



Addressing Dementia in Tribal Communities

Emerging Models of Care Opportunities and Resources

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Teresa Martin – Northern Valley Indian Health

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Objectives

After this session, attendees will be able to:

- Assess their systems of care for the capacity to provide high quality care for people living with dementia and their caregivers.
- Describe approaches to comprehensive dementia care emerging from the IHS Alzheimer's Program Grantees for relevance and applicability to their Tribal/Urban Indian healthcare program.
- Identify training and education resources available to build workforce capability in care for the elderly and those living with dementia and their caregivers in their Tribal/Urban healthcare program.



What We'll Talk About Today

- Dementia – what it is, why it matters
- The Alzheimer's Grant Program – and models of dementia care emerging from Tribal and Urban health programs
- Northern Valley Indian Health
- Indian Health Council, Inc.
- Opportunities and resources to help you address dementia in your Tribe or community



Nana's Story

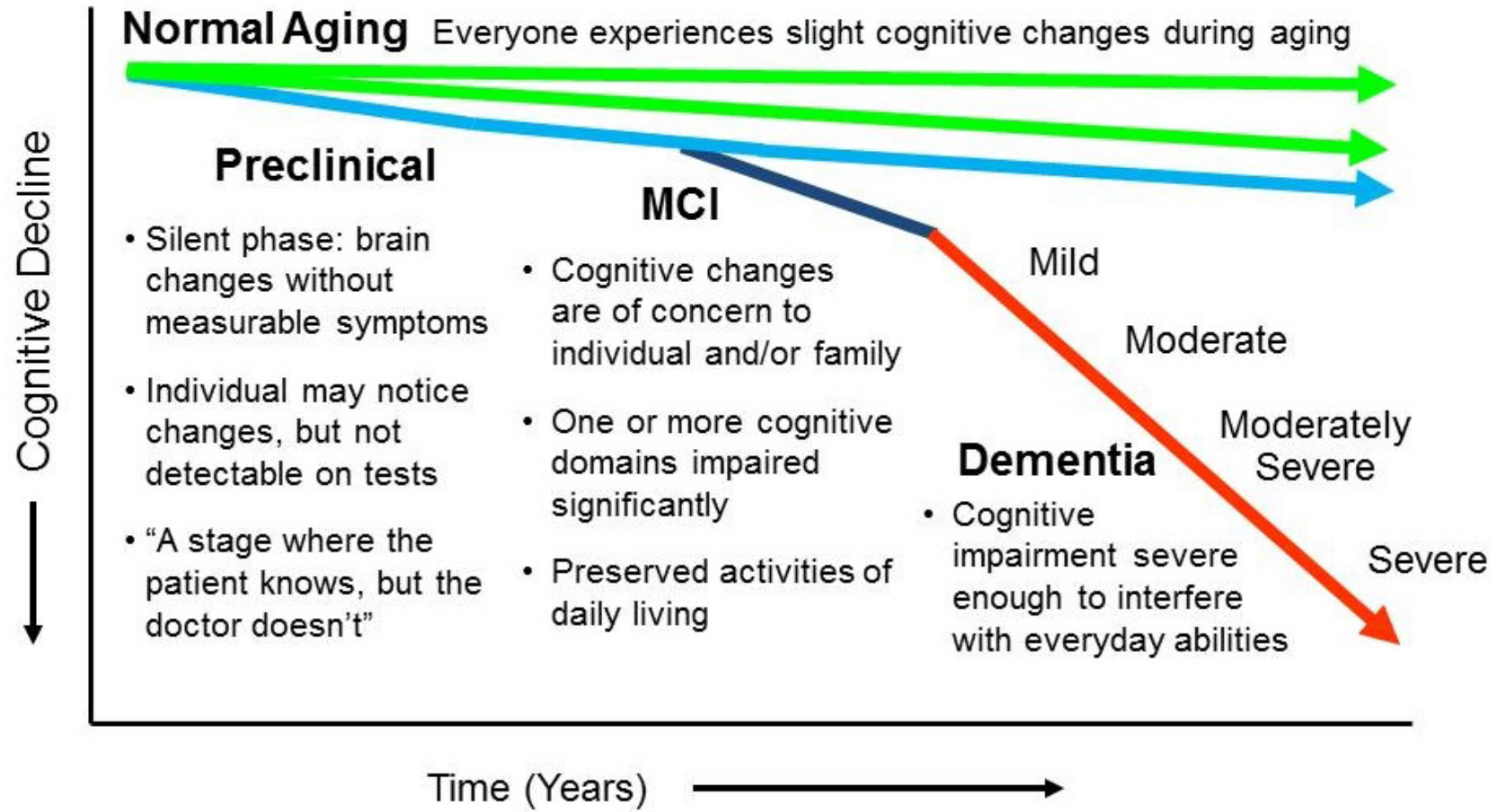
“Now, at times, she thinks that Dad is out fishing and will be home soon. In some ways, this is good, because she does not always have to know that he is gone, and continuously have to suffer the pain that loss can bring after a lifetime like theirs together.

But there are many times that she is totally lucid and knows that he is not with her, but is waiting for her to be with him when her time comes too. We have as a family kept Nana in her home, in the surroundings most familiar to her.

