Rural Long-Term Services and Supports: A Primer

Lead Authors

Andrew F. Coburn, PhD Jennifer P. Lundblad, PhD, MBA

Prepared by the RUPRI Health Panel

Charlie Alfero, MA
A. Clinton MacKinney, MD, MS
Timothy D. McBride, PhD
Keith Mueller, PhD
Paula Weigel, PhD

Contributing Author

Erin M. Mobley, MPH

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EXECUTIVE SUMMARY

This paper provides policymakers and other interested stakeholders a primer on rural long-term services and supports (LTSS): (1) the fundamentals of the rural LTSS system, (2) rural access to and use of LTSS, and (3) discussion of the opportunities within and limitations of current Federal and State LTSS policy for advancing rural health system transformation toward a high-performing rural health delivery system. The paper focuses principally on the population of older (i.e., aged 65+ years) LTSS users.

Defining LTSS

LTSS services provide older individuals and those with disabilities assistance with activities of daily living to enable them to live as independently as possible.² LTSS services include both medical and social support services (e.g., skilled nursing, personal care assistance, homemaker services) provided in nursing facilities, residential care facilities, individuals' homes, and other community settings.

Rural Significance

In an ideal health system, primary care, acute care, post-acute care, and LTSS form a continuum of coordinated services designed to meet individuals' needs based on their level of clinical, social, behavioral, or other chronic care needs and preferences. In reality, these services tend to be fragmented, with only weak coordinating connections. This fragmentation is the result of multiple funding sources, each with their own legislatively and policy-defined boundaries regarding eligibility, scope of services, and payment rules. The issues that arise as a result of fragmentation are exacerbated in rural areas, where the availability of, and access to, LTSS services is more limited.

Federal and State policies, consumer preferences, and other factors have sought to shift the balance of LTSS services toward a greater emphasis on home- and community-based services (HCBS), with the goal of enabling people to live independently in their own home or in the community as long as possible. Yet much of the evidence indicates that compared with those living in urban areas, rural older adults tend to rely more heavily on institutional services, such as nursing home care.^{3,4} Rural older Americans face multiple challenges accessing and affording LTSS. With lower incomes, many rural elderly have difficulty affording LTSS. Once private funds are exhausted, most rural consumers rely on Medicaid funding to pay for their necessary care. Although Medicare covers post-acute care (i.e., skilled nursing and home health services), the program benefits do not include HCBS and other services that seniors may need to remain independent, living in their own home or the community. In addition to problems paying for services, rural elderly and the agencies that serve them are often challenged finding certified caregivers.^{5,6}

Innovative Policy and LTSS Models

With future moves toward value-based payment arrangements, health care organizations are partnering with LTSS and social service providers to identify and implement models and strategies to increase access to services appropriate to their patients' and residents' needs and ensure that care is integrated and coordinated across sectors and services. However, the level of rural focus

and participation in innovative delivery models has been limited. There is limited evidence of what works and why in rural communities, given unique challenges such as more limited access to services and support, their geographic constraints, and their absence of an adequate workforce and infrastructure.⁷ In order to provide coordinated, comprehensive care to rural adults in need of LTSS, service integration across delivery systems, along with creative and flexible providers working together differently than occurs in urban and suburban areas, may be necessary to improve care management, quality of care, and quality of life.⁷

Key Rural Considerations

The growing population of older adults in rural areas, combined with the more limited capacity of rural LTSS systems, suggests the need for targeted initiatives such as the following:

<u>Expanding Community-Based Service Options</u>: Communities across the country are developing innovative, volunteer programs to enable older community members to age in place. Helping rural communities learn about and adopt these strategies would represent an important step toward building HCBS capacity in rural communities.

<u>Workforce</u>: The absence of an adequate and sustainable workforce and service infrastructure in many rural areas will make it increasingly difficult to address the growing need and demand for LTSS services. Federal, State, and local initiatives are critical to support developing and sustaining the needed LTSS workforce.

<u>Care Coordination</u>: Rural communities, with the support and encouragement of State policies, are demonstrating the importance of integrated care models to deliver LTSS to their older residents. Support for these efforts includes grants and Medicaid payment programs for demonstration projects or other initiatives.

