Addressing Dementia in Indian Country

I. PROGRAM AWARD OPPORTUNITY

Addressing Dementia in Indian Country

Program Award for Federal Service Units Working in Coordination with Direct Service Tribes. Key Dates:

Application Deadline Date: July 18, 2022

Earliest Anticipated Start Date: August 31, 2022

Background

Alzheimer's disease and Alzheimer's disease-related dementias affect lives in every Tribal and Urban Indian community. Alzheimer's disease is the most common cause of dementia – a progressive cognitive impairment that adversely affects function. Other forms of dementia include vascular dementia, Lewy-Body Disease, Fronto-Temporal Dementia, alcohol-related dementia, dementia related to traumatic brain injury, and mixed dementia (attributable to more than one cause of cognitive impairment). Age is the most significant risk factor for Alzheimer's disease. Although the average age of American Indians and Alaska Natives (AI/AN) is younger than the population as a whole, the group age 65 and older is growing more rapidly than the United States (U.S.) population. The Centers for Disease Control and Prevention (CDC) notes that the number of AI/AN age 65 and older is expected to triple in the next 30 years, with the oldest - those 85 years and older - increasing even more rapidly. While age is the most substantial risk factor for Alzheimer's disease, early-onset occurs in younger populations and in persons with Down Syndrome or Trisomy 21, who are at markedly increased risk for Alzheimer's Disease. Conditions such as diabetes, cardiovascular disease, chronic kidney disease, chronic liver disease, and traumatic brain injury increase the risk of dementia and can

lead to a more rapid worsening.

Dementia of all types is under-recognized, underdiagnosed, and undertreated in all populations in the U.S., and anecdotal evidence suggests that this is very much true for the AI/AN population. Many individuals go unrecognized in the community, never seeking care and living with impaired cognition that puts them at risk for financial exploitation, poor health outcomes, and accidental injury. Individuals and their families may not recognize the cognitive changes that dementia brings. They may think the changes are due to normal aging or may accept the changes and not seek care out of concern for the elder's dignity. Failure to recognize dementia may also stem from the stigma associated with dementia and from lack of awareness of resources available. Often it takes a crisis or illness to bring attention to the condition. Diagnosis of dementia is most often made in the primary care office or clinic, with specialty referral needed when the presentation is not typical or apparent. But primary care providers may lack the confidence to make the diagnosis or plan effective care and may not have access to an interdisciplinary team to support care or specialists through consultation or referral to support diagnosis and management decisions. Effective management of dementia crosses many boundaries, involving medical care, personal care, social services, legal and financial services, and housing. Management of dementia requires coordination between clinical services and community-based services. Those living with dementia and their caregivers are too often left to coordinate this complex care themselves. Most persons living with dementia receive some care and assistance from caregivers, and sometimes, but not always, family members. Care for the person living with dementia should include consideration for their caregivers but unfortunately this is not common.

Effective models for addressing dementia in Tribal and Urban Indian communities will be supported by evidence and will emerge through development or adaptation and evaluation from those communities. A recent reports by the National Academies of Science, Engineering, and Medicine point to the Resources for Enhancing Alzheimer's Caregiver Health II (REACH II) caregiver support intervention and models of coordinated care as interventions that have evidence for benefit and are ready for implementation and further evaluation¹. The REACH into Indian Country initiative successfully trained public and community health nurses to provide the REACH intervention in Tribal communities. Communities across the country, including some Tribal communities, use the Dementia-Friendly Communities approach to building community-based efforts to improve care for persons living with dementia and their families². The Healthy Brain Initiative Roadmap for Indian Country, developed by the Centers for Disease Control and Prevention and the Alzheimer's Association, is designed to support discussion about dementia and caregiving with Tribal communities and encourage a public health part of a larger holistic response³. These models can help inform the design of Tribal and Urban Indian health models.

¹ National Academies of Sciences, Engineering, and Medicine. 2021. Meeting the challenge of caring for persons living with dementia and their care partners and caregivers: A way forward. Washington, DC: The National Academies Press. <u>https://doi.org/10.17226/26026</u>.

