
ACCESS TO QUALITY HEALTH SERVICES IN RURAL AREAS— LONG-TERM CARE: A LITERATURE REVIEW

by Linnae Hutchison, Catherine Hawes, and Lisa Williams

SCOPE OF PROBLEM

- Access to quality health services was identified as the top ranking rural health priority in a national survey of state and local rural health leaders and stakeholders.¹
- By the year 2030, the elderly population will double. One-fifth of the U.S. population will be over age 65.²
- Approximately 75 percent of those over 65 suffer from at least one chronic illness.³
- Nearly 22 percent of the nation’s elderly reside in rural areas.⁴
- Rural elderly represent a larger proportion of the rural population than the urban population.⁴
- The elderly in rural areas have access to fewer and a narrower range of long-term care services.^{5,6}

GOALS AND OBJECTIVES

Improving access to comprehensive, high-quality health care services is the goal of the first Healthy People 2010 focus area—Access to Quality Health Services. Included in this focus area are objectives relating to improving access to primary care providers and emergency services, increasing the number of individuals with health insurance, and improving access to the long-term care continuum and rehabilitative services.⁷ This literature review focuses on long-term care and the unique challenges faced by the rural elderly in accessing these services including access to nursing homes, assisted living, home health, hospice, and home and community-based services.

The following Healthy People 2010 objective drives this discussion:

- 1-15. Increase the proportion of persons with long-term care needs who have access to the continuum of long-term care services.⁷

IDENTIFIED BY PEOPLE LIVING IN RURAL AREAS AS A HIGH PRIORITY HEALTH ISSUE FOR THEM

Improving access to long-term care and rehabilitation is one of the goals under the Healthy People 2010 Access to Quality Health Services focus area. This area was the top-ranked rural health priority among state and local rural health leaders in a national survey.¹ Approximately two-thirds of the leaders of state agencies and associations, rural hospitals, rural health centers/clinics, and local public health agencies identified access to quality health services as one of the five top priorities among the 28 Healthy People 2010 focus areas.¹

PREVALENCE AND DISPARITIES IN RURAL AREAS

Access to long-term care (LTC) and rehabilitation services includes improving access to those providers, services, and facilities that play a vital role in the long-term care continuum. While hospitals often serve as the entry point for elderly into the long-term care system, for the purpose of this discussion, the long-term care continuum includes those services outside the acute hospital setting. These services may be classified as residential (e.g., assisted living, nursing homes) and non-residential (e.g., home health, hospice, and home and community-based services).⁸ In addition, the role of informal care providers (e.g., spouses, children, and friends), who are invaluable in meeting the needs of the elderly, will be included in this discussion.

An Aging Society

The United States is poised for what has been described in the literature as a “gerontological explosion”⁹ as a confluence of factors will significantly increase the ranks of the elderly population over the next 50 years. Since 1900, the

U.S. population has experienced a 10-fold increase in the number of those over 65—from three million (4 percent of the total population) at the turn of the last century to 35 million (12.4 percent of the total population) in 2000.^{2, 4} By the year 2030, the population over age 65 will double to 70 million, and one in five individuals will be 65 and older.²

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Overall, Americans are older. The average age of U.S. citizens is 35.3 years, while the average life expectancy is 77 years—a significant increase from 1900 when the average life expectancy

was 43 years.^{71, 72} This “graying of America” is attributed to simultaneous advances in medicine prolonging life, improvements in health, decreasing fertility rates, and aging of the baby boom generation.^{11, 12} Baby boomers, identified as those born between 1946 and 1964, currently comprise nearly one-third of the United States population and will begin to reach retirement age beginning in 2011.¹¹ Between 1990 and 2020, the population age 65–74 is expected to increase 74 percent compared to only 24 percent for those under 65.¹¹

Given the increases in life expectancy, it is important to recognize that the 65 plus age bracket is comprised of smaller subgroups (65–74, 75–85, 85 plus, and centenarians), each with unique characteristics that influence long-term care demands. One trend of particular relevance to long-term care and aging services is the growth in the population termed the “oldest old,” those over age 85. In 2000, there were 4.26 million people over age 85, representing the most rapidly growing segment of the elderly population and growing 38 percent in the last decade.^{10, 74} This age group is anticipated to increase five-fold between 2000 and 2050—growing to 20.8 million, with the largest growth between 2030 and 2050 coinciding with the baby boom generation turning 85 and over.¹⁰ This trend portends future increased demands on formal and informal providers as persons over 85 are the most likely to need and use long-term care services.⁵⁶

Other demographic information is relevant to understanding the long-term care demands. One observation is the inverse relationship between heterogeneity and advancing age. Those over 65 are disproportionately women, widowed, and predominantly white—comprising 87 percent of those 65 and older.^{2, 74} Regional differences also exist. The western and southern regions of the U.S. exhibit the fastest growth in total population and also the most rapid growth in the elderly population—growing 20 percent and 16 percent, respectively, between 1990 and 2000.⁷⁴ Such regional differences may reflect overall population growth as well as choices of elderly regarding geographic location for retirement living.

Long-term Care Spending

Long-term care spending is expected to continue increasing as a result of the growth in the older population. The Congressional Budget Office projects total long-term care spending to reach 160.7 billion dollars by 2010 and 207.3 billion dollars by 2020. Assisted living and adult day care are not included in this projection.⁷⁵ It is estimated that half of all elderly over age 65 will require some care in a nursing home, and approximately 75 percent will require home care.⁵⁶

Approximately 64 percent of long-term care spending for institutional care and home care (e.g., home and community-based services, personal assistance, and home health) is from public sources, with Medicaid being the primary funder (27 percent) followed by Medicare (17 percent).^{77, 78} The remaining expenses are covered out-of-pocket (21 percent), by private insurance (10 percent), and by other private and public sources (5 percent).⁷⁹ Approximately one quarter of Medicare and Medicaid expenditures occur in the last year of life.^{80, 81} In 2003, two-thirds of LTC spending was directed toward institutional

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care versus one-third spent on home-care services, including home and community-based services, personal care, and home health.⁷⁹ Medicaid, the largest payer of LTC, is available only after other sources of private funding are exhausted. This spend-down requirement is a significant concern for those in need of long-term care services, as well as their families.

Elderly in Rural and Urban Areas

Long-term care and aging is an important concern for rural areas given the proportionately larger number of elderly in rural areas than in urban areas combined with less access to health resources. According to the 2000 census, 12.3 percent of the urban population is over age 65 compared to 12.8 percent of the rural population.⁴ Of the nearly 35 million elderly over age 65, 21.6 percent of this group resides in rural areas.⁴ Rural elderly are older than urban elderly. Studies have found age increases as one moves along the continuum from urbanized to rural areas, with a greater proportion of those over age 65 and those over 75 residing in isolated areas compared to more urban areas.^{13, 14} Rural areas are also home to a greater proportion of the oldest old population segment (those over age 85), which is an age group more likely to need long-term care and aging services, comprising 7.8 percent of the population over age 60 in nonmetro areas compared to 7.5 percent in metro areas.^{15, 75} An estimated 50 percent of those over age 85 need personal assistance with everyday activities (e.g., bathing, meal preparation, and mobility within the home).⁷⁵

Rural areas are home to a greater proportion of the oldest old population segment.¹⁵

Profile of the Rural Elderly

The key predictors of institutionalization are health status, sociodemographic factors, and the role of social support networks.¹⁶⁻¹⁸ Among the indicators used in assessing overall health status, as well as determining the need for and degree of long-term

care services, are the perception of health, number of medical conditions, cognitive status, functional status, and the number and severity of activities of daily living (ADLs) and instrumental activities of daily living (IADL) impairment. Assessing the degree to which rural and urban elderly differ in health status is complex; studies comparing the health status of the elderly across different locales vary not only in the health indicators utilized but also in the definitions of rural and urban employed. Despite these limitations, a series of national reports conclude that rural and urban differences exist for some measures of health, functional, and cognitive status among elderly populations.

