ELDER CAREGIVING IN RURAL COMMUNITIES

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Executive Summary

Projected increases in older persons over the next decade, particularly in minorities and the "oldest-old" population segments (those 85+years), make elder care one of the most pressing health care issues for the 21st century. In that the characteristics of a community influence the health care of its residents, nowhere is the delivery of elder health care more challenging than in rural communities, where low population density and large catchment areas combine with lack of service access and reimbursement in creating barriers to community-based elder care. Such factors contribute to long-term care admission rates for rural elders that exceed those of urban communities.

Community norms and cultural values as well as the strongly-held belief that families should "take care of their own problems," influence service acceptability in rural communities. Family members, friends and neighbors often fill the service gap, providing both direct and indirect care services for poor, socially isolated, underserved, frail and chronically ill elders in rural communities. Spouses, adult children, children-in-law and other extended family members are expected to provide informal care services for elders. However, out-migration of adult children to urban centers for employment often reduces the number of family members available to function as caregivers and many elders must depend upon loosely-articulated combinations of informal services from friends and neighbors.

Issues of limited service access and reimbursement that create care barriers for elders also complicate delivery of assistance programs for their informal caregivers. Various surveys document the difficulties informal caregivers in rural communities experience in attempting to secure the information, disease-specific education, skill training, respite and on-going support necessary to care for a frail and impaired elder in the home. However, descriptive studies of caregiving in rural communities indicate that almost half of all caregivers do not receive assistance because they:

- Do not know they are eligible for caregiver assistance services;
- Are unaware that such programs exist in their community;
- Are too embarrassed to accept services they view as 'welfare';
- Are reluctant to seek services unless there is a "crisis" and,
- Find existing services too geographically distant to be helpful

Demonstration projects in rural communities across a variety of states indicate that successful rural caregiver assistance programs are those: developed in collaboration with rural caregivers: endorsed by community leaders; and, staffed by persons who live in or are familiar with the cultural and social values of the community. Programs that compensate for geographic isolation through the combination of periodic home visits and innovative information technologies and telecommunications (e.g., peer caregiver telephone networks, telemedicine and telenursing contact systems), may offer the greatest promise for helping informal caregivers of rural elders.

Strategies for developing caregivers assistance programs in rural communities
Based on the diverse needs of rural caregivers and the characteristics of their social networks, successful caregiver support and training programs will:

- Offer programs suitable for both non-kin as well as kin caregivers.

- Provide a variety of informational programs for caregivers on topics such as healthy aging, symptoms and management of common chronic diseases, managing medical and drug regimens, emergency care, marital and family issues around long-term caregiving.

- Offer preventive counseling as well as supportive mental health services for distressed and depressed caregivers.

- Avoid labeling caregiver assistance programs with terms that may that make them socially unacceptable or stigmatizing for caregivers in a rural community (e.g., "Adult Day Care," "Respite Care" or Caregiver "Support" Group).

- Provide transportation services for community-based programs offerings, as well as home visitation services to individual caregivers.

- Offer caregiver "health promotion" programs in community centers e.g., blood pressure checks, pap smears, mammograms, during weekday, daytime hours so busy caregivers can combine self-care activities for themselves with a doctor's appointment for the elder during a trip into town.

- Provide telephone contact and referral service for urban-dwelling family members who are 'long-distance' caregivers for elders in the rural

community.

- Make local fund-raising activities a regular part of programs.

- Staff programs with professional, paraprofessional and volunteer personnel who are both knowledgeable about and sensitive to community culture and traditions as well as health care problems and service needs.

Policy implications for helping elders and their caregivers in rural communities

Policy makers and program makers should consider the following strategies:

- Implement needs assessment and data collection systems that accurately document the changing needs of elders and their informal caregivers in rural communities.

- Collaborate with local high schools and nearby community colleges to offer credit courses in visiting and working with frail elders and their caregivers.

- Encourage urban health profession schools to include rural family caregiving courses in their curricula.

- Project the need for rural health care service providers by discipline and offer more post-graduation incentives for providers who practice in rural communities.

- Create articulated models of caregiver assistance programs between urban and rural health care centers.

- Develop, implement and evaluate "promising practice" models of caregiver assistance that are designed to be sensitive to the social, ethnic and geographic characteristics of rural communities.

- Expand elder care insurance coverage to include informal caregiver education and skill training.

