

DEPARTMENT OF HEALTH AND HUMAN SERVICES

STATEMENT OF

BRUCE FINKE, M.D.

**ELDER HEALTH CONSULTANT
INDIAN HEALTH SERVICE**

BEFORE THE

SPECIAL COMMITTEE ON AGING

UNITED STATES SENATE

FIELD HEARING ON

ALZHEIMER'S DISEASE:

A BIG SKY APPROACH TO A NATIONAL CHALLENGE

BILLINGS, MT

August 13, 2014

Good Morning Chairman Walsh and Members of the Committee. I am Dr. Bruce Finke, Elder Health Consultant for the Indian Health Service (IHS). I am also the IHS representative to the U.S. Department of Health and Human Services (HHS) Advisory Council on Alzheimer's Research, Care and Services. I am pleased to have the opportunity to testify before the Senate Special Committee on Aging on the impact of Alzheimer's disease and related dementias on American Indian and Alaska Native communities, and on the work being done in Indian Country to address this issue.

As you know, IHS plays a unique role in HHS because it is a health care system that was established to meet the Federal trust responsibility by providing health care to American Indians and Alaska Natives (AI/ANs). The mission of IHS, in partnership with AI/AN people, is to raise the physical, mental, social, and spiritual health of AI/ANs to the highest level. IHS provides comprehensive health service delivery to approximately 2.1 million AI/ANs from 566 Federally-recognized Tribes in 35 states. The IHS system is organized and administered through its Headquarters in Rockville, MD, 12 Area Offices, and 168 Service Units which provide care at the local level. In support of the IHS mission, health services are provided directly by IHS Federally-operated facilities, through Tribally-contracted and -operated health programs, through services purchased from private providers, and through urban Indian health programs.

Alzheimer's disease in Indian Country

While reliable prevalence or incidence data on Alzheimer's disease or other types of dementia in the American Indian and Alaska Native population are not currently available, we do know that in every Tribal community there are individuals with dementia and caregivers struggling to support them. IHS data from 2001 indicated death rates from Alzheimer's Dementia were approximately half of that of the U.S. All Races, but had risen dramatically in the previous 20 years in a pattern similar to that of the US All Races¹. These data appear to underestimate the true prevalence of dementia in Indian Country. IHS workload statistics of a subset of IHS beneficiaries showed nearly 17,000 unduplicated patients with dementia between 2007 and 2013². High rates of diabetes, cardiovascular disease, and traumatic brain injury indicate a high population risk for dementia. The experience of IHS clinicians suggests that dementia is under-recognized and diagnosed at later stages in American Indian and Alaska Native communities, even relative to the low rates of diagnosis in the nation as a whole.

From conversations with Tribal leaders, Tribal aging network providers, health care providers, and elders and their families over the past 15 years, we understand a number of factors that contribute to low rates of recognition and diagnosis. The strong tradition of extended family caregiving in Tribal communities often compensates for the decreasing function of the elder with dementia. Families may use traditional and cultural views of

¹ Trends in Indian Health 2002-2003

<http://www.ihs.gov/dps/index.cfm?module=hqPubTrends03>

² Workload data derived from the National Data Warehouse, accessed July 25, 2014, for fiscal years 2007 – 2013.

aging to explain the changes associated with dementia, thus normalizing the changes rather than seeing them as a disease in need of treatment. Diagnosis of dementia across divides of culture and language can be challenging for clinicians, especially in the early stages of the condition.

Care for persons with dementia and support for their families requires care coordination and care management often beyond the capacity of many IHS, Tribal, and Urban Indian health programs. Caregiving challenges are amplified by the relative lack of formal long-term services and supports in Indian Country. Prior to 2010, Tribes took the lead in using their own resources or grants, contracts or reimbursements from other federal and non-federal entities to provide long term services and supports. The IHCIA reauthorization in 2010 provided new authorities for long-term services and supports to the IHS and to Tribes. The capacity of the local tribal and federal care systems to expand access to services remains a significant challenge to implementing these new authorities.

In response to a request for consultation on the implementation of the IHCIA, Tribes indicated that they would like to develop the long term services and supports that will allow elders to remain in their community as they age, regardless of disability. During IHS' annual budget consultation with Tribes, long term care services are discussed among the many other Indian health priorities.

National Alzheimer's Project

Much of the work to address Alzheimer's disease in American Indians and Alaska

Natives takes place within the context of the National Alzheimer's Project. On January 4, 2011, President Obama signed into law the National Alzheimer's Project Act (NAPA), requiring the Secretary of the U.S. Department of Health and Human Services (HHS) to establish the National Alzheimer's Project to:

- Create and maintain an integrated National Plan to overcome Alzheimer's
- Coordinate research and services across all federal agencies
- Accelerate the development of treatments that would prevent, halt, or reverse the disease
- Improve early diagnosis and coordination of care and treatment of the disease
- Improve outcomes for ethnic and racial minority populations at higher risk
- Coordinate with international bodies to fight Alzheimer's globally, and
- Create an Advisory Council on Alzheimer's Research, Care, and Services to create, review and maintain the National Plan and work on its implementation.

