ltqa
LONG-TERM QUALITY ALLIANCE

OCTOBER 2023

Literature Review of Home- and Community-Based Services in Diverse Communities: Rural Communities

LITERATURE REVIEW

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Introduction

Long-Term Quality Alliance (LTQA) in partnership with O'Leary Management Associates worked with the Minnesota Department of Human Services (DHS) to explore the feasibility of programs that would assist older adults to stay in their homes as they age and their long-term care needs increase. As part of this work, LTQA conducted literature reviews on home- and community-based services (HCBS) in diverse communities with special consideration given to **trends in diverse communities' utilization of HCBS**, **diverse caregivers**, and **rural communities**. This literature review focuses on HCBS in rural communities.

Rural older adults and their caregivers face unique challenges. Rural older adults are much less likely to utilize HCBS than urban older adults and comparatively more likely to use nursing home care. A great deal of this difference is driven by the lack of services in rural areas; although the home care workforce is going through a major staffing crisis throughout the country, this issue is especially prominent in rural areas where long distances to clients' homes and particularly low rates of pay represent a significant challenge for workers. Rural cultural values related to self-reliance, as well as the perception from service providers that rural people are "hardier," may also contribute to a preference for family caregiving and a reluctance to seek formal services. Rural caregivers also struggle with lack of awareness of the services available to them, as well as the physical and social isolation associated with providing care in rural areas.

Methods

The process for this literature review involved a scan of databases for relevant literature related to LTSS and the population groups of interest, as well as the targeted outreach to and investigation of the websites of relevant advocacy groups. Promising programs were identified from existing lists of innovative HCBS programs as well as via general web searches and from the sites of relevant advocacy organizations. The identified relevant literature was then examined in detail in order to identify key findings, which are summarized in this document. A full list of the literature and programs identified can be found in the **Appendix**.

Rural Communities

A section of diverse communities which may experience disparities in access to and utilization of HCBS is the rural population. Although the country's population as a whole is aging, this trend is particularly visible in rural areas; in 2015, rural Americans older than 65 years accounted for 17.2 percent (nearly 8 million people) of the 46 million people living in rural areas versus 13.6 percent in urban areas (Coburn et al. 2017). Projections from Wisconsin found that the population of older adults in rural areas would surpass the population of working-age women by 2025 with continued growth into the 2030s, while urban areas were not projected to face the same issue before 2035 (Campbell et al. 2018). Rural adults also face significant economic constraints. (Coburn et al. 2017). There has been limited rural focus and participation when it comes to innovative models like value-based payment. Although there are some more recent examples of innovative rural LTSS models, there is not yet much evidence on their performance and more generally what does and doesn't work in a rural setting. Targeted initiatives are needed which expand community-based service options, develop and sustain the LTSS workforce, and support care coordination (Coburn et al. 2017).

Current Status of HCBS in Rural Areas

Utilization

Currently, older adults in rural areas are less likely to use HCBS and more likely to use institutional services compared to adults living in urban areas, with one study showing that rural Medicaid beneficiaries were 12 percent less likely than urban Medicaid beneficiaries to receive any HCBS while using nursing home services at higher rates (Coburn et al. 2017). MAX data from 2008 shows that the proportion of expenditures for personal care, home health, hospice, adult day care, and rehabilitation were all significantly lower for rural Medicaid LTSS users compared to urban ones; however, they were more likely to receive targeted case management than urban LTSS users (Coburn et al. 2016). Rural residents have also been found to enter

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nursing homes with lower levels of disability than their urban counterparts, indicating that functional need is not the driver for greater use of institutional care (Coburn et al. 2017). In addition to being more likely to be White and female, rural populations tend to be older, have lower incomes, and have lower self-reported health status, all of which are factors associated with greater use of nursing home care. However, beneficiary characteristics alone do not explain rural-urban disparities; eligibility policies and differences in the availability of services also contribute (Coburn et al. 2016). Notably, there is a larger supply of nursing home beds per older adult in rural areas than urban areas (Melnick and Shanks 2017).