There, every day she is close to all of her family who love her and accept her, wherever she may be mentally. She knows that she is home, and that she is safe and loved, despite her confusion.”

Marquart K. **Nana**. *The IHS Primary Care Provider*. Vol 29 No. 5. May 2004.

Cognitive Changes Continuum



Mild Neurocognitive Disorder (DSM V) or Mild Cognitive Impairment - MCI

- Cognitive complaint (self-reported or informant)
- Objective cognitive impairment
- No impairment of function
- Absence of delirium

Progression to dementia

- About 10% in one year and 15% over 2 years (age 65 and older).
- Typically over 2-3 years but as long as 8 years.
- Cumulative incidence 33%

Pre-clinical

MCI

Mild

Moderate

Severe NCD

Major Neurocognitive Disorder (DSM-V) or Dementia

- A. Evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains
- Learning and memory
 - Executive function
 - Complex attention
 - Perceptual-motor
 - Social cognition
- B. The cognitive deficits interfere with independence in everyday activities. At a minimum, assistance should be required with complex instrumental activities of daily living, such as paying bills or managing medications.
- C. The cognitive deficits do not occur exclusively in the context of a delirium.
- D. The cognitive deficits are not better explained by another mental disorder (e.g. major depressive disorder, schizophrenia).

Pre-clinical

MCI

Mild

Moderate

Severe NCD

DEMENTIA

Umbrella term for loss of memory and other thinking abilities
severe enough to interfere with daily life

ALZHEIMER'S
60-80%

LEWY BODY
DEMENTIA 5%

FRONTOTEMPORAL
DEMENTIA 3%

VASCULAR
DEMENTIA 5-10%

PARKINSON'S
DISEASE 4%

OTHER 3%

MIXED DEMENTIA 50%

What does this look like in your Tribes and communities?

- Matthews et al. - prevalence in identified AI/AN people in Medicare data
 - 10.5 % - comparable or higher than other populations studied
- Suchy-Dicey et al. – prevalence of MCI and dementia in Strong Heart Study population
 - 10% prevalence of dementia in age 72-95
- Moon et al. – prevalence in nationally representative sample of Medicare beneficiaries using data from the National Health and Aging Trends Study (NHAT)
 - 9% - higher than rate in non-Hispanic white (5%), similar to non-Hispanic Black, and lower than Hispanic beneficiaries.
- Mayeda, et.al – incidence in self-identified Native beneficiaries enrolled in Kaiser Permanente Northern California, 2000 - 2013
 - 22.2/1000 person/years – higher than all other populations in the sample except for African-Americans

Matthews KA, et. al. Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015-2060) in adults aged ≥ 65 years. *Alzheimer's & Dementia*, 15(1), 17–24.

Suchy-Dicey AM, et. al. Epidemiology and prevalence of dementia and Alzheimer's disease in American Indians: Data from the Strong Heart Study. *Alzheimer's & Dementia*.

Moon, H.E., Kaholokula, J.K., MacLehose, R.F., & Rote, S.M. (2023). Prevalence of Dementia in American Indians and Alaska Natives compared to white, black, and Hispanic Medicare beneficiaries: Findings from the National Health and Aging Trends Study. *Journal of Racial and Ethnic Health Disparities*, 10(4), 1527–1532.

Mayeda, E. R., Glymour, M. M., Quesenberry, C. P., & Whitmer, R. A. (2016). Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimer's & Dementia*, 12(3), 216–224.

Identify and address modifiable risk factors

Cognitive Impairment

Detection

Slow progression

Avoid anticholinergic and psychoactive medications

Control Blood Pressure
Optimize DM management
Cholinesterase Inhibitors and memantine

