

Emerging LTSS Issues in Indian Country:

Rebalancing LTSS Funding for HCBS

Department of Health & Human Services, Centers for Medicare & Medicaid Services

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Introduction

Health disparities combined with complex demographic and geographic factors result in serious challenges to providing long-term care for individuals with chronic and disabling conditions in Indian Country. Home- and community-based services (HCBS) provide promising options to improve access to and quality of long-term services and supports (LTSS) in Indian Country. This report explains efforts to rebalance or shift the majority of LTSS Medicaid spending from institutional care to HCBS in Indian Country. The report:

- Provides an overview of rebalancing efforts,
- Explains the demand for HCBS in Indian Country,
- Outlines funding for HCBS in Indian Country,
- Provides recommendations, and
- Profiles two innovative programs focused on HCBS in Indian Country.

Based on the available literature and interview content, Medicaid funding for LTSS and HCBS in Indian Country is incredibly complex. Sources on the topic are difficult to find and existing information is often a challenge to understand. More research is needed on the topic, as very few evaluations have been conducted of existing or former programs and available academic literature is scarce.

This report provides a snapshot of the current information on efforts to rebalance LTSS funding for HCBS in Indian Country, breaks down Medicaid funding information, and provides insight from two current programs. The findings from the research paired with background information from the programs profiled inform a set of recommendations for tribal communities interested in improving and expanding HCBS in their communities.

Background

Overview of Rebalancing Efforts

Similar to the rest of the United States, the preference for LTSS in Indian Country favors HCBS. In fact, Indian Country has an arguably greater need for HCBS due to complex health disparities and geographic and demographic factors. Several state efforts to improve and increase HCBS have been replicated in Indian Country. Two state-level, Medicaid-funded programs implemented and introduced at the tribal level are the Money Follows the Person (MFP) program and the Wisconsin Community Options Program (COP).

The MFP program has been expanded as the MFP – Tribal Initiative (MFP-TI) to focus specifically on American Indian and Alaska Native (AI/AN) populations in five states. The Oneida Tribe specifically implemented the Wisconsin COP as the Oneida COP – Waiver Program (COP-W). These programs serve as examples of creative and collaborative efforts to increase and adapt HCBS in Indian Country. Interviews conducted with representatives from Oneida COP-W and the MFP-TI program in North Dakota offer insights that highlight the complexities of Medicaid HCBS funding in Indian Country.

Over the past several decades, there has been a national effort in the United States to shift the balance of Medicaid LTSS spending from institutional care to HCBS (Reaves & Mousumeci, 2015). LTSS cover a broad set of services—including health care, personal care, and social services for the chronically ill,

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people with disabilities, or elderly individuals who need assistance with basic daily activities over an extended period of time (National Quality Forum (NQF), 2015). HCBS is a subset of LTSS that focuses on care outside an institution (NQF, 2015). More specifically:

[HCBS] refers to an array of services and supports that promote the independence, well-being, self-determination, and community inclusion of an individual of any age who has significant, long-term physical, cognitive, and/or behavioral health needs and that are delivered in the home or other integrated community setting (NQF, 2015, p. 7).

HCBS includes a wide set of services, which include:

- Assisted living facilities (and other residential facilities in the community),
- Home health services,
- Home-delivered meals,
- Home modifications,
- Personal care assistance, and
- Transportation assistance (Centers for Medicare & Medicaid Services (CMS), 2014).

Overall, consumers prefer HCBS to institutional care: According to a 2008 AARP research report, 87% of individuals with a disability over the age of 50 preferred to receive LTSS in their homes (AARP, 2008; Reaves & Mousumeci, 2015). HCBS also cost less to provide than institutional care. AARP (2008) estimates the Medicaid costs of caring for a single person in a nursing facility equates to, “nearly three older people and adults with physical disabilities in [HCBS]” (p. 1).

Given the rural location of many tribal communities, HCBS is a practical and accessible option for LTSS in Indian Country. Due to these preferences and advantages, the federal government encourages states to deliver Medicaid-funded LTSS in the home and community, rather than in institutions. Congress promotes HCBS by providing funding opportunities for a number of different federal and state programs.

Demand for HCBS in Indian Country

AI/AN elders (65 years and older for the purposes of this discussion) are one of the fastest growing minority populations in the United States. By the year 2030, the population of AI/AN elders will be 2.5 times greater than it was in 2012 (Ortman, Velkoff, & Hogan, 2014). More than half of the current AI/AN elder population have a disability.¹ It is important to note, however, that groups other than tribal elders are in need of HCBS. In fact, one out of three AI/AN adults with a disability and in need of LTSS is under the age of 65 (Artiga, Arguello, & Duckett, 2013). The rapid growth of the AI/AN elderly population, in combination with increasing disability rates, highlights the need for tribally provided LTSS in the community.