Foremost among these differences is self-reported perception of health. These assessments, which are tied to *objective indicators* of health status such as number of physician visits, illness presence, and lifestyle choices (e.g., exercise, smoking, etc.), provide insight into the health of a population group.⁸² A number of studies have found rural elderly report a lower or worse perception of health than their urban counterparts.^{19- 21} Mueller and colleagues found that Medicare beneficiaries residing in nonmetro areas were more likely to rate their health as fair or poor and less likely to rate their health as good or excellent than their metro counterparts.²² Coward and Cutler found the lowest perceived health status among nonmetro nonfarm elderly (the largest population of rural elderly); however, the reported perception of health did not decrease with increasing rurality. Instead, elderly residing in the most rural locales had a slightly higher perceived health status than the nonmetro nonfarm elderly, although the perception was still lower than that of metro residents.¹⁹ Eggenbeen and Lichter found that rural elders were—in addition to reporting a lower perceived health status—more likely to report greater unhappiness.²³

Rural and urban elders also differ in the number of medical conditions and utilization of preventive services. Data from the Behavior Risk Factor Surveillance Survey (BRFSS) from 1993–1997 found rural elders had a higher incidence of obesity and physical inactivity, and they were more likely to never have smoked; however, if they did smoke, they

were more likely to be a current smoker (i.e., smoked in the last 30 days).⁸³ The same source found rural older women less likely to have received a mammogram or pap smear, and rural males and females were less likely to have received a cholesterol check in the last six months.⁸³ Overall, rural elderly are more likely to have chronic conditions such as arthritis, hypertension, diabetes, and heart disease.²⁴⁻²⁶

Physical and cognitive functioning are essential measures in assessing an individual's need for long-term care services. Cutler and Coward found that elderly in nonmetro-nonfarm rural areas had the highest number of medical conditions and functional limitations of the four groups (central city, noncentral city, non metropolitan statistical area [nonMSA] nonfarm, and nonMSA farm).¹⁹ The same study found residence did not affect the number of ADLs or IADLs performed with difficulty. A study using 1988 National Survey of Families and Households data found rural elderly and rural young were more likely to report lower health status and report greater unhappiness, but there were no significant residential differences in functional limitations (ADL limitation) or presence of chronic illnesses and disabilities.²³ Braden and Van Nostrand found no significant rural-urban differences in functional status.²¹ Though not statistically significant, Schlenker found that rural residents had a higher number of ADL and IADL impairments.²⁵ Dansky et al. found greater ADL and IADL impairment in rural elders.²⁷

While ADL and IADL presence appear similar in rural areas, the response to these limitations is different. Using data from the National Survey of Self-Care and Aging, one study found rural elderly more likely than urban to perform functional activities in the presence of disabilities.²⁸ The author posits that rural elderly perceive aging differently than their urban counterparts, tending to “normalize the trajectory of aging” and reporting fewer functional limitations even in the presence of disabilities.²⁸

Understanding not only this group's health but also their socioeconomic status (e.g., education and

income) is important in predicting utilization of services; higher education and income are associated with more positive health self-assessments.²⁹ Rural elderly are poorer than their urban counterparts, with 21 percent of rural elderly classified as poor compared to 10.1 percent of the general population age 65 and older.³¹ Nearly half of nonmetro elders live below 200 percent of the federal poverty level compared to slightly over one-third of urban residents over age 65.³² Rural elderly are more likely to own their own homes; however, the homes may be in poorer condition.³⁰ This group is more likely to rely on Medicaid and Medicare and less likely to have private pay insurance.⁸⁴ Rural elderly are also less educated.³⁰ Finally, although it is commonly perceived that rural elders are more likely to be cared for by family members than their urban counterparts, the research is mixed on this point.⁶⁷ Some studies have concluded rural elders are more likely to receive care from family members; others have found the opposite—rural elders are not more likely to rely on family members for caregiving.^{62, 67, 85}

Rural-Urban Differences in Utilization of Services

As the elderly population grows, so do the demands on the acute care and long-term care systems. One study estimates that 7.3 million people in rural areas need long-term care services, accounting for one-fifth of those persons needing LTC.⁸⁶ Meeting the health-care demands for this population may be especially challenging for rural areas with more limited resources and greater barriers to providing these services. For the purposes of this review, the components of the LTC system are analyzed separately under two broad categories—residential and non-residential providers.

Residential Providers

Assisted Living

Assisted living has emerged as one of the fastest growing segments of the long-term care market. For those seniors who are unable to remain in their homes but do not require the intensive nursing care provided in nursing homes, assisted living serves as

an attractive alternative to more costly institutional care. Nonetheless, understanding the availability and utilization of these services, as well as identifying any associated rural-urban disparities, is complicated by variability in estimates of the actual number of facilities.

Hawes and colleagues point out that this is largely the result of the lack of

Rural ALFs are more likely to offer a combination of low or minimal services and low privacy.³³

a national definition of assisted living and adoption of national licensing standards.³³ Estimates may include not only assisted living facilities (ALFs) but also other services that fall under the broader residential care category, which include providers such as board and care homes. According to the National Academy of State Health Policy, 36,399 licensed assisted living facilities with 910,486 beds were reported by states in 2002—increasing 14.5 percent from 2000 to 2002, although not all states reported.⁸⁷

Despite the growth in the assisted living industry, there is limited research on the breadth, scope, and quality of this industry in rural versus urban areas. Coburn notes that the “availability and accessibility to assisted living facilities in rural areas is largely unknown.”³⁴ To bridge this gap, Hawes et al., in a national study of assisted living in rural areas, found variation in distribution, size, mix of services and privacy, and cost among rural and urban assisted living facilities. The report concluded that assisted living is predominantly an “urban industry,” with roughly 76 percent of ALFs located in metro areas. Rural and urban ALFs differed in other ways as well, including size; rural ALFs were 40 percent smaller than urban ALFs. Significant differences between locales were noted in the mix of service and privacy levels offered, with rural ALFs more likely to offer a combination of low or minimal services and low privacy compared to urban ALFs, which were more likely to offer a combination of high service/high privacy.³³

While assisted living is suggested as a less expensive alternative to nursing home care,³⁵ the cost may be unaffordable to low-income seniors. Hawes and colleagues found the price of ALF services in rural areas averaged less than in urban areas among those facilities with multiple rates (\$17,000/year versus \$19,500/year, respectively); nonetheless, the cost remains out of range for many low-income elderly.³³ During the same time period (1998), approximately 12.5 percent of seniors in areas outside of metro areas were below 100 percent of the federal poverty level (FPL) compared to 9.8 percent of those over 65 in metro areas. The disparity in poverty levels increases to 43.6 percent and 35.3 percent, respectively, at the 200 percent of FPL.⁸⁸

Coverage of ALF services through public sources is an important and debated policy issue. If assisted living is funded through a Medicaid program, then it is an entitlement. However, if covered by home and community-based services (HCBS) Medicaid waiver programs, states have flexibility in the catchment area served, types of services offered, and groups covered although HCBS beneficiaries must meet the state’s nursing home level of care eligibility criteria.³⁵ Forty-one states have authorization to cover licensed ALF or board and care facilities through the state Medicaid program, waiver program, or a combination of both.⁸⁷ Medicaid does not, however, pay for room and board costs. For low-income seniors, these costs are borne by supplemental security income (SSI) payments or state supplements to SSI.⁸⁷

As mentioned earlier, a number of types of facilities fall under the broader heading of non-medical residential care. One such facility—the board and care home—is similar to the ALF, but it is generally smaller, privately owned, and often adapted from a single family home.⁸⁹ Board and care homes offer few on-site medical services and may or may not be licensed.⁸⁹ These homes generally provide services to elderly clients as well as those who have mental or developmental disabilities.⁹⁰ There is limited information regarding rural-urban differences in availability of board and care homes.