Workforce

Rural adults often having significant difficulty in finding certified home care workers in their area (Coburn et al. 2017). While the home care workforce faces many of the same challenges in rural areas as in urban areas, such as low pay and physically demanding work, there are some differences. Home care workers are overwhelmingly female in both rural and urban areas but are 75% White in rural areas compared to 41% White in urban areas. Similarly, only 3% of home care workers in rural areas are immigrants compared to 30% in urban areas. Workers in rural areas are also slightly more likely to have a high school education or less, and the median hourly wage 55 cents lower in rural areas ($10.20 vs. $10.75), resulting in lower median annual earnings ($13,800 vs $14,800) (Campbell et al. 2018). A Pennsylvania study found that fifteen counties (26.8%) had no identifiable organizations providing HCBS services, and an additional 12.5 percent had only one identifiable HCBS provider. In addition to the typical problems related to recruiting direct care workers, workers in rural areas also reported problems with long travel distances to clients' homes (Melnick and Shanks 2017). Distance and lack of transportation are also issues for individuals who want to utilize community-based services; one earlier study found that longer travel time to the closest service is correlated with lower service utilization rate of home health services (Li 2006).

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Social and Cultural Attitudes and Barriers

Rural older adults may be at heightened risk as they are more likely to be isolated both physically and socially, while they are also more likely to be poor and have more health care needs than urban seniors. Contrary to some popular beliefs, rural older adults are not more likely than urban older adults to have large families with multiple available caregivers. Rural older adults may be less willing to seek and receive services and rural communities may be less likely to provide services due to cultural factors, attitudes regarding self-reliance, individualism, family orientation and family responsibility for care, may also decrease the willingness of the rural elderly to seek and receive assistance and of the rural community to provide services. In particular, individuals living in rural communities may interpret HCBS as hand-outs or welfare, leading to a negative perception of the services. Some of these attitudinal barriers may be addressed with education. Deterrents to service use on the part of families and consumers also include the desire for privacy in the home as well as the presence of more severely impaired individuals in programs like adult day services (Melnick and Shanks 2017).

Barriers to HCBS in Rural Areas

Awareness

Several common themes in terms of barriers to the utilization of HCBS in rural areas emerged in the literature. One study using data from the 1999 National Long Term Care Survey found that caregivers most frequently reported access barriers to respite care, transportation, and homemaker services. Meanwhile, barriers to assistive devices were by far the lowest. The main access barriers were lack of availability, awareness, and affordability of HCBS. Lack of awareness was the most significant barrier for respite care, lack of availability for transportation, and affordability for home modification. The older adults' race, educational attainment, and Medicaid enrollment were significant predictors of access barriers to homemaker services. The older adult's educational attainment and annual household income were also significant predictors of access barriers to home modification services. As seen in the aforementioned studies of

> *One study found that caregivers most frequently reported access barriers to respite care, transportation, and homemaker services. Meanwhile, barriers to assistive devices were by far the lowest.*

caregivers, higher education level was associated with greater awareness of barriers. A potential solution to the significant barrier posed by lack of awareness may be outreach programs providing information about entitlement programs and the services that are available to older adults, especially due to the fact that even among individuals who were aware of services, a significant portion mistakenly believed they were not eligible for them or did not know how to access them (Li 2006). There is also reluctance among some state administrators to promote HCBS waivers in rural areas when they knew that some services may not in fact be available to individuals where they lived (Siconolfi et al. 2019).