² Dementia Friendly America <u>https://www.dfamerica.org</u> <u>https://iasquared.org/news-release-ia2-is-now-a-national-dementia-friends-sub-licensee-for-</u> american-indian-and-alaska-native-tribal-communities/

³ <u>https://www.cdc.gov/aging/healthybrain/indian-country-roadmap.html</u>

Purpose

The purpose of this Program Award is to support the development of models of comprehensive and sustainable dementia care and services that are responsive to the needs of persons living with dementia and their caregivers for Tribes receiving primary health care services from IHS Direct Services.

Required Activities

- 1. Plan and implement a comprehensive approach to care and services for persons living with dementia and their caregivers that addresses:
 - Awareness and Recognition.

Enhance awareness and early recognition of dementia in the community and increase referral to clinical care for evaluation leading to diagnosis. The United States Preventive Services Task Force has concluded that "current evidence is insufficient to assess the benefits and harms of screening for cognitive impairment in older adults." Still, there is broad consensus supporting case findings to promote early recognition and diagnosis of dementia.

• Accurate and Timely Diagnosis.

Individuals and their families should have confidence that concerns about potential cognitive impairment will be evaluated thoroughly and lead to an accurate and timely diagnosis. Most diagnoses of dementia can be made in primary care, but clinical programs should have referral and consultation mechanisms in place (either in person or via telehealth) to support diagnosis when needed. • Interdisciplinary Assessment.

Persons living with dementia will have complex and evolving care needs. An interdisciplinary assessment helps identify goals of care and gaps in services and sets the stage for appropriate care and services. In best practice, this assessment includes an attempt to understand the cultural, religious, and personal values that will guide goals and preferences for care. It assesses family and other caregiving resources and the needs and capabilities of those partners in care, as well as housing security and safety risks.

• Management and Referral.

Care for the person living with dementia is guided by the assessment and most often requires coordination of health care and social services to meet their needs and support caregivers. Those living with dementia and their caregivers often need support and assistance in navigating through the various systems providing this care.

• Support for Caregivers.

Care for persons living with dementia includes care for their caregivers. Families and other caregivers need help in navigating services and mobilizing respite care, help in understanding what to expect and how to respond to the challenges of living with dementia, and support for self-care. Interventions that provide that care and support (e.g., REACH) and provide education and training (e.g., Savvy Caregiver) have been adapted for use in Tribal communities.

- 2. Develop, in collaboration with the Alzheimer's Grant Program in the Division of Clinical and Community Services (DCCS), Office of Clinical and Preventive Services (OCPS), best and promising practices to include tools, resources, reports, and presentations accessible to Federal, Tribal, and Urban Indian Organizations as they plan and implement their own programs.
- 3. Identify and implement reimbursement and funding streams that will support service delivery and facilitate sustainability. Opportunities for reimbursement and funding streams dependent on the specific interventions planned, but potential sources might include:
 - Medicare reimbursement through the Physician Fee Schedule, including Cognitive Assessment and Planning codes and Chronic and Complex Care Management codes.
 - Medicaid and other state programs.
 - Purchased and Referred Care resources.
 - IHS and Third Party Revenue.

The IHS Alzheimer's Grant Program will provide technical assistance to awardees in development of a plan for sustainability.

II. AWARD INFORMATION

Estimated Funds Available

An estimated \$600,000 will be distributed over a two-year period in 2-3 program individual awards, depending on availability of funds, with awards anticipated to be up to \$150,000 per

year.

A brief continuation application with a progress report and budget narrative will be required for continuation of funding into the second year. Second year funding will be contingent compliance with reporting requirements and submission and approval of a continuation application.

III. ELIGIBILITY INFORMATION

The Program Awards are intended to provide an opportunity for Tribes electing direct services from the IHS to use those federally-operated programs to develop a model of comprehensive care and services for individuals living with dementia and their caregivers.

IHS Service Units providing primary care direct services are eligible for program awards at the request of the Tribe or Tribes they serve. They must be working in close coordination with the Tribe or Tribes for whom they provide direct services and demonstrate that the approach developed under the program award will be integrated with Tribal programs serving the elderly.

