Finke, MD
Indian Health Service

Debra Miller
Oneida Nation

Laura Gitlin, PhD, FGSA, FAAN
Drexel University

Anna Sampley, MPH
Alzheimer's Association

Kassara Kneeland, LICSW
Veterans Administration Caregiver Support Program

Alan Stevens, PhD
Baylor Scott & White Health

Guest Presenters

Laurai Atcitty
Inter Tribal Council of Arizona, Inc.

Brooke Bryson
OCCK, Inc.

Sarah Dulaney, RN, MS, CNS
University of California, San Francisco

Jane Ferril
Thrive Alliance

Bruce Finke, MD
Indian Health Service

Laura Gano, PhD, MPH
Indiana University School of Medicine

Amber Hoon
Great Lakes Inter-Tribal Council, Inc.

Stacey Kahre
Generations

Jordan P. Lewis, PhD, MSW, CPG
University of Alaska Anchorage

Mary Weston
Inter Tribal Council of Arizona, Inc.

Indian Health Service Team
Jolie Crowder, PhD, RN, MSN, CCM
Valerie Jones, MPA, MA
Jamie Olsen, R.T. (R)(M), FAC-COR III

Northwest Portland Area Indian Health Board
Jessica Rienstra, PNP, PMHNP
David Stephens, BSN, RN

Cardea
Emily Nakamura, MDiv
Wendy Nakatsukasa-Ono, MPH
Beatriz Reyes, MPA

For any inquiries, please contact the Indian Health Service:
Jolie Crowder, PhD, MSN, RN, CCM
National Elder Services Consultant
Division of Clinical & Community Services (DCCS)
Indian Health Service
Email: jolie.crowder@ihs.gov
Phone: 301-526-6592

Executive Summary

The Indian Health Service (IHS) Dementia Caregiving Report highlights the growing need for culturally responsive dementia caregiving solutions in American Indian and Alaska Native (AI/AN) communities. Developed through a collaboration between the IHS Elder Care Team, the Northwest Portland Area Indian Health Board (NPAIHB), and Cardea, the report brings together findings from a literature review, key informant interviews, and a Workgroup of experts, caregivers, and community representatives.

Background and Purpose

This report aims to guide the selection and adaptation of caregiving interventions that reflect AI/AN values, community realities, and available resources. It also defines the role and responsibilities of a **Caregiver Coach** and assesses evidence-based interventions that can be successfully implemented in AI/AN communities.

Key Findings

- **Cultural Relevance is Critical**: Caregiving programs are most effective when they honor Indigenous knowledge, integrate traditional practices, and reflect community strengths and values.
- **Barriers and Gaps:** Many communities face structural challenges such as workforce shortages, limited internet access, and few dementia-specific education and support services.
- **Caregiver Needs:** Caregivers need culturally grounded support that includes skill-building, emotional wellness, family involvement, and access to peer mentors, offered through flexible delivery models.

Evidence-Based Interventions Reviewed

- Aging Brain Care
- Care Ecosystem
- Powerful Tools for Caregivers
- REACH Community
- Savvy Caregiver®

Each intervention was reviewed for its structure, content, outcomes, and adaptability in AI/AN communities.

Caregiver Coach Framework – "Head, Heart, Hands"

- **Head:** Knowledge and skills in dementia education, care planning, and health system navigation.
- **Heart:** Empathy, cultural humility, and emotional support.
- **Hands:** Practical help with symptom management, home safety, respite care, and care coordination.

Recommendations

The report identifies eight priority actions for IHS and its partners:

1. Center culture, community, family, and Indigenous knowledge.
2. Adapt and implement existing evidence-based interventions.
3. Establish and support a Caregiver Coach model.
4. Build workforce capacity.
5. Address structural and social determinants of health.
6. Create coordinated clinical and community care systems.
7. Measure impact and share learning.
8. Secure sustainable funding.
9. Advance policy alignment and partnerships.

These actions will strengthen culturally aligned, community-led, and sustainable caregiving programs so that people living with dementia and their caregivers receive the respect, support, and dignity they deserve.

Detailed recommendations and implementation strategies are provided in the "Recommendations" section of this report.

Background

Alzheimer's disease and other related dementias (ADRD; dementia) affect the lives of American Indian and Alaska Native (AI/AN) people across generations. Alzheimer's disease is one of the most common causes of dementia, though many individuals experience "mixed dementia," meaning two or more causes contribute to cognitive decline. Dementia is a progressive condition that affects memory, communication, problem-solving, and other thinking abilities.

While there is no cure, the Indian Health Service (IHS) Alzheimer's Program works to reduce risk factors for dementia and improve quality of life for people living with dementia and their caregivers.

Aging is the greatest risk factor for dementia. A study of IHS patients found that a higher proportion had younger-onset dementia (ages 45–64) compared to global rates. The number of older AI/AN adults is expected to triple in the next decade, which will in turn significantly increase the number of people living with dementia.

Dementia is a life-limiting, progressive disease, meaning symptoms worsen over time. As dementia progresses, most people will require both formal and informal caregiving support from family, friends, and community members. The support caregivers provide often becomes increasingly complex and time-intensive as dementia advances.

Currently, one in four AI/AN adults identifies as an unpaid caregiver, though some people or communities do not recognize the term "caregiver." In this report, the term *caregiver* refers to a family member, friend, or relative who provides care for a person living with dementia. In many AI/AN families, this role is shared by multiple people involved in an Elder's life.

Older AI/AN adults—often referred to as Elders—hold a deeply valued place in their communities. As highlighted in the *Healthy Brain Initiative: Road Map for Indian Country*, [1] Elders are recognized for their wisdom, experience, knowledge, and community contributions. They are blessings to their families and tribes, serving as bridges to the past and keepers of language, history, and tradition.

The journey of each person living with dementia is unique, as is the journey of their caregivers. Caregivers need person-centered, tailored support to maintain their own health and well-being while caring for their loved one.

Recognizing this critical role, the IHS Elder Care Team, in partnership with the Northwest Portland Area Indian Health Board (NPAIHB) and Cardea, convened a Dementia Caregiving Informal Workgroup (Workgroup) to:

- Inform the prioritization of caregiving evidence-based interventions (EBIs).
- Support the development of recommendations for Caregiver Coach roles and responsibilities and other key caregiver services and supports.

As a partner to the IHS Elder Care Team and NPAIHB, Cardea collaborated with IHS and the Workgroup to develop this report. The report synthesizes insights from the Workgroup, findings from the literature review on caregiver interventions, and results from key informant interviews. It concludes with recommendations for future work to strengthen caregiver services and supports across the Indian health system.

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[1] Alzheimer's Association and Centers for Disease Control and Prevention. *Healthy Brain Initiative, Road Map for Indian Country.* Chicago, IL: Alzheimer's Association; 2019.

Literature Review

The team conducted a literature review examining the current research on dementia caregiving interventions within AI/AN communities, focusing on evidence-based interventions (EBIs), culturally-tailored interventions, and universal support for caregivers and people living with dementia.

We used the following keywords and phrases: *evidence-based intervention, intervention, caregiving, caregiver, caregiver coach, American Indian, Alaska Native, Aboriginal, tribe, tribal, Indigenous, rural, Alzheimer's, dementia, Native American, family caregivers,* and *cognitive impairment*. The review was limited to the 10-year period from 2014 to 2024 to ensure results reflected current best practices and the most recent discussions of interventions and adaptations. Based on the review, 18 articles were identified addressing various aspects of dementia care, including the integration of traditional practices, the role of family and community in caregiving, and the effectiveness of evidence-based interventions adapted for AI/AN settings.

This body of research offers a comprehensive overview of dementia care, with a particular focus on culturally responsive interventions, caregiving support, and implementation in diverse Indigenous communities. Of these, 11 articles include research on specific interventions. These include:

- **Fortinsky et al. (2020)**,
- **Gallagher-Thompson et al. (2015)**,
- **Gitlin et al. (2024)**,
- **Gitlin et al. (2015)**,
- **Kellett et al. (2023)**,
- **Martindale-Adams et al. (2017)**,
- **McCarthy et al. (2021)**,
- **Paone (2014)**,
- **Smith & D'Amico (2020)**,
- **Teri et al. (2020)**, and
- **Van Mierlo et al. (2016)**.

For a complete list of articles reviewed, see Appendix 1.

These studies cover a range of interventions, including COPE (Care of Persons with Dementia in their Environments), REACH (Resources for Enhancing Alzheimer's Caregiver Health), multicomponent interventions, sensory-based therapies, and psychosocial caregiver support programs. Several of these articles not only evaluate outcomes but also explore how to adapt and embed interventions in community-based or publicly funded service settings, emphasizing the real-world translation and cultural tailoring.

In contrast, seven articles are primarily descriptive, theoretical, or exploratory, providing critical insight into how dementia is experienced and understood within specific cultural contexts. These include **Browne et al. (2017), Browne et al. (2014), Ketcher et al. (2023), Lewis et al. (2021), Pace (2020), Racine et al. (2022), and Wyman et al. (2023)**. Many of these studies employ qualitative or ethnographic methods to capture the voices of American Indian, Native Hawaiian, and Alaska Native Elders, caregivers, and health providers. For instance, **Browne et al. (2014)** and **Lewis et al. (2021)** highlight culturally grounded perspectives on aging and dementia that often diverge from biomedical frameworks, emphasizing spiritual, relational, and community-oriented understandings of cognitive change. Similarly, **Ketcher et al. (2023)** and **Pace (2020)** examine how Indigenous caregiving practices are rooted in place-based values and holistic relational care.

The following themes emerged from the review:

Cultural Relevance and Adaptation

- **Alignment with Indigenous values and ways of knowing:** Culturally relevant dementia care that respects and integrates Indigenous knowledge systems is crucial for successful implementation. Interventions need to be adapted or enhanced to align with Indigenous cultural values, beliefs, and practices.
- **Consideration of cultural contexts:** Adapting or enhancing existing interventions for Indigenous families and communities requires thoughtful consideration of cultural contexts, requiring consultation with community members, caregivers, and leaders to ensure interventions are appropriate and effective.

- **Decolonizing Western perspectives of dementia:** Decolonization includes understanding what dementia means for Indigenous peoples and integrating Indigenous peoples' voices into research, development, and implementation of interventions and systems of support, with an emphasis on holistic approaches to physical, emotional, spiritual, and cultural well-being.