- Provide state and federal funding for rural health centers through "dollar matching" grant mechanisms that encourage rural communities to participate in fund raising and ownership of local caregiver assistance programs.

ELDER CAREGIVING IN RURAL COMMUNITIES

In 2000, 35 million persons age 65 and older were counted in the United States (U.S.) Census (U.S. Census Bureau, 1990; 2000). Demographers project a dramatic increase in this elder population segment over the next decade, as baby boomers (persons born from 1946 to 1964) reach age 65. Thus, one of the most pressing issues for the U.S. in the 21st century will be care of its elders. In that informal caregivers provide more than 70% of care services for community-dwelling elders, the need to support those family members, neighbors and friends who are essential providers of the informational, emotional and instrumental aid necessary to maintain elders in their homes is a crucial community health care program planning issue. Although the proportion of elders living in rural environments varies between regions (Clifford et al., 1993), rural communities have proportionally more elders. Twenty-nine states, primarily in the Midwest and South, currently have elder populations that exceed the 12.4% national average (U.S. Census, 2000). In the South, which has a larger proportion of Blacks, almost one in three Black elders lives in a rural area (Coward & Krout, 1998). This chapter explores the barriers and challenges faced by caregivers of elders in a rural community, identifies caregiver assistance needs, highlights programs that have been successful in meeting those needs, and presents the R.U.R.A.L model for developing successful caregiver assistance programs. The paper begins by setting the socio-demographic/economic context for service provision to elders residing in rural communities.

Overirew of the Rural Caregiver Population

Elders in Rural Communities
The Office of Management and Budget uses population size and density to differentiate metropolitan from non-metropolitan areas, while the U.S. Census Bureau uses settlement size and density to differentiate rural from urban settings. The terms are used interchangeably and this paper will use rural to designate these sparsely populated areas. The rural population has increased since 1950 and has been aging rapidly as a result of the desire to "age-in-place", of out-migration of youth from agricultural and mining areas, and the immigration of elders from urban areas (Siegel, 1993). Currently, 25% of elders in the U.S. live in a rural community, either alone or with their spouse.

The number of elderly persons at risk for disability, functional limitations, and chronic health problems continues to increase, creating a greater need for medical, mental health and social services, as well as economic and physical support. Indeed, an estimated 87% of the rural aged have some sort of chronic illness (Johnson, 1991), and a recent study supported by the Robert Wood Johnson Foundation concluded that at least 1 in 3 persons with chronic health conditions do not understand services they are eligible to receive, how to use these services, or who provides these services (The Institute for Health and Aging, UCSF, 1996). This is particularly true for the "oldest-old" segment of the population (those 85+years), which increased by 37% from 1980-1990, compared to only a 16% increase in the 60-84 year old cohort (Rogers, 1999). Thus, the stereotype of the "hale and hardy" rural elder is unfounded (Coburn & Bolda, 2001).

As there are fewer young and middle-aged adults in rural communities (because of employment-related migration to urban centers), fewer elders in these communities live with or have regular access to their children. Magilvy and colleagues (2000) note that this is true even among rural Hispanic families, where cultural norms are changing because fewer adult children are available to provide care. Children and grandchildren often live far away and are unable to visit, engendering stressful life events and chronic strain for rural elders (Johnson, 1998).

The loss of young and middle-age adults also has an adverse effect on the economy of a rural community, reducing the per capita income as well as the tax dollars available for education and health care. Older adults who reside in rural communities have less formal education, are more likely to be poor, and are less likely to have health insurance coverage than their urban counterparts (Coward, McLaughlin & Duncan, 1994; Schwenk, 1994). This is especially true for older women, the primary family caregivers in rural communities, who have the greatest economic vulnerability (Rogers, 1998). In that more rural workers are self-employed or work for small, privately-owned businesses, fewer elders in these communities will have pension, savings or investment incomes and will depend more heavily on Social Security benefits after retirement (Glasgow, 2000; Vrabec, 1995). Changes in state and federal policy will impact both rural elders and service providers, as Social Security, Supplemental Security Income and Medicare account for a major part of rural elders' incomes and provide critical support for local services (Rogers, 1999, p. 23).

Further, rural health care services are less accessible, less specialized and more costly to deliver than those in urban areas (Rogers, 1993). The access of rural elders to a range of health care services is also narrower than their urban counterparts, and fewer community-based care alternatives are available to them. And, although federal and state policies have encouraged community-based and in-home services as economical alternatives to more costly institutionally based care, rural elders continue to have a higher utilization rate of nursing home services (Coward et. al., 1996).