PURPOSE

This paper adds to the RUPRI Health Panel's continuing series on the high-performing rural health system. The core elements of a high-performing rural system are affordability, accessibility, community health, high-quality care, and patient-centeredness. 1,8-11 Long-term services and supports (LTSS) provide vital medical and social support for those older than 65 years and those with disabilities, who are a large and growing segment of the rural population. As such, LTSS are a critical component of the high-performing rural health system. Providing access to an appropriate continuum of LTSS services that rural residents need and want is challenging for myriad reasons.

The RUPRI Health Panel envisions a high-performing rural health care system built on foundations of affordability, accessibility, community focus, high quality, and patient centeredness.¹ The Panel specifically notes as follows:

"Care integration and coordination in rural communities also ensures that patients have access to the full continuum of care, such as skilled nursing, home health, hospice, palliative, dental health, and behavioral health. Rural health care services are available as proximate to the patient as possible to reduce travel costs, time, and burden. When needed services are not available locally, strong consultation and referral relationships and systems exist such that the right information is available to the right care team at the right time."

This paper provides policymakers and other interested stakeholders a primer on the complexities of ensuring access to an affordable, high-quality LTSS system in rural communities. The paper addresses (1) the fundamentals of the rural LTSS system, including population(s), services, and funding sources; (2) rural access to and use of LTSS; and (3) models for rural LTSS, including their implications for advancing rural health system transformation toward a high-performing rural health delivery system. The paper focuses principally on the LTSS system serving the population of older users (i.e., aged 65+ years).

BACKGROUND

Figure 1. Illustrating Long-Term Services and Supports



Adapted from Centers for Medicare & Medicaid Services' Home- and Community-Based Services and Facility-Based Care webpages. 12,13

Demographic data indicate that the population of older adults in need of LTSS is proportionately larger in rural versus urban areas; five-year population estimates (2011-15) indicate that 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. ¹⁴ Those older than 85 years represent the fastest growing segment of the U.S. population, and much of that population growth is expected to occur in rural areas.²

As Americans age, their reliance on others for support increases due to changes in their mobility or other physical limitations, chronic disease, or disability. Almost 70 percent of those older than 65 years will need some form of care or support before they die. A significantly higher proportion of the rural population utilizes LTSS. LTSS provide older individuals and those with disabilities assistance with activities of daily living to enable them to live as independently as possible. As indicated in Figure 1, LTSS include both medical and social support services (e.g., skilled nursing, personal care assistance, homemaker services) provided in nursing facilities, residential care

facilities, individuals' homes, and other community settings. 12,13 Among older adults, the need for LTSS ranges from short-term care during recovery from an injury, surgery, or illness to long-term personal and social support to remain independent and living at home. 2

In 2010 the American Association of Retired Persons conducted a survey of Americans aged 45 years and older that indicated strong preferences for being able to receive supportive services at home or in the community as they age. When respondents were asked to provide more information regarding their reason for preferring to stay in their home or community, two-thirds said that they wanted to be close to family and/or friends and be near places they wanted to go (e.g., grocery store, doctor's office, etc.). Notwithstanding seniors' preferences to stay in their home or community, nursing home care is often the only LTSS option available in rural communities. According to the Census Bureau, in 2010 more than 1.5 million Americans lived in nursing facilities. According to the Census Bureau, in 2010 more than 1.5 million Americans lived in nursing facilities.

Historically, Federal and State Medicare and Medicaid policies favored institutional LTSS services such as those provided in skilled and intermediate care nursing facilities. ¹⁹ Since 1981, however, Federal and State policies, consumer preferences, and other factors have sought to shift the balance of services toward a greater emphasis on HCBS, with the goal of enabling people to live independently in their own home or in the community as long as possible. ¹⁹ These policy trends have been driven in part by court decisions, including *Olmstead v. LC*, that have codified the rights of people with disabilities, including older adults, to have access to services that allow them to live in settings that maximize independent living. ^{20,21} Figure 2 illustrates the dramatic shift in Medicaid LTSS expenditures for HCBS, which, for the first time in 2014, were greater (53 percent) than those for institutional services (47 percent). ²²