Quote:

> "Decolonizing Western perspectives of dementia translates into culturally safe approaches that aim to integrate Indigenous cultural perspectives of holism, reciprocity, wisdom, respect of older people and relationality into nursing practice. The support of Indigenous informal caregivers requires future studies to address the stigmatizing Western views of dementia."[2]

Barriers to Implementation and Sustainability of Evidence-Based Interventions

- **Systemic and structural barriers:** Indigenous people often face unique barriers to accessing and implementing caregiving interventions (e.g., geographic isolation, lack of culturally responsive health care).
    - Systemic barriers include limited awareness and understanding of dementia, such as the perception that dementia is a normal part of aging, social stigma, and a lack of caregiver supports.
    - Structural barriers include shortages of dementia care specialists, limited culturally safe and relevant dementia services, and inadequate financial support for dementia care.
- **Resource constraints:** Limited access to financial and educational resources for caregivers and care recipients in Indigenous communities affects the implementation and sustainability of interventions.

Quote:

> "A long-term funding or business strategy is needed. There must be an ongoing discernible funding source to cover direct costs of the program and/or a clear business model that has reachable targets related to service provision and likely payment for services rendered."[3]

Caregiver Support

- **Sustainable support systems:** All caregivers, including AI/AN caregivers, are affected by the demands of providing care and may experience exhaustion, stress, or other challenges. AI/AN caregivers' experiences are further shaped by unique cultural, communal, and spiritual aspects of caregiving, as well as historical and systemic factors that continue to impact families and communities.
- **Community and family involvement:** It is important to center the role of the community, family, and, when applicable, faith in supporting caregivers, reflecting AI/AN values of collective responsibility and care.

Quote:

> "Relational, family, and community-based care is a culturally appropriate form of care for most elders in Indigenous communities. This model will be most effective when culturally appropriate

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[2] Racine, L., Ford, H., Johnson, L., & Fowler-Kerry, S. (2022). An integrative review of Indigenous informal caregiving in the context of dementia care. Journal of Advanced Nursing, 78, 895–917. https://doi.org/10.1111/jan.15102

[3] Paone, Deborah (2014) Using RE-AIM to Evaluate Implementation of an Evidence-Based Program: A Case Example From Minnesota, Journal of Gerontological Social Work, 57:6-7, 602-625, DOI: 10.1080/01634372.2014.907218.

> community support services such as personal support and home care nursing services, as well as adequate respite, are included."[4]

Leadership and Advocacy

- **Community leadership:** Successful implementation of caregiving interventions in Indigenous communities often requires strong leadership from within those communities. Leaders are key advocates for culturally responsive and safe care that aligns with community values.
- **Advocacy for equity:** Advocacy is essential to addressing the inequities these communities face in accessing health care and caregiver supports. Interventions must be informed by and exist alongside community-driven efforts to create systemic change.

Quote:

> "Family and community-centered care cannot be implemented without addressing the systemic and social determinants of health impacting Indigenous caregivers, care receivers, and communities. There is a pressing need to develop community interventions to support Indigenous caregivers' needs as caregiving needs remain unmet due to colonial policies and specific historical traumas adding to an already precarious situation."[5]

Knowledge and Skills Development

- **Community education and community-centered care:** Providing community education can increase support for people living with dementia. This may include information about prevention strategies, symptoms, risk factors, and treatments. Providing this type of education supports more community-centered care while maximizing opportunities for people to remain at home.
- **Skill development for caregivers:** Caregivers benefit from training that is culturally responsive and addresses the unique needs of their families and communities, integrating traditional healing practices, communication styles, cultural protocols, and Indigenous languages and medicines.

Quote:

> "Caregivers and health care providers expressed concerns about the lack of understanding, resources, and awareness of [Alzheimer's disease and related dementias] among [Alaska Natives] in rural and urban communities. Both caregivers and providers recognized the need to obtain an early diagnosis, blend Western and traditional medicines, promote lifestyle and dietary changes, and foster training for caregivers. Health care providers acknowledged their limited exposure to [Alaska Natives] understanding of [Alzheimer's disease and related dementias] and wish to receive culturally relevant training to better serve AN."[6]

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[4] Ketcher, D., Jacklin, K., Warry, W., Lewis, J. P., Blind, M. J., Dertinger, M., Arredondo, B., Pederson, C., Johnson, J., Trudeau, R., Pitawanakwat, K., Strong, L., Summers, M., Martin, W., Lambrou, N. H., Zuelsdorff, M., Gleason, C. E. Relational, Community Dementia Care for All: Observations and Lessons from On-Reservation Providers, Administrators, and Formal Caregivers in the US and Canada. Alzheimer's Dement. 2023;19(Suppl. 19):e074841. https://doi.org/10.1002/alz.074841

[5] Racine, L., Ford, H., Johnson, L., & Fowler-Kerry, S. (2022). An integrative review of Indigenous informal caregiving in the context of dementia care. Journal of Advanced Nursing, 78, 895–917. https://doi.org/10.1111/jan.15102

[6] Lewis, J.P., Manson, S.M., Jernigan, V.B., Noonan, C. "Making Sense of a Disease That Makes No Sense": Understanding Alzheimer's Disease and Related Disorders Among Caregivers and Providers Within Alaska Native Communities. Gerontologist, 2021, Vol. 61, No. 3, 363–373. doi:10.1093/geront/gnaa102.

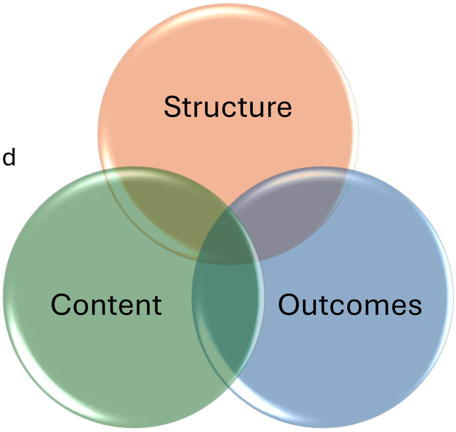
Key Informant Interviews

We identified individuals with experience in curriculum adaptation and implementation in AI/AN communities and/or expertise in developing evidence-based interventions (EBIs) for dementia caregiving. Of the 10 people invited, eight participated in interviews. Interviewees included health care providers, researchers, curriculum developers, and subject matter experts working at both national and local levels.

An interview guide was developed to explore the following areas:

- Values and guiding principles to center in the development, adaptation, and implementation of caregiving interventions.
- Core elements of caregiving interventions.
- Contextual factors to consider when developing, adapting, and implementing an intervention.
- Caregiver Coach roles and responsibilities.
- Suggestions for future directions of this work.

Key takeaways from the interviews are organized into three categories—**structure, outcomes, and content**—which align with the recurring framework used by the Workgroup.



Considerations – Structure

Interviewees emphasized the importance of a **flexible format** for caregiver interventions, allowing caregivers to choose between digital (e.g., online) and non-digital options. For some, a digital platform represented the future of caregiving and aligned with the preferences of the fastest-growing segment of caregivers. For others, digital platforms posed barriers, particularly in communities without reliable internet access or familiarity with online tools.

Several interviewees discussed **workforce considerations** in the selection and implementation of interventions. In many settings, there are simply not enough staff to deliver programs, especially those that are more labor-intensive (e.g., requiring in-home visits rather than virtual or phone-based sessions). One interviewee noted that interventions designed in academic settings often fail to consider real-world implementation contexts, making replication difficult.

Interviewees also identified the need for **interventions tailored to caregivers**, enabling them to access knowledge and skill-building modules as the needs of both the caregiver and the person living with dementia change. A “pick-and-choose” approach was viewed as beneficial for meeting caregivers where they are in their journey with the person living with dementia. The **culture of both the caregiver and the person living with dementia** was also identified as important in intervention adaptability and flexibility. Some interviewees emphasized the power of AI/AN stories and case studies within curricula, while others highlighted the importance of broader *person-centered approaches* that respect a person’s culture, values, and wisdom.

Finally, one interviewee noted that, often, people living with dementia will have multiple caregivers. As a result, interventions should address the needs of the **family unit** rather than focusing on a single caregiver.

Considerations – Content of Caregiving Interventions

Info About Disease Progression

Assessment to Guide Care

Skills for Caregivers

Behavior Management

Caregiver Health and Well-being

Interviewees agreed that effective interventions give caregivers **basic information about dementia and disease progression**. This foundational knowledge includes understanding stages of dementia, symptoms and behaviors, communication challenges, and how to support day-to-day care needs.

They emphasized the importance of a formal **assessment to guide care** planning. These assessments help tailor care planning to each caregiver's and patient's strengths, needs, and the unique caregiving context. Specific tools mentioned included the *Risk Assessment Measure* (used in *REACH*), *Positive Aspects of Caregiving*, *Burden of Care*, and the *Zarit Caregiver Burden Interview*.

Person-centered care was defined by participants as integrated health care delivered in a setting and manner that is responsive to individuals' goals, values, and preferences, while fostering strong communication between patients, caregivers, and providers. Person-centered care empowers individuals receiving care as a partner working with their providers to create effective care plans together.[7]

Interviewees identified several critical **skills for caregivers**:

- Understanding the roles of different health care team members.
- Communicating effectively with people living with dementia (e.g., how to respond to repeated questions and hallucinations).
- Creating a safe home environment and practicing everyday tasks (e.g., transferring from chair to bed).
- Managing medication.
- Supporting transitions between care settings (e.g., from hospital to home).

Increase Self-Efficacy

Reduce Symptoms of Depression

Impact Health Care Use

Improve Social Connections

Gounded in Values

Caregivers also need support and guidance with **behavior management,** including strategies for addressing behaviors such as wandering, repetition, aggression, and mood swings. Interviewees noted that interventions should prepare caregivers with both context and practical strategies for managing these behaviors.

Finally, participants stressed the importance of addressing **caregiver health and well-being.** Interventions should include tools, information, and strategies to mitigate depression, stress, and anxiety. One interviewee noted discomfort with many existing caregiver "burden" measures, citing cultural bias and negative framing of caregiving as a "burden." They emphasized that such measures may not reflect how Indigenous caregivers view their role.