Unfortunately, many challenges impede the provision of adequate LTSS for the chronically ill, people with disabilities, or elderly individuals who live in Indian Country. The remote and rural locations of

¹ <http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk>

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many tribal communities often result in long travel times to medical facilities with few options for locally available LTSS (Center for Rural Health, 2005). Institutional nursing care is also not typically an appealing option to many AI/ANs, due to a cultural preference for in-home care and a frequent lack of cultural sensitivity found in institutions (Goins, Tincher, & Spencer, 2003). Factors such as these make HCBS a preferred option for LTSS in Indian Country.

In addition, findings from the Institute of Medicine (2008) indicate that AI/AN family members provide 90% of caregiving support to elders or people with disabilities—10% more than the general U.S. population (Baldrige & Aldrich, 2009). Native culture emphasizes respect for elders and an obligation to provide care to family (National Indian Council on Aging, 2013). Consequently, AI/AN communities often have an overall cultural preference to provide care for family members in their own homes and communities, rather than placing them in a formal institution for LTSS care. These cultural values and preferences further demonstrate how HCBS is a logical fit for most Native communities.

In addition to (or perhaps as a result of) cultural values and preferences, elder AI/ANs who remain in their own homes and communities tend to have a higher quality of life versus those in institutions (DeCourtney, Jones, Merriman, Heavener, & Branch, 2003). The physical distance between many tribal communities and available nursing facilities often completely separates individuals in need of LTSS from their homes and families. This distance also separates individuals from other fundamental aspects of daily life, including traditional foods and tribal language. AI/AN elders express concern about the lack of cultural competency in most nursing facilities (Goins et al., 2003). Services offered on reservations, especially by tribal members, are also more likely to be culturally appropriate than services offered off of reservations (Goins et al., 2003). However, only 16 tribally run nursing facilities currently operate in the U.S., indicating a gap between the growing need for culturally competent, tribally located and operated LTSS and the availability of such services (CMS, 2015; Goins et al., 2003).

Funding HCBS in Indian Country

Medicaid

There are a number of different funding sources for HCBS in Indian Country; however, Medicaid is the primary source (CMS, 2013d). In the United States, Medicaid funds over half of all LTSS spending (Reaves & Mousumeci, 2015). In 2013, over half (51.3%) of the total Medicaid LTSS funding was spent on HCBS (Eiken, Sredl, Burwell, & Saucier, 2013). While Medicare funds some of the same services, the funding is short-term, generally following a hospitalization or medical event that requires rehabilitation. Medicaid LTSS funds, in contrast, support people to live with a disabling and chronic condition on a long-term, permanent basis (A Place for Mom, 2015).

Within Medicaid, there are a number of different HCBS funding options. The multitude of options and requirements associated with each can become quite complicated. In general, however, these options include:

- **Medicaid waivers:** State-specific Medicaid programs that allow states to utilize new or existing ways to pay for and deliver health care covered by Medicaid. There are several different types of Medicaid waivers. However, 1915(c) HCBS waivers are the most common for HCBS funding. In

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fact, 1915(c) waivers made up 28% of all Medicaid LTSS spending in 2013 (Eiken, et al. 2015). 1915(c) waivers allow states to waive certain federal Medicaid requirements and “provide HCBS to people who otherwise would have to access LTSS in an institutional setting” (Reaves & Mousumeci, 2015, p. 6).

1915(c) waivers vary widely by state. Through 1915(c) waivers, states can provide HCBS to specific populations, limit the geographic areas and services provided, and provide services not typically covered by a state’s Medicaid plan (Kitchener, Ng, Miller, & Harrington, 2005). Tribes can apply for and administer a 1915(c) waiver, but that practice is uncommon. The Oneida Nation, however, successfully administers a 1915(c) waiver to provide HCBS to tribal members in Wisconsin (CMS, 2013b). (See the Program Profile on the Oneida COP-W program for more information.)