Nursing Homes

Nursing homes (NHs) serve as important providers of long-term care services to the chronically ill and disabled, especially in rural areas where other service options such as home and community-based care are more limited. Currently, there are over 17,000 Medicare and Medicaid certified nursing homes in the United States, with nearly 1.6 million residents or roughly 4 percent of the elderly population.^{13, 36} While many services are lacking in rural areas, nursing homes remain the notable exception. A national study of quality differences in rural and urban nursing homes found 40 percent of nursing homes were located in rural areas.¹³ In 2001, over one-half million nursing home residents (approximately one-third of all long-stay nursing home residents) were in homes outside of major metro areas.³⁶ Utilization patterns—measured by the number of nursing home residents per 1,000 persons over age 75—vary by residence, with the highest rates found in areas outside of urban locales. For every 1,000 persons over age 75 in urban areas, there were 82.3 nursing home residents. This is in contrast to 99 residents/1,000 in isolated rural areas; 121.5 residents/1,000 in rural areas with small towns; and 106.7 residents/1,000 in rural areas with large towns. Small town, rural areas also had the highest rate of nursing home use, with 12 percent of the population over age 75 in nursing homes in 2000 compared to 8.2 percent in urban areas.¹³ Nursing homes in rural areas had fewer beds, a larger percent of homes below the Centers for Medicare and Medicaid Services (CMS) suggested nurse staffing thresholds, and fewer specialized services such as Alzheimer’s units.

Rural and urban nursing home residents differ along a number of dimensions. Rural nursing home residents are older and more likely to be dependent on Medicaid. They have lower ADL dependency than their urban counterparts but similar levels of moderate to severe cognitive impairment.^{13, 36, 91} Rural homes have a larger proportion of residents diagnosed with dementia.¹³ The highest rates of depression without therapy were found among residents in the most isolated areas.³⁶

The availability of nursing home beds in rural areas in contrast to shortages in other LTC options has raised the question of whether nursing home care is being substituted for other LTC services in rural areas.^{38, 92} A number of studies have investigated with mixed results whether rural elderly are at risk of premature institutionalization. An Arizona study of 282 patients in skilled nursing units found rural elderly at heightened risk of premature nursing home admission—that is, admitted at a younger age and with less impairment.⁹³ A Colorado study also found rural residents at higher risk of premature institutionalization due to a lack of alternatives.⁹⁴ A study using LSOA (Longitudinal Study of Aging) data found incontinent elders in rural areas were at higher risk of nursing home admissions than urban elderly with incontinence; the authors suggest this is attributable to the lack of HCBS and an increased burden on the informal caregiver.¹⁶ Another study found rural residents had higher nursing home admissions that could not be explained by differences in sociodemographic, health, and social support network variables.⁹⁵

Other studies, however, found residence was not a predictor of premature institutionalization. In a 2001 study of rural and urban Nebraskans, rural residents were not at a heightened risk of premature institutionalization to nursing homes.⁹⁶ McConnel and Zetzman, using data from the Longitudinal Study of Aging, found residential location was unrelated to likelihood of nursing home admission, physician visit, or hospitalization.⁹² Additionally, an eight-county study in Florida found few differences between rural and urban NH admissions.⁹⁷

Still other studies have found rural residents at lower risk of institutionalization. Dwyer, Barton, and Vogel found rural residents at lower risk of NH admission than urban.⁹⁸ This study found that the level of impairment and race were greater predictors in rural areas than rural residence—that is, minorities are more likely to report functional limitations but less likely to be institutionalized. The authors suggest this finding may be attributed to more familial support among minority groups. The discrepancy between studies may be due to differences in study design, population studied, coding, and other factors.

In addition to health status and functional limitations, the role of support networks is a predictor of NH admission. High levels of loneliness—often as a result of death of a spouse and isolation from family and friends—contribute to diminished support networks, which increase the likelihood of NH admission.¹⁸ This is important in anticipating NH use given the oldest-old rural elderly are more likely to live alone.^{99, 100}

While quality of care in nursing homes is a national issue, few studies have investigated how quality differs across the rural-urban continuum. Phillips et al., in a national study of long-stay nursing home resident assessment data, found significant differences in quality indicators across nursing homes located in urban, large town, small town, and isolated areas.³⁶ Among 19 indicators of potential quality problems, 10 were higher in nursing homes located in rural areas (categorized in this study as large town, small town, and isolated), indicating potentially more quality-of-care problems in nonurban areas; three indicators were lower in rural areas, and six indicators were mixed among the three rural categories. The authors also found significant variation in quality indicators across the 10 regions of the United States.³⁶

Another study finds rural-urban differences in nursing home discharge patterns. A Maine study found rural residents with hip fractures were less likely to be discharged within the first six months than urban residents.⁸⁶ The same study also found rural residents were less likely to be discharged to lower-care facilities.

Finally, some studies have suggested that nursing homes are a more entrenched part of rural life and the rural community. Consequently, rural residents may be more accepting of admission to nursing homes as a long-term care option if they are no longer able to live alone.¹⁰¹ However, a longitudinal study found rural elderly are twice as likely as urban elderly to report they would live with family members rather than move into a NH if they could no longer live alone—a finding conflicting with the belief there is greater acceptance of nursing homes by rural residents.¹⁰¹

It should be noted that one of the two Healthy People 2010 Access to Long-term Care objectives focuses on decreasing the incidence of decubitus ulcers (bed sores). The presence of and degree of severity of decubitus ulcers are indicators of the quality of care for nursing home residents. In a national study of nursing home quality in rural and urban areas using 2001 Minimum Data Set (MDS) data, Phillips et al. found the incidence of bed sores decreased with increasing rurality, with nursing homes in the most isolated areas having the lowest incidence of bed sores.⁹¹

Non-residential Care Providers

Home Health

A keen sense of independence and self-reliance are characteristics frequently associated with rural residents. Remaining in one's home is a vital component in maintaining this sense of independence. Studies support that consumers, when faced with the need for chronic care, prefer to remain in their homes to receive such care.¹⁰²⁻¹⁰⁴ Home health (HH) fosters and promotes this independence while providing necessary medical care in the patients' homes for those with chronic disease or those recovering from an acute incident. Medicare, the primary payer of home health services, allows an unlimited number of visits per year provided the beneficiary remains eligible for home care services.¹⁰⁵

Studies reveal uniformity along a number of dimensions regarding differences in the characteristics of rural and urban home health agencies (HHAs) and the clients they serve. Overall, rural HHAs differ substantially from urban HHAs in organizational structure as well as provision of services, as summarized below.³⁷ Rural home health agencies are generally:

- smaller than urban agencies (i.e., provide less than 5,000 visits per year),³⁷
- more sparsely located with fewer HHAs per square mile and per county compared to urban centers,³⁸

- more likely to be hospital based,³⁷
- more likely to be not for profit,³⁷
- more likely to offer a narrower range of ancillary services (physical therapy, occupational therapy, speech therapy, and social services),³⁷
- more likely to use health aides,¹⁰⁶ and
- focused on providing post-acute care.^{107, 108}

The availability and scope of ancillary HHA services are important in the ability of HHAs to effectively meet the health care demands of clients. The research concludes rural HHAs tend to offer fewer of these specialized services. While 70 percent of metro HHAs provide a range of ancillary services, less than 20 percent of nonmetro HHAs offer these services.³⁷

In addition to HHA-provider differences, there are also differences in the profile of the rural and urban home health patient. Rural patients are less likely to be from a racial or ethnic minority. Rural home health patients also tend to be long-term care patients versus urban beneficiaries who are more likely to be post-acute-care patients.³⁹ Schlenker found that rural home health patients tended to have more ADL and IADL disabilities—although the differences were statistically significant for only one ADL and two IADLs measured, significantly more intractable pain, more neuro/emotional/behavioral status problems, terminal conditions, and slightly more chronic conditions (1.98 versus 1.77, a difference that is not statistically significant) but fewer acute conditions (a difference that is marginally statistically significant). Associated outcomes at discharge from home health also differed by locale. Rural residents were less likely to be discharged with their goals met and more likely to have a poor prognosis.²⁵