Considerations – Outcomes

Interviewees identified three primary outcomes for dementia caregiving interventions: **increased self-efficacy, reduced symptoms of depression, and improved health care utilization.**

Increasing **self-efficacy** helps caregivers feel more confident managing the complex responsibilities of caregiving through practical skills such as handling difficult behaviors, managing medications, and navigating the health care system.

As affirmed in the literature and by the Workgroup, interviewees noted that caregiving can be isolating and emotionally challenging. Interventions **grounded in the caregivers' and communities'**

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[7] Centers for Medicare & Medicaid, "Person-Centered Care." https://www.cms.gov/priorities/innovation/key-concepts/person-centered-care

values, that include skill development and opportunities for social connection, can reduce symptoms of anxiety and depression.

Multiple interviewees also noted that well-designed caregiver interventions can impact **health care utilization**, particularly in preventing avoidable emergency room visits and hospitalizations. Ideally, caregivers are integrated members of the care team and can partner with other health care staff to improve access to supportive resources throughout the dementia journey.

One interviewee emphasized the benefit of having assessment tools to measure these outcomes, noting their use of the Positive Aspects of Caregiving Questionnaire and the Zarit Burden Interview.

Caregiver Coach – Insights

One objective of the interviews was to explore the understanding and use of the term **Caregiver Coach**. While none of the interviewees used this exact term, several reported using related concepts such as peer mentor or care navigator. One interviewee noted that there is a consensus that providing caregivers and families with access to a real person for support is essential.

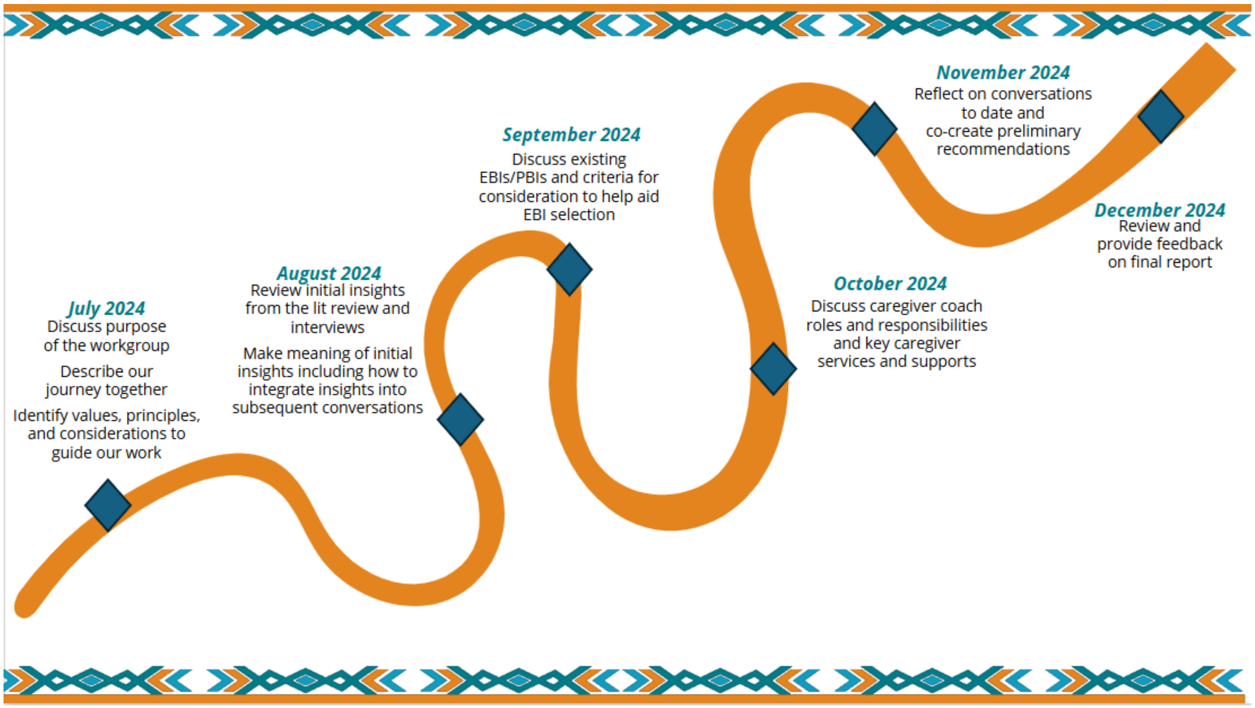
One interviewee described recruiting peer mentors to help implement the *Savvy Caregiver* program. These mentors complete the program and then host talking circles to adapt the intervention for local settings. Another interviewee noted adding a peer mentor to their team, with responsibilities still being refined.

Dementia Caregiving Informal Workgroup

In June 2024, the IHS Elder Care Team, the Northwest Portland Area Indian Health Board (NPAIHB), and Cardea invited IHS grantees, Public Health Nurses, former Administration for Community Living Alzheimer's and Dementia Programs Initiative (ACL-ADPI) grantees, and subject matter experts with experience implementing evidence-based interventions (EBIs) to participate in the Dementia Caregiving Informal Workgroup.

The Workgroup held its kick-off meeting on July 24, 2024, and met every other week from August through December 2024.

The graphic below shows the general timeline and milestones for the Workgroup. For a list of meeting agendas and key discussion questions, see Appendix 2.



Values and Guiding Principles

During the initial meeting on July 24, the Workgroup discussed the following questions in small groups:

- What values should guide our work together?
- What guiding principles do we want to center?
- What considerations do we want to keep in mind as we think about recommendations for caregiving EBIs and caregiver coach roles and responsibilities?

From these discussions, the Workgroup identified the following **values**, **guiding principles**, and **considerations** to center its work.

Values

- Accountability
- Adaptability
- Collaboration
- Commitment to the process, outcomes, and group
- Empathy (centering the person)
- Integrity
- Lived experience (acknowledging different backgrounds/walks of life)
- Relationships
- Respect
- Responsibility
- Truth/honesty

Guiding Principles

- **Listen, especially if you are not part of the community.**
- **Center patients and caregivers.** Involve them throughout the process, and remember they can continue to live full, healthy, meaningful lives.
- **Respect tribal sovereignty.** Recognize the authority of tribes, particularly when it comes to data and decision-making.

- **Recognize that the mainstream is not the model.** Adapt approaches to reflect tribal beliefs, culture, customs, and systems; one size does not fit all.
- **Be realistic and reliable.** Especially in rural settings, show up consistently and build relationships based on trust.
- **Plan for sustainability.** Offer long-term solutions and resources that create lasting value and bridge clinical and community systems.
- **Honor the Principle of Seven Generations.**

Workgroup Member Quote:

> "At its core, the Seven Generations Principle teaches that the decisions we make today should create a sustainable world for the seven generations that follow."

Applying the Guiding Principles

To translate these principles into action, the Workgroup identified five areas of focus for implementing dementia caregiving interventions and supports across AI/AN communities:

- **Ground efforts in culture and community.** Ensure interventions are guided by each community's culture, history, and values, integrating traditional healing, language, and locally meaningful practices.
- **Prioritize trust and engagement.** Build lasting relationships through consistency, collaboration, and presence. Recognize that caregiving is often family-centered and that meaningful engagement takes time.
- **Expand access and awareness.** Address barriers such as limited technology, health literacy, or language access. Use culturally relevant education to reduce fear and stigma related to dementia.
- **Strengthen systems and workforce.** Develop provider skills and caregiver supports that connect clinical, community, and cultural care systems. Offer adaptable training for diverse skill levels and settings.
- **Plan for realistic, sustainable change.** Acknowledge competing priorities and resource constraints in tribal and rural communities. Implement programs that grow gradually, build local capacity, and sustain progress over time.

Criteria for Caregiving Interventions or Programs

The Workgroup identified criteria to guide the selection and evaluation of caregiving interventions. The IHS Elder Care Team provided a draft list organized into three areas—**structure, content**, and **outcomes**—and the Workgroup expanded on these to reflect AI/AN community perspectives and priorities.

Structure

Effective caregiving interventions should:

- Use a **coach or navigator model** to provide support for both caregivers and people living with dementia.
- Be implementable by a range of professionals, including registered nurses (RNs), public health nurses (PHNs), social workers, case managers, community health representatives/workers (CHRs/CHWs), and medical assistants (MAs).
- Allow **flexibility** based on community needs, care settings, caregiver situations (e.g., single caregiver or family caregivers), and stage of dementia.
- Be designed for **in-person or hybrid** delivery, enabling caregivers to select content that meets their individual needs.
- Demonstrate **adaptability** for different community environments, including border towns and areas with limited diagnostic resources.

- Include practical **resources and tools**, such as train-the-trainer (TOT) materials, AI/AN-specific case studies, caregiver handbooks, and supplemental videos or learning aids.
- Be **no- or low-cost** to ensure sustainability and accessibility.
- Provide **support for caregivers of individuals without a formal dementia diagnosis**, recognizing community realities.
- Consider a **peer mentor model** to promote shared learning and community support networks.

Content

Caregiving interventions should include:

- **Integration of traditional practices**, such as drumming, sweat lodges, smudging, singing, and praying, and should prioritize the inclusion of community healers.
- **Education** about dementia, including the stages of progression for both caregivers and family members.
- **Assessment of caregiver needs** to guide personalized support.
- **Care planning**, including end-of-life care, advance directive checklists, and provider visit preparation—integrating AI/AN views and values on end-of-life.
- **Clinical and community resource connections** to ensure caregivers know where to turn for support.
- **Practical caregiving skills**, such as strategies for bathing, safety, transferring from bed to chair, and daily care tasks.
- **Problem-solving training** for managing behavioral and psychological symptoms of dementia.
- **Respite and self-care** guidance to protect caregiver health and well-being.
- **Crisis prevention and response tools**, including the Describe–Investigate–Create–Evaluate (DICE) method or partnerships with Psychiatric Emergency Response Teams (PERT).

Outcomes

Successful caregiving interventions should demonstrate:

- **Enhanced quality of life** for people living with dementia.
- **Improved well-being for caregivers**, including reduced stress and anxiety, stronger coping skills for grief and loss, and re-engagement in community and social life.
- **Increased caregiver confidence (self-efficacy)** in providing care.
- **Improved knowledge** about dementias among caregivers, families, and community members.
- **Reduced stigma** and increased participation in shared care planning and decision-making.
- **Greater awareness of available resources** across local, tribal, state, federal, and private sectors.
- **Improved referrals** for specialty care, including nutrition consultations and other supportive services.
- **Expanded access** to clinical programs and professional consultation.
- **Reduced health care costs**, such as fewer hospitalizations or emergency room visits.