Exercise
Care Management

Environmental Modification

Optimize Oral Health and Nutrition

Improve function and quality of life

Supportive therapies, socialization

Support in Activities of Daily Living

Attention to safety

Care Planning

Respite care

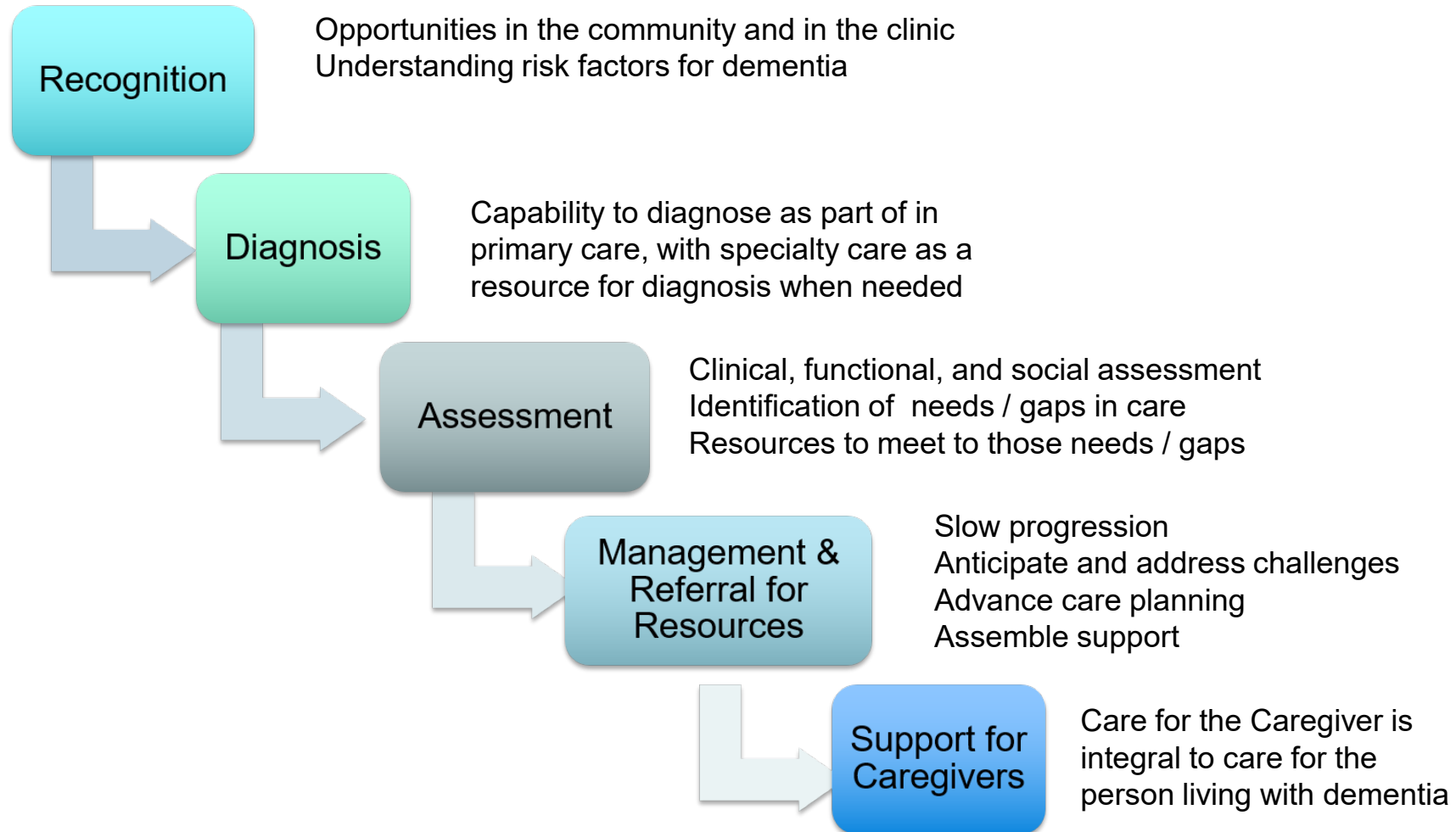
Caregiver support

Stop progression or reverse decline

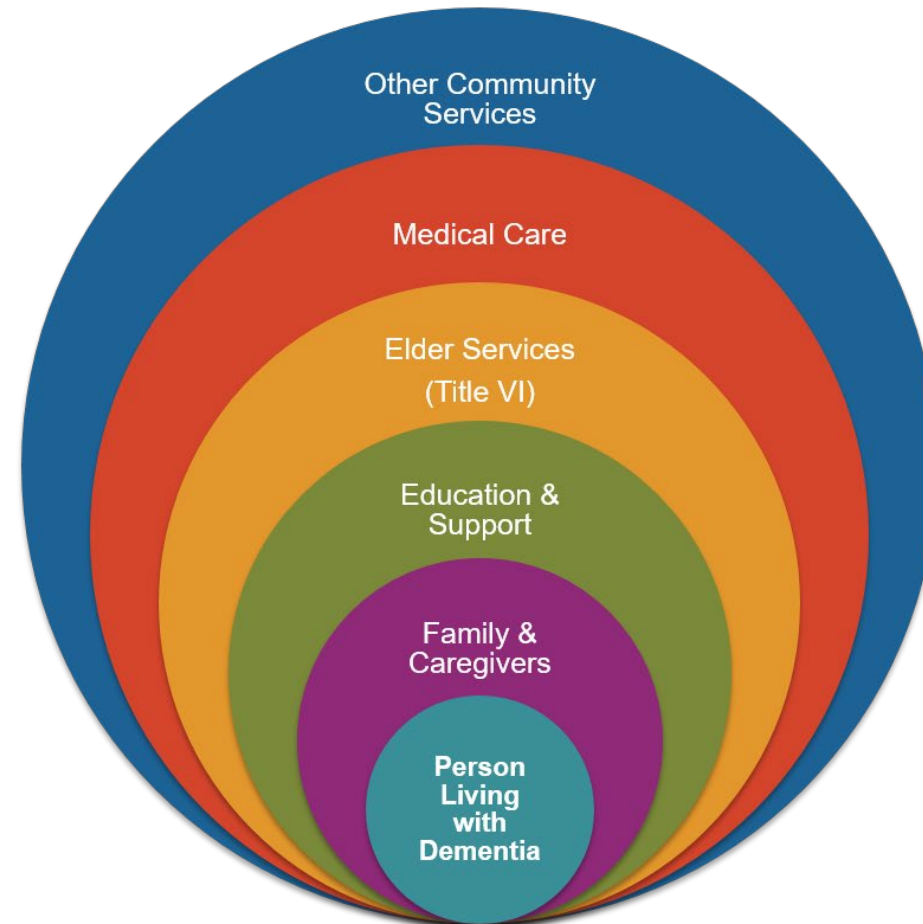
Immunotherapies??
Aducanamab
Lecanamab

In the future:
Targeted, disease-specific therapies dependent on disease-specific biomarkers, imaging and new diagnostic criteria

What does it take to improve the lives of people living with dementia and their families?