The National Plan was released by then HHS Secretary Sebelius on May 15, 2012. The Plan includes a detailed listing of current federal activities, and, as directed by the NAPA and the Advisory Council, recommendations for priority actions to expand, eliminate, coordinate, or condense federal programs.

The Plan was updated in April 2014 and describes the progress made throughout 2013 in the areas of research, care and supports, and interagency collaboration. It also includes updates to a number of the Plan's goals and strategies, reflecting the recommendations of the Advisory Council.

Indian Health Service Response and Partnerships

Through the National Plan to Address Alzheimer's Disease, the Indian Health Service is working with the Office of American Indian, Alaska Native, and Native Hawaiian Programs at the Administration on Aging (AoA) in the Administration for Community Living (ACL) around four person-centered goals for improving the care for and the lives of American Indians and Alaska Natives with dementia and their families. These goals are expressed as four statements that every individual with dementia should be able to make:

“I was diagnosed in a timely way.”

Individuals and families need help recognizing cognitive impairment at its earliest presentation and should expect a timely and accurate diagnosis so that they understand what is going on, what to expect, and how to prepare.

“I know what I can do to help myself and who can help me.”

Often persons with dementia and their families struggle in isolation to adapt and cope with the inevitable changes that this condition brings to their lives. They need reliable access to culturally appropriate information and to the resources available in their community to help them - both formal long-term services and supports and less formal support through peer-led groups such as those provided by the Alzheimer's Association and other similar groups.

“Those helping to look after me feel well supported.”

Persons with dementia should know that their caregivers will receive the help and support they need.

“My wishes for care are understood and honored.”

Individuals with dementia may not be able to express their wishes for care as the condition progresses. Those who have specific wishes or advance directives should have confidence that these wishes will be honored.

Our work on these goals builds on Indian Country strengths: strong families and a tradition of family caregiving, community-oriented primary care, committed and active public health nursing and community health representatives, and the Tribally operated aging network. The challenges in rural and frontier settings require significant coordination and service integration efforts to improve the lives of those with dementia across the usual boundaries of clinical and community-based services.

The IHS works with multiple partners to improve care for those with dementia. The IHS and ACL are working with the Department of Veterans Affairs (VA) to adapt and implement the evidence-based REACH (Resources for Enhancing Alzheimer’s Caregiver Health) VA program of caregiver support in Tribal communities through both public health nursing and the Tribal aging network. REACH VA is an evidence-based translation of the REACH II behavioral intervention that uses structured interventions to provide caregivers of individuals with dementia with the tools and skills to manage ongoing problems that arise in the course of caregiving. The IHS is building on VA work to test strategies for early recognition among family members as well as clinical and aging services staff. Participation in the VA Dementia Steering Committee links the IHS to the approaches and tools in use at the VA to improve dementia care. The VA is also a

source of clinical expertise in diagnosis and management of dementia for the many Native Veterans who receive primary care in IHS and Tribal sites.

The IHS, ACL, and the Centers for Medicare and Medicaid Services are working under a Memorandum of Understanding to coordinate and collaborate in the provision of technical assistance to Tribes in the development of long-term services and supports. Together we have developed a series of webinars and web-based technical assistance resources. We worked together in development of the CMS Money Follows the Person Tribal Initiative to build infrastructure to support home and community-based care for Tribes in states participating in that initiative. IHS and ACL are collaborating to provide training on Alzheimer's disease and related dementias for the Tribal aging network.

Most care for persons with dementia can and should take place in primary care. IHS, Tribal, and Urban clinics are building better primary care, improving access and continuity using our Improving Patient Care Initiative, which is our Patient-Centered Medical Home model. In IHS, we have expanded participation in our Improving Patient Care Initiative from 38 sites in 2009 to 172 sites in 2014 which is helping improve coordination of care for patients. Increased funding for Purchased and Referred Care (formerly Contract Health Services) has allowed IHS and Tribal programs to gain access to referrals for specialty services that support the provision of primary care in IHS facilities.

Increasing awareness and recognition of dementia in Indian Country starts with access to quality care and meaningful support for individuals with dementia and their caregivers in Tribal communities. The IHS is committed to working in partnership with tribes, federal agencies, and community organizations to improve quality and access to care for individuals with dementia. We are working to change and improve the IHS, and these efforts will help us continue to strive to provide the best possible care for patients with dementia.

Thank you and I am happy to answer questions.