Caregiver Coaches – Roles and Responsibilities

During two Workgroup meetings, members discussed the potential role of Caregiver Coaches and developed a set of roles and responsibilities the position could encompass. The group used the **HEAD–HEART–HANDS** model to define the essential skills, values, and actions of a Caregiver Coach:

HEAD – the knowledge and skills a Caregiver Coach possesses.

HEART – the spirit and values a Caregiver Coach embodies.

HANDS – the actions a Caregiver Coach implements in the community.

HEAD – Knowledge and Skills

A Caregiver Coach may:

- Conduct **assessments** of the person living with dementia to determine disease stage, set shared goals for both the person and the caregiver, and create individualized care plans.
- **Educate caregivers and family members** about best practices for dementia care, including safety, communication, behavior management, family dynamics, and end-of-life considerations.
- Provide caregivers with a **clear outline of responsibilities**, taking into account durable power of attorney, advance directives, HIPAA requirements, and identifying where outside support may be needed.
- Offer **education on medications and medication management**, particularly when multiple prescriptions are involved, and help caregivers coordinate follow-up appointments for medication reviews.
- **Assist with benefits and enrollment**, such as Medicare A/B/D and Medicaid programs, and coordinate with IHS, tribal, and urban (I/T/U) Indian organizations as needed.

HEART – Spirit and Values

A Caregiver Coach should:

- Work to **enhance the daily quality of life** for both the person living with dementia and their caregivers, helping to restore normalcy at home.
- Help create a **confident, collaborative care team** that includes caregivers and family members.
- Facilitate **positive change** through clear communication, compassionate guidance, and honest feedback.
- **Promote independence** for people living with dementia to the greatest extent possible.
- Provide **emotional support** to reduce caregiver stress and isolation, and build caregiver confidence and effectiveness.
- Help caregivers **address stigma** and challenges related to caregiving, connecting them with resources—even when they do not identify themselves as caregivers.
- Support families **in planning for the future** and navigating grief and loss associated with dementia care.
- Bring **a lens of cultural humility and health literacy**, ensuring education and support are accessible and respectful of each family's background and values.

HANDS – Actions and Implementation

A Caregiver Coach may:

- Develop and share **strategies to manage dementia symptoms**.
- Help families **understand the disease** and its progression.
- **Recommend safety measures** to create supportive home environments.

- Design care settings that help **reduce stress, anxiety, and guilt** for caregivers and families.
- Provide **structure and guidance** to help caregivers respond confidently to daily challenges.
- Collaborate with families to **problem-solve ongoing dementia-related issues**.
- **Strengthen caregiver confidence** through ongoing education and encouragement.
- Build **teamwork among family members** to promote shared caregiving.
- Offer **objective feedback and personalized guidance** to caregivers.
- **Prepare caregivers and clients for care transitions**, such as moving from hospital to home.
- **Mediate family disagreements** by facilitating care planning and communication.
- Encourage **respite and self-care**, helping caregivers take time to rest and maintain their own health.
- Provide or facilitate **training opportunities**, such as the *Virtual Dementia Tour*, to deepen understanding and empathy.

The Workgroup and several interviewees identified additional programs and tools—beyond formal evidence-based interventions—that can further support caregivers and people living with dementia. These include:

- **Care of Persons in their Environment (COPE):** An evidence-based program addressing the unmet needs of families through assessment and skill development. Designed for individuals living at home, COPE is implemented by nurses and occupational therapists.
- **Dementia Capable Care:** A virtual, evidence-based dementia and behavior training program for health care workers focused on preventing and de-escalating distress behaviors without medication.
- **Dementia Friendly America:** A national initiative that promotes community support for people living with dementia and their care partners so they can safely remain engaged in their communities.
- **Dementia Friends:** A public education program that helps individuals and community members recognize signs of dementia and take supportive actions. Dementia Friends may include individuals or employees of local organizations such as banks, retail stores, libraries, or restaurants.
- **Music and Memory:** A program that enhances quality of life through personalized music playlists for individuals in nursing homes or care facilities, encouraging social connection and engagement.
- **Tailored Activity Program:** An evidence-based program for people living with dementia and their caregivers that can be delivered in home, hospital, residential, or adult day care settings by occupational therapists and other trained health professionals.
- **WeCareAdvisor:** A forthcoming online tool designed to help family caregivers manage dementia-related behavioral symptoms. The platform guides families to assess, manage, and track behaviors and provides tailored, in-home, non-pharmacological strategies for behavior management.

Review of Five Evidence-Based Interventions

The Workgroup reviewed **five evidence-based interventions** for dementia caregiving across five meetings. Each session featured a presenter familiar with one of the interventions, who provided an overview of its **structure, content, and outcomes**, as well as information on whether and how the program had been adapted for use in AI/AN and rural communities.

The following tables summarize each intervention, with content adapted from program websites and the Best Programs for Caregiving database.

Each summary is followed by the **Workgroup's reflections**, highlighting key insights about the intervention's relevance, adaptability, and potential fit within tribal and rural settings.

Aging Brain Care

Developer: Indiana University School of Medicine
Presenters: Laura Gano, Stacey Kahre, and Jane Ferril
Date of Presentation: October 30, 2024
URL: Aging Brain Care – Indiana University School of Medicine
BPC Database Link: Best Programs for Caregiving: Collaborative Care

Overview

The **Aging Brain Care (ABC) Program** provides ongoing in-person and telephone sessions for caregivers and people living with dementia and/or depression. The program offers tools, processes, and strategies for care management and includes optional support groups.

Program History and Development

- Developed the initial ABC model (*ABC Beta*) in 2000–2001.
- Evaluated the model in a randomized controlled trial (2001–2006).
- Translated findings into a local clinical program (*ABC 1.0*) in 2007.
- Served 1,000 patients in Indianapolis by 2012.
- Developed a scalable clinical version (*ABC 2.0*) in 2012 and served 5,000 patients statewide by 2015.
- Began development of an **Alternative Payment Model** (2018–2023).
- Created a scalable community version (*ABC 3.0*) between 2016–2019, including *iCare ABC* and *ABC Community*.
- Currently evaluating *ABC 3.0* (2019–2027).

Program Structure

Intended Audience: Professionals and paraprofessionals.

Goals: Care coordination and management, caregiver education and support, and respite services.

Topics Covered:

- Home-based assessments of caregiver stress and patient cognitive, behavioral, psychological, and functional status.
- Protocol-driven interventions in collaboration with the primary health provider.
- ABC staff do not assume care of the patient but supplement existing care by adding coordinated resources and support.

Intervention Type: Individual (not group-based).

Session Format: Ongoing sessions, 30–60 minutes each.

Materials Provided: Protocol handouts.

Delivery Method: In-person and telephone sessions.

Cost: To be determined; fees apply.

Adaptation Guidance: None provided on the intervention website.

Caregiver Coach or Similar Role

The ABC model includes a **Care Coach** component:

- Care Coaches receive 40 hours of training.
- Deliver caregiver education and skills training.
- Routinely complete the *Healthy Aging Brain Care (HABC) Monitor* to assess caregiver stress and guide intervention protocols.
- Implement the *Caregiver Stress Prevention Bundle (CSPB)*, which focuses on support group participation, problem-solving, and crisis planning.

Aging Brain Care – Workgroup Reflections

ABC has several strengths, including the use of non-licensed staff as coaches, which helps address workforce considerations in rural areas. The program emphasizes caregiver well-being, recognizing that caregivers are individuals who also need care, ultimately leading to improved patient outcomes. *ABC*'s community-centered approach, which includes caregiver assessments and support, helps reduce stress and provides valuable respite for caregivers. The model is **compassionate, flexible, and can be enhanced with culturally relevant components**. Evidence shows that it reduces emergency room visits.

However, there are challenges in adapting and implementing *ABC*, such as travel barriers in rural tribal communities and underutilized support groups due to caregivers' time constraints. Stigma surrounding Alzheimer's and dementia impacts support group engagement, and questions remain about the program's sustainability, model clarity, training process, and funding. While caregiver assessments show promise, **concerns persist about long-term engagement** and monitoring the program's impact across diverse communities.

Care Ecosystem

Developer: University of California, San Francisco
Presenters: Sarah Dulaney, Brooke Bryson
Date of Presentation: October 16, 2024
URL: Care Ecosystem – UCSF Memory and Aging Center
BPC Database Link: Best Programs for Caregiving: Care Ecosystem

Overview

The **Care Ecosystem** is a model of dementia care designed to provide personalized, cost-effective, and accessible support for people living with dementia and their caregivers. This telephone- and web-based intervention addresses unmet needs through regular contact, education, and resource navigation.

Program History and Development

- Developed and tested between 2014–2018 through an award from the **Center for Medicare and Medicaid Innovation (CMMI)** (grant number 1C1CMS331346).
- Further supported by the **National Institute on Aging (NIA)** (grant numbers R01 AG056715, 2017–2022, and R01 AG074710-01, 2022–2024).
- Initially implemented across California, Nebraska, and Iowa, with ongoing evaluation across six health systems.

Program Structure

Intended Audience: Health systems, clinics, and community organizations providing dementia-capable care.

Goals: To address the unmet medical, social, and emotional needs of people living with dementia and their caregivers.

Topics Covered:

- Behavior, mood, and personality changes
- Caregiver well-being
- Decision-making and planning
- Early-stage and disease-specific information
- End-of-life care
- Long-term care and respite options
- Medication management
- Personal care and activities of daily living (ADLs)
- Research and safety considerations

Intervention Type: Individual (not group-based).

Session Duration: Ongoing.

Delivery Method: Telephone and online.

Cost: No cost; open source.

Materials Provided

The **Care Ecosystem Toolkit** includes:

- Care protocols and educational materials.
- Staffing and workflow guidance.
- Billing mechanisms to support sustainability.
- A free self-paced online training course available on the Canvas Network (access code: R9B67G).

Caregiver Coach or Similar Role

The Care Ecosystem incorporates a **Care Team Navigator (CTN)** model:

- CTNs serve as the **primary point of contact** for patients and caregivers.
- They are not licensed clinicians but are trained to screen for dementia-related needs and provide educational and emotional support.
- CTNs follow established care protocols and are **supervised by licensed clinicians**, such as nurses, pharmacists, and social workers.
- The model combines **clinical expertise and care navigation**, ensuring that both caregivers and people living with dementia receive ongoing, coordinated support.