A comprehensive approach to addressing dementia takes partnerships and collaboration across boundaries, services, service lines, and organizations.



IHS Alzheimer's Grant Program



Funding:
FY 2021: \$5M
FY 2022: \$5.5M
FY2023: \$5.5M
FY2024 \$5.5M

IHS Alzheimer's Grant Program Timeline of Initiatives

2021

1st Congressional Appropriation
Tribal Consultation & Urban Confer

2022

Program support hired
4 Grants awarded
Indian Health GeriScholars Pilot 1st cohort
MOU with Alzheimer's Association
Dementia & Caregivers ECHOs
Coordination with HRSA GWEPs

2023

8 Grants awarded
Indian Health GeriScholars Pilot 2nd cohort
Dementia & Caregiver ECHOs
Coordination with HRSA GWEPs
Geriatric Emergency Department Accreditation (GEDA) initiative w/ Division of Nursing
Geriatric Nurse Fellowship pilot w/ Division of Nursing
Dental Mini-Cog screening pilot w/ Division of Oral Health
CHR Mini-Cog screening pilot recruitment w/ CHR Consultant
Communications initiative

2024

New NOFO for grants to established programs
Indian Health GeriScholars Pilot 3rd cohort
Dementia & Caregiver ECHOs
GEDA initiative w/ Nursing
Geriatric Nurse Fellowship pilot w/ Nursing 2nd cohort
Dental Mini-Cog Screening pilot expansion w/ Oral Health
CHR Mini-Cog screening pilot implementation
Communications initiative
Elder health promotion/ brain health regional events*
Dementia caregiving initiative*
Clinical Workforce Training initiative*
Dementia Training @ DCCS Conference*
Exploring CHR Risk Reduction*

*New planned activities

Grants and Program Awards

Addressing Dementia in Indian Country: Models of Care

“...to support the development of models of comprehensive and sustainable dementia care and services in Tribal and Urban Indian communities that are responsive to the needs of persons living with dementia and their caregivers.”

2023 – 8 Awards

- Absentee Shawnee Tribal Health System (OK)
- Cherokee Nation Health Systems (OK)
- The Cheyenne and Arapaho Tribes (OK)
- The Confederated Tribes of Grand Ronde Community of Oregon (OR)
- The Fallon Paiute-Shoshone Tribe (NV)
- The Kenaitze Tribe (AK)
- The Norton Sound Health Center (AK)
- The Seattle Indian Health Board (WA)

2022 - 4 Awardees – entering into their 2nd year

- The Indian Health Board of Minneapolis, Inc. (MN)
- **The Indian Health Council, Inc. (CA)**
- The Nez Perce Tribal Health Authority (ID)
- **The Northern Valley Indian Health (CA)**

Northern Valley Indian Health (NVIH) is a private, nonprofit tribal organization founded in 1971 by a group of Northern California American Indians seeking to reestablish health services in California.

A board of Directors from the Mechoopda Indian Tribe (MIT) of Chico Rancheria, the Grindstone Indian Rancheria (GIR) of Wintun-Wailaki Indians of California, the Yocha Dehe Wintun Nation of California, and the Kletsel Dehe Band of Wintun Indians of California govern the organization.

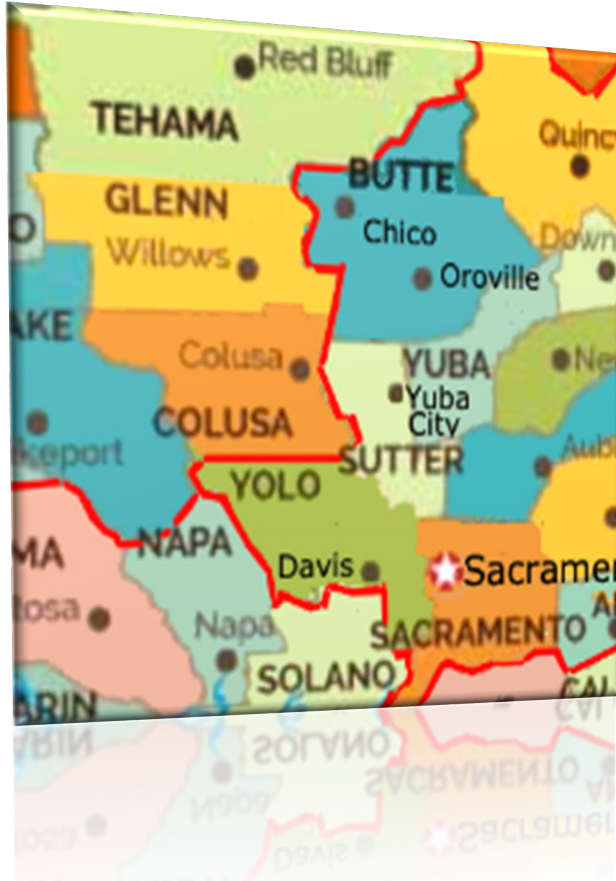
NVIH Mission:

