



Understanding the Public Health Crisis of Long-Term Care in Indian Country;

Exploring the Needs and Opportunities for Tribal Communities



Introduction to Long –Term Care In Indian Country

In a National Survey
802,510
Native People with
Disabilities*




There is **NO IHS FUNDING** or
TRIBAL-FOCUSED PROGRAM for
DISABLED ADULTS 18-54
and **DISABLED CHILDREN**



Nearly 10% of those with
disabilities
are **CHILDREN**
Under the Age of 18

*Out of 253 Native Communities Surveyed,
not including AI/AN people who were inpatient/nursing homes



Native Elders population age 65 and older is projected to nearly **double** in the next 30 years

- Higher Demand for Supportive Services to Remain in the Community

89.7% of Elders have at least one chronic disease

- Higher Cost of Care

Aging means increased chronic illness and disease such as dementia and Alzheimer's

- Higher Level of Needs to Support Families

Continuum of Long-Term Care

Long-Term Care is a combination of medical and non-medical supports. Skilled nursing facilities or similar institutions are the end result, especially when there is not support in the community.

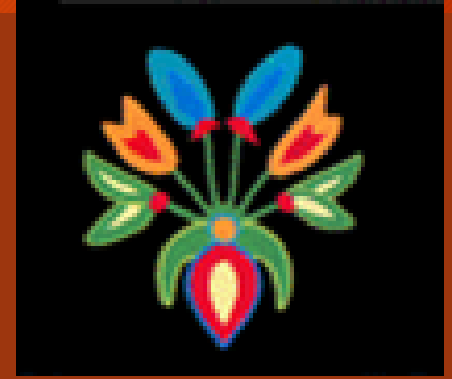
Needs at
Home

Assisted
Living

Nursing
Home

Keeping People in the Community - LTSS/HCBS

- Long Term Services/Supports such as Home and Community-Based Support enable people to live at home or in their community
- Most, if not all Tribes are providing HCBS to their Elders or disabled adults and are paying out of Tribal funds
- These services live in different departments, not just the clinic or medical services



Long Term Services and Supports are any service that helps Elders and people with disabilities stay in their own home or community.



Activities of Daily Living

Basic self-care tasks such as bathing or getting dressed



Instrumental Activities of Daily Living

More complex tasks to take care of regular needs such as shopping or keeping house



Aging In Place

Elders and adults living at home or in their community as independently as possible for as long as possible

Examples of Services & Where to Find LTSS/HCBS in Tribal Communities

Home Delivered Meals

Transportation (medical appointments, bank, shopping, ceremony)

Chore Work (lawn mowing, cutting firewood)

House Keeping

Durable Medical Equipment

Snow Removal

Life Alert (Personal Emergency Service)

Medical Care

Home Health

And much more....

Tribal Housing

Human/Social Services

Elder Services

Community Health & CHRs

Transportation

Health Center/Clinic

Leadership



LTSS/HCBS Funding For Tribes

Title VI - Older Americans Act (Tribal Funds)

- Only federal funding directly to Tribes for LTSS, but only for Elders
- Elders age 60+ counted for funding, though Tribe can serve Elders of any age

Title III - Older Americans Act (State Funds)

- Must coordinate with Title VI, but not many states do
- Tribal providers are eligible for reimbursement

States count ALL people 60+ for funding (this includes Tribes)

There is NO IHS Funding for LTSS/HCBS

Medicare

- Provides for mostly medical care such as inpatient
- Non-medical supportive care not covered
- Can be difficult to be certified as a provider

Medicaid

- Primary payor program for LTSS/HCBS
- Administered under State Waivers
- Tribes may need to meet differing state requirements to be payable providers

Tribally Administered LTSS = Improved Care + Jobs

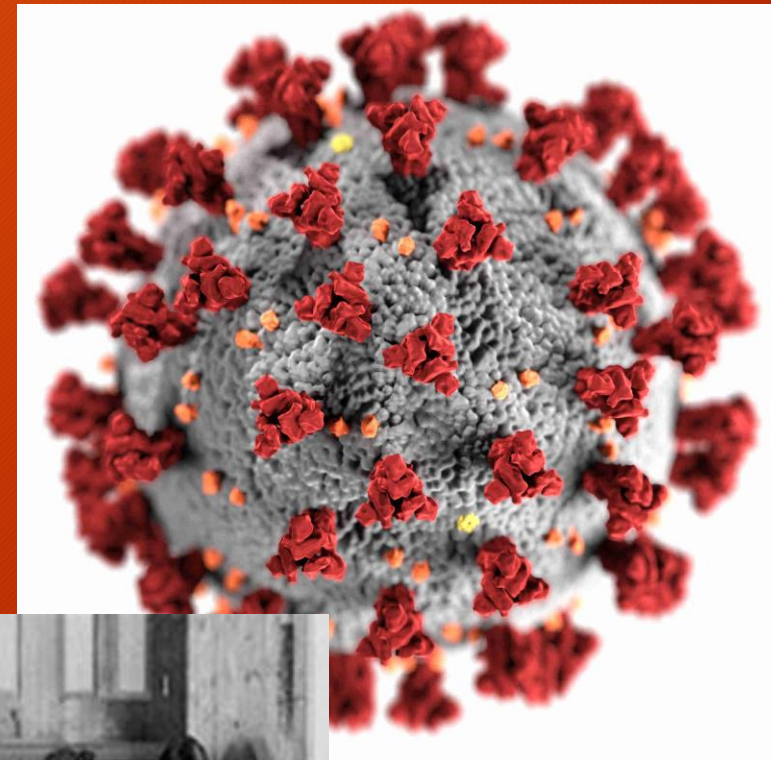
SERVICE	2019 TITLE VI TOTALS	AVERAGE RATES*	POTENTIAL REIMBURSEMENTS
HOME DELIVERED MEALS	2,583,369	\$5.50/meal	\$14,208,529.50
PERSONAL CARE	45,333	\$14.60/Hour	\$661,861.8
HOMEMAKER	109,438	\$14.60/hour	\$1,597,794.8
TRANSPORTATION TRIPS	762,798	\$0.55/Mile, Average round trip 40 miles	\$16,781,556