Adaptation and Licensing Guidance

All Care Ecosystem materials are protected under a **Creative Commons license**. Users may copy, adapt, and redistribute materials with appropriate attribution. Any materials used without modification must be branded or co-branded as *Care Ecosystem* and include the following note:

> "Used with permission from the Care Ecosystem, memory.ucsf.edu/Care-Ecosystem."

Adapted materials should include the attribution:

> "Adapted from the Care Ecosystem, memory.ucsf.edu/Care-Ecosystem."

Care Ecosystem - Workgroup Reflections

The Workgroup recognized the *Care Ecosystem* as a flexible, low-cost model that could be adapted to both medical and social care systems in tribal and rural communities. Members noted its accessibility through phone and online services and the value of its built-in resources—such as clinical skills workshops and cognitive care navigators—to support caregivers. They appreciated that the model's sustainability is reinforced by opportunities to bill certified Community Health Representatives (CHRs) and Community Health Workers (CHWs) under Medicare, offering a pathway for long-term funding.

However, participants also identified **implementation challenges**. Navigating the Medicare and Medicaid billing process can be complex, particularly for caregivers and families who do not qualify for specific programs. Access to Medicare Part A–certified home health services remains limited in some tribal and rural areas, which can hinder implementation. Additionally, the availability of providers to follow up on screenings or maintain continuity of care may be scarce in remote communities.

Legal and financial considerations—such as advance directives and powers of attorney—can also be difficult to apply within some tribal jurisdictions, limiting the program's effectiveness. The Workgroup emphasized the importance of clarifying billing processes, ensuring telehealth reimbursement, and developing sustainable funding models to support long-term implementation.

Powerful Tools for Caregivers

Developer: Headquartered at Iowa State University
Presenters: Mary Weston and Laurai Atcitty
Date of Presentation: September 4, 2024
URL: Powerful Tools for Caregivers
BPC Database Link: Best Programs for Caregiving: Powerful Tools for Caregivers

Overview

Powerful Tools for Caregivers (PTC) is an evidence-based education program that helps caregivers develop skills to reduce stress, manage emotions, and make effective decisions. The program offers six in-person or online self-care education sessions designed for caregivers of people living with dementia or other chronic conditions.

Program History and Development

The PTC curriculum was developed over three years of pilot testing in Portland, Oregon, and has been offered nationally since 1998. Originally designed for caregivers of adults with chronic conditions, it has expanded to include classes for parents of children with special needs.

Each six-week series is led by certified class leaders and includes 6–15 participants. The program has received support from several major foundations, including Meyer Memorial Trust, the Northwest Health Foundation, the Oregon Community Foundation, and the Robert Wood Johnson Foundation.

PTC meets the highest-level criteria for evidence-based disease prevention and health promotion programs, as recognized by the Administration on Aging/Administration for Community Living, and received the 2007 National Family Caregiving Award.

Program Structure

Intended Audience: Spouses/partners, adult children of aging parents, caregivers of individuals with special health or behavioral needs, and caregivers in rural or urban communities. The program is available in both Spanish and Korean.

Goals: To teach caregivers self-care tools that reduce stress, improve confidence, and increase awareness of community resources.

Topics Covered:

- Self-care behaviors such as exercise, relaxation, and regular medical checkups.
- Emotion management to reduce guilt, anger, and depression.
- Strategies for confident decision-making and problem-solving.
- Guidance on locating and using community resources.

Intervention Type: Group program (6–15 participants).

Session Duration: Six weekly sessions lasting 90 minutes to 2½ hours, depending on format.

Delivery Method: In-person or virtual.

Materials Provided: The Caregiver Helpbook, which supports each class session and serves as a long-term reference. The book is available in English and Spanish and covers topics such as stress reduction, time management, communication, problem-solving, and decision-making.

Cost: $200 for Class Leader certification (either a five-day, three-hours-per-day online course or a two-day in-person training).

Adaptation Guidance: Select materials are available in Spanish and Korean to support diverse participants.

Caregiver Coach or Similar Role

While PTC does not explicitly include a Caregiver Coach role, class leaders serve a similar function during the program. They provide structured instruction, encouragement, and opportunities for participants to practice new skills and receive support throughout the six-week period.

Powerful Tools for Caregiving - Workgroup Reflections

The Workgroup viewed *Powerful Tools for Caregivers* as a program adaptable to tribal communities of various sizes and resources. Members highlighted opportunities to blend PTC with existing dementia education—such as integrating Banner Alzheimer's Institute (BAI) content through a "zero" or pre-PTC training—to better meet local needs.

They emphasized that PTC's **train-the-trainer (TOT) model** promotes sustainability by empowering tribal members to become Class Leaders and Master Trainers, enabling long-term delivery within the community. The inclusion of traditional music and community-driven graduation ceremonies was seen as enhancing engagement and cultural relevance.

However, members also discussed several challenges. They noted that additional support may be needed for single caregivers, those with limited internet access, or individuals who face barriers to attending all six sessions. The scripted curriculum, while ensuring consistency, can be difficult to adapt for specific cultural or family contexts. Coordination with Title III and Title VI funding programs may require careful planning.

Advance care planning, guardianship, and family dynamics were also noted as areas that can be complex in tribal communities due to jurisdictional and legal considerations. The Workgroup concluded that ensuring the program's **relevance, flexibility, and accessibility**—particularly for families without reliable technology or transportation—will be essential for successful implementation.

REACH Community

Developer: The University of Tennessee Health Science Center Caregiver Center, Department of Preventive Medicine
Presenter: Dr. Bruce Finke
Date of Presentation: October 2, 2024
URL: REACH Community – University of Tennessee Health Science Center
BPC Database Link: Best Programs for Caregiving: REACH Community

Overview

The **REACH Community** program is a dementia caregiving intervention designed to educate and empower caregivers through personalized skills training, problem-solving, and stress management. The model includes four in-person or telephone sessions and builds on the success of the REACH VA program, which was a clinical translation of the *Resources for Enhancing Alzheimer's Caregiver Health (REACH II)* study conducted from 2001–2004.

Program Structure

Intended Audience: Caregivers of persons living with dementia.

Goals:

- **Education:** Increase caregiving skills and knowledge, provide practical tools, and enhance caregiver–care recipient interactions.
- **Problem Solving:** Improve issue management, coping strategies, and daily caregiving problem-solving.
- **Mood Management:** Reduce caregiver burden, anxiety, depression, and frustration; support emotional well-being.
- **Stress Reduction:** Strengthen management of problem behaviors and enhance safety in caregiving environments.

Topics Covered:

The *Caregiver Notebook* includes 48 concise chapters. Most focus on understanding and responding to behavioral symptoms of dementia (e.g., bathing, wandering, repeated questions).

Additional chapters provide tools and strategies to help caregivers manage stress.

Intervention Type: Individualized sessions (not group-based).

Number and Duration of Sessions: Two sessions, totaling approximately 4.5 hours.

Materials Provided: *Caregiver Notebook* and *Interventionist Notebook*.

Delivery Method: In-person or telephone.

Cost: $3,500 for licensing and initial certification to deliver the program.

Adaptation Guidance: None provided on the intervention website.

Caregiver Coach or Similar Role

The REACH Community model includes a caregiver coach or trainer role. Program facilitators are trained to deliver individualized education and coaching to caregivers, following cognitive-behavioral techniques to promote skill-building, problem-solving, and emotional support.

REACH Community - Workgroup Reflections

The Workgroup viewed the REACH Community intervention as **highly personalized** and adaptable, with caregivers directly involved in the learning process. Members appreciated that REACH emphasizes building relationships over time and uses cognitive-behavioral techniques to enhance caregiver health and confidence. The comprehensive *Caregiver Notebook* and flexibility in delivery—through in-person, telephone, or telehealth formats—make it well-suited to a range of community settings. The *train-the-trainer (TOT)* model was also recognized as a strength, promoting long-term sustainability by allowing organizations to develop internal trainers.

However, the Workgroup also discussed several **challenges and considerations**. Maintaining fidelity to the program can be difficult when adapting it for smaller tribes, especially if master trainers leave and replacement training is delayed. Participants expressed concern about the **cost of certification and implementation**, which may pose barriers for some communities. Additionally, the curriculum has not been updated since 2015, potentially limiting its relevance and accuracy in current practice.

While REACH is considered **culturally adaptable**, its effectiveness depends on periodic content review and ongoing support for those implementing the program. The Workgroup suggested future efforts should focus on ensuring cultural and contextual relevance, supporting continuity of coaching, and identifying sustainable funding mechanisms to maintain program delivery in smaller or rural tribal communities.

Savvy Caregiver

Developer: Savvy Systems, LLC
Presenters: Jordan P. Lewis, PhD, MSW, CPG, and Amber Hoon
Date of Presentation: September 18, 2024
URL: Savvy Caregiver
BPC Database Link: Best Programs for Caregiving: Savvy Caregiver

Overview

The **Savvy Caregiver** program provides six in-person or online group education and skills-training sessions for caregivers. The curriculum focuses on enhancing caregiving knowledge and skills, supporting caregiver self-care, and promoting active participation of people living with dementia in daily tasks and activities.

Program History and Development

The Savvy Caregiver curriculum was originally developed and validated in 2002 and remains the foundation of several specialized versions. Program content focuses on understanding dementia, supporting caregiver well-being, and promoting effective care strategies. Through weekly home practice, participants apply new skills to their family situations.

Beginning July 1, 2021, use of Savvy Caregiver materials requires licensing to ensure copyright compliance with the University of Minnesota, Emory University, and other copyright holders.

Program Structure

Intended Audience: Staff from health and social service agencies serving people living with dementia and their caregivers.

Goals:

- Deepen caregiver understanding of Alzheimer's disease and related dementias.
- Promote self-care and stress management among caregivers.
- Provide strategies for meaningful daily engagement and family involvement.
- Help caregivers identify and use available family and community resources.

Topics Covered:

- Dementia education and cognitive understanding.
- Caregiver self-care and coping skills.
- Disease progression and stage identification.
- Structured approaches to daily activities and decision-making.
- Expanding family and community support networks.

Duration: Six sessions, held weekly for two hours.