Utilization of home health services, as measured by number and length of visits per health episode, is useful in evaluating rural-urban disparities; however, there is less than unanimity regarding the subject. The mixed results may be attributed to variation in study design, classification of rural and urban areas, and the degree of control for other factors known to impact HH utilization.^{25, 109} A study utilizing 1987 data, found an inverse relationship between

availability of NH beds and use of home health agencies, visiting nurses associations, ancillary service availability, and higher reimbursement ceilings.¹¹⁰ Higher HH use was found in those areas that had fewer NH beds per Medicare enrollee, more visiting nurses associations, availability of ancillary services, and higher Medicare reimbursement ceilings. Consequently, HH use was found to be lower in rural areas.¹¹⁰ A 1997 study found rural beneficiaries, fitting the profile of long-term care users, had more visits than urban clients.³⁹ A national study, utilizing 1991 and 1992 data, found residents in completely rural areas used more HH services and skilled nursing facility (SNF) days but fewer hospital and physician office visits compared to more urbanized rural areas and urban areas (Dansky used a five-category rural-urban continuum: large metro, large metro fringe, medium lesser metro, nonmetro urbanized, and completely rural).¹⁰⁹ Urban residents tended to use less post-acute services (home health and SNF) but more inpatient and office visits.¹⁰⁹ The most remote rural clients were found to average more HH visits but fewer physician office visits than any of the other four groups. Clients from completely rural areas were found to receive 3.5 more HH visits than more nonmetro urbanized areas—a significant difference. Furthermore, of the five locales, nonmetro urbanized areas had the lowest rates of HH use but the highest rates of HH worker availability. Dansky suggests that HH may provide a “safety net” for rural elderly in the most remote places where both formal and informal care may be lacking.¹⁰⁹ McCall et al. found rural residents used a slightly higher rate of home health services and had more visits/user.^{25, 111} However, Schlenker et al., in a national study of Medicare-certified HHAs using a two category rural-urban classification system, found rural clients used fewer HH services, averaged fewer total visits per patient in a 120-day period, had lower resource consumption, experienced longer lengths of stay (54.1 days versus 46.7 days in urban), and were more likely to have services provided by nurse aides. It should be noted that the studies referenced in the above discussion utilized data collected prior to the Balanced Budget Act of 1997 (BBA 1997), an act that significantly impacted home health as well as other health providers. These studies serve as a baseline for

evaluation of the impact of this legislation on rural and urban utilization of home health services.

The home health industry grew substantially between 1986 and 1996 in response to significant increases in the number of beneficiaries as well as number of visits per beneficiary. Implementation of a hospital prospective payment system decreased the number of inpatient days and led to earlier discharges and greater use of home health services.¹⁰³ Home health providers were reimbursed on a cost-per-visit basis (up to predetermined limits). During the same time period, Medicare expenditures grew from \$3 billion to \$18 billion.¹⁰³ In an attempt to control soaring costs and promote industry efficiency, the Balanced Budget Act of 1997 was passed. Passage of BBA 1997 brought a fundamental change to home health reimbursement, shifting the industry from a cost-based system to an interim-payment system and ultimately to a permanent prospective-payment system (PPS). Under PPS, services are reimbursed based on a predetermined cost per episode rather than on a per visit basis, forcing agencies to strive for greater efficiencies in delivery of care.¹⁰³ The impact of this change between 1998–2000 was widespread, as reflected by a 36 percent reduction in HH agencies across the U.S.¹¹²

BBA 1997 not only affected reimbursement to HH providers but also to other health care providers, including hospitals and nursing homes. As mentioned earlier, rural HHAs are more likely to be hospital based than in urban areas. BBA 1997 cut reimbursements to hospitals for inpatient, outpatient, nursing care, and home health care.¹¹³ Many small hospitals switched to or are in the process of converting to critical access hospital (CAH) designation (agree to 15 acute care beds, allow swing beds and acute-care reimbursement at cost) to maintain cost-based reimbursement.¹¹³ In a study of 448 rural hospitals to determine the impact of BBA 1997, researchers found 13 percent of rural hospitals operating a home health agency closed this service by 2000, and 14 percent closed their skilled services. Seventeen percent of surveyed rural hospitals delayed discharge due to lack of home health services, while 30 percent delayed discharge due to

lack of skilled nursing services.¹¹³ However, with the exception of one area, the residents had access to skilled and home health services from another provider in the community. The Benefits Improvement and Protection Act of 2000 (BIPA 2000) offset the reductions in payment for these hospital services, increasing payments by 10 percent. Stensland and Moscovice concluded, as a result of BIPA's implementation, that rural hospitals would not decrease HH services.¹¹³

Since implementation of BBA 1997, there has been a decrease in the expenditures for HH services and the number of agencies providing care. There are more limited studies on the differential impact on rural areas since implementation of BBA 1997. An analysis of 1997 HH data found one-quarter of rural home health residents were served by urban-based HHA agencies. This finding is significant given that many of the agencies that closed as the result of BBA 1997 were urban, free-standing, for-profit, and located in the South—the same group that served many rural areas.¹¹⁴

A 1999 General Accounting Office (GAO) report found 14 percent of rural HHAs closed in the 15 months following full implementation of BBA 1997; however, interviews in these counties did not reveal concerns regarding access.^{115, 116} Another study concluded HHAs altered their selection process to identify patients with less chronic diseases.^{116, 117} McCall found patient characteristics changed.¹¹⁶ There were fewer patients with a diagnosis of hypertension, diabetes, and heart disease but a larger percentage of patients with orthopedic diagnoses. In a study of the post-BBA 1997 impact on HHAs in Pennsylvania, researchers found an increased need for technical assistance to deal with the added administrative burden, an increased use of informal care providers and private pay nurse aid services, a decrease in HH visits (by 42 percent), and increased financial challenges.¹¹⁸ Another Pennsylvania study found that providers decreased the number of visits, but the length of the visit increased; slightly over one-third of HHAs reported decreasing the number of beneficiaries served; one-half of agencies reported staffing reductions; and over 80 percent of the

reporting HHAs reported a greater amount of care was shifted to the informal provider.¹¹²

A 2004 GAO report examined HHA Medicare cost report data for freestanding HHAs and concluded Medicare’s PPS reimbursements to urban and rural HHAs sufficiently covered the costs in providing HHA services. This report, however, did not include hospital-based HHAs, which play a significant role in providing care in rural areas.¹⁰⁵ A Medicare Payment Advisory Commission (MedPAC) report in March 2004 found one-quarter of rural home health patients reported access problems.¹¹⁹

Home and Community-based Services

Coburn observed that the “landscape of long-term care is changing, forcing increased reliance on private funding for services, expansion of nonresidential care alternatives, increasing in-home options, and attempts to integrate care across the acute and LTC system.”³⁴ Section 1915c of the Social Security Act established the home and community-based services waiver program as the *Medicaid alternative to long-term institutional care*. Waiver programs serve the elderly and those with disabilities. Prior to the waiver program, only institutional care, personal care, and home health care were covered Medicaid benefits. The waiver program allows states to offer a wide range of services, including *homemaker/home health aide services, personal care services, adult day health, habilitation, case management, respite care, and “other” services* (such as home-delivered meals or transportation services).^{8,40} All 50 states offer some form of HCBS; however, there is variation in the programs offered.⁸ States may choose to offer a range of services, provided the programs are necessary to avoid institutionalization and remain “cost neutral.” In 2000, an estimated 13 million elderly received care in community settings (board and care homes, adult day care, hospice, group homes, and private

Rural elderly have access to a narrower range of and fewer alternatives to HCBS.^{5, 6}

homes); two million received care in institutional settings.¹²⁰

While it is generally agreed that rural elderly have access to a narrower range of and fewer alternatives to HCBS^{5, 6} and confront greater barriers in accessing care—such as such as transportation difficulties and provider shortages,^{6, 41}—the degree to which these constraints affect utilization is complex.⁴¹ Rabiner, using national long-term care survey data from the early 1980s, found that residents in the northeast and those living in moderately densely populated areas were more predisposed to using *some* HCBS than those living in remote areas. Rabiner also found for some services, such as congregate meals, rural elderly were less likely to utilize those services but not less likely to use others such as formal in-home care and adult day care and senior centers.¹²¹ In a South Carolina study of a regional Area Agencies on Aging (AAA) of utilization patterns of HCBS (case management, congregate meals, home-delivered meals, outreach, and recreation) among three elderly age groups, researchers found the youngest age group (65–74) used the most services. The predictors of increased use of HCBS were white race, urban residence, payment source, access to transportation, and greater functional impairment.⁴²