- **Medicaid-funded models:** These care models promote tribal involvement and are tailored to meet the HCBS needs of the communities they serve.
 - **MFP-TI Rebalancing Demonstration Grant:** The MFP-TI is a federal demonstration grant program that provides funding to five states to help tribal communities create sustainable HCBS (Medicaid.gov, 2015a). MFP-TI is part of a larger, state-focused program. The five state MFP-TI grantees are: Minnesota, Oklahoma, North Dakota, Washington, and Wisconsin (CMS, 2013). MFP-TI funding is limited to states that received the original MFP grants. Because it is a demonstration program, MFP-TI funding is limited primarily to start-up activities (CMS, 2013). MFP-TI requires that tribes work with state Medicaid agencies (CMS, 2013). Activities and programming that MFP-TI can fund include:
 - Developing tribal and tribal organization LTSS infrastructure to support MFP implementation,
 - Transitioning AI/ANs from institutions back to their communities, and
 - Strengthening partnerships with state Medicaid agencies (CMS, 2013). (See the Program Profile on a North Dakota MFP-TI program for more information.)
 - **Program of All-Inclusive Care for the Elderly (PACE):** PACE is an integrated program that includes Medicaid and Medicare funding. It covers medical care through Medicare and HCBS through Medicaid. PACE helps individuals over the age of 55 in need of LTSS receive HCBS and stay out of institutions with interdisciplinary medical staff who provide all necessary medical care and supportive services in the home or community (Medicare.gov, 2015). PACE programs provide services including home care, hospital services, dentistry, meals, nursing home care, and physical therapy (Medicare.gov, 2015). In 2008, Cherokee Nation was the first tribal nation to implement a PACE program.
 - **White Earth Long-Term Care Consultation (LTCC):** The White Earth Band of the Ojibwe has a contract with the State of Minnesota to provide HCBS in their community and administer five different waivers (CMS, 2016b). The program receives 80% of its funding through Medicaid, with additional funding from Medicare, the Veterans Administration, and the

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Tribe (CMS, 2016b). Services provided by the LTCC program include skilled nurse visits, home-delivered meals, and transportation assistance (CMS, 2016b).

- **Medicaid Reimbursement for Tribal Communities:** HCBS and other, select services provided to Medicaid-eligible AI/ANs in Indian Health Services (IHS) or tribal facilities are eligible for higher Medicaid reimbursement rates (CMS, 2016c). These higher reimbursement rates are beneficial for both state and tribal communities. They save states money and increase the tribes' capacity to provide HCBS to their communities.
 - **100% Federal Medical Assistance Percentage (FMAP):** The federal government matches state Medicaid rates at various percentages, also known as their FMAP. FMAP varies by state, typically from 50% to 74%, with wealthier states receiving a lower FMAP (Medicaid.gov, 2015b; Artiga & Damico, 2016). However, certain services provided to Medicaid-eligible AI/ANs by IHS or tribal facilities—including HCBS—are eligible for 100% FMAP reimbursement, rather than the state's regular FMAP rate. This means that for a tribal facility with 100% FMAP, there is no charge to the state for Medicaid-covered services (Medicaid.gov, 2015b; Artiga & Damico, 2016).

Other Funding Sources

While Medicaid is the primary source of funding for HCBS, there are a number of other options for tribal communities in search of HCBS support. These other options include:

- **Medicare:** Medicare coverage of HCBS is more limited than Medicaid. Medicare will provide LTSS in the home for up to 100 days (CMS, 2016d). This coverage offers a temporary fix, but is not a long-term option. Medicare also only covers individuals over the age of 65, persons with disabilities, and persons with end-stage renal disease or amyotrophic lateral sclerosis/ALS (CMS, 2016d).
- **Older Americans Act (OAA) Title VI and Title III Funding:** Some federal funding provided through Title VI and Title III of the OAA is available for tribal communities to support elder AI/ANs. Title VI specifically provides grants to tribes to attend the needs of AI/AN elders through services such as caregiver support.² Title III provides grants to states and communities, including those for in-home services, which may also apply to tribes.³
- **IHS:** IHS can cover HCBS for a tribe if LTSS funding is explicitly added to a tribe's IHS funding agreement (CMS, 2016d). However, as a consequent of long-standing agency funding issues, money for LTSS has not yet been allocated to IHS for this purpose (Artiga, Arguello, & Duckett, 2013; CMS, 2016d).
- **Tribal Support:** Some tribes are able to provide funds for HCBS. However, competing health and human service needs of tribal communities can make this challenging.