**Excellence in healthcare services to Native Americans
and all community members**

Values:

Compassion
Integrity
Respect
Customer Service
Teamwork





Comprehensive and integrated medical, dental, behavioral health, women’s health, nutrition and community health and outreach services are provided to over 6500 American Indians and Alaska Natives (AI/AN) who reside in the NVIH five county service area. The NVIH service area includes Glenn, Yolo, and portions of Colusa, Butte, and Tehama counties. NVIH clinics are in the cities of Chico, Willows, Red Bluff, and Woodland.



COMMUNITY HEALTH & OUTREACH

Provide services to the Native American population, including members of the Native households

CHICO: 530-899-5156 WILLOWS: 530-934-5431 WOODLAND: 530-207-5483

Terri Martens, MSN, RN
Community Health & Outreach Director

Lisa Huerta
CH Admin Asst.

Debbie Guzman
Health Continuity Specialist

Gina Quinn
Health Continuity Specialist

Tonya Tyler
RN Coordinator

Raquel Gomez
RN Coordinator

Sahar Ameri
RN Coordinator

Franjesca Wilson
LVN

Cynthia Garcia
CHR

Alma Gomez
LVN

Brian Northan
CHR

Angelita Thomas
LVN

Bambi Eagle
MA/CHR

Daniella Duran- Arias
CHR

Alida Allen
CHR

Open Position
CHW/CHR

Open Position
CHW/CHR

Kiara Shuster
CHW

Joscelin Rodriguez
CHW

Amanda King
Program Coordinator

Imalda Starling
Program Coordinator

Amanda Holley
Program Coordinator

Alisa Sinclair
Program Coordinator

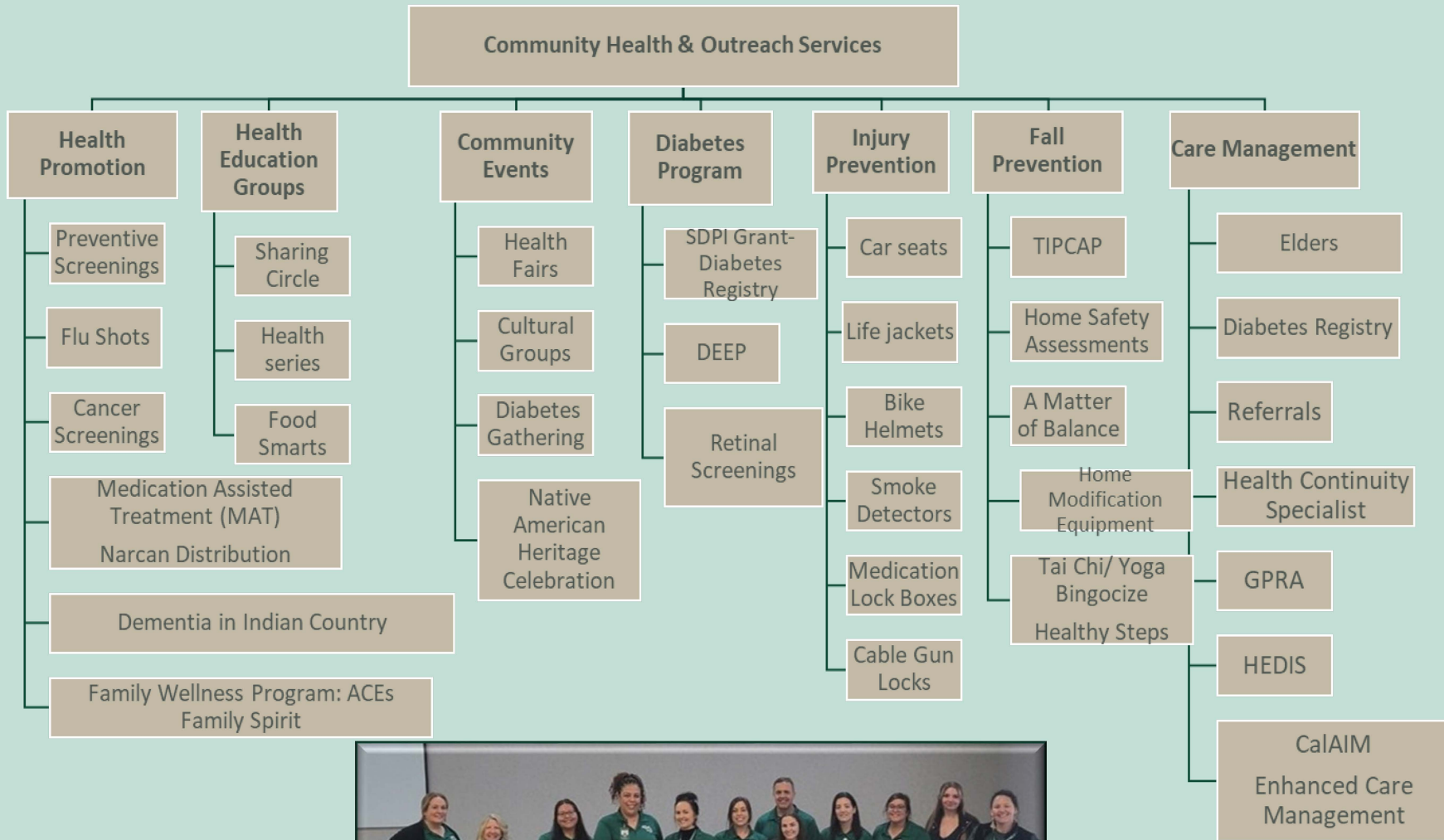
Jennifer Disch
CHR

Joy Jackson
MAT CHW

Provides services to portions of Butte and Tehama Counties within NVIH Service Area designated by IHS

Provides services to all of Glenn and parts of Colusa County within NVIH Service Area designated by IHS

Provides services to Yolo County within NVIH Service Area designated by IHS





Goals

1. Raise Awareness of Dementia

a. Training:

1. CH/OR Team attended Dementia Care Aware

2. Community Education Sessions

a) Alzheimer's Association

b) Agency on Aging: Passages

3. Medical Providers and Support Team

a) Training for Primary Care's role - Dr. Finke

2. Selecting Screening Tool

a. Mini-cog/AD-8

b. CH/OR staff training in administration of screening tools

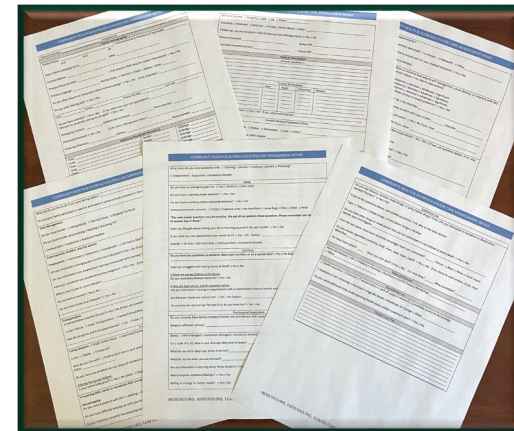
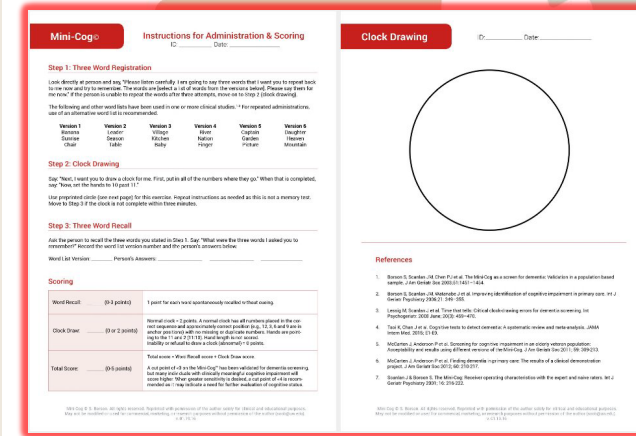
3. Identified Target Populations