From the statistics cited above, the "at risk" person in a rural community would appear to be an elderly Black woman, living alone and depending on others for transportation, with only a social security pension income and whose children live at a distance. However, service providers and policy makers in rural settings must recognize that the rural aged are a heterogeneous lot, and the growing diversity that characterizes rural America defies simple definition (Buckwalter, Russell, & Hall, 1994). This argues for comprehensive and ongoing needs assessment by the Aging Network before beginning any rural caregiver projects (Lemke, Saha, Yankey, & Baenziger, 2001). (See Resources section for information on how to construct a comprehensive needs assessment survey from extant AAA databases-Dr. Jon Lemke).

Elder Care
Caregiving for an elder characteristically begins with indirect care services i.e., assistance with transportation, household maintenance, meal preparation and financial management. As an elder becomes more fragile and functionally limited over time,

informal caregivers provide more direct care services such as assisting with mobility, dressing, eating and toileting. Nearby friends and neighbors may help with less personal care such as grocery shopping or transportation. However, family members: first spouses, then adult children and children-in-law and finally, other family members are expected to provide most of these services. Barnes (1997), in her examination of the long term care needs of older rural women, notes that this segment of the population may be at particular risk, as family caregivers may not be readily available to care for them. Further, culturally bound differences in values and beliefs, especially those that underlie family patterns and intergenerational relationships, influence service efforts in rural settings (Bastida, 1988).

Kelley, Buckwalter and Maas (1999) examined and refuted three commonly held societal assumptions embedded in the social expectation of family care for elderly persons with dementia. These assumptions are that family members: 1) are not providing enough care; 2) have innate skills and knowledge about how to provide care; and 3) have access to the appropriate resources for the provision of care. Although not specific to rural caregivers, these assumptions are very relevant to this group. Indeed, a national survey of caregivers of older adults found that 59% of caregivers received NO instruction about how to perform any of the activities of care for their ill family member. In this same survey, caregivers of persons with dementia reported a great need for someone to talk with and for help understanding long term care resources (National Alliance for Caregiving, 1997). Rural elders and their families are reported to find the formal health care system too complex and confusing, especially as the number of care transitions (e.g. from hospital to home) increase (Magilvy & Congdon, 2000). The transition to care provider may be particularly difficult for adult children, especially if they must give up their role as a wage earner, resulting in financial hardship (Henderson, 1992). The complexities of providing support are compounded for long distance caregivers, who must often make decisions and implement actions without onsite assistance.

While a recent national survey of caregivers indicated 52% provided direct care services and 42% reported giving medications and monitoring vital signs, almost two thirds of the caregivers surveyed reported they did not live with the care recipient (National Family Caregivers Association, 2000). However, the contributions of informal caregivers are significant; they are estimated to provide from 45 to 94 billion dollars of direct and indirect care service costs each year (Arno, Levine & Memmott, 1999).

The Rural Caregiver
With the exception of affluent elders who make "amenity" moves for retirement to less-populated rural areas (Glasgow, 2000), the majority of elders who live in rural settings are commonly assumed to be long-term residents who benefit physically, emotionally and spirituality from the stability and continuity of living in a close-knit, small community. Because kin relationships and geographic proximity traditionally determine who is an informal caregiver, conventional wisdom holds that caregivers of rural elders will be their spouses, adult children, other family members and life-long, friends and neighbors, who

also live in the community. This may not be the case. Table 1 lists some of the realities of rural caregiving.