² http://www.aoa.acl.gov/AoA_Programs/HCLTC/Native_Americans/index.aspx

³ 45 CFR Part 1321 (Title III)

Recommendations for Next Steps

Though population changes and health disparities in Indian Country place significant strain on tribal communities to provide LTSS, the cultural preference for HCBS and available funding sources are promising. Cultural emphasis on in-home care and respect for elders make HCBS and rebalancing efforts particularly salient in Indian Country. While funding for HCBS in Indian Country exists, the majority comes from Medicaid, which is complex and difficult to understand. Despite these challenges, a growing number of successful Medicaid-funded programs in Indian Country demonstrate tribal communities' ability to navigate the complexities of Medicaid, assess the needs of their communities, and deliver HCBS to tribal members.

More research is needed to further examine the HCBS needs of tribal communities and tribal capacity to provide HCBS. Based on information gained from the literature and interviews, the following recommendations may help programs and Native communities improve and increase HCBS in Indian Country:

- Increase tribal management of HCBS, which can result in culturally competent programs tailored to meet the needs of specific communities.
- Build strong relationships with federal, state, and tribal partners.
- Assess whether non-Native partners, including state government staff, possess an adequate understanding of Indian Country and the various laws and regulations that impact AI/AN health care coverage and reimbursement.
- Suggest and provide educational resources for state staff on the specific laws, regulations, and needs of tribal communities.
- Communicate the benefits that a state will receive from tribally managed HCBS. Tribally run care allows for 100% FMAP, which enables a program to serve a greater number of tribal members, brings resources into the state, and saves the state money.
- Educate and assist tribal community members with Medicaid eligibility and enrollment.

Program Profile: Oneida Nation’s Community Option Program Waiver Program

“In Indian Country, our costs and the need for services tend to be higher than in the rest of the state because of health problems and bad health care received over the years.”

– David Larson, Director, Oneida Nation’s COP-W Program

Program Description

The Oneida Nation’s Community Option Program – Waiver Program (COP-W) operates through a contract with the state of Wisconsin, which the tribe signed in 1994. They are currently the only tribe in the state with a COP contract. The contract allows the tribe to administer a Medicaid HCBS 1915(c) waiver program to Medicaid-eligible tribal members. The program offers every HCBS that Wisconsin authorizes under its 1915(c) waiver program, including adult day care, respite care for caregivers, transportation assistance, and home-delivered meals. This enables tribal members in need of LTSS to remain in their homes and communities, rather than be placed in an institution.

Population Served

- **Tribal elders and/or individuals with disabilities:** The HCBS needs of these tribal community members tend to be greater than the rest of the state’s elderly and disabled population. Tribal community members often need a greater number of HCBS and at younger ages (CMS, 2016c).
- **Enrolled Oneida tribal members or residents within Oneida Nation’s reservation boundaries:** The program serves about 25 community members per month.

Funding

Oneida’s COP-W program has been fully funded through Medicaid since 2007. The Oneida are the only tribe to have this type of 1915(c) waiver arrangement with IHS. Federal funding increased the program’s capacity and removed a previously existing cap on the number of individuals the program can serve (CMS, 2016a).

Challenges with State Partnership

“The biggest problem is getting the various [state] staff educated on of the different laws that apply in Indian Country.” – David Larson

Various law exceptions and different Medicaid reimbursement rates apply to tribal communities, which is a challenge for state and tribal COP-W staff. Lack of institutional knowledge and turnover of state staff contribute to the issue. The majority of new state employees are not aware, for example, that IHS and tribally run facilities are eligible for 100% Federal Medical Assistance Percentage (FMAP) and other

enhanced forms of reimbursement. To help with this issue, COP-W staff provide educational materials and facilitate trainings and meetings for state staff to inform them about working with tribal communities and funding intricacies that apply to tribes, such as FMAP.

Challenges with Health Care Reform

Due to changes under the Affordable Care Act (ACA), Wisconsin is moving towards a consolidation of LTSS and other health care into a single provider or grouped providers. Designating medical care to specific providers can help reduce costs and improve efficiency, so the ACA encourages states to move toward integrated financing approaches. However, these changes pose particular challenges for tribes that independently provide HCBS and other care through tribally run facilities and federally qualified health centers. There is a lot of ambiguity about how these changes will impact the future of the COP-W program.

Challenges with Medicaid Enrollment

“Especially with some of the elders, they don’t want to give out their personal information. That is the biggest reason for not wanting to apply for Medicaid.”

– David Larson

To qualify for the COP-W 1915(c) waiver services, individuals must be Medicaid-eligible. COP-W staff, however, noted several challenges to Medicaid enrollment:

- Medicaid enrollment can be very overwhelming, particularly for tribal elders.
 - To alleviate stress and confusion, COP-W case managers and economic support staff work very closely with individuals to guide them through the process.
- Staff find that some tribal members, especially tribal elders, are very wary about applying for Medicaid. Anxiety with giving out personal information and fear of giving up hard-earned savings in order to qualify for Medicaid are common reasons for avoiding enrollment.

