



The Technical Assistance Center for Lifespan Respite *Fact Sheet Number 35, October 2012*

Respite for Rural Family Caregivers: Overcoming the Challenges

Introduction

Family caregivers living in rural areas face unique challenges to accessing supports, including respite, regardless of the age or condition of the care recipient. Family caregiving can be stressful, but when faced with fewer job opportunities and financial resources, limited access to health and social services, transportation barriers and the geographic isolation that predominate in many rural areas, family caregivers may experience added stressors.

Rural areas have evolved over time and reflect current social, economic and political climates. The number of family farms has declined and dependence on agriculture for economic stability is significantly less than it was several decades ago. For many years, young people have been leaving rural areas for economic and social reasons. The result is a larger rural aging population increasingly dependent on individuals other than immediate family members for day-to-day caregiving assistance. This change, and the fact that family members have returned to the workplace out of necessity, have reduced the supply of family caregivers, and lessened the available pool of possible formal service providers. A large number of veterans in rural areas, many of whom may have health and social service needs, results in an even greater demand for caregiving services.

At the same time, while rural poverty remains entrenched in some areas, changing economic and social trends have altered many preconceived notions of rural areas. The fact sheet will touch on some of the factors that are changing the rural landscape, including economic diversification

and encouragement of new industries in many rural areas. In addition, amenities that attract new residents, including retirees, and urbanites eager to escape the stresses of city living have had an impact on the makeup of rural populations.

The purpose of this fact sheet is to present a clear picture of care recipients and their caregivers who live in rural and frontier areas and to offer suggestions to assist family caregivers, respite providers and administrators, and Lifespan Respite grantees in finding or developing respite resources.

The Changed Rural Landscape

In 1953, there were 54 million rural people in the United States, representing 36% of the U.S. total population (Tarmann, 2003). The definition of rural has changed a bit since then, but comparisons are still noteworthy. According to the U.S. Census Bureau in 2010, "rural encompasses all population, housing, and territory not included within an urban area," generally meaning areas with fewer than 2,500 residents. The 2010 Census found that the rural population was 59 million, representing only a slight increase from 2000 and certainly more than in 1953. However, the proportion of the US population living in rural areas declined from 21% in 2000 to 19% in 2010, down dramatically from 36% in 1953 (US Census Bureau, 2010).

The population living on farms in rural areas has changed even more dramatically. Seventy years ago, there were nearly seven million US farms, and 43% of the rural population lived on farms (Tarmann, A., 2003). Today, there are about two million farms and less than 1% of the U.S. population live on

farms (U.S. Census Bureau, Statistical Abstract of the United States: 2012; U.S. Department of Agriculture, 2012). However, loss of farms has not been the only factor affecting rural demographic and economic shifts, especially in more recent years. There are other struggling industries related to natural resources - such as mining and logging – that have affected rural economies (Rural Assistance Center, ND). Much of the rural population now live in rural or small town areas close or accessible to jobs and services in urban areas or commute to their jobs.

Frontier Areas

Many of the barriers and challenges discussed in this fact sheet are exacerbated for family caregivers living in frontier areas. Frontier areas may be defined as sparsely populated rural areas that are isolated from population centers and services. Most frontier areas are located in the western United States. The definition sometimes includes having a population density of six or fewer people per square mile, but this may not take into account other important factors that may isolate a community. For more information on frontier areas, see the Rural Assistance Center website at <http://www.raconline.org/topics/frontier/frontierfaq.php#county>

Demographics and Living Arrangements of Rural Caregivers and Recipients

From a 2009 National Caregiver Survey (NCS), it was found that care recipients age 50 and older are slightly less likely to live in a rural area (28%) than their urban (32%) or suburban (38%) counterparts, and this pattern has not changed since the last survey in 2004. A similar situation exists for their caregivers: 29% live in urban areas, 39% in suburban areas, and 31% in rural areas. Female caregivers of someone over age 50 are more likely

than male caregivers to care for someone who lives in a rural area (31% vs 23% of male caregivers). Nearly four in ten caregivers of a younger adult live in a rural area (36%) or a suburban area (35%), and about 1 in 4 live in urban areas (27%), while 30% of caregivers of children live in urban settings, 40% in suburban, and 26% in rural settings (National Alliance for Caregiving, 2009).

In an effort to further illuminate the unique demographics and needs of rural family caregivers and care recipients, Easter Seals and the National Alliance for Caregiving produced a report on rural caregiving in 2006 using data results from the 2004 National Survey of Family Caregivers. In the report, caregivers were defined as people age 18 and over who help another person age 18 or older with at least one of 13 tasks that caregivers commonly perform (e.g., manage finances, shop for groceries, provide assistance with activities of daily living).

Select demographic highlights include:

Caregivers:

- A higher proportion of rural caregivers report being married (64%) compared with urban (50%) and suburban (56%) caregivers.
- Similar to urban (25%) and suburban (21%) caregivers, 25% of rural caregivers reported living in the same household as the care recipient; 60% live within a one-hour drive.

Care recipients:

- Seventy percent of the rural care recipients were women and 30% were men.
- Twenty percent of the rural care recipients were under 50 years of age and 80% were 50 and over; 27% were between the ages of 75-84.
- Nearly 74% of the rural care recipients lived in their own homes.
- Twenty-nine percent of the rural care recipients were married, 48% widowed, 13% single, and 10% divorced or separated (NAC and Easter Seals, 2006).

The Rural Environment

Rural areas have unique, although not exclusive, strengths, resources, and challenges particular to both people and place. Rural communities typically have older populations, are somewhat poorer, and more reliant on public programs like Medicaid and Medicare than other parts of the country. However, it is important to note regional differences. Three quarters of rural residents live in the South and Midwest, compared to only one-quarter in the Northeast and West. While five million people live in isolated and remote locations, around 31 million people living in rural counties live close to an urban area. More recently, younger populations and retirees have been drawn to new opportunities in rural parts of the South and West (UnitedHealth Center for Health Reform and Modernization, 2011).

A sense of community is often heightened in small communities. Family, extended family, and shared cultural beliefs frequently provide natural supports. A greater sense of independence and self-reliance may also exist. Reluctance to use formal services, as well as a lack of availability of a service, may become barriers to seeking outside help. Faith communities are often central to rural life and a natural place to turn for support.

Unique Stressors in Rural Areas

Rural areas may impose challenges that serve as additional stressors for family caregivers.

Geographic

Geographic isolation and dispersion is typical in rural or frontier areas where a sparse population is spread across large land areas. In a number of states, mountainous terrain, large bodies of water, and climate (long, severe winters or summers) may create even more isolation (Rural Assistance Center, ND).