Availability

There is a serious deficit in the availability of HCBS providers in rural areas, such that many rural older adults receive approval for HCBS but cannot find someone to provide services. Interestingly, interviewed patient advocates and service agency staff are more likely to note issues with business viability and worker shortages in rural areas than interviewed state Medicaid administrators. One driver of workforce issues is transportation, as the costs of travel to clients' homes may outweigh the pay given to direct care workers. Additionally, LTSS rebalancing efforts that limit the institutional LTSS safety net may have unintended consequences in rural contexts if they do not account for supply-side barriers to HCBS; recent studies have found that in rural areas, nursing home closures were occurring despite the limited availability of HCBS services to replace them. The spatial isolation of beneficiaries may contribute to a perceived lack of demand and reduce chances of funding for new services (Siconolfi et al. 2019).

Infrastructure

The communication infrastructure in rural areas is often not adequate for communicating and coordinating the availability of HCBS, making it difficult for rural older adults to be aware of or access services. Shifts towards web-based outreach ignore the fact that many rural individuals have limited or no Internet access (Siconolfi et al. 2019). An increased emphasis on the role of electronic health records in care coordination may also present a challenge for rural service delivery, as rural providers may struggle with the cost of implementation and maintenance (NACRHHS 2019).

Culture

Regarding the acceptability of services, some informants had the perception that rural people were "hardier" and had a strong cultural preference for informal caregiving. However, this observed preference may merely be an adaptation in response to gaps in HCBS, not an inherent trait of rural culture (Siconolfi et al. 2019).

Recommendation from the National Advisory Committee on Rural Health and Human Services

A report by the National Advisory Committee on Rural Health and Human Services to the Secretary of Health and Human Services noted several key themes in barriers to HCBS in rural areas and put forward four main recommendations to the Secretary of Health and Human Services:

1. Create a comprehensive resource on the aging and long-term services and supports available to older adults in rural areas.
2. Continue to expand flexibility in Medicare telehealth billing and provide a comprehensive resource of telehealth offerings in rural areas.
3. Ensure the promotion and encouragement of age-friendly concepts within rural health grant programs.
4. Explore the entry of Medicare Advantage Dual-Eligible Special Needs Plans into rural areas, identify potential barriers, and work with states to adopt policies that encourage or expand the reach of these plans to rural beneficiaries.

Additional recommendations included maintaining non-emergency medical transportation as a mandatory Medicaid benefit, including social isolation within the Healthy People 2030 framework, valuing the need for peer navigators in the care delivery process, and promoting and expanding unpaid caregiver support programs (NACRHHS 2019).

Rural Caregivers

Rural caregivers also face unique challenges. Rural residents anticipate needing more help from caregivers with ADLs as they age compared to urban residents, and rural

caregivers who are employed have fewer workplace supports available to them. Interviews conducted with key informants from several sectors have identified several common issues for rural caregivers, most of which are related to access to resources, transportation, culture, demography, and isolation. There are few formal caregiver support programs in rural areas, as well as more restricted access to healthcare in general. Workforce shortages, which are prevalent for HCBS in all regions but are particularly acute in rural areas, have led to less access to home care and respite services. Even for those who do receive help from a direct service worker, this still means there is rarely a backup option when that worker cannot come to work, putting more pressure on informal caregivers. Rural caregivers also have to deal with traveling long distances, the expenses associated with driving such as gas and car maintenance, and limited public transportation. Informants also reported that rural culture strongly emphasizes self-reliance, leading to a potential reluctance for caregivers to seek help, although community members are also likely to care for one another. Caregivers also face the pressure caused by demographic changes, as the aging rural population is seeing increasing rates of disability and need for care. Many rural caregivers experience low incomes, leading many young adults to leave rural areas due to economic pressure. Finally, rural caregivers may lose social ties easily due to the physical isolation of rural areas and the social isolation of caregiving duties, leading to a greater risk for depression and anxiety (Henning-Smith and Lahr 2018).

Rural culture strongly emphasizes self-reliance, leading to a potential reluctance for caregivers to seek help, although community members are also likely to care for one another.