IHS Service Units whose Tribe(s) have been awarded an IHS grant under the Addressing Alzheimer's in Indian Country Grants program will not be eligible for the Program Awards.

In the instance of IHS Service Units serving more than one Tribe or Tribal Organization, if one

or more, but not all, Tribes or Tribal Organizations served by the IHS Service Unit have been awarded an IHS grant under the Addressing Alzheimer's in Indian Country Grants program or are awardees of the Dementia Capability in Indian Country Grant program of the Administration for Community Living, the IHS Service Unit will be eligible for program award if the majority of their IHS Service Unit User Population comes from Tribe(s) not awarded the grant.

Applications for Program Awards must include:

1. An official, signed Tribal Resolution indicating that the IHS Service Unit is applying for this Program Award at the request of the Tribe or Tribal Organization and in coordination and collaboration with all affected Tribes to be served. However, if an official, signed Tribal Resolution cannot be submitted with the application prior to the application deadline date, a draft Tribal Resolution must be submitted with the application by the deadline date in order for the application to be considered complete and eligible for review. The draft Tribal Resolution is not in lieu of the required signed resolution but is acceptable until a signed resolution is received. If an application without a signed Tribal Resolution is selected for funding, the applicant will be contacted by the Office of Clinical and Preventive Services (OCPS), Division of Clinical and Community Services (DCCS) and given 90 days to submit an official, signed Tribal Resolution to the DCCS. If a signed Tribal Resolution is not received within 90 days, the award will be forfeited. Tribes organized with a governing structure other than a Tribal council may submit an equivalent document commensurate with their governing organization.

2. Letters indicating support from appropriate Tribal agencies, offices, or enterprises with

which the IHS Service Unit has indicated in the proposal a plan to partner in development of the model of care.

 A letter of endorsement for the application from the Area Director or Area Chief Medical Officer.

IV. APPLICATION AND SUBMISSION INFORMATION

- 1. Mandatory documents for all applicants include:
 - Abstract (one page) summarizing the project.
 - Project Narrative (not to exceed 10 pages). See Section IV.1.A, Project Narrative for instructions.
 - 1. Background information on the organization.
 - 2. Proposed scope of work, objectives, and activities that provide a description of what the applicant plans to accomplish.
 - Budget Justification and Narrative (not to exceed five pages). See Section IV.1.B, Budget Narrative for instructions.
 - One-page Timeframe Chart.
 - Tribal Resolution
 - Letters of Support from appropriate Tribal agencies, offices or enterprises.
 - Letter of Endorsement from the Area Director or Area Chief Medical Officer.
 - Organizational Chart.
 - Identification of all key personnel and both current and expected duties and of

Senior Sponsor (Service Unit leadership accountable for success of the program).

• Contractor/Consultant resumes or qualifications and scope of work, as applicable.

Requirements for Project and Budget Narratives

A. Project Narrative: This narrative should be a separate document that is no more than 10 pages and must: 1) have consecutively numbered pages; 2) use black font 12 points or larger; 3) be single-spaced; and 4) be formatted to fit standard letter paper ($8-1/2 \times 11$ inches).

Be sure to succinctly answer all questions listed under the evaluation criteria (refer to Section V.1, Evaluation Criteria) and place all responses and required information in the correct section noted below or they will not be considered or scored. If the narrative exceeds the page limit, the application will be considered not responsive and will not be reviewed. The 10-page limit for the narrative does not include the work plan, standard forms, Tribal Resolutions, budget, budget justifications, narratives, and/or other items.

There are three parts to the narrative: Part 1 – Program Information; Part 2 – Program Planning and Evaluation; and Part 3 – Sharing with Other IHS Service Units, Tribes, Tribal Organizations, and Urban Indian Organizations. See below for additional details about what must be included in the narrative.

The page limits below are for each narrative and budget submitted.

Part 1: Program Information (limit – 4 pages)

Section 1: Organizational Overview

Provide a brief description of the Service Unit and the Tribe) served, including the, health care delivery system and resources, elderly services and resources, long-term services and supports, and other Tribal or community-based services that might be involved.