Socio-Economic Indicators

There are fewer financial, health and social resources in rural areas and pay is often lower. The

share of residents with incomes below the poverty level is greater in nonmetro than in metropolitan (metro) areas, a trend that has persisted since the 1960s. In recent years, poverty in rural areas has risen. Between 2000 and 2009, nonmetro median household income has decreased from \$40,999 to \$40,135 (in 2009 dollars), while the nonmetro poverty rate rose from 13.4 percent to 16.6 percent (US Department of Agriculture, 2011). The 2010 nonmetro poverty rate (16.5 percent) did not change significantly from 2009 (US Department of Agriculture, 2012). Between 1988 and 2008, over one-third of non-metropolitan counties lost at least 10% of their population as youth left for urban centers in search of greater economic opportunities (McGranahan, Cromartie, and Wojan, 2010).

Health and Insurance Disparities

Socio-economic status, risky health behaviors, too few physicians and other health care workers, and limited access to employer-provided health care coverage have contributed to health disparities in rural communities. The rural population is older, has fewer economic resources, and poor overall health compared to their urban counterparts (Rural Assistance Center, ND). In fact, rural residents experience greater rates of chronic disease than any other segment of the U.S. population (US Dept of Health and Human Services, Health Resources and Services Administration, ND)

Access to mental health services and rates of suicide, stress, depression, and anxiety disorders have been identified as major health concerns among state offices of rural health. In 2003, mental health was named by nearly 50% of national and state experts as a rural health priority behind access to health care (Gamm, Larry D., et al, 2003). In 2010, mental health remains a significant concern, with close to 60% of national and state experts listing mental health and mental disorders as the third rural health priority just after health care access and diabetes (Bolin, J. and Bellamy, G., 2011).

Mobile Day Care Program in Georgia

The **Mobile Day Care Program in Georgia** allows caregivers in rural counties a period of respite from their 24 hour-a-day caregiving responsibilities for persons with dementia. Mobile day care enables rural communities to have their own day care program while “sharing” staff who travel between locations. With funds from the Administration on Aging’s (AoA) Alzheimer’s Demonstration Grants, the Greater Georgia Chapter Alzheimer’s Association developed the innovative concept, and the program was implemented by the Augusta Area Chapter Alzheimer’s Association, with technical assistance from the Central River Savannah

Area (CSRA) Area Agency on Aging. Though initially developed for caregivers of persons with Alzheimer’s Disease, mobile day care is a program which can serve other adults in need of day care, and is a service option which may be viable whether serving a rural county or the borough of a large metropolitan area. More information is available from Georgia DHS Division of Aging Services at <http://aging.dhs.georgia.gov/mobile-day-care>. For another example of a rural mobile respite option, see **Oklahoma Lifespan Respite’s Mobile Respite Program** under the Federal Funding, Lifespan Respite section of this fact sheet.

Social Isolation

Additionally, although some rural communities are tight knit, in many places, there are few social outlets or resources to provide a haven for people to gather for conversation and recreation. Faith-based organizations may be the only source of social support for many rural residents. This situation may be exacerbated in frontier areas, where population and services are even more sparse.

Transportation Barriers

Transportation can be a particular problem for families in rural areas who need access to planned or emergency respite services. Families may not have their own means of transportation, they may have to travel a long distance to receive respite, and/or their children with health care needs or aging dependent family members may be difficult to transport.

Nearly 40% of the country’s transit dependent population, primarily senior citizens, persons with disabilities and low-income individuals, resides in rural areas (Community Transportation Association, 2010). Yet, in many of these communities public and community transportation are limited or absent.

Nearly 40% of all rural residents live in areas with no public transportation, and another 28% live in areas with limited levels of service (Rural Assistance Center, ND).

Lack of public transportation, and often great distances between communities, result in high travel costs and time expenditures. For people with disabilities living in rural areas, transportation may be of paramount concern. Limited or inadequate transportation options can keep individuals with disabilities from fully participating in community life and may even impede access to health care and other services (Association of Programs for Rural Independent Living, 2011).

It is important to note that limits in transportation options, including limited public transportation, also pose significant barriers for respite workers trying to reach family caregivers in their homes or even to get to a place of employment. Respite workers or volunteers may also have to travel long distances. When long distances are coupled with high gas prices and seasonal road and weather conditions, transportation barriers can be even more imposing. Moreover, when fewer people can be served per day due to significant travel time in

rural and geographically isolated areas, providing respite in rural areas may not be financially viable for traditional agency-based service providers and direct service workers (Brown, D. Kip, et al, 2011).

Minority and Cultural Concerns

While minority populations may be relatively small, rural communities are increasingly composed of lifestyle, ethnic, or racial minorities with language, culture, or family structures that differ from the dominant culture and from one another. In the rural farming community, despite the decline in the number of farms, the 2007 USDA Census of Agriculture found that farmers and ranchers are becoming more diverse and that the number of Asian, Spanish, Hispanic or Latino, and Black or African American farm operators continues to rise (US Department of Agriculture, 2007 Census of Agriculture, 2012).

Native Americans who live on tribal lands which are most frequently associated with rural and frontier areas comprise a large rural minority population with unique caregiver needs. The Native American Caregiver Support Program makes grants available to Tribes for the delivery of supportive services, including respite, to eligible older individuals. Volunteers In Service To America (VISTA) programs partner with Tribal organizations to help support and create sustainable caregiver programs in Native American communities, many of which are geographically isolated. Tribal leaders maintain that a core value of Native American Caregiver Support Services is not to replace the tradition of families caring for their elders, but to support it in order to strengthen the family caregiver role (U.S Department of Health and Human Services, 2012).

Many minority or other culturally diverse population groups who live in rural areas face the same barriers to services as other rural caregivers. They may have the added obstacles of mistrust of service providers, particularly if they are different from their own culture, language barriers, or fear seeking providers or facing exclusion from services because of immigration status, perceived biases or other issues.

Rural Respite Barriers

There are many barriers to a rural caregiver's ability to find respite that are related to the unique rural stressors described previously. Many rural areas struggle with providing quality home-based supports such as respite due to geographic isolation, fewer available services, transportation limitations, demographic trends reducing the supply of family and professional caregivers, and less ability to recruit an adequate supply of direct service workers. It is a challenge to find care providers, both informal providers, such as family members, friends or relatives, as well as formal respite providers who work for an agency that provides respite. In most cases, specialists such as physical/occupational and communication therapists, special education professionals, psychologists, and crisis counselors as well as respite providers tend to concentrate in urban areas. As a result of the shortage of respite and other service providers with particular areas of expertise, rural programs may face difficulty in recruiting and retaining respite providers.