Characteristic/Situation	Assumption	Reality
Caregiver-care recipient kin relationship	Rural caregivers usually are family kin (spouse, adult child, grandchildren) of the frail elder	Rural caregivers are likely to include a combination of: 1. Spouses who are equally frail and impaired. 2. Adult children who live at a distance are "weekend" caregivers for their elderly parents. 3. Neighbors or friends who live at some distance & have their own health problems. 4. It may be difficult to determine who the caregiver is of the two frail spouses because of mutual levels of impairment/health conditions.
Caregiver Socio-Economic Situation	Because of longevity in the community, rural elders and their caregivers have financially stable situations, and live in comfortable, healthy situations on family farms or large, comfortable homesteads	1. The incidence of poverty among elders and their families is higher in rural when compared to urban communities. 2. Caregivers in rural communities often give care in substandard situations lacking basic amenities (e.g., bathrooms, energy efficient heating/air conditioning systems), located in limited access areas, without public transportation.
Caregiver Support / Aid Network	Caregivers can draw on their large, extended families for additional support.	1. Caregivers may be unwilling/unable to seek assistance from other family members because of the belief that caring for the elder is their "exclusive" responsibility, or they are not able to receive assistance as needed. 2. Family conflicts around elder care issues may not be discussed with service providers because of caregiver concern that information will be shared with others in the community.
Caregiver Health / Well-Being	Because of early, healthy, physically-active lifestyles, rural elders and their caregivers have fewer	1. Caregivers may not seek routine health screening / maintenance programs for themselves because of the belief that the elder's health

	physical or mental heath problems than their urban counterparts.	problems are more important, or they are unable to ask for or find some one to care for their care recipient. 2. Caregivers may not seek chronic illness care unless / until there is a crisis episode. 3. Caregivers may not seek mental health services because of fear of acquiring a stigmatizing label in the community.
Caregiver Formal Service Utilization	Rural caregivers do not need and will not use formal services.	Service programs for caregivers and elders often are unavailable, fragmented, inaccessible, or subject to the vicissitudes of federal/state funding for rural initiatives. Services are not offered because they are not deemed eligible because of age or income.

The following three situations were drawn from clinic files in one southern state to illustrate caregiver needs and challenges in rural communities, including: program availability and acceptability, inadequate mental health services, and changing needs over time. Additionally, the role of caregiver attitudes, values and beliefs, stigma and caregiver reluctance to seek help and to spend money on services, as they impede program provision in rural settings, are discussed and illustrated from the findings of a rural caregiver survey.

Situation 1: Mr. And Mrs. J.
Leroy J., a 74-year-old Black man is the primary caregiver for his wife Ethel who was diagnosed with Alzheimer's Disease four years ago. Mr. J. is wheelchair-bound because of a mining accident and he and his wife have been dependent on a cousin and his wife down the road for weekly grocery shopping in an adjacent community with a population of 2500. The Js 55 year-old son and his wife drive 200-miles round-trip from the city twice a month to provide routine home maintenance chores. The Js' daughter-in-law spends her visit time doing household chores and providing minor hygiene care for her 72-year old mother-in-law (doing the laundry, filling the freezer with home-cooked meals and washing her mother-in-law' hair). The Js managed with this type of support until recently, when the 68 year-old-cousin had a stroke. The cousin's children are admitting him to a nursing home and move his wife into the city with them. The next closest neighbor is almost five miles away. The Js' son is trying to get his parents to move into the city too. Although the elder Mr. J. is having difficulty managing his wife's increasing confusion, he is adamant that they are not moving from this house where they have

lived for 50 years.

One of the first challenges in developing rural caregiver assistance programs is ensuring program services are available and acceptable to the caregivers. The Js exemplify caregiving situations common in many rural communities, where increasing health problems of an ancillary caregiver disrupts the relative stability of the home situation and the primary caregiver, who often is as impaired as the elder for whom they are caring, is resistant to change. In this situation, while they looked for someone in the community who could do the weekly shopping, the J's son and his wife increased their trips from the city to once a week. The situation resolved three months later, when the elderly Mrs. J died from a cerebral aneurysm and Mr. J finally agreed to move into the city.

Situation 2: The G. Brothers
B.G. and R.G. are unmarried brothers who live together on the family farm. B.G. is 68 years old and R.G is 65. B.G. has been the primary caregiver for his younger brother, a chronic schizophrenic, since the death of their parents 15 years ago in an automobile accident. Their closest neighbor lives three miles away. The G. home is at the end of a long, winding gravel road, but bad weather often makes the road temporarily impassable. A married sister age 76, who lives 50 miles away in another small farming community, contacted the regional community health center to ask that someone stop by the family homestead to 'check' on her brothers, who have stopped answering the phone. When a volunteer goes out to the house, B.G. answers the door but refuses to admit the visitor. He is dirty, unkempt and has bruises on his face.