<u>Figure 2</u>. Medicaid HCBS Expenditures as a Percentage of Total Medicaid LTSS Expenditures, FY 1995–2014

Adapted from Eiken S. et al., "Medicaid Expenditures for Long-Term Services and Supports in FY 2014."22

PATTERNS OF RURAL LTSS USE

Notwithstanding the dramatic shift in Medicaid expenditures toward HCBS, little is known about how rural older adults use LTSS services and about the balance of use between institutional and HCBS. Numerous early studies showed higher use of institutional services (e.g., skilled nursing facilities) among rural older adults than among urban older adults.^{3,4,17,19} This research raised the question of whether rural-urban differences in LTSS use were the result of consumer preferences, the availability and capacity to deliver HCBS in rural areas, State policies, or some combination of these and other factors.^{17,19} Several more recent studies have indicated continuing differences in how rural versus urban older adults use LTSS.^{3,4,17,19} One recent study showed that rural Medicaid beneficiaries were significantly more likely than their urban counterparts to use nursing home services (45 percent versus 35 percent) and were 12 percent less likely to receive any HCBS.¹⁵ Bolin et al. have also shown that rural residents enter nursing homes with lower levels of disability than their urban counterparts, again raising the question of whether lack of access to HCBS may be a contributing factor to their nursing home admission.^{15,23} Variations in the use of LTSS are most likely accounted for by variations in State Medicaid policy, the distribution and supply of skilled nursing facility and HCBS within states, and other unobserved factors.¹⁵

Non-medical residential care, often referred to as "assisted living," has become critical in providing non-institutional alternatives to people who are not able to live independently but do not require 24-hour skilled nursing care. A recent study using a national survey of residential care facilities

(RCF) showed some significant differences between rural and urban settings in the characteristics and capacities of facilities, the populations they serve, and the services they offer. ¹⁹ In general, older adults served in rural RCFs were more likely to be privately covered and tended to be less disabled than those in urban RCFs. ¹⁹ A greater proportion of rural RCF residents who move go on to nursing homes compared to urban RCF residents. ¹⁹ Rural RCFs play more diverse roles and offer more diverse services than their urban counterparts, reflecting perhaps rural RCFs' need to address the broader needs of their smaller population base. ¹⁹ As in the case of LTSS services generally, rural-urban differences in RCFs are likely driven by state policy variations governing staffing, physical design requirements, and consumer choice, privacy, and autonomy. ¹⁹

Fragmented, uncoordinated care across primary care, acute care, and LTSS systems contributes significantly to poor outcomes, such as avoidable emergency department use, hospitalizations, and unnecessary institutionalization.² To address these problems, State Medicaid programs have implemented a variety of care coordination or care integration models to help both the individual and their family member(s) through the complex health care delivery system, while ensuring that the appropriate providers and services are utilized to meet the individual's needs, severity of medical conditions, and preferences.² Some of these models are discussed later in this paper.

AFFORDABILITY AND BURDEN OF LTSS

Rural elderly Americans face multiple challenges accessing and affording LTSS. As indicated in Figure 3, the next largest payment sources for LTSS after Medicare and Medicaid are out-of-pocket or private funds, meaning that individuals and their families pay for services themselves. Due to rural residents having lower incomes than urban residents, many rural elderly in particular experience difficulties affording LTSS.² Once private funds are exhausted, most rural elderly rely on Medicaid funding to pay for their care.² Although Medicare covers post-acute care (i.e., skilled nursing and home health services), the program benefits do not include HCBS and other services that seniors may need to remain independent, living in their own home or the community.² The Medicaid program is the largest source of public funding for LTSS, covering both institutional and HCBS.² In addition, states fund a variety of home care and other LTSS services.² Private long-term care insurance is a very limited source of funding, despite some growth.²