Additionally, when respite programs are available, they are typically small and locally funded. State and federal funding may be inadequate to support needed personnel. Lack of transportation affects choice and use of respite services; and if programs are accessible, they may be under-utilized because families are not comfortable asking for help from people they do not know. Similarly, programs that match care receiver and provider by ethnicity are often not widely available.

Consequences of Caregiving in Rural Areas

In 2004, 45% of rural caregivers provided care for 1-9 years, and 14% provided care for at least 10 years. Rural caregivers spend an average of 21 hours per week caregiving, but 19% of them spend more than 40 hours per week caregiving (NAC and Easter Seals, 2006). Forty-one percent have children or grandchildren living with them. More rural caregivers have reported caregiving was "very stressful" compared to their urban and suburban counterparts (NAC, 2009). Caregiver

stress is a strong predictor of nursing home entry, and physical strain and financial hardship are important predictors of high levels of caregiver stress (Spillman, 2007).

Often not identified by health and social service providers until a crisis has arisen, especially in rural areas, family caregivers of older adults frequently experience feelings of burden and depression. This was demonstrated by the Maine Primary Partners in Caring (MPPC) project in 2004, which identified rural family caregivers of older adults through physicians' offices and offered preventive support services. High levels of caregiver burden and depression were found among this sample of rural caregivers. The project demonstrated that providing family support and knowledge of caregiver tasks decreased caregiver burden and depression, while isolation predicted increased caregiver burden (Butler, S.S., et al, 2005; University of Maine, Maine Primary Partners in Caring Project, ND)

Rural caregivers are often separated from extended family because education and job opportunities

for the younger generation are typically located elsewhere. This makes the isolated rural caregiver older than average. Further complicating matters, rural families have less access to skilled nursing and other long term care services than families in other areas (The National Advisory Committee on Rural Health and Human Services, 2006).

Caregivers' Use of Services

Rural caregivers are less likely to use formal services that might support them in their caregiving efforts. According to the National Caregiver Survey, fewer rural caregivers surveyed reported using formal services compared with their urban counterparts (NAC and Easter Seals, 2006). In addition, fewer rural caregivers tend to use formal respite, adult day care or support groups, perhaps because these services are not readily available, while urban caregivers utilized adult day care more often (NAC and Easter Seals, 2006). The survey also suggests that few rural residents access services through the internet. Only 25% of rural caregivers reported using the Internet to find information, while 37% of both urban and suburban caregivers reported using it (NAC and Easter Seals, 2006).

Education, Employment and Caregiving in Rural Areas

In rural areas, some caregivers may feel additional burden from economic stressors. In the NAC survey of rural family caregivers, about 28% reported annual incomes under \$30,000 and 27% reported experiencing a moderate to high level of financial hardship. Lack of higher education is often related to fewer career opportunities and lower incomes. Only 27% of rural caregivers are college graduates, significantly lower than their urban or suburban counterparts (NAC and Easter Seals, 2006).

A majority of family caregivers in rural areas are working full time. They have felt the burden of the economic downturn as well as the stress of working and being a caregiver. More than half of rural caregivers (54%) reported working full-time or part-time during the period in which they were providing care. In order to provide care,

Tri-County Caregiver Relief Services in Northern California

The **Tri-County Caregiver Relief Services in Northern California** provides both in-home and community respite in a 5 county, mostly rural area for individuals with developmental disabilities across the lifespan. The care is funded by California's Lanterman Act, which is an entitlement for individuals with developmental disabilities in the state and provides 8-30 hours of respite per month. Respite providers come to the home or take the care recipient to community activities where they can enjoy mainstreamed events and places such as dances, sports and the library. Some respite is provided for seniors, but through private pay only. Contact information: 530-755-3500 or caregiverrelief@yahoo.com.

56% of rural caregivers had to make workplace accommodations, such as take time off and/or leave their job early; 18% took a leave of absence; 8% went from full-time to part-time employment; 4% turned down a promotion; 3% took early retirement; 5% lost some job benefits; and 7% gave up work entirely (NAC and Easter Seals, 2006).

Rural Veterans and their Caregivers

A significant number of veterans live in rural areas. About 6.1 million (28%) of the 22 million veterans nationwide live in rural areas. Nearly half (3.3 million) of rural veterans are enrolled in the VA system. A disproportionate share of service members overall are from rural areas. These men and women comprise about one-third (31.9%) of the enrolled veterans who served in Operation Enduring Freedom and Operation Iraqi Freedom (OEF/OIF); many of these soldiers, including those who are injured, return to their rural communities as veterans (US Dept. of Veterans Affairs, 2012).

Veterans who live in rural settings have greater healthcare needs than their urban counterparts (US Dept of Veterans Affairs, ND). Yet, because of the rural barriers to health and social services discussed previously, as well as to VA services in some areas, frail, rural older veterans and the newer young veterans with injuries living in rural areas may be especially at risk of poor health outcomes and limited support for their family caregivers.

According to a 2010 survey of caregivers of veterans, urban and suburban caregivers of veterans reported that they are more likely than rural or small town caregivers to turn to support groups (41% vs. 30%) and local government and community organizations (52% vs. 40%) for information. At the same time, rural caregivers of veterans are more likely than their urban and suburban counterparts to report that there is no care manager at all to assist them (49% vs. 38%). Not surprisingly, caregivers of veterans who live in a rural area or a small town are more apt to experience depression as a result of caregiving (68%) than are urban or suburban caregivers (59%) (NAC, 2010).

Rural Respite Options

Consumer-Directed Respite

In rural areas where formal services may be in short supply, family caregivers may turn to informal providers for help. Informal providers may be considered family members or friends who provide the respite for the caregiver. They may be paid or volunteer their help. Respite can be provided in-home or out-of-home, with various types of providers and environments. In a consumer-directed model, family caregivers and care recipients are able to choose among available providers.

Some states, and now several state Lifespan Respite programs, have used consumer-directed models (also known as participant-directed) for respite and other home and community-based supports. This can be especially useful for low-income caregivers living in rural areas where formal supports are limited and less likely to be used by this group. In one study based in rural Georgia, self-directed caregivers reported financial,

Family Resource Center (FRC) in Iowa

The **Family Resource Center (FRC) in Iowa** provides a registry of respite providers for family caregivers in 20 rural counties. The Center's role is to provide guidance on assuring safety of care receivers and to assist in matching providers to families through a network of local coordinators. Local coordinators work with the families and their respite providers and assure compliance with state rules for the program. The respite providers are paid hourly. The FRC also operates a network of registered family day care homes in rural Iowa which are used to provide respite for seniors in the evenings or on weekends. Some of the homes are registered for child care, but only provide respite care. Contact information: 800-999-5101 or 712-792-6440.

physical, and emotional relief as well as the ability to provide better care. For example, compared to rural caregivers using traditional services, rural self-directed caregivers were significantly more satisfied with overall services and more often reported that these services enabled them to extend the time they could provide care in the home, thus avoiding nursing home placement (Perkins, et al, 2004).