Delivery Method: In-person or online (Zoom-based).

Materials Provided:

- Trainer's manual.
- Caregiver's manual for home use.
- Training videos, PowerPoint slides, and handouts.

Cost:

- Savvy Caregiver Foundational Group Leader Training and Certification – $1,499 per person.
- Advanced, Express, or Tele-Savvy Trainings – $499 per person (following foundational certification).
- Licensing fees range from $199 per workshop to $999 for bundles, with no expiration.

Adaptation Guidance: *Savvy Caregiver in Indian Country* offers a framework for culturally adapting the program for tribal and Indigenous communities.

Caregiver Coach or Similar Role

The Savvy Caregiver program does not formally include a *Caregiver Coach* role. However, trained facilitators—often with social work or community health experience—serve in a similar capacity by guiding caregivers through structured education, reflection, and peer learning.

Savvy Caregiver - Workgroup Reflections

The Workgroup viewed the **Savvy Caregiver** as a valuable and adaptable program with strong potential for use in AI/AN and other community settings. Members noted that its **personalized, in-home involvement** with caregivers and extended family members has been especially beneficial for families seeking additional support. The program's flexibility allows for adaptation to specific cultural contexts, such as Native Hawaiian communities, and emphasizes strengths rather than deficits. One-on-one interactions were seen as effective for building empathy, rapport, and understanding—key elements in navigating complex family dynamics.

The Workgroup also highlighted that program delivery is further strengthened when facilitated by a Masters in Social Work (MSW)-credentialed professional, adding expertise in both social work and community engagement. This combination was seen as critical to maintaining the program's quality and ensuring responsiveness to caregivers' emotional and practical needs.

However, several challenges were identified. Members noted the need for **ongoing updates** to program materials and the **high cost of training and licensing**, which can be barriers for small or resource-limited organizations. Staff turnover and reliance on a single facilitator can also limit continuity and scale.

There were also questions about whether the program's design is suitable for Community Health Representatives (CHRs) or Public Health Nurses (PHNs), given that the curriculum typically requires a trained facilitator team with both social work and caregiving expertise. The Workgroup agreed that **tribal and medical leadership** are essential to establish and sustain the program, and that implementation in rural areas—where caregivers may live far apart—remains a logistical challenge.

Overall, the Workgroup concluded that the Savvy Caregiver model is **culturally adaptable and impactful**, but long-term success will depend on updating materials, expanding access to facilitator training, and providing the local support needed for implementation across diverse tribal communities.

Five Evidence-Based Interventions – Takeaways

After reviewing the five evidence-based interventions (EBIs), the Workgroup reflected on key insights and priorities through a series of five questions. Thirteen members participated in this final review process. The summarized themes and responses below represent the collective perspectives of the group. Full, unedited responses are available in *Appendix 3*.

1. Ranking of the Five Interventions

Workgroup members were asked to rank the interventions based on alignment with the group's values, guiding principles, and criteria for consideration. The results were as follows:

1. **The Savvy Caregiver**
2. **Powerful Tools for Caregivers**
3. **Aging Brain Care**
4. **REACH Community**
5. **Care Ecosystem**

The rankings suggest that programs with strong cultural adaptability, caregiver engagement, and clear implementation models were viewed as most compatible with the needs and realities of AI/AN communities.

2. Factors Influencing the Rankings

Participants identified several themes that influenced their rankings:

- **Content and Structure:** Respondents valued programs that were evidence-based, well-structured, and tailored to the needs of both caregivers and care recipients.
- **Cultural Fit:** Interventions adapted for AI/AN communities (such as *Savvy Caregiver*) ranked highest.
- **Care Planning and Flexibility:** Flexibility in delivery—whether virtual, in-person, or phone-based—and a focus on individualized care planning were key strengths.
- **Cost and Feasibility:** Cost-effectiveness and the inclusion of train-the-trainer (TOT) models were viewed as important for long-term sustainability.
- **Outcome-Focused:** Participants prioritized programs that improved emotional and mental health outcomes for caregivers and care recipients alike.

3. Priorities for IHS Dementia Caregiving Programming

When asked what IHS should prioritize in future dementia caregiving efforts, Workgroup members identified the following key areas:

- **Cultural Relevance:** Incorporate storytelling, language, and culturally tailored education materials.
- **Caregiver Support:** Provide caregiver education, respite care, inclusion in care teams, and regular wellness checks.
- **Community-Based Approaches:** Support programs that are adaptable and replicable within tribal and community contexts.
- **Training and Access:** Expand training opportunities for IHS staff and tribal providers to improve access to diagnosis, referral, and long-term care.
- **Monitoring and Metrics:** Develop clear and consistent evaluation methods to measure program success and impact.

4. Support Needed from IHS

When reflecting on what would help them most in their caregiving work, participants emphasized the following supports:

- **Education and Resources:** Increase access to dementia-specific education, training, and practical caregiving tools for both staff and caregivers.

- **Financial Support:** Provide funding for caregiver services and training; address gaps in health care coverage that affect program implementation.
- **Collaboration and Planning:** Engage community stakeholders and develop long-term strategic plans to ensure coordination and sustainability.
- **Staffing and Assessment:** Employ Community Health Representatives (CHRs), Public Health Nurses (PHNs), or Qualified Support Professionals (QSPs) to assist with caregiver assessments and direct services.

5. Practical Recommendations for Future Programming

Participants also offered practical ideas to guide future IHS programming, training, and resource development:

- **Centralized Support:** Establish caregiver navigation and support hubs within health facilities.
- **Expand CHR Programs:** Train local community members to support families directly in home and community settings.
- **Integrate Mental Health and Traditional Practices:** Combine mental wellness approaches with culturally traditional and spiritual care practices.
- **Data and Evaluation Capacity:** Provide education and tools for data tracking, program evaluation, and feedback collection.
- **Accessible Resources:** Ensure that dementia training and caregiver resources are available to a wide range of professionals across I/T/U systems.

Five Evidence-Based Interventions – Comparison Tables

Criteria for Consideration by Intervention—Structure

	Aging Brain Care	Care Ecosystem	Powerful Tools for Caregivers	REACH	Savvy Caregiver
1. Uses a coach/navigator model; provides support for caregiver and person living with dementia	♦			♦	
2. May be implemented by a range of professionals, including RNs, PHNs, social workers, case managers, CHRs/CHWs, MAs	♦	♦	♦		♦
3. Allows for flexibility, based on community needs, settings, caregiver situation (e.g., single caregiver, family as caregivers), and stage of dementia	♦	♦	♦	♦	♦
4. Includes resources (e.g., scripted training for TOT models, case studies specific to AI/AN and other similar communities, caregiver handbook or other resources such as videos)	♦	♦	♦	♦	♦
5. Designed to be delivered in-person or in a hybrid format	♦		♦	♦	♦
6. Is no/low cost		♦	♦		
7. Promotes sustainability		♦	♦		
8. Uses a peer mentor model to support the development of a peer network/support system					

***Criteria for Consideration by Intervention—Outcomes*[8]**

	Aging Brain Care	Care Ecosystem	Powerful Tools for Caregivers	REACH	Savvy Caregiver
1. Enhanced quality of life for caregiver (e.g., reduced anxiety, stress, ability to navigate grief and loss; re-engagement in community and social life)	♦†	♦†	♦†	♦†	♦†
2. Improved knowledge of Alzheimer's and related dementias among family and community members	♦	♦	♦	♦	♦
3. Enhanced quality of life for person living with dementia	♦†	♦†		♦†	♦†
4. Increased self-efficacy in providing care	♦	♦	♦	♦	♦
5. Decreased costs (e.g., reduction in hospital visits)	♦†	♦†			

† Research articles pertaining to outcomes are available on the intervention/program website

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[8] Outcomes were determined based on the team's review of intervention/program websites, including:

Aging Brain Care | imAGE | Geriatrics | IU School of Medicine

Care Ecosystem | Memory and Aging Center

Home – Powerful Tools For Caregivers

Resources for Enhancing Alzheimer's Caregiver Health II (REACH II)

The Savvy Caregiver® Program – Official Website

Criteria for Consideration by Intervention—Content

	Aging Brain Care	Care Ecosystem	Powerful Tools for Caregivers	REACH	Savvy Caregiver
1. Integration of cultural/traditional practices into caregiving					
2. Education about Alzheimer's and related dementias, including stages of progression for both caregivers and family members	♦	♦	♦	♦	♦
3. Care planning, including end-of-life care		♦		♦	
4. Clinical and community resources	♦	♦	♦		
5. Basics of caregiving – tips and strategies for bathing, safety, transferring from bed to chair		♦	♦	♦	♦
6. Problem-solving, particularly related to behavioral and psychological symptoms	♦	♦	♦	♦	♦
7. Assessment of caregiver needs	♦			♦	
8. Respite/self-care	♦	♦	♦	♦	♦

Recommendations

Building on the findings from the literature review, key informant interviews, and the Workgroup, the following recommendations are offered to guide the IHS, tribal health organizations, and community partners in advancing dementia caregiving services and supports across AI/AN communities.

These recommendations are intended to be both **actionable and scalable**, beginning with local or pilot-level efforts that can grow over time. IHS and tribal partners may consider **phased implementation**, starting with one or two adaptable interventions, evaluating impact, and expanding regionally based on community feedback and outcomes.

1. Center Culture, Community, and Traditional Knowledge

- Ensure caregiving interventions incorporate traditional healing practices, Indigenous knowledge, and community-specific values.
- Engage tribal Elders, cultural advisors, and caregivers in the design, adaptation, and implementation process to build trust and local buy-in.
- Leverage existing cultural frameworks and resources—such as music, storytelling, and food—as core components of caregiver support.

2. Adapt and Implement Existing Evidence-Based Interventions

- Avoid “reinventing the wheel” by adapting existing dementia caregiving interventions such as *The Savvy Caregiver, Powerful Tools for Caregivers, Aging Brain Care, REACH,* and *Care Ecosystem*.
- Select flexible, scalable interventions with potential for cultural enhancement to reflect Indigenous values and caregiving practices.
- Prioritize interventions that offer hybrid delivery models (in-person, phone, or online) to account for internet availability and geographic barriers.