a. Age 55+, risk factors that increase incidence of cognitive decline

b. Assigned screening with CH/OR intake

c. Patients referred for a home safety assessment

d. Patients verbalizing a change in their health status



CARE MANAGEMENT

Comprehensive Assessment is key to patient-centered care plan

Visit type: Home/Clinic/Community

Intake includes immediate functional needs questions

- Stay Independent – assess fall risk, Sit and Stand as second assessment
- Home Safety Assessment
 - Home modifying equipment
- Mini-cog
 - Caregiver training
- Adverse Childhood Experiences (ACEs)
 - Stress Busters
- PHQ2
 - Potential referral to Behavioral Health
- Substance Use
 - Potential referral to PCP, Addiction Specialist

SELF MANAGEMENT GOAL WORKSHEET

A SELF-MANAGEMENT PLAN IS AN ACTION YOU CHOOSE TO IMPROVE YOUR HEALTH

You are being treated for: _____

What action would you like to set a goal for? _____

Scale: 1 = Impossible 2 = Not Very Sure 3 = Pretty Sure 4 = Very Sure 5 = Absolutely Sure

What will you do?	When will you do it? How often?	How important is this to you? How confident are you that you can work on this goal?
Self monitoring Blood glucose Blood pressure Take medications	_____ times a day _____ times per week as prescribed	1 2 3 4 5 1 2 3 4 5
Make appointments Primary care Specialist Dentist Vision	With whom? _____ By When? _____	1 2 3 4 5 1 2 3 4 5
Nutrition – Increase Vegetables Fruit Protein Water Other	_____ per day or _____ per week _____ per day or _____ per week	1 2 3 4 5 1 2 3 4 5
Nutrition – Decrease Carbohydrates Fats Sweets Salt Caffeine Soda Alcohol Eating out	_____ per day or _____ per week _____ per day or _____ per week	1 2 3 4 5 1 2 3 4 5
Exercise Walk Run Bike Swim Other	_____ minutes a day _____ days a week	1 2 3 4 5 1 2 3 4 5
Tobacco Use Cessation method:	Cut back to _____ Quit Date _____	1 2 3 4 5 1 2 3 4 5
Stress Management <small>How include: breathing, yoga, meditation, walking, etc. Learning Journal & Journaling</small>	What? _____ _____ per day or _____ per week	1 2 3 4 5 1 2 3 4 5

Things that could make it difficult for you to reach your goal: _____

My plan for overcoming these difficulties: _____

Our plan to follow-up with you is: _____

Name: _____ Date: _____





PATHWAY OF CARE



Indian Health Council, INC.