Volunteer Respite

With appropriate training and staff supervision, volunteers can be used in almost any respite model and fulfill many roles. Volunteers can be used to provide direct care, organize and oversee activities, and carry out a variety of other tasks in programs such as day or overnight camps for individuals with special needs, adult daycare, after-school programs, and park and recreation programs. Even facility-based respite, which can take place in nursing

homes, residential facilities, assisted living, crisis nurseries, and group homes, can use volunteers in some capacity.

However, finding volunteers is more of a challenge in rural areas. Often, with the rural culture of “taking care of one’s own,” family members or neighbors may be solicited as respite volunteers. While this may not be an option for all rural caregivers, networking with others through faith-based and other organizations in the community can put the caregiver in touch with those willing to help. Campus ministries, 4-H clubs, high schools, and college organizations, such as the Key Club, may also be useful sources for recruiting volunteers. Businesses in the local community may expect its employees to provide some form of community service, or a local community college may need placement for its students in suitable internship positions as part of their education.

Northern Nevada RAVE (Respite and Volunteer Experiences) Family Foundation

The RAVE Family Foundation runs three respite programs that focus on the needs of rural families.

- The RAVE Family Center is a center-based program that provides respite care to families caring for children with special needs and their siblings ages 3 months to 6 years, while training high school volunteers to care for the young children.
- The Rural and Adult Respite program allows families residing in Washoe County and in the rural areas of Nevada to choose respite care options based on their unique needs, through the provision of an annual respite voucher. Families caring for a child or adult with a disability with the onset prior to age 22 may qualify to receive the respite vouchers based on the individual’s specific needs.
- Teen RAVE is a program for teens 14 to 17 years old with developmental delays and

special needs, supporting them in positive social experiences in the community. It is an opportunity for families to receive respite care while encouraging child-to-child interaction and social skill development with their peers in a variety of community environments. Teen and other volunteers are trained at the RAVE Family Center. The Teen RAVE program began as a pilot program from the Fund For A Healthy Nevada in 2006, and continued with a private donation from a Teen RAVE family.

All RAVE programs are currently funded through state, county and local foundations, as well as private donations and fundraising efforts. This allows RAVE to provide respite at no cost to the families. For more information, visit the website at www.raveforkids.org; call (775) 334-9647; or email at ravecenter@att.net. The address is P.O. Box 2072, Sparks, NV 8943.

Many innovative opportunities for the development of respite programs in rural areas rely on the use of volunteers. Hosting an event for a group with special needs can often be respite for family caregivers. For example, a day of horseback riding for children with autism or a lunch program for those with dementia can provide a much needed break for family caregivers. Another type of volunteer respite is mentoring programs. Volunteers are matched with a client in a targeted population. The volunteer provides support, guidance and activity. The time the mentor is spending with the care recipient often provides relief for the family caregiver. Respite co-ops have also been used successfully in rural areas. In some co-op programs, families who have recruited their own local respite providers become resources for families who are looking for a care provider. In many cases, this contact has led to the families themselves sharing care with one another.

Faith-based Respite and Support

In many cases, the effect of economic stress and out-migration for jobs has isolated rural families from neighborly supports. As a result, for many, the church continues to be the one source of strength and support in many rural communities (US Dept. of Agriculture, 2011). Faith-based organizations may offer a significant source of caregiver support and respite.

In rural areas, where government resources have often been scarce, faith-based organizations may be expected to serve the needs of their constituents beyond the spiritual. While respite programs in rural areas struggle to find and obtain limited resources, faith communities may have resources such as

Family Connection of South Carolina, Faith-based Partnerships for Respite

With initial funding from the SC Developmental Disability Council in the Governor's office and later a grant from the Robert Wood Johnson Faith In Action program, a co-op respite model was developed and is currently implemented in 6 sites around the state. The co-op model is a collaboration between parents and faith communities. A group of approximately 8-15 parents agree to cooperate (Co-op) and share the care of their children. Parent volunteers are the "experts in child care for children with special needs". Local churches and child care facilities provide facilities free of charge. Parents, as lead volunteers, mentor other faith-based community volunteers as they share the care of their children. Family Connections also developed a Benevolence Policy to allow churches to help families pay for respite care. For more information, contact WC Hoecke wchoecke@familyconnectionsc.org or visit the Family Connections website at <http://www.familyconnectionsc.org/programs/respite> For more information specifically on Benevolence Policies, see http://archrespite.org/docs/Faith-Based_Church_Policy.pdf.

facilities, volunteers and, in some cases, expertise that should be explored by those seeking respite services in rural areas. Tapping into these resources can be a great benefit in expanding a respite program.

Some faith communities sponsor parent or caregiver support group meetings in their facilities. During the meetings, a youth or adult group from the congregation provides childcare or eldercare in the same facility. Congregations often have a myriad of existing programs: mother's morning out, child development center programs, church school or youth programs, or social programs for seniors. Inclusion, or opening these programs to children or adults with special needs, gives families another option for respite on a regular or as needed basis. A faith community may decide to create a provider registry by training members of the congregation to provide direct respite services, either for pay or as volunteers, to individuals or in group settings, for children or for adults (Hoecke, WC and Mayfield-Smith, K., 2010).

Funding for Respite Services and Programs

A range of possible state and federal funding sources may be available to help caregivers pay for respite. In addition, rural public health centers, cooperative extension service or other caregiver cooperatives may provide or have access to respite funding resources. Faith-based organizations may have benevolent funds to help family caregivers pay for respite. Other respite funding may be available at the state, regional or local level through private nonprofit agencies such as the Alzheimer's Association, the ARC, or Easter Seals, although the reach of these organizations may be limited in rural and frontier areas. It is incumbent upon rural respite programs, State Respite Coalitions, and Lifespan Respite programs to actively seek these funding streams to help families pay for respite and to work with state funding administrators to determine if any of these funds are available to be used to support, expand or enhance respite services.

Federal Funding

The information in this section was adapted from ARCH's *Federal Funding and Support Opportunities for Respite: Building Blocks for Lifespan Respite Systems, 2012*.

Medicare

Medicare covers individuals age 65 and older, people under age 65 with certain disabilities, and individuals with end-stage renal disease. Coverage of respite care is limited to Medicare Hospice benefits and Medicare Advantage Special Needs Plans.