Section 2: Needs

Provide any data available about the number of persons living with dementia, their needs, and the needs of their caregivers. If data is not currently available, indicate this here and in Part 2 below, and describe in detail how the applicant will obtain or develop this data in the first year of the program.

Part 2: Program Planning and Evaluation (limit – 4 pages)

Section 1: Program Plans

Describe fully and clearly the applicant's plan to implement a comprehensive approach to care and services for persons living with dementia and their caregivers and identify funding streams that will support service delivery. The plan should include a vision for a comprehensive approach to care, recognizing that achievement of the fully implemented approach may not be feasible within the period of performance. Section 2: Program Evaluation

Describe fully and clearly the elements of the comprehensive approach to care described in Section 1 that the applicant expects to implement over the period of performance. Describe the metrics that will be used to assess the achievement of these goals. If the applicant will need to obtain or develop data about the number of persons living with dementia and their needs and the needs of their caregivers as an element of this award, the applicant should indicate that data and describe how that data that will be developed or acquired in the first year.

Part 3: Sharing with Other IHS Service Units, Tribes, Tribal Organizations, and Urban Indian Organizations (limit – 2 pages) Section 1: Describe how your program will develop, in collaboration with the IHS, best and promising practices that include tools, resources, reports, and presentations, accessible to stakeholders across the Indianl health system including Tribal and urban health partners.

B. Budget Narrative (limit – 5 pages)

Provide a budget narrative that explains the amounts requested The budget narrative should specifically describe how each item will support the achievement of proposed objectives. For the second budget year, the narrative should highlight the changes from year 1 or clearly indicate that there are no substantive budget changes during the period of performance. Do NOT use the budget narrative to expand the project narrative.

2. Submission Dates and Times

Applications must be submitted to DCCS by 11:59 p.m. Eastern Time on the Application Deadline Date. Any application received after the application deadline will not be accepted for review.

Applications must be submitted using the IHS Secure Data Transfer Service.

V. APPLICATION REVIEW INFORMATION

Possible points assigned to each section are noted in parentheses. The project narrative and budget narrative should include only the first year of activities; information for multi-year projects should be included as a separate document. See "Multi-year Project Requirements" at the end of this section for more information. The project narrative should be written in a manner that is clear to outside reviewers unfamiliar with prior related activities of the applicant. It should be well organized, succinct, and contain all information necessary for reviewers to fully understand the project. Attachments requested in the criteria do not count toward the page limit for the narratives. Points will be assigned to each evaluation criteria adding up to a total of 100 possible points. Points are assigned as follows:

1. Evaluation Criteria

- A. Introduction and Need for Assistance (10 points)
 - Description of the clinical services, elder services and resources, long-term care services, and supports available through the applicant's organization, either as a direct service or through agreement, contract, or Purchased and Referred Care (PRC). Applicants must be able to provide ambulatory care services directly and

must be able to coordinate with elder services in the Tribe or communities served.

- 2. Description of the number of individuals living with dementia to be served, any data available about the prevalence of risk factors for dementia (including age as reflected in the population's demographics), and any limitations of the data available.
- 3. Identification of the most urgent and pressing gaps in availability or quality of care and services for persons living with dementia and their families. If this information is not available, the acquisition of this information should be part of the Project Objective(s), Work Plan, and Approach.
- B. Project Objective(s), Work Plan, and Approach (30 points)
 - The overall vision for a comprehensive approach to care and services for persons living with dementia and their caregivers, including:
 - Awareness and recognition.
 - Timely and accurate diagnosis.
 - Multidisciplinary assessment.
 - Management and referral.
 - Caregiver Support.
 - 2. The elements of this vision that the awardee anticipates implementing over the oneyear budget period, including planning activities and assessment of need, if not already available.
 - 3. The work plan and approach, including planning activities and assessment of need, if not already available. This work plan should be responsive to the most urgent and pressing gaps in availability and quality of care and services for persons living with

dementia and their families. This work plan must include, at the minimum, both the provision of clinical services and the engagement of elder services.