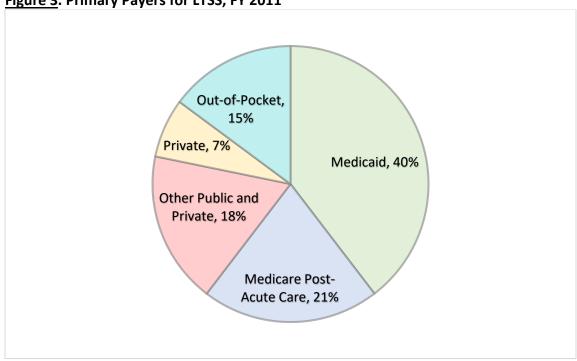


Figure 3. Primary Payers for LTSS, FY 2011

Adapted from Reaves, et al., "Medicaid and Long Term Services and Supports: A Primer."²

In addition to problems paying for services, rural elderly and the agencies that serve them are often challenged finding certified caregivers. ^{5,6} Shortages of therapists, certified personal care attendants, and other providers challenge the abilities of family and friends to support rural elders needing care in their own homes or in the community. ⁵ If these types of providers are available locally in rural areas, there will be a strong preference for rural people to stay in rural areas if they need LTSS; if they are not, rural elderly may need to migrate to other areas where a caregiver workforce is more readily available. ^{5,6} Lower pay and travel costs contribute to formal caregiver turnover in rural areas. ²⁴

As a result of workforce shortages and the costs of formal LTSS services, the burden of caregiving often falls on informal caregivers such as family members, friends, and neighbors.⁵ Nationally, 87 percent of those who need LTSS services receive them from informal caregivers.⁵ However, family, job or other obligations often make it difficult for informal caregivers to provide the level of support and care that may be needed, adding to the burden of caregiving and potentially accelerating moves to assisted living and other higher levels of care.⁵

The absence of an adequate and sustainable workforce and service infrastructure in many rural areas will make it increasingly difficult to address the growing need and demand for LTSS services. 8,23,25 In the absence of both informal and formal LTSS capacity, including family caregiving, HCBS, residential care, and nursing home care, rural seniors and their families are forced to consider options such as moving to larger communities or placement in a local nursing home. 15,23,25 These options are often not preferred, nor are they a good match in terms of quality of life, quality of care, or cost. 15,23,25

State-level Medicaid policies are important factors shaping the availability, access, and use of LTSS in rural areas. ¹⁵ States have the ability to design their Medicaid programs and benefits within a framework they feel best supports the needs of their beneficiaries. ¹⁵ Although skilled nursing home care is a required service in all states, many states have promoted non-medical residential care and HCBS options as an alternative to institution-based services. ¹⁵ Medicaid programs also have the ability to manage access to services through financial and medical eligibility criteria, provider payment rates, and licensing standards for providers and organizations that affect provider supply. ¹⁵

RURAL LTSS MODELS, POLICIES, AND TRENDS

Over the past 30 years, there has been significant innovation in the organization and delivery of LTSS in the U.S.²⁶ Not surprisingly, most of these innovations have originated in urban areas, where LTSS services and resources are concentrated.²⁶ Although there are examples of innovative rural LTSS models, most are relatively recent, and in general, we know very little about what works and why in rural communities, especially those challenged by limited access to services and support, geographic constraints, and the absence of an adequate workforce and infrastructure.⁷ The challenges and diversity of circumstances in rural communities suggest that greater flexibility and creativity will be needed to adapt strategies and models for organizing and delivering coordinated, comprehensive care for adults in need of LTSS to rural communities and populations.⁷

As indicated previously, family and friends are the primary and largest source of LTSS.⁵ For those needing formal, paid services, Area Agencies on Aging (AAAs) are often the first point of contact with the formal LTSS system.²⁷ In 2014, 618 AAAs helped to serve seniors in communities across the country. In some states, a state-level aging agency functions as the AAA in rural communities.²⁸

AAAs were established through the Older Americans Act in 1973 to provide local services to help older adults live independently in their home or in the community.²⁸ AAAs plan, develop, and coordinate services for clients needing LTSS.²⁸ These services include meals, transportation, case management, health insurance counseling, and respite care, among others.²⁸

Flexibility and adaptability to local circumstances is a core element of one approach, characterized by the growing Village movement and the CAPABLE initiative based at Johns Hopkins University, which uses a consumer-driven, community-based process to create aging-friendly communities that help elders live independently at home or in the community.^{29,30} In addition, states and their provider partners are developing new models to integrate and coordinate care across primary care, acute care, and LTSS.^{29,30}

In a recent paper on rural integrated care models, the Maine Rural Health Research Center identified four model types for LTSS delivery: (1) the Rural Program of All-Inclusive Care for the Elderly (PACE) Provider Grant program, (2) primary care-led models, (3) LTSS provider-led models, and (4) managed LTSS (MLTSS).⁷ A fifth model, the Medicaid Testing Experience and Functional Tools (TEFT) project is also briefly highlighted below. While not all of these models are rural-

specific, they are inclusive of rural and are demonstrating the importance of community integrated approaches to LTSS.