- **Medicare Hospice Benefits.** Hospice care is a program of support and care for individuals who are terminally ill and their families. Hospice is chosen to provide comfort at the end-of-life, rather than cure. Medicare covers a range of hospice services, generally at home, from a team which may include doctors, nurses, counselors, other medical professionals, social workers, aides, homemakers, and volunteers. In addition, inpatient respite care from a hospice in a Medicare-approved facility is available when

the patient's usual family caregiver needs a rest. Individuals receive hospice care in a Medicare-approved facility, allowing family caregivers a break. Such respite stays can last up to five days at a time, and there is no limit to the number of times respite can be used. There is a co-payment for respite services, which is 5% of the Medicare-approved amount for inpatient respite care. The hospice benefit is only available to individuals who:

- are eligible for Medicare Part A (Hospital Insurance)
- have been certified by a doctor and hospice medical director to be terminally ill with six months or less to live if the illness runs its normal course
- have signed a statement choosing hospice care instead of other Medicare-covered benefits that would treat the illness; and
- receive care from a Medicare-approved hospice program.

Medicaid

Medicaid is a federal and state entitlement program that pays for medical assistance for certain individuals and families with low incomes and resources. Federal regulations limit the ability of states to cover the cost of respite care directly as a regular Medicaid benefit, because it is considered a non-medical expense. The exception, begun in 1985, is the Medicaid Hospice option. However, there are a number of research, demonstration and waiver programs under Medicaid that have allowed states to provide respite as a low-cost alternative to treatment in a medical facility.

- **Medicaid Hospice Benefits.** For Medicaid-eligible individuals, hospice care is an optional benefit which may be available if chosen by the state. Respite is available to family caregivers who are caring for the patient at home on an occasional basis and for no more than five days at a time. Respite is not available if the patient is a resident of a nursing facility. As with the Medicare Hospice Benefit, the consumer must be terminally ill, elect to receive palliative

care (rather than treatment) for that illness, and receive care from an approved program.

- **Section 1915(c) Home and Community-Based Services Waivers (HCBS).** In addition to traditional medical services, states can also provide services not usually covered by the Medicaid program, as long as these services are required to keep a person from being institutionalized. Services covered under waiver programs can include respite care. Generally, every state offers some respite assistance through various home and community-based Medicaid Waivers. Each state's eligibility criteria and funding for waivers is different; check with your state's Medicaid office or visit state information on the National Respite Locator Service (www.respitelocator.org).
- **Programs of All-Inclusive Care for the Elderly (PACE)** programs provide social and medical services primarily in an adult day health center, supplemented by in-home and referral services in accordance with the participant's needs.

Rural PACE Pilot Grant Program

The Rural PACE Pilot Grant Program was a one-time grant program established under the Deficit Reduction Act of 2005 by Congress and administered by the Centers for Medicare and Medicaid Services (CMS). It provided fifteen providers with start-up funds to develop PACE organizations serving rural elders. All but three (Hawaii, Montana and West Virginia) of the original 15 grantees are still operational. In 2011, a Centers for Medicare and Medicaid Services (CMS) evaluation of the Rural PACE Pilot found that this approach produced numerous benefits, including reduced burden among family caregivers (CMS, 2011). For more information and a list of the original fifteen rural providers funded in the grant, see: <http://www.npaonline.org/website/article.asp?id=42>.

The PACE service package must include all Medicare- and Medicaid-covered services and other services determined necessary by an interdisciplinary team for the care of the PACE participant. A PACE program can incorporate caregiver services into the care plan and make respite services available to caregivers as a service determined to be necessary by the consumer's interdisciplinary team. In addition to breaks available to family caregivers during the provision of services at an adult day health center, respite may be available.

National Family Caregiver Support Program

Funding may be available for caregivers providing care for someone over the age of 60 or someone of any age with Alzheimer's disease or other neurological conditions. Also eligible are: grandparents and other relative caregivers (not parents) 55 years of age or older providing care to children under age 18, and grandparents and other relative caregivers (not parents) 55 years of age or older providing care to adults age 18-59 with disabilities, to whom they are related by blood, marriage, or adoption. Tribal Organizations can set an age lower than 60 at which members can be considered as elders eligible for services. In most states, the National Family Caregiver Support Program is administered through local Area Agencies on Aging (AAA). The Elder Care locator service at <http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx> provides links to local AAAs.

Veterans Programs

Veterans eligible for outpatient medical services can also receive non-institutional respite, outpatient geriatric evaluation and management services, and therapeutically-oriented outpatient day care. Respite care may be provided in a home or other non-institutional setting, such as a community nursing home. Ordinarily, respite is limited to no more than 30 days per year. The services can be contracted or provided directly by the staff of the Veterans Health Administration (VHA) or by another provider or payor. A new program administered by the Department of Veterans Affairs, the Family

Caregiver Program of the Caregivers and Veterans Omnibus Health Services Act of 2010, provides additional respite and support to eligible post-9/11 veterans who elect to receive their care in a home setting from a primary family caregiver. For more information about the VA Caregiver Support Program, visit the Department of Veterans Affairs website at <http://www.caregiver.va.gov>.

Additional veterans' benefits may exist to provide financial assistance for veterans in rural areas. Such benefits could be used to pay for respite or other family caregiver supports. For example, Aid and Attendance and Housebound Benefits are benefit programs that provide supplemental financial support to veterans with special needs who are receiving general Veterans Benefits. The Title IV of the Older Americans Act created an opportunity for the VHA to partner with the Administration on Aging to fund Veteran Directed Home and Community- Based Services (VD-HCBS) for veterans. The VD-HCBS Program offered through the Aging Network (e.g., State Unit on Aging, Area Agencies on Aging) provides veterans with a person-centered alternative to traditional home care services and programs. This consumer-directed approach allows veterans to select the services and goods, including respite, that will best meet their long-term care needs, to prevent an avoidable hospital admission or premature nursing home placement (Dougherty, 2012).

Lifespan Respite

Since 2009, the Administration on Aging has awarded federal Lifespan Respite grants to 30 states and the District of Columbia. Lifespan Respite grants are awarded to states to implement or enhance statewide coordinated systems of community-based respite for family caregivers of children and adults. Some states used their initial funding to bring respite to otherwise isolated rural communities.

- The **Oklahoma Lifespan Respite grant funded a Mobile Respite Program** designed to bring respite services, staff and materials to new locations across Oklahoma and to provide

respite for full time caregivers in an existing respite program. A vehicle that had been used for the Federal Transit Administration's Section 5310 transportation program was released for use to the state's Lifespan Respite Program. The van was then provided to the Mobile Respite Program. The van may be kept by the local grantee to ensure sustainability of the program once funding ends.