- The work plan and approach should include developing tools, resources, reports, and presentations to support the development of programs by other IHS Service Units, Tribes, Tribal organizations, or Urban Indian health programs.
- C. Program Evaluation (30 points)
 - 1. Clearly identify plans for program evaluation to ensure that objectives of the program are met at the conclusion of the period of performance.
 - Include SMART (Specific, Measurable, Achievable, Relevant and Time-based) goals to establish a specific set of evaluation criteria to ensure the objectives are attainable within the period of performance.
 - 3. Evaluation should minimally include metrics that provide insight into the implementation of those elements of a comprehensive approach to care and services for persons living with dementia and their families that the applicant has proposed to implement. The evaluation should also include metrics for important outcomes of care for persons living with dementia and their family, such as avoidance of crisis-driven care (e.g., emergent transfers and undesired out-of-home placement) as well as processes of care that contribute to better outcomes (e.g., reduction of medications that impair cognition).
- D. Organizational Capabilities, Key Personnel, and Qualifications (20 points)
 - 1. Include an organizational capacity statement that demonstrates the ability to execute program strategies within the period of performance.

- Project management and staffing plan. Detail that the organization has the current staffing and expertise to address each of the program activities. If capacity does not exist, please describe the applicant's actions to fulfill this gap within a specified timeline.
- Identify any partnerships or collaborations that will be needed to implement the work plan and include letters of support or intent to coordinate or collaborate with those partners.
- 4. Demonstrate that the applicant has previous successful experience providing technical or programmatic support to Tribal communities.
- E. Categorical Budget and Budget Justification (10 points)
 - 1. Provide a detailed budget and accompanying narrative to explain the activities being considered and how they are related to proposed program objectives.

Multi-Year Project Requirements

Applications must include a brief project narrative and budget (one additional page per year) addressing the developmental plans for each additional year of the project. This attachment will not count as part of the project narrative or the budget narrative.

Additional documents can be uploaded as Other Attachments in Grants.gov.

These can include:

- Work plan, logic model and/or timeline for proposed objectives.
- Position descriptions for key staff.
- Resumes of key staff that reflect current duties.

- Consultant or contractor proposed scope of work and letter of commitment (if applicable).
- Organizational chart.
- Map of area identifying project location(s).
- Additional documents to support narrative (i.e., data tables, key news articles, etc.).

2. Review and Selection

Each application will be prescreened for eligibility and completeness by DCCS. Applications that meet the eligibility criteria shall be reviewed for merit by an Objective Review Committee based on evaluation criteria. Incomplete applications and applications that are not responsive to the administrative thresholds (budget limit, project period limit) will not be referred to the ORC and will not be funded. The applicant will be notified of this determination.

Applicants must address all program requirements and provide all required documentation.

3. VI. Notification of Disposition

All applicants will receive an Executive Summary Statement from the IHS DCCS within 30 days of the conclusion of the ORC outlining the strengths and weaknesses of their application.

Approved applications not funded due to lack of available funds will be held for one year.

If funding becomes available during the course of the year, the application may be reconsidered.

VI. PROGRAM AWARD ADMINISTRATION INFORMATION

1. Reporting Requirements

A. Progress Reports

Program progress reports are required semi-annually. The progress reports are due within 30 days after the reporting period ends. These reports must include a brief comparison of actual accomplishments to the goals established for the period, a summary of progress to date or, if applicable, provide sound justification for the lack of progress, and other pertinent information as required. The progress reports should include an expenditures report. A final report must be submitted within 90 days of the end of the two-year performance period.

Continuation of funding in the second year of the performance period will be contingent on compliance with reporting requirements.

B. Data Collection and Reporting

The program awardee will participate in periodic (not more frequently than monthly) web-based calls with the program office or designee and the other awardees as well as grantees of the Alzheimer's Grant Program to share their progress, experience, tools, and resources that might be useful for other awardees and grantees. The awardee will be expected to work with the program office to develop a driver diagram (an action-oriented logic model) that describes the comprehensive approach to care and services for persons living with dementia and their caregivers and identifies key performance metrics based on their evaluation plan.

The awardee will be expected to share, on a semi-annual basis, the tools, resources, reports, and presentations produced that may support the development of programs by other Tribes, Tribal organizations, or Urban Indian health programs.

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