- Rural PACE Provider Grant Programs utilize an integrated care model to assist adults aged 55 years and older, most of whom are considered dual eligible. The goal of the PACE program is to keep adults in their communities rather than in an institutional setting, if possible, and provide coordinated, integrated care. PACE participants must be in need of nursing-home-level care, as certified by the State. PACE services are provided in an individual's home or community, or at a designated PACE center. Providers receive a capitated payment from Medicare and Medicaid funds for comprehensive, integrated services for rural participants. Reimbursement through capitation is beneficial from the providers' perspective due to the fact that they may offer a participant any needed service rather than limiting services to those that are reimbursable under fee-for-service Medicare and Medicaid. However, providers are also at full risk for the costs of care for all participants that they manage. In 2006, 15 original grantees were awarded Rural PACE Provider Grants.
- Primary Care-Led LTSS Models build on the principles of the patient-centered medical home model of primary care to create networks of primary care practices linked to an accountable care organization to manage the full range of medical and LTSS services.⁷ Colorado's statewide Medicaid Accountable Care Collaborative offers the best example of this model.⁷ Care integration is the responsibility of the medical provider and requires a significant investment in building linkages to the LTSS system.⁷
- LTSS Provider-Led Models for delivering care and support that an individual may need in a rural setting incorporate integrated care using an LTSS provider rather than a traditional medical provider. Vermont has tested this model using integrated care providers (ICPs) to focus on assisting dual-eligible individuals. ICPs were selected based on their area of expertise: mental health, substance abuse, developmental or long-term care, or a type of specialized care coordination program. Consumers in this provider-led model select their medical home and ICP. Georgia has also implemented an LTSS provider-led model with their Service Options Using Resources in a Community Environment (SOURCE) program, which is funded by Medicaid to serve rural communities statewide. The LTSS provider is the SOURCE contractor that is ultimately responsible for coordinating all care for consumers.
- MLTSS Models use capitated payments to health plans or other entities (e.g., counties) to manage the medical and LTSS services for enrolled Medicaid beneficiaries.⁷ In MTLSS models, the managed care organization is ultimately responsible for coordinating integrated care and payment to providers.⁷ While MLTSS models have largely been limited to urban areas, a number of states, such as Minnesota and Arizona, have extended the model to rural areas.⁷
- Medicaid Testing Experience and Functional Tools (TEFT) is building and testing various combinations of four components to support and improve community-based LTSS for Medicaid beneficiaries: (1) the use of personal health records, (2) experience of care surveys, (3) functional assessments, and (4) quality measurement. The program runs from 2014 to 2018 in nine states (Arizona, Colorado, Connecticut, Georgia, Kentucky, Louisiana,

Maryland, Minnesota, and New Hampshire), and some of the states are focusing their efforts in rural communities.³²

Common elements across these models that represent opportunities for further elaboration and testing in rural communities include the following:

- Strategies to integrate and coordinate care across primary care, acute care, and community-based LTSS providers and resources to address clinical and social needs;
- Establishment of clear accountability (and a defined role) for coordinating and supporting patient/client services and information flow between and among points of care and service; and
- Within alternative payment models, strategies to risk stratify patients/clients and serve them based on their needs.