Perception of availability and adequacy of HCBS may be important factors in utilization patterns, particularly in rural areas. In a study of rural and urban Floridians, perceived inadequacy of service was identified by rural elderly as the primary reason for not using HCBS. Compared to their urban counterparts, the rural participants identified more barriers to accessing these services. It is suggested that the combination of real and perceived barriers partly explains lower utilization of HCBS found in some studies.⁴¹ The barriers identified were lack of awareness of service, inadequate transportation, and perceptions regarding eligibility standards.¹²² Another Florida study found rural elderly were three times more likely than urban elderly to perceive a needed HCBS was unavailable to them prior to NH admission. Among the services perceived as unavailable were 24-hour assistance, home health aides, physical therapy, homemaker services, and transportation.¹²³ The same study found that one-half

of rural elderly reported a service was unavailable to them prior to NH admission compared to only 25 percent of urban elderly.¹²³ While the rural elderly perceived more service constraints, it is interesting to note the same study found no significant differences in the use of formal services prior to NH admission among rural and urban NH patients.¹²³

Organizationally located under the Administration on Aging, the estimated 661 Area Agencies on Aging play a vital role in the provision of HCBS, targeting vulnerable populations including rural, minorities, the poor, and disabled.¹²⁴ In 1999, it was estimated that one-third of AAA clients resided in rural areas.¹²⁴ One study estimates 90 percent of AAAs have rural elderly in their service area.^{41, 125} In the absence of other service providers, AAAs partly fill a service void for many rural areas. AAAs contract with providers to deliver home and community-based services or, in areas lacking in service providers, provide a range of services directly. Rural AAAs are twice as likely to provide services directly than urban AAAs but offer a narrower range of services and serve a much larger service area, covering more than 3,000 square miles compared to less than 500 square miles in more urban areas.^{41, 126} Nonetheless, rural AAAs face many of the same difficulties faced by rural communities—lack of resources and subsequent inability to offer a broad range of services. A national study of AAAs found that almost a third of rural AAAs reported they were unable to provide adult day care, and 18 percent did not provide respite care; this is compared to only 2 and 3 percent, respectively, of urban AAAs reporting these services were not available.^{41, 126} Given the role of AAAs in rural areas, increased targeting of rural populations as well as other vulnerable populations is an important objective in AAAs performance plan.¹²⁴

A national study of AAAs found that almost a third of rural AAAs reported they were unable to provide adult day care, and 18 percent did not provide respite care.^{41, 125}

Adult day care and respite services are programs under the larger home and community-based services umbrella. Adult day care, or adult day health services, are designed to address the social and health needs of individuals at risk for institutionalization.⁴¹ Respite services provide needed relief for informal caregivers, such as family members, and may be provided in-home or facilitated through an adult day center. Day adult services often target those with Alzheimer's Disease. A national study found 20 percent of centers exclusively target those with Alzheimer's Disease but also provide needed health services for those requiring other health needs associated with the frail elderly, neurological disorders, cardiovascular disorders, respiratory conditions and other diseases requiring health care assistance such as dressing changes, skin care, and medication supervision.^{63, 127}

In assessing level of need for adult day care services, only seven states reported having their needs met above the 67th percentile. The remaining states report unmet needs below this level.¹²⁷ Interactive maps showing state and county levels of need for day adult services are available at the Robert Wood Johnson website: <<http://www.rwjf.org/news/special/adulthoodEvolution.jhtml>>. As noted above, these services are less commonly available in rural areas. Even in those areas providing these services, cultural barriers, such as feelings of guilt or mistrust of service providers, may prevent use.⁴¹ Transportation difficulties may further exacerbate access difficulties.

Rural-urban differences also exist in client characteristics and disease diagnoses. A Maryland study of metro and nonmetro day care centers and disease patterns of clients revealed differences in these populations. Metro day clients were more likely to have a diagnosis of Alzheimer's Disease compared to nonmetro clients, who were more likely than their urban counterparts to have a diagnosis of cancer, cardiovascular, respiratory, or endocrine disease.¹²³ The same study found nonmetro clients tended to be older (in the 75–84 age range) and more likely to be nonwhite, live alone, and less likely to be self-pay. The national average age of clients was 72.¹²⁷ There were no significant differences in the

use of day adult services in the 85 plus category.¹²⁷ These services, requiring higher levels of nursing care and small staff-to-patient ratios (1:8), are resource intensive, which hinders the development of these services in many communities.¹²⁷

Respite care provides a necessary relief for the caregiver and is important in delaying institutionalization of the family member.⁴³ However, respite care has been found to be the most-often-requested service but also one of the most underutilized and least available.⁴³ In a study of the impact of providing care for an ill family member, it was determined that caring for those with brain-related conditions posed the greatest psychological stress on the family. Financial burdens further exacerbate family stress.¹²⁸ A New Jersey study found that use of adult day services is effective in reducing caregiver stress in families caring for family members suffering from dementia problems.¹²⁹

Overall, the attractiveness of many types of LTC services lies in their ability to facilitate aging-in-place. This concept has many meanings.^{130, 131} In its simplest form, it means the ability to remain in one's current environment, maintaining independence and control over the environment across settings.¹³¹

Hospice

A 1996 Gallup poll found 90 percent of Americans prefer to receive care in their homes if diagnosed with a terminal illness.⁴⁵ Incorporated into Medicare in 1982 as part of the Tax Equity and Fiscal Responsibility Act, hospice serves as an invaluable component of the long-term care system for those requiring end-of-life palliative care.⁴⁷ Between 1992 and 2000, Medicare enrollment in the hospice benefit increased at an annual rate of 16 percent, with the number of Medicare decedents who used hospice increasing from 9 percent to 23 percent during this period.⁵² Hospice patients typically enter the system one month before death.⁴⁵

Hospice care involves a team-oriented approach to caring for persons with a life-limiting illness or injury.⁵² Core beliefs of hospice are that each person

should be able to die pain-free with dignity and that the patient's family should receive the necessary support to allow the patient to do so. The care is usually provided in the patient's place of residence (i.e., personal home, nursing home, or assisted-living facility) but can also be provided in the hospital or in a hospice facility. The hospice team generally consists of the patient, physician(s), nurses, home care aides, social worker, trained volunteers, clergy (if desired), counselors, and therapists as needed.¹³²

There are 2,154 hospices, with the majority in urban areas (1,314) versus 840 in rural areas, providing over 28 million home care days.⁴⁶ Hospice utilization, service availability, and organizational structure varies widely by area of residence. Rural hospices tend to be smaller and are more likely to be hospital-based, whereas urban hospices are more often stand-alone. One measure of hospice utilization is the number of hospice deaths per 100 beneficiaries. Researchers in one study found that the rate of hospice utilization varied significantly between rural and urban areas, with rural areas having the lowest rates (22.9 percent in urban areas compared to 15.2 percent in rural areas not adjacent to an urban area).⁴⁷ While the rate of hospice deaths varied by region, the researchers pointed out the rate of hospital deaths did not. Low-income individuals, minorities, rural residents, and the old were less likely to use hospice services than urban, higher income, and younger individuals.⁴⁷⁻⁵³ Nonetheless, a MedPAC report noted a sharp increase in hospice use among rural decedents, tripling from 6 percent in 1993 to 19 percent in 2000, compared to a doubling among urban decedents from 10 percent to 25 percent.⁵²

