

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

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Indian Health Service

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Thank You!



We acknowledge and thank the American Indian and Alaska Native people and communities who allowed their photographs to be used in this presentation.

These photographs are for informational and educational purposes only and do not imply a dementia diagnosis or any other health condition.

We appreciate their contribution to improving the care of Native elders.

Dementia Caregiving Is a Growing Community Reality

- Dementia prevalence is increasing across American Indian and Alaska Native (AI/AN) communities
- Younger-onset dementia is more common in AI/AN populations
- 1 in 4 AI/AN adults identifies as an unpaid caregiver
- Workforce and access barriers strain families and systems



Caregiver support must be embedded into clinical and community programs.

About the IHS Dementia Caregiving Report



- **Purpose:** guide culturally responsive caregiver services and define the Caregiver Coach Framework
- **Developed by:** the IHS Elder Care Team in partnership with Northwest Portland Area Indian Health Board and Cardea
- **Informed by:** literature review, key informant interviews, and a national Workgroup
- **Workgroup:** CHRs, nurses, providers, researchers, and tribal partners

A framework emerged directly from Workgroup recommendations.

Source: IHS Dementia Caregiving Report, 2024

What the IHS Report Identified



Caregivers need structured, skills-based support

Emotional isolation and stress remain significant risks

Family-centered approaches reflect caregiving realities

Cultural alignment determines program success

Source: IHS Dementia Caregiving Report, 2024



Caregiver Coaching: A Core Recommendation of the Report

The Workgroup identified caregiver coaching as essential infrastructure:

- Designed to support both the caregiver and the person living with dementia
- Structured, relationship-based support — not one-time education
- Integrates clinical and community systems of care

Caregiver coaching was a primary recommendation of the report.

Source: IHS Dementia Caregiving Report, 2024



Why the Report Emphasizes Caregiver Coaching

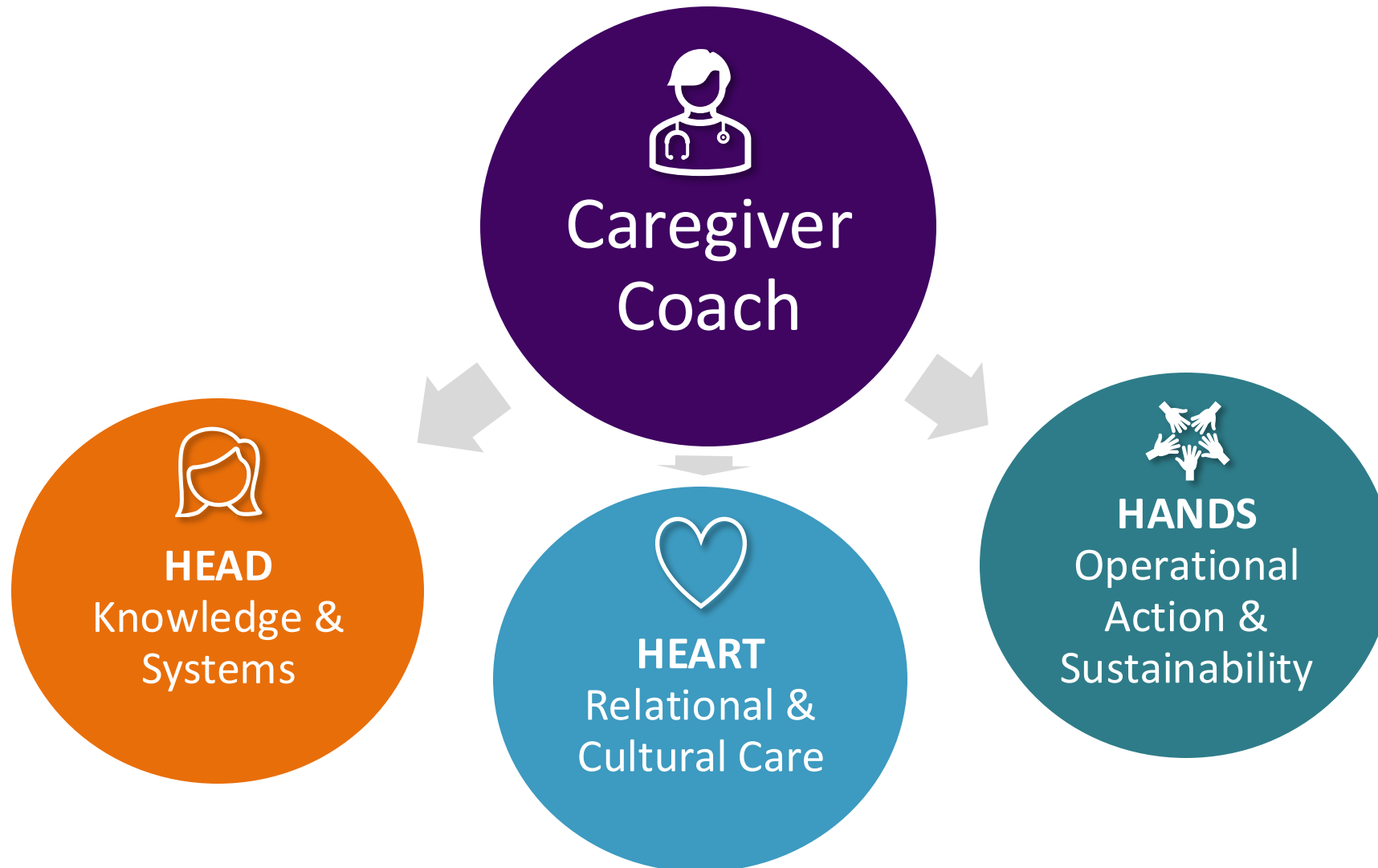
- Most dementia care happens outside clinical settings
- Caregivers are the primary providers of daily care
- Without structured support: stress increases and safety risks rise
- Coaching strengthens sustainability and quality outcomes

If we don't strengthen the caregiver,
no care model will hold.