Although building an integrated, coordinated LTSS infrastructure in rural areas is challenging, some states, providers, and communities are doing it. At the State level, Medicaid programs are modifying policies to better enable care integration.⁷ At the local level, communities and providers are leveraging integrated networks already in place or establishing new networks to creatively meet their needs.⁷ Ultimately, these communities are adapting to the ever-changing needs of their citizens by asking State programs and community providers to make changes that will improve the quality of LTSS in their community.⁷

CONCLUSION

In an ideal health care system, primary care, acute care, post-acute care, and LTSS form a continuum of coordinated services designed to meet individuals' needs based on their level of clinical, social, behavioral, or other chronic care needs and preferences. In reality, these services tend to be fragmented, with only weak coordinating connections. This fragmentation is the result of multiple funding sources, each with their own legislatively and policy-defined boundaries regarding eligibility, scope of services, and payment rules. The issues that arise as a result of fragmentation are exacerbated in rural areas, where the availability of, and access to, LTSS is more limited.

The core elements of a high-performing rural health system are affordability, accessibility, community health, high-quality care, and patient-centeredness. These core elements extend to include the services encompassed in LTSS, which individuals need and use. As rural populations have aged, rural hospitals and others have responded by adding services, such as home health care, and/or building various types of supportive housing (e.g., assisted living). With more recent moves toward value-based care approaches and incentives, health care providers, in partnership with other LTSS and social service providers, are looking for models and strategies to increase access to services appropriate to residents' needs. The applicability and replicability of the emerging models may vary, based on state regulation and populations served. Rigorous evaluation of the models underway and broad dissemation of their results are essential so that policymakers, and federal and state agency leaders, can use the information to guide future LTSS related policy and program decisions.

The health care sector is moving toward a high-performance system to deliver care. Innovation in the organization and delivery of LTSS services has been slower to evolve and diffuse, especially in rural areas. In many rural communities, access to essential or basic HCBS will be a priority. In rural communities with LTSS services, building a system with the appropriate provider collaboration, workforce, IT, and other capacity to coordinate and integrate care across the continuum of primary, acute, and LTSS services will be a next step. Although this can be done through demonstration projects, changes in State policy, such as in Medicaid LTSS payment systems, will be needed to achieve sustainable results.

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About the Authors

The RUPRI Health Panel is led by Keith J. Mueller, PhD. He can be contacted at (319) 384-1503, keith-mueller@uiowa.edu.

Charles Alfero, MA, is the executive director of the Center for Health Innovation, Hidalgo Medical Services (HMS) based in Silver City, NM. He has over 36 years of experience in rural health policy, systems, and program development. The Center for Health Innovation is a research and development organization supporting innovative programming for frontier and underserved population health.

Andrew F. Coburn, PhD, is a research professor of public health and directs the Maine Rural Health Research Center in the Muskie School of Public at the University of Southern Maine.

Jennifer P. Lundblad, PhD, MBA, is president and CEO of Stratis Health, an independent nonprofit quality improvement organization based in Bloomington, Minnesota, that leads collaboration and innovation in healthcare quality and patient safety. Dr. Lundblad has an extensive background in leadership, organization development, and program management in both nonprofit and education settings.

A. Clinton MacKinney, MD, MS, is a clinical associate professor in the Department of Health Management and Policy, College of Public Health, University of Iowa. He is also a board-certified family physician delivering emergency medicine services in rural Minnesota. He is the deputy director, RUPRI Center for Rural Health Policy Analysis.

Timothy D. McBride, PhD, is a professor at the Brown School, at Washington University in St. Louis. He also serves as one of the principal analysts in the RUPRI Center for Rural Health Policy Analysis, and serves in many state and federal roles, including serving as chair of the state of Missouri's MOHealthNET Oversight Committee, which oversees the state's Medicaid program.

Keith J. Mueller, PhD, is the Rural Health Panel chair. Dr. Mueller is the Interim Dean, University of Iowa College of Public Health, where he is also the Gerhard Hartman Professor, Department of Health Management and Policy and the director of the RUPRI Center for Rural Health Policy Analysis.

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The Rural Policy Research Institute (RUPRI) provides unbiased analysis and information on the challenges, needs, and opportunities facing rural America. RUPRI's aim is to spur public dialogue and help policymakers understand the rural impacts of public policies and programs. RUPRI is housed within the College of Public Health at the University of Iowa. RUPRI's reach is national and international and is one of the world's preeminent sources of expertise and perspective on policies impacting rural places and people. Read more at www.rupri.org.