In 2011, the Administration on Aging awarded expansion grants to focus on service delivery to seven of the original thirty state Lifespan Respite grantees. Many of the states elected to first begin providing services to individuals who do not qualify for existing public respite resources or funding streams or live in areas with limited respite options and providers, such as rural areas. A few examples are:

- **Nevada's Lifespan Respite Balancing Initiative** established a respite voucher program that is directed primarily at under-served populations state-wide. This program provides a reimbursement voucher award to those who qualify of up to a maximum of \$600/year to pay for respite services. High priority is given to rural caregivers, Hispanic families, and those caring for adult care recipients between ages 18-64. Vouchers can be used to pay for respite services from a respite program, agency, or facility that the caregiver wants to use for respite (requires approval); a friend, neighbor, or relative who will provide care in the care recipient's home but does not live there themselves; or an independent caregiver/respite provider selected by the family.
- In **North Carolina**, the goal of the one-year expansion project is to sustain the state's "Just One More" initiative to bring new or enhanced respite services to each of NC's 100 counties. Selected public agencies and non-profit organizations that have a history of successfully delivering respite services were awarded mini grants in two areas: direct respite service funding for new recipients across the lifespan; and "Just One More" funding to enhance and/or expand

respite in underserved counties. The direct service funding will be targeted to those with incomes slightly above NC's Medicaid threshold who do not qualify for other publicly-funded resources; caregivers whose family member requiring care is between the ages of 18 and 59; caregivers of individuals with a traumatic brain injury or sudden disabling condition; caregivers whose family member is on a waiting list for CAP services; and, caregivers who live in counties with few or no respite providers.

- **South Carolina** has targeted underserved populations for receipt of respite services. The Lt. Governor's Office on Aging is the grant recipient, with project management delegated to the SC Respite Coalition. The focus is on family caregivers caring for adults between 18 and 60 years old who are not currently receiving respite. Mini-grants for faith-based and sustainable respite initiatives have also been awarded.

State Funding

State Funded Family Caregiver Support: Some states have state-funded Family Caregiver Support Programs, through which respite may be available. For more information, visit the Family Caregiver Alliance Family Care Navigator Program at http://www.caregiver.org/caregiver/jsp/fcn_content_node.jsp?nodeid=2083.

Considerations for Family Caregivers

Finding and paying for respite services in rural areas are among the greatest challenges to family caregivers using respite. If there is a State Lifespan Respite program or State Respite Coalition, family caregivers should reach out to them for assistance in finding, selecting and paying for respite services. Additional options exist for caregivers to consider in their search for respite and other support. To find contact information for State Lifespan Respite Programs or State Respite Coalitions, visit the ARCH website at www.archrespite.org.

Family Driven/Consumer Guided Services and Supports

Even though respite options may be limited in rural areas, when seeking respite, families should consider respite services that are family driven and centered on the needs of both the caregiver and the care-receiver. For more information on how to find and choose respite, see the ABCs of Respite: Consumer Guide for Family Caregivers (<http://archrespite.org/consumer-information>). Referrals to available respite programs may be available through a State Lifespan Respite Program, State Respite Coalition, health care, or mental health care provider, case managers, area agencies on aging, or a community mental health association. The ARCH National Respite Network and Resource Center maintains an online respite locator at <http://www.archrespite.org/respitelocator>, where family caregivers can search for respite services by zip code.

Supply of Respite Providers

There are limited formal respite resources and facilities such as assisted living or adult day care in rural areas. In many communities, there may even be limited services available through traditional respite providers such as The Arc, Easter Seals or the Alzheimer's Association. Nursing homes may have a bed or two to provide overnight respite, paid by the caregiver, in some cases for persons with dementia, but requirements are stringent and services may be costly.

Due to the limited availability of formalized services in rural areas, use of volunteer respite or participant or consumer-directed respite where family caregivers and recipients hire and train their own providers may be the only options. Many family caregivers of individuals of all ages with disabilities may depend on informal care provided by their families and friends to carry out routine activities of daily life and may have to turn to this population for respite more frequently than caregivers in urban areas do. Still, finding family or friends to provide respite in rural areas may still be a challenge. Use of nontraditional sources of providers, such as trained

teenagers, family day care providers, or faith-based programs resulted from rural respite providers and advocates thinking creatively and may provide extremely useful respite options.

Family caregivers may consider hiring their own professional respite providers, but challenges for recruiting, retaining and training direct service workers in rural areas may be significant. Direct service providers, sometimes called formal caregivers, include certified nursing assistants, support professionals, personal and home care aides, and home health aides. These direct service workers often provide respite. They are typically on contract with an agency that provides respite services, but some may work independently. State Lifespan Respite programs or State Respite Coalitions may be able to help family caregivers find direct service providers in local communities.

Seeking Caregiver Supports in Rural Areas Helps Access Respite

Caregiver support groups in rural areas may assist caregivers in finding and using respite care. Several online communities exist where family caregivers can join virtual support groups and search for resources, such as respite, in their state. The Rural Caregivers Website, sponsored by Purdue

AgrAbility Project

AgrAbility is a program sponsored by the U.S. Department of Agriculture (USDA) that provides assistance to farmers, ranchers, other agricultural workers, and farm family members affected by disability. It consists of a National Project and State/Regional Projects (currently serving 24 states), each involving collaborative partnerships between land grant universities and various nonprofit disability services organizations. For more information, visit the National AgrAbility Project website at <http://www.agrability.org> or call toll-free 800-825-4264.

University and the State Office of Rural Health in Indiana, contains links to support communities and collections of resources. Purdue University's Breaking New Ground Resource Center in cooperation with the Minnesota AgrAbility Project has developed a publication, *To Everything There is a Season*, to provide support and resources especially for family caregivers of farmers and ranchers with disabilities. To download a copy, visit <http://www.agrability.org/Documents/CaregiverManual.pdf>.

Training Respite Providers

Family caregivers in rural areas may have to take on the challenge and responsibility for providing the necessary training to a respite provider. However, training and recruitment may be coordinated with other local family caregivers, the County Extension Service, local service organizations, or existing rural agencies (Tribal health, public health or visiting nursing services, rural health clinics or hospitals).

Considerations for Providers and Administrators

Respite providers and administrators face worker shortages and numerous cultural, resource and funding challenges in rural areas. Lack of available transportation can be especially challenging to family caregivers and respite providers in geographically isolated areas or areas with limited public or private transportation options.

Transportation Solutions

Practical solutions which respite programs have utilized to overcome transportation barriers include: reimbursing care providers and/or families for mileage to and from the respite site; employing neighborhood networks and family members as respite providers; arranging a centralized meeting place for the family and care provider to meet and exchange children or other care recipients who are mobile; and linking up with other programs that provide transportation, such as Head Start or Senior Citizen's Transport. A local school district may even transport a child directly from school to the

child's respite provider. Some initiatives described elsewhere in this fact sheet have involved mobile respite that share staff between locations.