3. Establish and Support the Caregiver Coach Model

- Operationalize the **Caregiver Coach** role by building out responsibilities based on the **HEAD–HEART–HANDS** framework:
    - **HEAD:** Skills in assessment, care planning, health system navigation, and dementia education.
    - **HEART:** Cultural humility, empathy, emotional support, and connection.
    - **HANDS:** Practical support for symptom management, home safety, and care coordination.
- Train and empower a diverse workforce (e.g., CHRs, PHNs, peer mentors) to serve as Caregiver Coaches.
- Create training pathways and certification programs that enable tribal members to grow into these roles, supported by ongoing education and peer mentorship.

4. Build Workforce Capacity

- Develop and deliver culturally relevant training programs for health care providers, caregivers, and Caregiver Coaches, focusing on dementia literacy, cultural competence, and care navigation.
- Address workforce shortages by cross-training existing staff and expanding roles for paraprofessionals and peer mentors.
- Provide technical assistance to tribal health programs implementing or scaling caregiving supports.

5. Address Structural and Social Determinants

- Recognize and mitigate historical trauma, systemic inequities, and social drivers that affect caregiving and health outcomes in AI/AN communities.
- Invest in technology access, transportation, respite care, and translation services to reduce barriers to care.

- Support digital inclusion by developing culturally relevant online tools and training to expand access to telehealth, caregiver education, and peer support.
- Reduce stigma and increase dementia awareness through culturally grounded community education and public health campaigns.

6. Create a Coordinated System of Clinical and Community Care

- Integrate clinical care with community-based services, caregiver supports, and culturally specific resources.
- Establish clear referral systems for early diagnosis, advanced care planning, and behavioral health support.
- Encourage coordinated care teams that include caregivers as essential partners in care planning and decision-making.

7. Measure Impact and Share Learning

- Support tribal and IHS sites in collecting data on caregiver outcomes, program sustainability, and community impact using culturally appropriate tools that reflect Indigenous perspectives.
- Integrate both quantitative outcomes and community-defined measures of success, such as caregiver confidence, family harmony, or storytelling-based evaluations.
- Promote cross-site learning through regional and national collaboratives, technical assistance networks, and peer exchanges.
- Ensure data sovereignty by supporting tribes in defining how data are collected, analyzed, and shared.
- Recognize and uplift stories of success and adaptation within tribal communities to foster replication and resilience.

8. Secure Sustainable Funding and Policy Support

- Advocate for flexible, long-term funding models through IHS, Medicaid, Medicare, and private sources.
- Establish billing pathways that enable Caregiver Coaches and related personnel to deliver reimbursable caregiving services.
- Encourage cost-sharing models or resource pooling between tribal, state, and federal programs to sustain local implementation.

9. Advance Policy Alignment and Partnerships

- Collaborate with federal, state, and tribal partners to align dementia caregiving priorities across agencies.
- Advocate for policies that formalize caregiver support roles, establish reimbursement pathways, and protect tribal sovereignty in caregiving services.
- Integrate AI/AN caregiving perspectives into national aging, dementia, and caregiver initiatives to ensure visibility and equity.

These recommendations reflect the belief that caregiving is not only a medical or logistical responsibility, but a **relational, cultural, and community-centered role**. By investing in culturally aligned, community-led, and sustainable caregiving interventions, IHS can strengthen health equity, honor Elders, and ensure that people living with dementia and their caregivers receive the respect, support, and dignity they deserve.

Nurses and Other Health Professionals: Where to Start

For nurses and other health care professionals, here is some practical guidance on where to start and what to prioritize when supporting caregivers in your community.

1. Establish or Support a Caregiver Coach Role

The report strongly recommends implementing a **Caregiver Coach model**, for which nurses are well-positioned to serve as champions. This role:

- Supports caregivers in understanding the stages and symptoms of dementia. Provides culturally appropriate education, resources, and emotional support.
- Helps families plan for care, coordinate services, and manage symptoms at home.
- Builds caregiver confidence through ongoing relationship-based support.

Caregiver Coaches can be CHRs, public health nurses, social workers, or peer mentors, and nurses can help lead, train, or refer to this role.

2. Choose a Culturally Adaptable Intervention to Implement

Start with one of the five evidence-based interventions (EBIs prioritized by the Workgroup and tailored for flexibility and tribal settings.

Select one that aligns with your clinic's capacity, community preferences, and staff skills—and adapt it based on community input.

Key Services You Can Provide or Advocate For:

Even if you don't launch full intervention right away, you can begin offering the following supports immediately:

Education & Training

- Teach caregivers the basics of dementia progression, behavior changes, safety, and communication.
- Offer printed materials, videos, or talking circles to reduce stigma and increase understanding.
- Use culturally relevant examples, traditional knowledge, and storytelling where appropriate.

Care Planning & Navigation

- Help caregivers create simple, person-centered care plans.
- Provide checklists for provider visits, safety assessments, and end-of-life care.
- Guide families through Medicare/Medicaid enrollment, advance directives, and service referrals.

Emotional & Peer Support

- Create a support group or talking circle—virtual or in-person.
- Offer peer mentorship programs where experienced caregivers offer guidance and support to newer caregivers.
- Include caregivers in care team meetings and acknowledge their central role.

Access to Respite and Community Resources

- Connect caregivers to respite care options, if available.
- Share information on local or virtual programs like Dementia Friends, Music & Memory, or Tailored Activity Program (TAP).

Work with community organizations, senior centers, or existing tribal programs to co-host caregiver events or services.

Appendix 1: Literature Review – List of Articles

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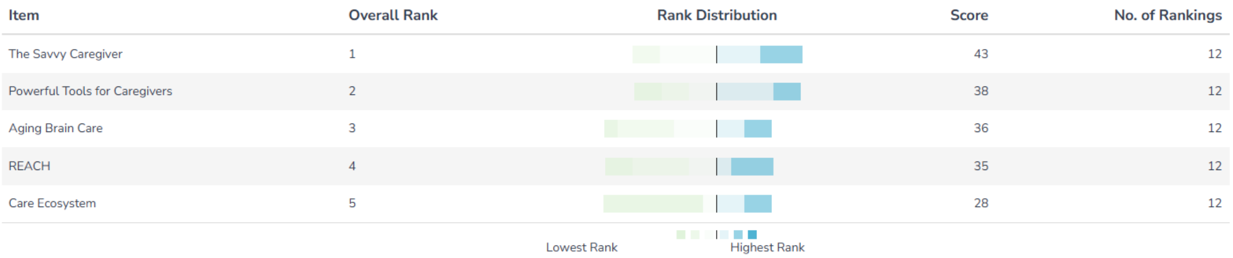
Appendix 2: Summary of Workgroup Meeting Agendas and Key Discussion Questions

Date	Agenda	Key Discussion Questions
July 24, 2024	• Purpose of the Workgroup • Our journey together • Values, principles, and considerations	• What values should guide our work together? • What guiding principles do we want to center? • What considerations do we want to keep in mind as we think about recommendations for caregiving EBIs and caregiver coach roles and responsibilities?
August 7, 2024	• Presentation—The Dignity – and Disruptions – of Dementia Caregiving • Presentation—National Caregiver Survey	• How do today's presentations align with or differ from your experiences in caregiving within AI/AN communities? • What daily challenges and support needs of caregivers in AI/AN communities are you most aware of?
August 21, 2024	• Introduction to and overview of evidence-based interventions • Key themes—literature review and interviews to date	• What are your experiences to date with EBIs and other caregiver services and supports? • Based on the information shared today, what questions do you have about EBI implementation? • What are the key considerations in EBI adaptation/implementation in Indigenous communities?

September 4, 2024	● Values and guiding principles ● Introduction to and overview of criteria for caregiver interventions and programs ● Featured intervention: Powerful Tools for Caregivers	In lieu of a small group discussion, the Workgroup stayed in a large group to discuss criteria for outcomes, content, and structure to consider when reviewing EBIs. ● What are the strengths of *Powerful Tools for Caregivers*? What questions do you have? ● As you think about criteria (structure, outcomes, content) and our values and guiding principles, what else is important to consider?
September 18, 2024	● Featured intervention: *The Savvy Caregiver*	● What are the strengths of *The Savvy Caregiver*? What questions do you have? ● As you think about criteria, what else is important to consider?
October 2, 2024	● Featured intervention: *REACH Community*	● What are the strengths of *REACH Community*? What questions do you have? ● What challenges do you see in the implementation of this intervention?
October 16, 2024	● Brief recap of our purpose and 'what's ahead ● Featured intervention: *Care Ecosystem*	● What are the strengths of *Care Ecosystem*? What questions do you have? ● What challenges do you see in the implementation of this intervention?
October 30, 2024	● Brief recap of our purpose and 'what's ahead ● Featured intervention: *Aging Brain Care*	● What are the strengths of *Aging Brain Care*? What questions do you have? ● What challenges do you see in the implementation of this intervention?
November 13, 2024	● Recap of intervention presentations; values and guiding principles; criteria for selecting intervention ● Workgroup survey	In lieu of small group discussions, the Workgroup took time to complete the survey.
November 25, 2024	● Workgroup survey ● Overview of final report ● Synthesis of criteria and observations ● Caregiver coach roles and responsibilities	● What additional insight can we offer IHS and each other? ● What recommendations do you have for "caregiver coach" roles and responsibilities?
December 11, 2024	● Review and edit "Criteria for Selecting a Caregiver Intervention" ● Review and edit "Caregiver Coach Roles & Responsibilities" ● Wrap up and next steps	● Workgroup members utilized shared documents to provide feedback on the following documents: "Criteria for Selecting a Caregiver Intervention" and "Caregiver Coach Roles and Responsibilities"

Appendix 3: Five Evidence-Based Interventions – Workgroup Survey Results

1. Please rank these five caregiving interventions from best aligned with values, guiding principles, and criteria for consideration to least aligned with values, guiding principles, and criteria for consideration:



Item	Overall Rank	Rank Distribution	Score	No. of Rankings
The Savvy Caregiver	1		43	12
Powerful Tools for Caregivers	2		38	12
Aging Brain Care	3		36	12
REACH	4		35	12
Care Ecosystem	5		28	12

2. Please share what most influenced your decision to rank the interventions in the way you did (e.g., content, structure, outcomes, cost, etc.).