Recent changes to rural caregiving involve technology, demographic shifts, financial pressure, and changes in awareness and information. Computers, smartphones, and other communication technology may help reduce social isolation, but not everyone in rural areas has access. The aforementioned demographic issues are worsening, and rural areas have had a slower recovery from 2008 recession and have an eroding tax base. However, key informants did feel that public awareness of rural caregivers and their needs is growing. Potential strategies to support rural caregivers include increasing

Computers, smartphones, and other communication technology may help reduce social isolation, but not everyone in rural areas has access.

funding, developing a national strategy, and expanding access to resources. There is potential for creativity in caregiver support funding, such as by using Department of Agriculture funding. Expanding Medicaid would also help. Informants felt that individual communities are doing good work, but there needs to be a more concerted effort from federal and state policymakers (Henning-Smith and Lahr 2018).

There has been some success in supporting rural caregivers by incorporating religious faith into interventions. In general, rural individuals may be mistrustful of providers and interventions which are coming from outside of their community and may be especially reluctant to use services which are not perceived to align with their family or religious values. In focus groups, rural caregivers of older adults with dementia have expressed a strong preference for working with providers who share their religious values and are from the same rural area. One study found that providers known as faith community nurses who delivered cognitive-behavioral and spiritual counselling to rural dementia caregivers were successful in improving caregiving problems and reducing depression (Glueckauf et al. 2009).

Promising Programs

Table 1 below contains a list of promising programs for rural communities which were identified over the course of the literature review (see also “Promising Programs” tab in the Appendix). Two of these programs are described in detail following the table.

Table 1: Promising Rural Programs

Program	Description	Link
CAPABLE (Community Aging in Place, Advancing Better Living for Elders)	CAPABLE is a five-month program developed at the Johns Hopkins School of Nursing for low-income seniors to safely age in place. The approach teams a nurse, an occupational therapist and a handy worker to address both the home environment and individual capacity. CAPABLE has been tested and found to be successful in rural environments.	Link
Great Plains Senior Services Collaborative	To support older adults living in rural areas of Minnesota, Montana, and North Dakota, Lutheran Services in America created the Great Plains Senior Services Collaborative. The Collaborative is geared toward older adults living alone, who often have	Link

	multiple comorbidities and high levels of social isolation and depression.	
Hawaii Community Living Program	The Hawaii Community Living Program provides seniors with long-term care and supports in their home in order to delay or prevent nursing home placement. Participants or individuals they designate direct their own personal care services and supports, using a monthly budget and a coach who assists in developing a care plan.	Link
Project C.A.R.E.	Project C.A.R.E. is a coordinated delivery system in North Carolina that responds to the needs, values and preferences of individuals who directly care for a family member or friend with Alzheimer's disease or related dementia (ADRD). Many individuals served by Project C.A.R.E. reside in rural areas of the state.	Link
SOURCE (Service Options Using Resources in a Community Environment)	SOURCE is designed for frail elderly and disabled Georgians who require a nursing home level of care, allowing them receive care in their homes or communities. For qualifying low-income participants, SOURCE provides both medical care and non-medical personal care services. The program has had success in serving Georgia's rural populations.	Link
Transportation for Health	The West Virginia Rural Health Access Program created the demonstration project Transportation for Health to build on existing transportation systems and expand nonemergency medical transportation access for rural seniors.	Link
Tri-County Rural Health Network Community	Tri-County Rural Health Network's (TRHN) mission is to improve access to health care. Its primary initiative is the Community Connector Program (CCP), which deploys trusted community members called "community connectors" to link those needing long-term care to home and community-based services by addressing socio-cultural barriers and system navigation.	Link
Wyoming Home Services Program	The Wyoming Home Services (WyHS) program is used to provide services to qualified individuals who are at risk of institutionalization. A client must be 18 years of age or older, and, through an ongoing evaluation, at risk of premature institutionalization. The program uses a sliding fee scale and a mutual agreement between the client receiving services and the service provider, and no person is denied services based upon their inability to pay.	Link

Project CARE: Rural Caregiver Support

Key Elements of Project Care:
- *Self-direction*
- *Local flexibility*
- *Targeting of individuals ineligible for other assistance*