Starting New Rural Respite Programs

Starting a respite program, particularly in a rural area will require working with local organizations to gain financial and other types of support. A respite program will have to piece together a

network of funding and resources through cross-program collaborations. For example, a respite program might link with a particular faith-based organization that will provide space for providing respite while a network of caregivers and volunteers provide transportation to and from the respite site.

A successful rural program builds on the strengths and resources unique to rural areas. Collaboration with existing local service programs will ensure that

respite is part of a continuum of services offered to family caregivers and care recipients. An emphasis on home-based or neighborhood service delivery that utilizes on-site training reduces transportation barriers. Extensive advertising, social media, social gatherings with both care providers and families, and active family involvement are essential to generate community participation and support.

National Direct Service Workforce Resource Center, Strengthening the Direct Service Workforce in Rural Areas, 2011

This report, written by D. Kip Brown, Sarah Lash, Bernadette Wright, Ashley Tomisek at the DSW Resource Center, highlights solutions to the problems of recruitment, retention, and training of direct service workers in rural areas. State Lifespan Respite program and others will find strategies that other states and rural agencies have implemented to overcome common challenges related to direct service worker concerns. These include:

- opportunities under the Affordable Care Act
- participant-directed service options in long-term care financing programs
- general recruitment/retention strategies
- “grow-your-own” initiatives (developing a direct service workforce of local residents)
- supports for rural family caregivers
- worker-owned cooperatives
- training/credentialing opportunities for rural workers
- worker access to transportation
- worker registries
- mobile adult day care
- collaborating with urban agencies
- telehomecare
- the Program of All-Inclusive Care for the Elderly (PACE).

The full report can be downloaded at <http://www.dswresourcecenter.org/tiki-index.php?page=Reports&catx=13&filter=dsw>

Considerations for Lifespan Respite Programs

Since rural family caregivers may be more dependent on seeking out and hiring their own respite workers, Lifespan Respite programs may be able to provide assistance by helping to develop and maintain rural respite registries of possible providers and systems to link family caregivers to this service. Transportation assistance may also be necessary. Some Lifespan Respite programs have attempted to focus on capacity building in rural areas through mini-grants to local agencies to develop new respite supports or developing partnerships with faith-based organizations which are the

predominant means of social support in many rural areas. Alabama's Lifespan Respite Network's special initiative, Sharing the Care, developed a manual, Hiring and Training Respite Providers. Sharing the Care is helping to build respite capacity in some rural areas through local partnerships that may help train and recruit respite providers (Alabama Lifespan Respite Network, 2011).

Funding shortages in rural areas compel Lifespan Respite programs to seek existing federal and state funding sources for respite. Partnering with other state agencies to explore use of some of the funding sources described in the funding section above, and with private organizations or community foundations, may be an absolute necessity. Many Lifespan Respite programs that have received federal expansion grants to improve access to services have given priority to unserved family caregivers in rural areas for receipt of respite vouchers to help them pay for respite. More information on establishing participant or consumer- directed respite, including case studies in Alabama and Oklahoma, is available in the ARCH Guide to Participant Directed Respite at <http://archrespite.org/productspublications#PartIDirection>.

Conclusion

Developing and implementing successful respite programs in rural areas present unique, but not impossible challenges. Successful rural programs exist across the country. Using a variety of creative methods to meet their unique challenges, these programs have implemented services that effectively meet families' needs. With a thorough understanding of the community and a strong commitment to working with families to provide family-driven respite, programs can be established in any rural locale.

Resources

eXtension Initiative

<http://www.extension.org>

The national eXtension Initiative is an Internet-based educational network providing access to

objective, science-based information from land-grant universities and partners nationwide. It is an integral part of and complements the community-based Cooperative Extension System. Major funding for eXtension is provided by member land-grant colleges and universities, and the USDA National Institute of Food and Agriculture (NIFA) under the New Technologies for Agricultural Extension Program and the Cooperative Foundation. For information on Rural Family Caregiving, including frequently asked questions, visit http://www.extension.org/family_caregiving.

Rural Assistance Center (RAC)

<http://www.raconline.org>

A product of the U.S. Department of Health and Human Services' Rural Initiative, the Rural Assistance Center (RAC) was established in December 2002 as a rural health and human services "information portal." RAC helps rural communities and other rural stakeholders access the full range of available programs, funding, and research that can enable them to provide quality health and human services to rural residents. For family caregiver information, see <http://www.raconline.org/topics/caregiving>.

Federal Office of Rural Health Policy

www.hrsa.gov/ruralhealth

The Office of Rural Health Policy (ORHP) coordinates activities related to rural health care within the U.S. Department of Health and Human Services. Part of the Health Resources and Services Administration (HRSA), ORHP has department-wide responsibility for analyzing the possible effects of policy on 62 million residents of rural communities. Created by Section 711 of the Social Security Act, ORHP advises the Secretary on health issues within these communities, including the effects of Medicare and Medicaid on rural citizens' access to care, the viability of rural hospitals, and the availability of physicians and other health professionals. ORHP administers grant programs designed to build health care capacity at both the local and State levels. These grants provide funds to 50 State Offices of Rural Health (SORH)

to support on-going improvements in care, and to rural hospitals through the Medicare Rural Hospital Flexibility Grant (Flex).

National Rural Health Association
www.ruralhealthweb.org

The National Rural Health Association (NRHA) is a national nonprofit membership organization with more than 20,000 members. The association's mission is to provide leadership on rural health issues. NRHA membership consists of a diverse collection of individuals and organizations, all of whom share the common bond of an interest in rural health.

**The Association of Programs
for Rural Independent Living (APRIL)**
<http://www.april-rural.org>

APRIL features newsletters and publications, helpful links, and information on accessible rural transportation and independent living in rural areas.

References

Alabama Lifespan Respite Resource Network. (2011). *Sharing the Care. Hiring and Training Respite Providers*. <http://www.alabamarespite.org/index.php/guides-manuals-presentations-2.html>

Association of Programs for Rural Independent Living (2011). *Accessible Rural Transportation*. <http://www.april-rural.org>

Bolin, Jane N., RN, JD, PhD, and Bellamy, Gail, PhD. (2011). *Rural Healthy People 2020*. College Station, Texas: The Texas A&M University System Health Science Center, School of Rural Public Health, Southwest Rural Health Research Center.