A 501 (c) (3) non-profit Tribal Health
Care Organization,
With AAAHC accreditation.

- Consists of Nine Tribes, and associated AI/AN populations, in San Diego's north county.
- Served by, and participate in, the *IHC Healthcare Consortium*:
 - La Jolla Band of Luiseño Mission Indians
 - Los Coyotes Band of Cahuilla & Cupeño Indians
 - Pala Band of Mission Indians
 - Pauma Band of Luiseño Indians
 - Mesa Grande Band of Mission Indians
 - Rincon Band of Luiseño Indians
 - San Pasqual Band of Mission Indians
 - Iipay Nation of Santa Ysabel
 - Inaja-Cosmit Band of Indians



Geographically diverse, 2 Health centers covering 1500 SQ MI in Northern San Diego County.

IHC Santa Ysabel Health Center



IHC Rincon Health Center



A whole new world for me!

Just an Old, 20 years in a County ER, kind of Nurse

- **FAMILIAR WITH**

- Meth abuse, and Bi-Polar disease.
- The Schizophrenic who decided that they don't really need their meds anymore.
- Emergence Delirium after Anesthesia.
- The Septic little old lady with a UTI, that's confused.

- **NOT SO MUCH**

- My exposure to, and knowledge of, the DX & TX of patients with Alzheimer's disease, or other forms of Dementia was really very limited, even less so, caring for, and supporting family members.
 - Our answer in the ED was;
 - Call the MSW, send them to BH, F/U with PCP, D/C to family.
-
- **Now suddenly I'm the Case Manager RN.**
 - **We had no existing program at our clinic, already starting year 2, of a two-year grant from IHS.**



My Initial Approach, Try to learn what I can about;

- Alzheimer's disease
- Cerebrovascular disease
- Frontotemporal degeneration
- Lewy body disease
- Mixed pathologies
- Parkinson's disease
- Mild cognitive impairment
- Referrals
- Case Management
- Testing
- National organization's
- Native culture
- Local resources
- Medications

- **It appears to be a constantly evolving, and ongoing journey.**



The next goal was: "Data extraction"

- We currently use NextGen as our EHR
(moving to OCHIN Epic in November)
- We also use I2I TRACKS (Population Health Analytics tool) to generate reports of Patients already diagnosed with AD / MCI / Other Dementias.
- Additionally, we use I2I to tell us **who doesn't** have that DX, but they have an appointment today, and would be a good candidate to screen IE: HX of DM, HTN, CVD, CAD, age >60

*(we write the search logic based on what were looking for, it extracts it from NextGen, **IF** platform exists)*



Attempting to understand the current level of Dementia disease burden, proved very difficult, due to a lack of data entered in the EHR, some of the reasons are:

1. No formal DX of Dementia or MCI, despite a low Mini-Cog or SLUMS screening score in the chart.
2. Perhaps some provider hesitation to label a PT, with a Dementia DX.
3. Misdiagnoses/Under Diagnosed IE: DX as Amnesia, Forgetfulness, or waiting for Neuro to make DX.
4. Failure to date the onset of a DX if one was given, thus making it difficult to understand the year over year, increase in cases.
5. Lack of patient compliance with coming into the clinic for annual PE, or Medicare Wellness exams.



Our current focus

Screenings:

- **SLUMS** testing, often during Medi-Care Wellness exams @ age 65:

112 performed from Jan-Dec2023

43 performed through April 2024

- **MINI-COG** screenings:

89 performed Aug to Dec 2023

34 performed through April 2024

- Tabling @ Outreach events.
- Participation in ECHO sessions.
- Completion of the Geriatric Nurse Fellowship program.

Providing resources for Families:

Educational information & resource recommendations from:

- The Alzheimer's association (print).
- International Association for Indigenous Aging (IA2) (print).

Providing a copy of The 36 Hour Day book, from Johns Hopkins press.

Discussing patients during weekly case management meetings as needed.

CHR visits to the home.