Using Data to Tell Your Stories



Health Impacts of Trauma - Past and Present

- Trauma changes methylation which changes genes which are passed on through generations
- Native Americans suffer from rates of disability 3% to 4% HIGHER than the national average for all races and ethnicities
- COVID isolation, illness and deaths have greatly impacted Tribal communities, resulting in increased disabling mental and physical health conditions



COVID IMPACTS ON LIFE EXPECTANCY

COVID reduced the average life expectancy of Native Americans back by 4.5 years in 2020 and 6.4 years in 2021.

CDC Reports the current AI/AN life expectancy at 65 years of age as a result.

Our Elders Voices - National Resource Center on Native American Aging (NRCNAA)

The Title VI Survey Results from Elders Across Indian Country*

*Based on a sample of 19,301 Elders aged 55+ within Title VI grantee programs.

There were 282 grantees for FY2022.

87% of Elders reported a 1 or more serious or disabling illnesses

29% are Disabled

42% Need Transportation

41% Need Home Health

36% Need Caregiver Programs

34% Need Home Repairs/Modification

30% Need Physical Therapies

34% of Elder Veterans are Disabled



LTSS Options for Indigenous People and Funding Opportunities to AI/AN Providers

LTSS Programs

Title VI (only Elders)

- Grant funded directly to Tribes, allows individual determination of “Elder”
- More than just meals, main source of Elder LTSS
- Roughly 250 Tribes participate
- May provide home delivered meals to disabled person living with Elder

Title III (only Elders 60+)

- Grant funded directly to States, some States create a Tribal allocation
- Administered by counties or other non-Native agencies
- Participants must be 60+

State Medicaid (All Ages)

- Partnership between Federal and State
- Administered by states
- Provides both medical and non-medical supports

Veterans Affairs (All Ages)

- Available to all enrolled veterans, but services must be available in their area
- Federally administered
- Limited HCBS supportive care
- Provides both medical and non-medical supports

Access Barriers for Elders and People with Disabilities

- Many non-Tribal agency offices are located a significant distance from Reservations and Native communities
- Most State and County agencies are unaware of federal provisions for tribes as providers and tribal members as program participants
- Most, if not all, forms and assessments are administered/maintained by non-Native agency staff in a format that is not culturally relevant, often incorrectly screening Native people's level of need
- Many States have waitlists for HCBS waiver services, furthering the equity gap



Barriers to Tribal Providers in Medicaid HCBS

- No official guidance to States on effectively including Tribal Agencies in HCBS Waivers
- Difficult and time-consuming process for amending HCBS Waivers
- Financial Verification of bank accounts not consider Tribal exemptions

CMS



- Lack of awareness of key Tribal provisions and exemptions (ARRA, IHCA, Estate Recovery, MAGI, etc)
- Tribes excluded from HCBS Waiver definitions as agents for Case Management and Functional Assessments**
- Banking verifications unable to differentiate exempted Tribal asset/funds

State



- Lack of State training on Tribal provisions for Native participants and Tribal provider authorities
- MAGI and Estate Recovery Exemptions Incorrect most of the time
- Failure to recognize Tribal authorities as a provider and government

County



- Capacity and resource constraints
- State information provided on LTSS is often inadequate and fails to meet Consultation guidelines
- Internal staff knowledge of LTSS for Elders and disabled people is often not complete and is lost with turnover

Tribe



LTSS Managed Care (So complex, it gets its own slide!)