Brown, D. Kip, Lash, S., Wright, B. and Tomisek, A. The Lewin Group. (2011). *Strengthening the Direct Service Workforce in Rural Areas*, Washington, DC: CMS National Direct Service Workforce Resource Center.

Butler, S.S., Kaye, L.W., Ruffin, L. & Downey, R. (2005). *Depression and caregiver burden among rural elder caregivers*, *Journal of Gerontological Social Work*, 46(2), pp.47-63.

Centers for Medicare and Medicaid Services. The Centers for Medicare & Medicaid Services' Office of Research, Development, and Information. (2011). *Evaluation of the Rural PACE Provider Grant Program – Report to Congress – January 2011*. <http://www.npaonline.org/website/download.asp?id=3841>

Community Transportation Association. (2010). *Rural Transportation*. <http://web1.ctaa.org/webmodules/webarticles/anmviewer.asp?a=19>

Crisp, S., Maguire, E., Selkow, I. and Singer, E., (2011). *Participant-Directed Respite Guidebook*. Chapel Hill, NC: ARCH National Respite Network and Resource Center.

Dougherty, Susan and Jill Kagan. (2012). *Federal Funding and Support Opportunities for Respite: Building Blocks for Lifespan Respite Systems*. Chapel Hill, NC: ARCH National Respite Network and Resource Center. <http://archrespite.org/productspublications#FederalGuide>

Gamm, Larry D., Hutchison, Linnae L., Dabney, Betty J. and Dorsey, Alicia M., eds. (2003). *Rural Healthy People 2010: A Companion Document to Healthy People 2010. Volume 1*. College Station, Texas: The Texas A&M University System Health Science Center, School of Rural Public Health, Southwest Rural Health Research Center.

Hoecke, W.C. and Mayfield-Smith, Kathy. (2010 Update). *Respite and the Faith-Community*. [ARCH Fact Sheet 53]. Chapel Hill, NC: ARCH National Respite Network and Resource Center.

McGranahan, D., Cromartie, J. and Wojan, T. (2010) *Nonmetropolitan Outmigration Counties, USDA Economic Research Report 107*. Washington, DC: US Department of Agriculture.

National Advisory Committee on Rural Health and Human Services. (2006). *Family Caregiver Support of the Rural Elderly, 2006 Report to the Secretary, Rural Health and Human Service Issues.*

National Alliance for Caregiving (NAC) & AARP. (2009). *Caregiving in the U.S.* Bethesda, MD: Author. <http://www.caregiving.org/research/general>

National Alliance for Caregiving (NAC) and Easter Seals. (2006). *Caregiving in Rural America.* Bethesda, MD: Author.

National Alliance for Caregiving (NAC). (2010). *Caregivers Of Veterans – Serving On The Homefront,* Bethesda, MD: Author.

National Pace Association, *Rural PACE Provider Grant Program* (ND), <http://www.npaonline.org/website/article.asp?id=42>

Perkins, M. M., Lepore, M., Sambhara, R., Jackson, K. & Ball, M. M. (2004). *Assessing Georgia's Self-Directed Care Program.* Report submitted to the Georgia Division of Aging Services, Atlanta, GA.

Rural Assistance Center. (ND). Topical web pages at:

- *Rural Health Disparities*, <http://www.raconline.org/topics/disparities>
- *Frontier*, <http://www.raconline.org/topics/frontier>
- *Transportation*, <http://www.raconline.org/topics/transportation>

Spillman, B.C. and Long, S.K. (2007). *Does High Caregiver Stress Lead to Nursing Home Entry?* Washington, D.C.: U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation. http://www.pascenter.org/publications/publication_home.php?id=728

Tarmann, A. (2003) *Fifty Years of Demographic Change in Rural America*, Population Reference Bureau, <http://www.prb.org/Articles/2003/FiftyYearsofDemographicChangeinRuralAmerica.aspx>

UnitedHealth Center for Health Reform & Modernization. (2011). *Modernizing Rural Health Care: Coverage, quality and innovation.*

U.S. Census Bureau, Statistical Abstract of the United States: 2012. Table 824. Farms—Number and Acreage: 1990 to 2010.

U.S. Census Bureau, Geography Division. (2010). *2010 Census Urban and Rural Classification and Urban Area Criteria.* Last Revised:15-May-2012. <http://www.census.gov/geo/www/ua/2010urbanruralclass.html>

U.S. Department of Agriculture. (2010). Economic Research Report No. (ERR-107), *Migration of Youth to Urban Areas.*

U.S. Department of Agriculture, Economic Research Service. (2011). *Rural America at a Glance, 2011 Edition.* <http://www.ers.usda.gov/media/123318/eib85.pdf>

U.S. Department of Agriculture, Economic Research Service. (2011). *Population and Migration.* <http://www.ers.usda.gov/topics/rural-economy-population/population-migration.aspx>

U.S. Department of Agriculture, Economic Research Service. (2012). *Rural Income, Poverty, and Welfare: Geography of Poverty.* <http://www.ers.usda.gov/topics/rural-economy-population/rural-poverty-well-being/geography-of-poverty.aspx>

U.S. Department of Agriculture, National Agricultural Statistics Service. (2012). *2007 Census of Agriculture. Demographics.* http://www.agcensus.usda.gov/Publications/2007/Online_Highlights/Fact_Sheets/Demographics

U.S. Department of Agriculture, National Agricultural Statistics Service. (2012). *2007 Census of Agriculture. Farm Numbers.* http://www.agcensus.usda.gov/Publications/2007/Online_Highlights/Fact_Sheets/Farm_Numbers/farm_numbers.pdf

U.S. Department of Health and Human Services, Administration on Aging. (2012). *FY 13 Justification of Estimates for Appropriations Committee.* http://www.aoa.gov/aoaroot/about/Budget/DOCS/FY_2013_AoA_CJ_Feb_2012.pdf

U.S. Department of Health and Human Services, Health Resources and Services Administration, Office of Rural Health Policy. (ND). *Rural Health*. <http://www.hrsa.gov/ruralhealth/grants/index.html>

U.S. Department of Veterans Affairs, Veterans Health Administration, Office of Rural Health. (ND). *About Rural Veterans*. <http://www.ruralhealth.va.gov/about/rural-veterans.asp>

U.S. Department of Veterans Affairs, Veterans Health Administration, Office of Rural Health. (2012). *Fact Sheet: Information About The Office Of Rural Health And Rural Veterans*. http://www.ruralhealth.va.gov/docs/ORH_GeneralFactSheet_April2012.pdf

University of Maine, Center on Aging. (ND) *Maine Primary Partners in Caring Project: A Project Manual*. http://umcoa.siteturbine.com/uploaded_files/mainecenteronaging.umaine.edu/files/MPPCManFweb.pdf

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