Providing comfort to those who need end-of-life care requires understanding an appropriate response to the care needs of the population. There is some evidence that rural hospices may be more restrictive in medications used to comfort hospice patients. Bolin et al. found rural hospice patients were more likely to use anti-depressants and anti-psychotics but less likely to use anti-anxiety medications compared to urban, large town, and small town areas.¹³³ Hospice patients in small towns and remote areas

were more likely to report experiencing pain on a daily basis.¹³³

Providing quality end-of-life care, particularly in rural areas, is complicated by a host of factors. Providers in rural areas face uniquely rural challenges. Long travel distances, the demands of a frequent on-call schedule, staff isolation, and lack of 24-hour pharmacy services are frequently cited problems faced by rural hospice service providers, which in turn, further exacerbates provider shortages.^{45, 134}

Finally, availability of providers may not be the only reason hospice use rates are lower, albeit growing, in rural areas. In a review of the economics of end-of-life care, Buntin found studies indicating other factors that may contribute to underutilization of hospice, although rural versus urban areas were not specifically compared. Namely, physicians may tend to overestimate a positive prognosis for patients; patients may misunderstand the course of treatment; and there may be differences in racial and ethnic groups in caregiving preferences.¹³⁵

Informal Care Providers

The majority of long-term care is provided by the informal network—the family (spouses and children) and unpaid caregivers.⁵⁴ An estimated 91 percent of informal caregivers in general are family members (spouses 25 percent and children 50 percent).⁵⁴ Fifty percent of those without an informal family network reside in nursing homes compared to 7 percent of those with a family network.⁵⁵ Approximately 86 percent of the elderly at highest risk for nursing home placement (more than three ADL impairments) receive care from informal care providers.⁵⁶

Informal care providers are vital in the long-term care system. The majority of these caregivers are female and over age 60. Most are retired or do not hold paying jobs; of those who do hold paying jobs, two-thirds report conflict in providing care and maintaining employment.⁵⁶

The burdens on rural informal caregivers may be especially pronounced. In a study of the conflicts

encountered by informal caregivers in providing care to elders, using National Survey of Families and Households data, researchers found rural caregivers worked more hours at their place of employment, in the home, and in providing care in comparison to urban caregivers. This disparity is attributed to the lack of formal services in rural areas.⁴⁴ Given the role played by the informal provider, support and respite services are needed resources across locales.

Recent national comparisons of rural-urban differences in utilization of formal and informal services are scarce. An older study using the Longitudinal National Long-term Care Survey compares the amount of formal and informal assistance received for ADLs and IADLs among noninstitutionalized disabled adults.⁵⁷ The study found that residents in areas categorized as open and farm areas were less likely to receive formal ADL and IADL assistance than urban residents. At the same time, residents of these areas were more likely to receive informal assistance with IADLs, such as grocery shopping, meal preparation, housework, and traveling. There was no difference by residence of the likelihood of receiving informal assistance with ADLs (e.g., eating, toileting, getting in and out of bed, walking inside, dressing, and bathing). Other factors may also play a role, such as preferences, informal support network, knowledge of services, and housing characteristics.⁵⁷ The study is uncertain as to the degree to which availability of services or cultural factors impact utilization of services (i.e., attitudes, preferences, etc.).

A commonly held belief is that rural elderly are at an advantage in having greater access to familial networks.¹³⁶ However, the research finds this is not the case. Braden found familial networks were relatively the same, with nonmetro elders as likely as metro to live alone or with nonfamily members.²¹ More recent literature suggest rural elderly may experience greater challenges in accessing familial networks of informal care, particularly adult children who may live at greater geographic distance.⁵⁸ Rural elderly, less able to access care due to out-migration of younger family members, must rely on other informal caregivers.^{93, 137, 138}

IMPACT OF THE CONDITION ON MORBIDITY AND MORTALITY

The mental and physical health of the aging population is a key determinant in estimating the demands on the long-term care system. Rural elders (in this case defined as those over age 55) have a lower risk of mortality; however, after age 75, this “protective factor” disappears.⁶⁰ Rural elders also experience more morbidity than nonrural.⁵⁹ This may be the result of delayed care; rural elders tend to seek care when other modes of relief have failed. It is suggested that the emphasis in rural areas is on the “cure rather than care.”¹³⁹

While expanded *quantity* of life is an indicator of improvements in health and health technology, the *quality* of life—the ability to remain active and engaged—is an essential consideration in choosing, designing, delivering, and evaluating long-term care services. In a North Carolina study of the relationship between population density across the five subsections of the rural-urban continuum and health-related quality of life, as measured by six indicators, the researchers found that there was a significant decrease in three quality-of-life factors (the degree of interference from chronic illness, number of IADLs, and number of depressive symptoms) as population density increased.¹⁴⁰ With the exception of ADLs, this study suggests that urban elderly experience a higher quality of life than those outside of urban areas.¹⁴⁰ This study, as well as others, reinforces that differences do not always fall along a simple and straightforward rural-urban continuum; utilizing a “continuous” measure of rurality (i.e., analysis of smaller subsets of the rural-urban continuum) is necessary to unmask more subtle differences by population density.¹⁴⁰

Key barriers faced in accessing care in rural areas include distance, geography, lack of providers, and limited knowledge of resource availability.⁶¹

BARRIERS

The need for long-term care services will continue to grow as the ranks of the elderly increase. Meeting this demand, particularly in rural areas, is complicated by a host of factors ranging from systemic (e.g., shortages of providers, scarcity of resources) to socioeconomic, cultural, knowledge, and geographic barriers (e.g., long travel distances and difficult terrain). Congdon says the key barriers faced in accessing care in rural areas include distance, geography, lack of providers, and limited knowledge of resource availability.⁶¹

Systemic Barriers

Systemic barriers include those constraints that impede access to services. One key barrier is the lack of availability of a broad range of long-term care services in rural areas and coordination of services. Travis and McCauley point out that this is the result of a lack of incentives to invest in coordinated long-term care networks. Specifically, the heavy reliance on state and federal funding diminishes market incentives to provide these services.⁶³

Provider Shortages

The shortages of skilled providers coupled with limited community resources further restricts expansion.⁶³ It is projected that personal and home care assistants will be the fourth fastest growing profession by 2006, experiencing an 84.7 percent growth rate. However, turnover rates are 70 percent for direct-care workers. In addition to poor pay (less than \$18,000/year), the work is physically and emotionally demanding. The Bureau of Labor Statistics, in 2000, estimated there were 1.8 million direct-care workers in long-term care; this is compared to 5.9 to 7 million informal caregivers providing care to elders over age 65.^{120, 141, 142} Overall, the need for LTC providers is projected to rise precipitously over the next 40 years as baby boomers reach retirement.¹²⁰ The highest employment projections are in the community-care setting between 2000 and 2010, growing 5.5 percent annually.¹²⁰

Cultural Barriers

Travis and McCauley point out another barrier to investment in long-term care networks is the preference of elderly to rely on informal caregivers.⁶³ Another barrier is the tendency of rural residents to only seek formal assistance when the informal system fails.⁶⁴ Estes and Swan estimate that 80 percent of home care is provided by unpaid persons, including family and friends or volunteer agencies.¹⁴³ A national study by Rabiner et al. found nonmetro elderly more likely to discount functional limitations, which the author attributes to attitudes of independence, better health status than their older peer group, and fear that reporting of limitations could result in institutionalizations.²⁸

Kosloski et al. analyzed the role of culture in the use of respite services among patients with Alzheimer’s Disease and their caregivers.¹⁴⁴ The study found a positive relationship between respect for the care recipient and use of respite services. African Americans were found to express higher levels of affection for the “care receivers.” Likewise, urban caregivers felt a higher obligation to care and accorded greater respect to elders.

Socioeconomic Barriers

Unless the rural elderly are able to qualify for Medicaid or other assistance programs, clients must utilize their own resources to pay for long-term care services. Services, such as assisted living, may be financially out of range for low-income seniors.