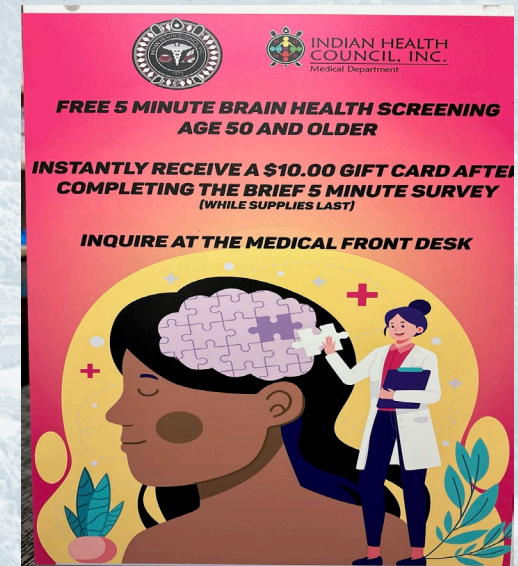
Travel with DM Team, great segway!

MSW involvement for family guidance with Advance Directives, Financial considerations, additional support services in the community.



Obstacles / Workarounds

- Current EHR capabilities.
- Lack of Neurology providers in our area.
- Short staffing in our clinic.
- Patient Compliance.
- Geography of our 9 Reservations.
- Stigma associated with Dementia.
- No designation of healthcare representative in chart.
- Manual tracking of screenings.
- Use of Neurology E-consults.
- PCP management in house.
- PT Incentives for screening.



Where we're headed in the future

If we can't get the Patient to the clinic, we will take the Clinic to the Patient. Our mobile clinic is currently on the production line.

We're partnering with our Dental Providers, to do Mini-Cog's in the Dental Clinic.

We will continue to do Co-Visits with our Diabetes team, a great door opener.

Collaborating with our Health Promotions Department, and our Elder Navigator at community outreach events.

Attendance at Tribal Council and Elder meetings.

Strengthening relationships with;

- IHS
- Alzheimer's association
- Veterans Department
- Alzheimer's San Diego.



Thank You

John Keller RN-CEN
Cognitive Health & Wellness
Nurse
Indian Health Council, Inc.
Valley Center, CA 92082



Opportunities and Resources

Indian Health Geriatric Scholars

- Primary care physicians, NPs, and PAs who want to deepen their skills and expertise in care of the elderly
 - Week-long intensive training – Board Review course in geriatrics
 - Apply learning to improve care locally
 - Mentoring
 - Be part of a community of primary care champions for elder care
- 3rd cohort recruitment this summer

Geriatric Nurse Fellowship in partnership with IHS Division of Nursing

- APRNs, RNs, and LPNs
- Training options for nurses in a variety of roles
- Complete local projects of importance to your elders and your facility
 - Addressing: medication safety, education, and compliance; palliative care and advanced directives, cognitive screenings, falls prevention, STIs, aging well

Opportunities and Resources

Indian Country Dementia ECHOs – provided by the Northwest Portland Area Indian Health Board

- **Clinically Focused ECHO**
 - Didactic and case-based learning to strengthen knowledge and confidence in detection, diagnosis and care for those living with dementia and their families
<https://www.indiancountryecho.org/program/dementia-echo-program/>
- **Caregiver Support ECHO**
 - Didactic and case-based learning and mentoring for those who support family and caregivers
<https://www.indiancountryecho.org/program/dementia-caregiver-support-echo/>
- Monthly with archives for viewing
- 526 participants from 27 states and all 12 IHS regions in since launch in May 2023

Other Opportunities

Dental Clinic Early Dementia Detection Initiative

- Partnership with IHS Division of Oral Health
- 2nd round of 5 IHS and Tribal facilities
 - Support to integrate cognitive assessment and referrals into dental care

Community Health Representatives (CHR) Dementia Detection Initiative

Partnership with IHS CHR program

- 6 Tribal sites from 6 IHS areas selected and funded to train CHRs to integrate detection of cognitive impairment into their usual workflow
 - Training in use of tools to detect (e.g. mini-cog)
 - Follow-up referrals and support services
 - Partner with Oklahoma University Dementia Care Network (GWEP) for dementia training

Geriatric Emergency Department Accreditation (GEDA) Initiative Continues

- Partnerships with IHS Division of Nursing
- Currently 9 IHS and Tribal sites with Bronze accreditation
- New cohort recruited - 4 sites engaged
 - New (Bronze) and advancing (Silver)



Grants and Program Awards

Addressing Dementia in Indian Country: Models of Care

“...to support the development of models of comprehensive and sustainable dementia care and services in Tribal and Urban Indian communities that are responsive to the needs of persons living with dementia and their caregivers.”

2024 – Anticipated Notice of Funding Opportunity (Forecast)

- Targeted toward programs with established efforts to address dementia
- 3 years additional funding support
- Further development of the models of care
- Sustainability



For More Info

The IHS Alzheimer's Grant Program

- www.ihs.gov/alzheimers/

2024 Alzheimer's Grant Program funding opportunities

- <https://www.ihs.gov/alzheimers/fundingopps/2024fundingopp/>

Education and training resources and opportunities

- www.ihs.gov/alzheimers/alztraining/

Dementia information and links

- www.ihs.gov/alzheimers/informationresources/alzdementiaresources/

Stay Connected and join the [IHS Elder Care Listserv](http://www.ihs.gov/alzheimers/)
at www.ihs.gov/alzheimers/



The IHS Alzheimer's Grant Program

**Division of Clinical and Community Services
Office of Clinical and Preventive Services
Indian Health Service**

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