ID	Response
1	All five are very informative, and it was challenging to rank them from best to least.
2	The Savvy Caregiver considers the wellness of both the patient and the caregiver.
3	I ranked the interventions the way I did because I feel that caregivers should have powerful resources and teachings on how to care for a person with dementia. I also believe that promoting awareness and providing education to not only caregivers but also other community members and family members, is essential.
4	Cost and train-the-trainer model.
5	SAVVY Caregiver - since it also has a curriculum geared towards Indian Country. It is more fitting for our community. Powerful Tools - I believe this would be more fitting, as per our caregiver's requests for resources. REACH- Care planning is very important for our population as well so this program would be very fitting. This seems to be the only program that covers care planning. Aging Brain Care- Addressing depression is also very important for our population. Many of our elders live rural and away from others and programs so they are high risk for depression. Care Ecosystem- Free and cost effective care is always a plus.
6	Adapted for use with Native Americans. Structure and content suited for HCBS
7	Content, sustainability and success in Tribal communities - Reason for top (3) choices. The USPHS Commissioned Corp work in the VA (conduct VA REACH and ECHO programs) and IHS systems, so REACH would be the easiest to transition into an ITU intervention. VA and IHS have similar programs and therefore REACH would be the most compatible to implement. Content to support caregivers and their clients/family member(s). Cost effectiveness of top (2) choices. Train the trainer models designed to empower professionals working and living in Tribal communities.
8	Care should be focused at home and to provide a broad educational base in which a patient and their community supports can move forward with a concise and system-based care plan. Health service delivery is important, but the community awareness of the problem drives the social will to address the challenge in the community.
9	I favor models with individualized assessment of caregivers and that are flexible in both mode of delivery (in person / virtual / phone) and timing and frequency of delivery), and that are oriented to just-in-time education, providing education and training that solve problems raised in the assessment or by the caregiver. I am less enthusiastic about models that are primarily educational

10	The program offers tailored classes for caregivers of adults with chronic conditions including those caring for children with special needs. I like that it focuses on the caregiver(s).
11	I have worked with the REACH caregiver program in the past, and believe it will be the most successful program for IHS because it provides a structured, evidence-based approach to addressing the specific needs of dementia caregivers, focusing on improving their emotional and physical well-being by teaching skills like problem-solving, stress management, and positive thinking, ultimately leading to reduced caregiver burden, depression, and frustrations related to caregiving challenges. The program can be provided by phone, virtual, or in-person in community settings. Trained staff or volunteers can provide this educational program, and community members can also be trained which will strengthen the program in Tribal communities. REACH has a very detailed and extremely informative notebook that accompanies the training, the training is short and well structured, and can be implemented within a short turnaround period. The program is not as costly as some other programs reviewed or that are available at this time for use. IHS should work with their staff to ensure referrals to the program will be made from staff and also educate at community-level to ensure referrals are being made from Senior Centers, Health Care Facilities, Tribal Social Services, CHR's, PHN's, etc.
12	I picked Aging brain first as I feel it is important to understand the disease progression first and then being able to support the caregivers.
13	Aging brain care focuses on patient's brain health/intervention/care/treatment. AI/AN population would benefit and the providers, Care Ecosystem, this is important for AI/AN, powerful tools for caregivers- important for family, savvy caregiver=important for caregivers/family, REACH, maybe different for AI/AN.

3. In light of the values and guiding principles created by the Workgroup, what should IHS prioritize in their dementia caregiving programming?

ID	Response
1	Healthy Habits - Hydration, nutrition, and activity just to name a few.
2	Patient needs and then the caregivers needs, knowledge, skills, and abilities
3	Education, awareness, and powerful resource tools.
4	Focus and center patients and caregivers; involve them along the way and remember they can continue to live full, happy, healthy lives
5	Making sure it is cultural responsive and respectful to native communities. Engage the caregiver and patient as much as possible. Person-centered.
6	1) Brain health 2) caregiver support. 3) Build and support geriatric, dementia, medical educational fields to get more doctors specializing in these medical fields. Scholarships. Target states with the largest NA populations.
7	Proactive steps - Brain Health and Education about Alzheimer's Disease Access to mental status evaluation at ITUs Education on referral process within the IHS system and Long Term Care (if needed) Medication management Education for caregivers of those with Alzheimer's Disease
8	Education based in a culturally specific milieu would be the ideal method for IHS to provide caregiving. Caregiving and the programming also should be duplicative. The process should involve a reiterative plan to implement, assess, modify, and reimplement a plan for a community. If SDPI has taught us one thing, is that a program needs to be fresh and engaging for it to have sustainability.

9	1. Provision of materials (online or in handbook) to support caregiver coach / support staff who are not "dementia specialists" 2. Ongoing mentoring and peer community for caregiver support staff 3. Guidance and training in a structured (but not overly rigid) assessment of the care partner and dyad 4. Flexibility in adaptation to tribal resources and culture. 5. Metrics that help manage the program.
10	Language resources-provide material and support in native languages to enhancing understanding and inclusivity. Elder knowledge-use relevant storytelling/traditional knowledge to convey dementia education, helping caregivers feel a sense of belonging and respect. Access to respite care-develop programs that allow family caregivers occasional breaks. Document caregivers in the electronic health records, include them in the care team. Guidance on behavioral health integration-include training on behavioral health needs of the person living with dementia and the caregiver. Wellness checks/health screenings for caregivers. Caregiver education-educate on self-care practices. Provide caregivers education on dementia progression, communication strategies, daily care techniques.
11	Choose a community-based program that will work well for Tribal communities. Train IHS staff (CHR's, PHN's, doctors, nurses, intake workers, etc.) to make referrals to the program.
12	Educating acknowledging caregivers strengths, being aware of caregiver breakdown
13	education on all for all including providers.

4. In light of the values and guiding principles created by the Workgroup, and based on your particular needs and context, what can IHS do to support you in your work?

ID	Response
1	More education to help caregivers or to point caregivers to tribal programs that offers education.
2	Assist in obtaining the training needed, especially financially
3	It would be nice if we had specific CHRs, QSPs and perhaps PHNs to assist with assessments and other assistance that will help the person caring for the person with dementia.
4	(left blank)
5	Having this open discussions and involving our program, community and tribe is very helpful. Allowing us a place at the table in creating programs is very beneficial.
6	Provide funding for caregiver support and services. It is difficult for clinics to support dementia services and cover associated costs, i.e. Medicare, Medicade, etc.
7	Strengthened relationship between Area Agencies on Aging to assist caregiver and patient with Care Coordination, Advance Directives, etc. Also, working with AAA's to look at cost sharing opportunities for Evidence Based Programs in Tribal communities.
8	Focusing on the plan for the next 1,5, 10, and 20 years would best serve the cause in addressing dementia. IHS can provide a strategic plan with the appropriate resources for the goals set out for the next 20 years. This will include the current awareness campaigns, but also the need for infrastructure and brick and mortar for adult day care, memory care units and clinical staff to address the burgeoning wave of clients that many communities will be inundated with.
9	Not applicable for me

10	Access to dementia specific resources. Data and outcome tracking for continuous improvement-caregiver feedback and measure caregiver health and quality of life to evaluate programs' impact.
11	Provide education to IHS on dementia awareness, understanding, and when and how to make referrals.
12	(left blank)
13	Provide further education, information exposure on the topic and provide resources that are adaptable in rural areas, for families, health care providers, patients

5. What practical recommendations do you have for future IHS programming, training, and resources that can be developed to best meet I/T/U staff needs in providing caregiver services and supports?

ID	Response
1	(left blank)
2	Integrate cultural teaching / training / considerations
3	Powerful Toolkit for Caregivers Memory Cafe Support Group
4	(left blank)
5	Adapting the program and training for AI/NA populations.
6	1) Help with getting health care costs covered through Medicare/Medicade/Insurances for dementia services so that clinics can provide better dementia/aging services. 2) incentives or grant funding to grow and support dementia programs that are home based. 3) specialized dementia training programs for CHR, CHW
7	Medication management with the assistance of the IHS Pharmacy Department. Education to public about existing services available in their community. Transition of services between VA and IHS. We have many Tribal members that utilize both systems.
8	Institutionalizing the fight against dementia would be the first best step for ITUs. For example, the American Cancer Society, The Alzheimer's foundation, The Susan B. Komen Breast Cancer Walk for Life are organizations and movement that have taken on lives of their own through institutionalizing their efforts. ITU staff also need the tools and a matrix in which to apply these tools for caregiver support. Something as simple as a Punch list for items needed for those with dementia. Advance Directive, Power of Attorney, Clinical support with neurology consult, radiology services for MRIs, directions to engage county, state and tribal services for home care, funding, and volunteers. Transportation resources either through funding or recommendations to engage local groups and metropolitan mass transit to facilitate patients getting to areas to access services.
9	Not applicable for me
10	Resource navigation-help program develop centralized hubs within their centers/facilities that can assist caregivers with service navigation. Expand CHR programs-allow trained community members to provide in-home education and act as liaisons between families and health care providers. Enhance focus on mental health-integrate self-care practices in caregiver programs, including traditional practices to support mental wellness. Funding and resource expansion. Data collection and program evaluation-education on collecting and analyzing data on service utilization. Provide guidance on how to establish community feedback mechanisms.

11	IHS dementia education/awareness training Family caregiver dementia education/awareness training ECHO training for physicians, nurses, and other medical professionals to promote more timely and effective referrals for dementia testing/evaluation
12	(left blank)
13	Provide it to a wide range of professions *(PHA, educators, BHA, don't limit to certain profession. Get the material out, do not see a lot of resources, training

6. Is there anything else 'you'd like to share or recommend that the work group or IHS considers as a next step?

ID	Response
1	(left blank)
2	(left blank)
3	(left blank)
4	(left blank)
5	NA
6	(left blank)
7	Advocacy to support dual use or flexibility of Evidence Based and Evidence Informed Programs. Transportation to gain access to the training program. Respite, so the caregiver can attend the training. Education for the person with Alzheimer's Dementia. What changes will they encounter?
8	Listen. Listen to what the community needs and describes as important. The most mundane items may be the most important. Listening to communities will allow them to have a voice. Additionally, recognizing that dementia is a disease that is best described from a Life Perspective approach. From neonates to elders, dementia affects everyone differently.
9	Not applicable for me
10	I'd like to hear the feedback from everyone and the next steps.
11	Make a decision on the program structure, seek funding, and begin implementation! Best wishes for much success!
12	Outside support programs? PACE? What other resources are there to support patient and families?
13	Implement on Cultural humility, health literacy, improving access for patients who are in a remote area,