Knowledge Barriers

Entry into the long-term care system is often precipitated by a health event such as an accident or fall. Decisions regarding choice of long-term care providers, as well as transitions between providers, are often made in “crisis” mode with little advance planning.⁹³ Many seniors and their families may be unaware of the services available in their areas. The knowledge barrier amplifies the need for coordination of care in rural areas.

Overall, the major barriers to access to care in rural areas for the elderly are isolation, economic (low incomes and tax base), lack of trained providers, and the rural culture itself.⁶²

KNOWN CAUSES OF THE CONDITION OR PROBLEM SO EFFECTIVE INTERVENTIONS OR SOLUTIONS CAN BE IDENTIFIED

Mollica points out “reimbursement and choice are the primary state and consumer forces driving development of the long-term care system.”³⁵ Choices in rural areas are constrained by a variety of factors including provider shortages; lack of economies of scale to support expansion of services and facilities; geographic barriers in the form of extended travel distances, often over difficult terrain; cultural barriers and preferences impacting care-seeking behavior; and financial difficulties at the individual, family, and community levels. Developing, implementing, and sustaining effective interventions across the long-term care continuum requires identification and understanding of the forces that impact access.

PROPOSED SOLUTIONS OR INTERVENTIONS THAT ARE FEASIBLE IN RURAL COMMUNITIES

Improving access to and capacity of a range of long-term care services in rural areas requires understanding of not only the diverse factors impacting treatment seeking and choice but also the host of barriers confronted in the provision and delivery of services. Solutions may be targeted toward improvements in access and availability of a single element in the continuum, such as development of affordable assisted living, or may be more global, such as comprehensive case-management initiatives that coordinate health resources for elders—essential in bridging the knowledge and communication gap between consumer need and availability of services. The approaches included in the following discussion can be categorized by the barrier addressed: structural, geographic, knowledge and communication, and economic. The common threads among the various

approaches are the recognition of disparities, capitalization on available resources, and development of innovative approaches to solve problems pervasive in rural areas.

Structural Barriers

One of the key challenges in rural areas is addressing the issue of provider shortages. A number of communities have implemented innovative programs that are designed to address the issue of provider shortages. One such example, as highlighted in the models for practice section, focuses on reducing turnover by emphasizing caregiver buy-in, literally and philosophically. Cooperative Care is a member-owned cooperative designed to provide in-home services to elderly, the disabled, the chronically ill, and those with developmental disabilities in rural Wautoma, Wisconsin, and the surrounding counties. Modeled after a New York-based cooperative, members receive higher wages, paid time off, holiday pay, health insurance, and other benefits previously unavailable to them. Overall, the benefits are improved access to a sustainable pool of trained providers. Turnover among Cooperative Care's workers is significantly lower than national averages. Simultaneously, 96 percent of the clients report satisfaction with the services provided.

Methods to sustain and expand the pool of providers may require looking beyond the traditional providers of long-term care services. One such example of this approach is the Rural Minority Geriatric Care Management Model (from the models for practice section) based in Charleston, South Carolina. This program utilizes paid geriatric coordinators—a new type of paraprofessional. The coordinators serve as client advocates, providing case management, outreach, and coordination of services. The model primarily targets older African Americans through a federally qualified health center (FQHC), satellite sites, and rural health clinics. A full description is included in *Rural Healthy People 2010, Volume 1*.¹

Funded by the Robert Wood Johnson Foundation (RWJF) and the Atlantic Philanthropies, *Better Jobs Better Care* is a four year research and demonstration program. This program provides

grants to test and evaluate innovative programs that address direct-care workforce shortages in the long-term care setting. Applied research grants have been awarded to research policy changes in long-term care; workplace culture, organization, and management; direct-care workers' job preparation and training; and new ways to increase the number of available workers. Demonstration grants have been issued to agencies, which have implemented methods to improve the training and benefits available to direct-care workers.¹⁴⁵

While formal providers are a crucial element in the LTC continuum, programs that engage and support informal providers are also important initiatives. Spouses, children, extended families, and friends, in providing informal and unpaid care, make a significant contribution to the health of an aging population. At the same time, they often experience heavy psychological and financial stress. In recognition of the challenges in providing care, the National Family Caregiver Support Program was launched in 2001 as part of the Older American's Act. This program provides grants to states to develop programs to assist family caregivers in providing care to elderly family members in the home.

Involvement in what has been termed "circles of formal and informal care" is suggested as an effective approach to care management.¹³⁸ The Social Care Model is a conceptual model in which elders are at the center of a formal and informal network of providers. This model, which capitalizes on existing family and friend relationships, may be particularly relevant in designing effective LTC programs in rural areas. A number of studies have pointed out that rural elders express a preference to receive care from informal networks. Therefore, models that integrate formal and informal services may successfully overcome barriers in rural areas by supporting effective collaboration between these "circles of providers."¹³⁸ Involvement of community leaders in the planning and implementation of models and encouraging "flexibility, creativity, and innovation" are key ingredients in program buy-in and sustainability.¹⁴⁶

Geographic Barriers

Throughout this document, geographic barriers are presented as a significant hurdle for rural residents and providers. Technologies such as telehealth, video monitoring, and e-health platforms have been utilized in a variety of settings including home health, hospice, elder education, and mental health counseling. Telemedicine has successfully been employed in rural areas of Kansas and Missouri using interactive video equipment installed in the hospice patient's home.⁶⁵ Tele-psychiatry is suggested for rural elderly with mental disorders.⁶⁶ This technology allows a psychiatrist to be centrally located as a method to more effectively distribute scarce resources—in this case, access to mental health providers. *Senior Navigator* is a free online resource available to elder Virginians that provides information regarding particular illnesses as well as extensive details regarding local health and aging services. The program has an “Ask the Expert” feature that links seniors to geriatricians, elder law attorneys, financial planners, occupational therapists, and caregivers in Virginia.¹⁴⁷ Senior Navigator is accessible at <www.seniornavigator.com>.

Pathways in Caring, a web-based training and support resource for caregivers that is available at <<http://caregivers.mc.duke.edu/>>, is produced by the Duke University Medical Center and the South Carolina School of Medicine.¹⁴⁸ This program was nominated as a best practice at the Geriatric Best Practices Conference in 2004, as part of an initiative by The Duke Endowment, the South Carolina Hospital Association, and the Sage Institute to increase awareness of innovative practices.

One service particularly impacted by geographic barriers is day adult services. Georgia—a state with only 23 percent of its need for day adult services met, according to the Robert Wood Johnson Foundation survey—developed an innovative approach in the use of mobile day health services wherein the providers capitalize on existing community infrastructure to bring day care to otherwise underserved areas.¹²⁷ The Georgia Mobile Day Care Program, as discussed in the models for practice section, brings day care to communities that

would otherwise not have the resources to support this service. The shared staff travel up to 50 miles per day to a program site, such as a community senior center.

Knowledge and Communication Barriers

Consumer decisions regarding health care and long-term care are often made with imperfect information; choices are frequently made in crisis mode without a full understanding of the range of resources available. Coordination and integration of services is an effective means to bridge this gap and improve care for elderly populations. A primary component of this model, as noted in a recent Institute of Medicine report, is the use of case management, connecting elders with necessary medical and social services.^{8, 67}

Cogdon and Magilvy point out that rural areas need “well-organized, consistent, efficient, and affordable community-based care management for rural older adults and their families.”⁶¹ Nonetheless, there are few examples of integration of primary, acute, and LTC.⁶⁸ A primary reason may be the difficulty in translating urban models into rural practice given the unique challenges confronted in rural areas. An integrated model, according to Bolda and Seavey, would differ from urban models due to limited managed care penetration, smaller service capacity, more limited supply of providers, and fewer residents. In a rural model, the hospital may play the dominant role by virtue of its position as the health care hub and its experience with managed care.⁶⁸ An example of this type of model is seen in the Community-Based Case Management Program of the Margaret R. Pardee Memorial Hospital in North Carolina. This case management model coordinates the medical, psychosocial, pharmacological, functional, and spiritual problems of those over age 45 with the intent of coordinating services to avert more expensive care needs. The Margaret R. Pardee Memorial Hospital serves as the hub for this service model.