Next Steps

“You have to work very, very closely with the state... If the state is not on board with you, there’s absolutely nothing the tribe can do.” – David Larson

COP-W staff recommended the following to tribal communities trying to expand and improve HCBS:

- Build strong relationships with the state, tribal, and federal partners.
- Communicate how the state benefits from tribally managed HCBS, in that tribally run care allows for 100% FMAP, which enables a program to serve greater numbers of tribal members, brings resources into the state, and saves the state money.

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- Educate state staff about the federal regulations and laws applicable to tribes and how they can benefit the state.
- Educate tribal community members about Medicaid eligibility and enrollment.

Program Profile: Money Follows the Person Tribal Initiative, North Dakota

“The goal of our program is to establish culturally specific, long-term services and supports in the tribal communities to help improve the quality of life for tribal elders and tribal members who have a disability.” – Melissa Reardon, MFP-TI Project Manager

Program Description

North Dakota is one of five states to receive Money Follows the Person – Tribal Initiative (MFP-TI) funding. MFP-TI programs ultimately seek to help transition American Indians and Alaska Natives from institutions back to their communities while creating sustainable HCBS in tribal communities. The North Dakota State University Department of Public Health runs the state’s MFP-TI program under contract with the North Dakota Department of Human Services. The program, launched in 2013, is currently in the capacity-building stage, working with tribal nations to assess currently available community LTSS and the number of available, qualified service providers. Assessment activities include conducting a tribal elders’ survey to gather information on the tribal communities of the participants, who self-identify as American Indian and currently reside in long-term care facilities.

Population Served

The American Indian population is the largest minority group in North Dakota at about 6% of the population. However, the number of tribal elders in the state is quite low due to a remarkably young average age of death. The average age of death for American Indians in the state is 56.6, compared to 77.4 for white North Dakotans. Further, the state’s tribal youth and adults between the ages of 18 and 64 have high rates of disability—17.5% among AI/ANs compared to about 8.7% among the general population. Among Native youth alone the disability rate is roughly 4%, compared to 2.7% of the general youth population in North Dakota.

So far, the MFP-TI program has found that more than 130 American Indian elders currently reside in long-term care facilities in the state, and 90 American Indian youth live in institutional settings throughout the state. Program staff estimate that at least half of these individuals could live in their homes and communities with adequate HCBS.

Funding

MFP-TI in North Dakota is a grant-funded program through Medicaid. However, because MFP-TI is a demonstration grant, funding limits the time period and amount of work that can be accomplished.

Challenges with Understanding Tribal Sovereignty

A lack of knowledge about tribal sovereignty and Indian Country is an issue among North Dakota state and county staff. MFP-TI staff facilitate connections and conversations between state and tribal staff to improve education. In addition, MFP-TI staff are creating a tribal-specific Medicaid enrollment guide as a resource for tribal communities and state staff.

Challenges with Medicaid Enrollment

“And what we are finding at the tribal nation level is that folks think, ‘I have IHS so I don’t need Medicaid.’” – Melissa Reardon

MFP-TI staff note challenges with tribal Medicaid enrollment as providers and as tribal members. Tribal programs and entities need to bill for third party reimbursement to sustain HCBS. For individual tribal nations, program staff may encounter a lack of education and an understating of Medicaid benefits. To alleviate these problems, MFP TI:

- Maintains excellent working relationships with the state’s human services executive director and Indian Affairs commissioner to ensure continued progress,
- Identifies and communicates hang ups that increase challenges in the state’s enrollment and billing systems
- Is developing a Medicaid enrollment toolkit specifically for tribal communities, and
- Partners with tribal navigator programs that help tribal members identify appropriate health care coverage.

Next Steps

“I would like to see tribal nations establish comprehensive home health service agencies.” – Donald Warne, MD, MPH, Chair, Department of Public Health, North Dakota State University

For MFP-TI, working closely with state and tribal staff and building strong partnerships are crucial. Although program staff preferred to avoid making generalizations about the needs of tribal communities due to tribal sovereignty, they did offer the following suggestions for tribal communities interested in enhancing HCBS:

- Build strong partnerships with key state leadership.
- Provide education and outreach for state staff on the specific laws, regulations, and needs of tribal communities.
- Work closely with community members to improve Medicaid enrollment.
- Create a tribally managed home health agency if tribal needs and capacity allow for it.
- Establish the ability to bill different entities for different services.

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