Medicaid Managed Care

- July 2021 reports 41 States have some type of Managed Care for Medicaid recipients
- MCO vendor relationships are with States, most contracts lack important information, instruction or requirements related to working with Tribes and Native participants

Case Management

- Case Management is where services are planned, Tribes often treated as “natural support”, i.e. unpaid providers
- Conflict of interest for MCO as the service broker AND program administrator Most capitated plans means MCOs are incentivized to reduce cost, which often result in cutting services to clients

ARRA
PROVISIONS
For TRIBES



Solutions in Indian Country; Indigenous
Communities Serving Indigenous People

Native Aging in Place Project (NAPP)

Who & What

- Collaboration between Spirit Lake Nation (ND), University of North Dakota National Resource Center on Native American Aging (NRCNAA)
- Accelerate and strengthen the local capacity to develop, deliver and evaluate home and community-based long term services and supports (including workforce development & caregiver support) allowing Spirit Lake elders to “age in place”
- Funded under a grant from the Margaret A. Cargill Philanthropies in 2016



TPAR & NECC

TPAR Model

- Six year period of “Community Conversations” to frame the discussion and identify needs for LTSS and NAPP
- Community involvement and engagement as stakeholder through all phases
- Creation of a Tribal Advisory Committee

NECC

- Guidance from Elders utilized to advise and guide the creation of teaching and training tool target at the needs of rural-based Elders
- Curriculum outline developed through collaborative focus group with Spirit Lake Nation Elders

**Don't make
a decision
about me
without me!**

Great Lakes Inter-Tribal Council (WI)- Together Strong Tribal Alzheimer's & Dementia Program

Funding & Partnerships

- ACL Alzheimer's Disease Program Initiative (ADPI) grant for Tribes/Tribal organizations
- GLITC Partner Tribes:
Lac du Flambeau, Lac Courte Oreilles, Mole Lake and St. Croix Bands of Lake Superior
Chippewa, Menominee Nation, and Oneida Nation

Project Objectives

- Introduce and implement Savvy Care Giver in Indian Country Curriculum with Tribal Partners
- Ensure a sustainable model for dementia awareness and capability in Tribal communities through creation of Native focused educational training and program support materials for the Tribal Partner's Dementia Care Specialist (T-DCS)
- Increase Alzheimer's and Dementia related disease awareness in Tribal Communities through a comprehensive mobile presentation to Tribal community members.



Together Strong Dementia Capable Tribal Model

T-DCS & Caregiver Training

- Collaborative development of culturally focused training and support materials
- Tribal DCS “Toolkit” for program/staff development
- Tribal Alzheimer’s & Dementia Carepartner Guide

Dementia Roadshow

- Dementia 101 & bingo for communities, “*In Our Own Voices Words from Our Elders*” & “*Tribal Dementia*” Videos
- Virtual Dementia Tour (VDT) Program
- Family Dynamics in Caregiving Presentation



Spirit Lake Nation (ND) QSP Agency: Realizing Tribal Success in LTSS

Spirit Lake Okiciyapi QSP Agency - Tribally-owned Caregiving Agency provides home and community-based services, including personal care to elders and disabled individuals in their homes

Elders have been able to return home after being in a nursing home because Spirit Lake Okiciyapi services were available.

Tribal members reaching out to request QSP services for themselves or their family members

- Effective **COMMUNICATION & COLLABORATION** increased services for Spirit Lake elders and elders in surrounding communities
- Reliable Community **OUTREACH** service is critical to building trust with service providers & community members
- Helping people to “age in place” is the overarching goal, but the economic implications - jobs, income, security - are essential too
- **Workforce Development** - It’s a marathon, not a race



**START WHERE YOU ARE:
Building for Success & Sustainability**

Common Starting Points: Population and Programs

Title VI



**Determine Your
Readiness for LTSS**



Invest in Staffing

**Ensure Training for
Critical Staff
Positions**



**Investigate State
Qualifications**



LTSS READINESS for TRIBES

Internal Resources and State Requirements

Key Federal Policy Changes for Self-Sustaining LTSS

LTSS Cost Shares & Equity

- Allow Tribal cost-of-care to off-set LTSS Cost Share
- LTSS waiver participation should be free for Tribal people to close the equity gaps and in holding with the legal Indian Cannons of Construction

HCBS Waivers

- CMS include Tribal requirements for state HCBS waiver filing (ex: Checklist of items to include such as Tribe as Case Manager and Assessment administration)
- Requirement for state compliance with Tribal MAGI/Estate Recovery and other Tribal LTSS provisions

Funding to Tribes

- IHS Funding Line Item for LTSS
- Changes to OAA Funding Formula
- Improved Coordination Guidance for Title III with Compliance Penalties
- FMAP - CMS direct guidance to states and policy that includes Tribes of all sizes

Ensure Tribal members understand they can have someone from their community present for screens & enrollment help to alleviate potential fear or mistrust and increase LTSS participation

Respect

Ensure Tribal staff education on Tribal provisions for Medicaid and improve training opportunities related to HCBS/LTSS issues.

Dignity

Educate States on recognizing Tribes as agency service providers, billable to state and federal programs.

Sovereignty

Request States improve LTSS/HCBS process for cultural congruency and show knowledge of Tribal provisions and authorities.

Culture



~ Chi-Miigwech ~

~ Pinagigi ~

~ Dogedinh ~

Thank you!

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