A well known model of service integration for the frail elderly is the Program of All-Inclusive Care for the Elderly (PACE). PACE initially began as a series of demonstration projects in the late 1980s and early

1990s and was granted permanent provider status as the result of BBA 1997.¹⁴⁹ The program is a multidisciplinary approach focused on the needs of the client, with the goal of preventing or delaying institutionalization by providing coordination of health and social services.^{69, 151} This model coordinates the continuum of health services from preventive care to primary, acute, and long-term care; it also integrates Medicare and Medicaid payment.^{149, 151} The Core Act is designed to promote PACE programs in rural areas.¹⁵² Hawes and Rushing, in a review of the ability of PACE to serve rural areas, found a number of studies noting the positive impact of PACE. Among these were lowered costs due to the decreased number and length of inpatient stays, reduced NH use, decreased polypharmacy, and improved medication compliance. While there are examples of successful implementation of PACE into rural areas, such as the South Carolina PACE Program, it is worth noting full implementation of PACE in rural areas requires identification of and plans to address significant barriers to rural implementation. Among these are transportation difficulties, lack of providers, difficulties in providing the required broad range of services, enrollment of sufficient numbers of participants, financial viability, and degree of experience with managed care. Hawes underscores that while these barriers represent significant areas of consideration for rural planners, PACE, nonetheless, serves as a model of the positive effects of care integration and coordination for frail elderly patients.¹⁴⁹

Navigating the long-term care system is often a daunting task for the elderly and their families. One suggestion to improve communication and coordination is the use of “single entry points.” A recent Kaiser Family Commission report notes the development in 31 states (and D.C.) of a “single entry point” that combines assessment, eligibility, care plan development, information, and referral under a single local entity for Medicaid recipients.¹⁵³

Overall, there is an increased emphasis on home and community-based services and active involvement of the consumer. The Kaiser Commission report pointed out seven goals of the Medicaid LTC

program to include *expansion of access to HCBS services, reduction in institutional bias, greater consumer choice in services and settings, expanded eligibility of care, stabilization of financing, improved capacity for strategic planning, and tool development.*¹⁵³ The group noted efforts by states to shift from provider focused to “consumer-centric” LTC systems that invite active participation in LTC planning by consumers, families, and advocates.

Economic Barriers

For many, long-term care often represents the single largest lifetime expenditure for care services. Personal choices regarding care options are not only limited by availability of services but the ability to finance these services. Assisted living is considered an attractive alternative for many seniors who are unable to remain in their homes but do not need the level of nursing care provided in nursing homes. As noted earlier, a key barrier is cost for rural elderly as well as community developers. The Robert Wood Johnson Foundation and the NCB Development Corporation have been instrumental in promoting the development of affordable assisted living in underserved areas through the *Coming Home* Program. The 13-year project has provided 14.3 million dollars in funding to communities to pay for feasibility studies as well as provide technical and financial expertise to communities that would otherwise not have the resources to develop assisted living facilities.⁷⁰ As highlighted in the models for practice section, one of the first projects was the River to River Residential Corporation in southern rural Illinois. River to River has developed three affordable assisted living facilities, offering high service and high privacy—a combination lacking in rural areas, to a 13-county area of southern Illinois with a disproportionately high number of low-income seniors. River to River is able to provide assisted living to low-income elders by utilizing a variety of funding vehicles, including low-income tax credits, tax-exempt bonds, and conventional loans.

The *Coming Home* Program and NCB Development Cooperation have developed a feasibility model that helps communities conduct a self-assessment to

determine the viability of assisted living in their community. The tool is available at <http://www.ncbdc.org/>.

Another example of an innovative approach to assisted living is to pool resources and share costs with a rural hospital. Matagorda Hospital District built 30 ALF units and 20 independent living units in Bay City, Texas. These units are attached to an existing skilled nursing unit and facilitate the sharing of laundry services, food preparation services, and some staff.⁷¹

Robert Wood Johnson Foundation’s “Respite Care and Dementia Services Program” and the subsequent “Partners in Care Giving” program addresses the need for day adult services for those with dementia and other diseases, as well as providing needed respite care for informal caregivers. Based on 10 years of experience in development of adult day services, program evaluators identified best practices and the elements of successful day care programs. Among these 10 keys are effective recruitment strategies, hours of operation (i.e., open during work week hours to facilitate the caregiver to maintain a job), financing strategies, and transportation. A full list of the lessons learned is available at <http://www.rwjf.org/reports/npreports/partnerse.htm>. In a national study of day adult services, RWJF found adult day cares require a population base of 20,000, with potentially 1 percent of the population as potential candidates, and must serve 20–30 people per day. Secondly, successful rural adult day care should focus on a range of disorders in contrast to an urban center that may have the ability to focus on a particular disease (such as dementia).¹²⁷

Given the recognition of the role played by informal caregivers, respite care provides an important relief for the caregivers. Administered through the Administration on Aging (AOA), The National Family Support Caregiver program was designed to address the needs of the informal caregiver. Through the Department of Health and Human Services (DHHS), the program provides grants to states to inform caregivers about the availability of services as well as to assist in accessing care, provide

counseling, caregiver training, problem solving, and respite services.¹⁵⁴

Financing of long-term care presents a significant challenge for elders and their families. Long-term care insurance is promoted as a means to decrease the financial burden. However, the cost may be unaffordable to low-income brackets, and plans may not cover the range of services needed. In 2000, less than 10 percent of those over 65 had LTC insurance; those ages 55–64 had even lower enrollment rates.¹⁵⁵

It is not possible in the space allowed to provide a comprehensive list of the range of solutions developed and suggested to improve access to necessary long-term care services. However, a number of organizations have resources available that offer extensive lists of programs in long-term care and aging. The Visiting Nurses Association of New York has compiled a list of best practices in long-term care and aging in rural and urban areas. This resource is available at <http://www.vnsny.org>. A collaboration between Duke Endowment, the South Carolina Hospital Association, and the Sage Institute developed a geriatric best practices initiative in the Carolinas. The initiative identifies best practices in rural and urban areas across a range of LTC services, including coordination of care, hospice, adult day services, and geriatric education, to name a few. The information is accessible at <http://www.bestgeriatrics.com>. The Archstone Foundation and the Gerontological Section of the American Public Health Association, as part of its philanthropic efforts addressing the needs of the elderly, recognize innovative geriatric programs through its Award for Excellence in Program Innovation. The list of recent awardees is available at <http://www.archstone.org/>. The West Virginia Center on Aging has also developed “Best Practices in Services Delivery to the Rural Elderly.”³¹

COMMUNITY MODELS KNOWN TO WORK

See the Models for Practice section of the Rural Healthy People 2010 website.

SUMMARY AND CONCLUSIONS

The aging of America represents one of the most significant challenges facing the United States health system, as acute and long-term care services strain to meet the associated care needs of this population. The long-term care system is challenged to provide a range of services that meet the diverse care needs of this population, ranging from community-based options to residential alternatives. Rural areas, with a disproportionately large elderly population and lacking the necessary resources to provide a range of long-term care services, may face even greater hurdles in providing a network of services. Overall, states are looking toward methods to integrate the LTC continuum as a means to control costs as well as promote community-based options.¹⁵³ Expanding assisted living options to low-income seniors and expansion of HCBS in rural areas are attractive options but face significant challenges ranging from staff shortages to inability to attain economies of scale. Finally, informal caregivers (spouses, children, friends) are the largest contributor to LTC. If the LTC system is to meet the demands of the growing elderly population, the significant contribution of informal caregivers should be recognized and supported.

In summary, improving access to LTC services requires addressing the range of factors from the system constraints to the unique rural barriers that impact provision of services and treatment seeking. Coordination of care promoting improved communication between providers (informal and formal) and patients, use of innovative technologies to bridge distance barriers, persistent focus on recruitment and retention efforts, support for informal care networks, initiatives to improve affordability for patients, and LTC feasibility for providers and communities are a few of the essential components in improving access to LTC services in rural areas.

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