There are a few programs at the local, state, and federal level which have shown promising results in terms of meeting the HCBS needs of rural older adults and their caregivers. One of these is Project C.A.R.E. (Caregiver Alternatives to Running on Empty), which has provided dementia-specific services to rural and minority caregivers in North Carolina since 2001. Project C.A.R.E. uses a consumer-directed family consultant model to provide respite care at multiple sites throughout the state, with each site having flexibility to administer the program differently based on the unique needs of the population it serves. Enrolled families are given a stipend of $2,000 per year to use on direct respite care services, including adult day services, in-home care, and overnight respite. The use of these services often helps to connect families to more comprehensive programs and services. In order to qualify for the program, care recipients must have dementia and may not already be served by North Carolina's Medicaid HCBS waiver for low-income disabled adults. The program is meant to serve people on fixed incomes as quickly and effectively as possible, and therefore seeks to minimize requirements for enrollment. Rural adults may find the stipend particularly useful as it can allow them to hire private home care in areas where adult day centers are not available, or they can use it on transportation to services. Project C.A.R.E. administrators have noted that rural families may require basic information about the types of services available to them and their eligibility for those services, as many participants are not aware of the options available to them. The program has also adapted to avoid using more technical terms such as "respite" in favor of wording that individuals and their families can more easily understand. Despite the differences in implementation, key themes that have led to success across Project C.A.R.E. sites include building relationships with local partners, making use of existing infrastructure, and pivoting to address emerging communities who were not originally part of the target population (Kelly and Williams 2007).

Hawaii Community Living Program: Rural Self-Direction

Key Elements of the Hawaii Community Living Program:
- *Self-direction*
- *Coaching support*
- *Adoption of local communication styles*

Another program which has had success in providing HCBS to rural populations is the Hawaii Community Living Program. A pilot of the program which ran from December 2011 to February 2013 in Maui, Kauai, and Hawaii targeted older adults who were at risk of institutionalization because of physical or mental impairment or a recent stay in a facility and have limited income and assets. Pilot participants were not eligible for Medicaid and had incomes between 101% and 300% of poverty level. The goal of the program was to help participants avoid institutionalization and spend down to Medicaid. Participants were given a fixed budget each month and were able use it to hire individual employees or contract with agencies to provide services as well as to purchase goods and supplies. Individuals with cognitive impairments had an authorized representative appointed who directed services. Participants were provided with coaching to assist in developing their support and spending plans and hiring and managing employees. Coaches needed to develop trust with members of tight-knit rural communities and take a friendly, informal conversational approach during meetings known as “talk story,” which is an element of Hawaiian culture. Participants were not interested in having someone enter their home and immediately begin to discuss business. In general, formal program structure and protocols were initially uncomfortable for participants, who were used to relying on informal support networks; they tended to prefer hiring employees that they already knew and trusted. Access to technology and electricity were essential for the submission of paperwork for the program but were often limited in certain areas of the islands. Shipment of supplies was also a challenge for some, as some companies did not ship to neighbor islands, leading participants and coaches to negotiate to make special arrangements with companies. Ultimately, 92% of participants were able to avoid institutionalization. After the successful pilot, the program has continued to operate in the same islands. Both Project C.A.R.E. and the Hawaii Community Living Program indicate that self-direction may be a promising means of dealing with challenges of HCBS in rural areas (Nishita and Trockman 2015).

Long-Term Quality Alliance

Long-Term Quality Alliance (LTQA) is a 501(c)3 membership organization aimed at improving outcomes and quality of life for people who need long-term services and supports (LTSS), and their families. LTQA advances person- and family-centered, integrated LTSS through research, education, and advocacy. For more information, visit **ltqa.org.**

Acknowledgements

This report was prepared for the State of Minnesota Department of Human Services (DHS) and is shared with the permission of the State of Minnesota.

Thank you to Juliet Mayer for leading the development of this literature review.

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