Source: IHS Dementia Caregiving Report, 2024

The Caregiver Coach Framework

Source: IHS Dementia Caregiving Report, 2024





Clinical Story: Mr. Jones

- Mr. Jones has been diagnosed with middle-stage Alzheimer's disease
- Two adult children live several states away; their youngest son lives on nearby reservation
- Mrs. Jones can manage household chores but sees that her husband's needs are increasing
- Limited community resources and support is stressful for Mrs. Jones
- When asked about potential family support, Mrs. Jones says that Mr. Jones gets a little aggressive when their son comes into the house

Small Group Reflection — Apply a Coaching Lens



What is the most immediate concern?



Where is caregiver stress showing up?



What systems gaps are visible?



Who would follow up in your setting?



HEAD — Knowledge & Systems



- Embed caregiver assessment into standard workflows
- Align care planning with dementia stage and progression
- Integrate caregiver goals into documentation and referrals
- Strengthen cross-system coordination (clinical & community)
- Clarify caregiver roles and responsibilities

IN PRACTICE

- Use a brief caregiver stress screen at each visit and document results.
- Review medications and confirm understanding of purpose and side effects.
- Clarify caregiver roles and establish a clear follow-up plan.

Source: IHS Dementia Caregiving Report, 2024



HEART — Relational & Cultural Care



- Make relational, culturally grounded care the standard
- Recognize caregiving as communal and intergenerational
- Address stigma and normalize dementia conversations
- Support caregiver confidence and resilience
- Honor elder dignity and independence

IN PRACTICE

- Begin visits by asking how the caregiver is coping and listening first.
- Normalize stress and identify one caregiver strength to reinforce.
- Include caregiver voice in care planning conversations.

Source: IHS Dementia Caregiving Report, 2024



HANDS — Operational Action & Sustainability

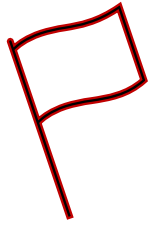


- Operationalize caregiver support in daily practice
- Provide real-time behavior and safety strategies
- Facilitate transitions and crisis planning
- Connect families to respite and community resources
- Build sustainability into program design

IN PRACTICE

- Develop a simple home safety and behavior response plan.
- Schedule structured follow-up check-ins (phone or in-person).
- Connect the family to one concrete respite or community resource.

Source: IHS Dementia Caregiving Report, 2024



Red Flags — When to Escalate or Refer

- Aggression or behaviors posing a safety risk
- Caregiver neglecting self-care or appearing exhausted
- Signs of depression, hopelessness, or burnout
- Frequent falls, medication errors, or crisis situations

Know when support shifts from coaching to clinical escalation.



Strengthening Dementia Care Across American Indian and Alaska Native Communities



- Caregiving is relational, cultural, and community-centered
- Clinical excellence and cultural grounding must work together
- Structured system changes create long-term impact

Investing in caregivers improves quality of life for elders and families.

Source: IHS Dementia Caregiving Report, 2024

From the IHS Dementia Caregiving Report

“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.”

Source: IHS Dementia Caregiving Report, 2024



Access the IHS Dementia Caregiving Report

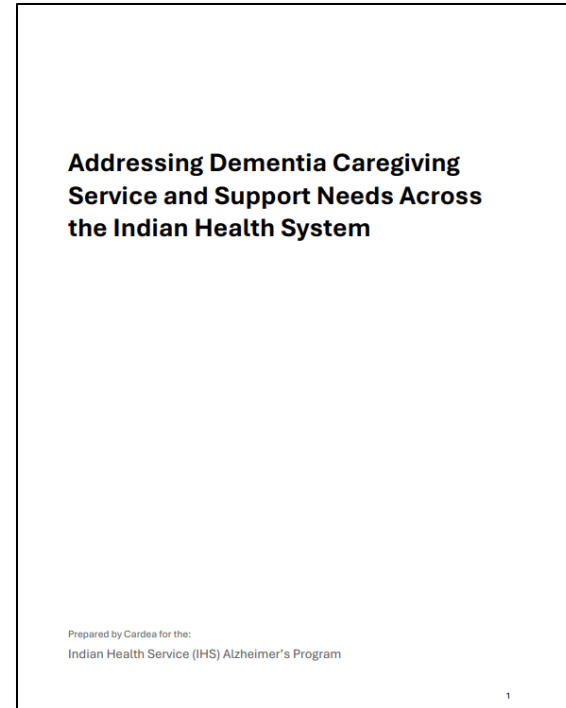


The full report provides detailed guidance on:

- Caregiver Coach roles and responsibilities
- Evidence-based interventions reviewed
- Cultural adaptation considerations
- Implementation and sustainability strategies
- Tips for nurses

To access the report:

- www.ihs.gov/Alzheimers >> Outreach and Awareness >> Announcements



Discussion — Intervention Use & Adaptation



Which interventions have you used? (Savvy, Powerful Tools for Caregivers, REACH, ABC, Care Ecosystem, others)



How did you have to adapt?



How did you integrate cultural elements?



What barriers did you encounter?



What worked well?

