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*

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

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

*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.

- **89.7%** of Elders have at least one chronic disease.

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

- Higher Demand for Supportive Services to Remain in the Community
- Higher Cost of Care
- 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
- Durable Medical Equipment
- Transportation (medical appointments, bank, shopping, ceremony)
- Snow Removal
- Chore Work (lawn mowing, cutting firewood)
- Life Alert (Personal Emergency Service)
- House Keeping
- Medical Care
- And much more….
- Home Health
- Leadership

Tribal Housing
Human/Social Services
Elder Services
Community Health & CHRs
Transportation
Health Center/Clinic
<table>
<thead>
<tr>
<th><strong>Title VI - Older Americans Act (Tribal Funds)</strong></th>
<th><strong>Title III - Older Americans Act (State Funds)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Only federal funding directly to Tribes for LTSS, but only for Elders</td>
<td>• Must coordinate with Title VI, but not many states do</td>
</tr>
<tr>
<td>• Elders age 60+ counted for funding, though Tribe can serve Elders of any age</td>
<td>• Tribal providers are eligible for reimbursement</td>
</tr>
<tr>
<td><strong>Medicare</strong></td>
<td><strong>States count ALL people 60+ for funding (this includes Tribes)</strong></td>
</tr>
<tr>
<td>• Provides for mostly medical care such as inpatient</td>
<td><strong>Medicaid</strong></td>
</tr>
<tr>
<td>• Non-medical supportive care not covered</td>
<td>• Primary payor program for LTSS/HCBS</td>
</tr>
<tr>
<td>• Can be difficult to be certified as a provider</td>
<td>• Administered under State Waivers</td>
</tr>
<tr>
<td><strong>There is NO IHS Funding for LTSS/HCBS</strong></td>
<td>• Tribes may need to meet differing state requirements to be payable providers</td>
</tr>
<tr>
<td>SERVICE</td>
<td>2019 TITLE VI TOTALS</td>
</tr>
<tr>
<td>-----------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>HOME DELIVERED MEALS</td>
<td>2,583,369</td>
</tr>
<tr>
<td>PERSONAL CARE</td>
<td>45,333</td>
</tr>
<tr>
<td>HOMEMAKER</td>
<td>109,438</td>
</tr>
<tr>
<td>TRANSPORTATION TRIPS</td>
<td>762,798</td>
</tr>
</tbody>
</table>

Tribally Administered LTSS = Improved Care + Jobs
Using Data to Tell Your Stories
• 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 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.
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

Our Elders Voices - National Resource Center on Native American Aging (NRCNAA)
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
- 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
- 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
- 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
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 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
LTSS READINESS for TRIBES

Internal Resources and State Requirements

Determine Your Readiness for LTSS

Invest in Staffing

Investigate State Qualifications

Ensure Training for Critical Staff Positions
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.

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

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

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

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Pinagigii
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Thank you!
Sources


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• National Resource Center for Native America Aging, Center for Rural Health. 2023 Data Booklet findings from “Identifying Our Needs: A Survey of Elders” VIII.


• CMS Tribal Nursing Home and Assisted Living 2022 Directory


Building sustainable programs in Native American Communities

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