In this situation, R.G. had stopped taking the psychotropic drugs necessary to control his schizophrenia and his increasingly frail elder brother became the object of his abuse. Based on the visitor's report to the community health center, welfare workers came out to the house and R.G. subsequently was admitted to the closest hospital as an acute psychiatric admission and finally to the state hospital as a psychiatric in-patient. One of the most frequently unmet needs in rural communities is for preventative and supportive mental health services (Neese, Abraham, & Buckwalter, 1999). Rural communities are less likely to have mental health professionals available in the community or to have the resources to offer in-service training on mental health techniques to their staff (Bane, 1997). Sources of mental health services in rural areas are often limited to community mental health centers, state hospitals, geographically scattered private practitioners, physicians and clergy, and utilization rates remain extraordinarily low (Neese et al., 1999).

Bane (1997) notes that service delivery problems in rural areas are also adversely affected by the passiveness of the system; that is, the system waits to be contacted rather than case-finding those individuals and their caregivers who are in need of assistance. One exception is the Gatekeeper program developed by the late Ray Raschko at the Spokane Community Mental Health Center Elderly Services. The Gatekeeper approach uses telephone information and referral, multidisciplinary in-home

evaluation, treatment, and case management. An established system of rural community "gatekeepers," including meter readers, county assessors, and postal workers, helps identify residents in need of services. There is a pressing need for state-sponsored mental health training for rural health care providers (e.g., through outreach and distance learning programs) as well as for 'mobile' mental health providers who can take services out to homebound rural caregivers who are caring for an elder with a chronic mental illness. Mental health outreach programs in rural Iowa and Virginia are described later in this paper, and serve as best practices models for overcoming the challenge of inadequate mental health services, and identifying persons who are isolated and in need.

Situation 3: Mrs. S.

Mrs. S. is an 86 year-old woman who has lived alone in the family home since her 88 year-old husband's death a year ago. While Mrs. S. initially was able to drive into town, she has not driven the car in the last few months because she had a couple of minor accidents. One occurred on a country road late at night when she misjudged a turn and ended up in a ditch. She was forced to stay in the ditch all night, until a school bus driver on her way to work found her the next morning. Now Mrs. S. activities are limited to mowing her lawn and working in her garden. Mrs. S's caregiver is her 82 year-old-sister Barbara, who lives across the road. While Barbara calls to check on Mrs. S. every day, her time is limited because she must care for her own husband, who has a progressive neuromuscular disease. Barbara also fell on an icy patch last year and fractured her arm in 3 places and now is physically limited. Mrs. S. only other living relative is a daughter who is a Christian missionary in Africa. Over the past few weeks, Barbara has begun to notice that Mrs. S. rambles a great deal and has a limited attention span. She is concerned about her sister but unsure what to do.

A dominant feature of elder caregiving networks is their continuous evolution over time (Peek, Zsembik & Coward, 1997). While most elders initially require only limited assistance, after reaching a certain level of frailty the need for assistance increases dramatically. In rural communities, the type of assistance needed may not be readily available or, may require a combination of caregivers and services be 'cobbled' together to keep the elder in the home. In the case of Mrs. S., over the span of a single year, she progressed from being her elderly husband's caregiver to independently living alone with daily, minimal support phone contacts from her sister, to being a frail elder who may or may not be able to continue living in her own home. As her sister's caregiver, Barbara needs help first to find transportation to get her sister in to town to see the doctor and dependent on the medical findings, help in planning for the future. Thus, appropriate services would be those designed with the recognition that need for different services could vary over time; care recipients and caregivers could seesaw between levels of professional care or care environments and community-based informal support systems. Transitions between levels of care should be as "seamless" and "fluid" as possible, which entails information transfer and exchange across care environments and providers (Chalifoux, Neese, Buckwalter, Litwak & Abraham, 1996, p. 477).

Lemke and colleagues (2001) report that service usage varies across counties even within the same rural region, in part because of lack of consistency in definitions and eligibility requirements for similar programs. He argues that potential caregiver clients must be followed from initial screening, which should be available upon demand. Agencies must be able to track caregivers, household composition and functional status over time. Data must be maintained and archived in order to maximize the information available to the system (Lemke et al., 2001).

Factors Impeding Service Provision to Rural Caregivers

According to Van Hook (1987), the rural elderly are often provided with "scaled down urban service models that fail to meet their needs or are insensitive to the real differences between urban and rural areas" (p.13). To be successful, services must mesh with other local programs and informal helping networks, and service providers must understand and be sensitive to the rural value system and social ecology of the area (Buckwalter et al., 1994). While geographic distance from urban centers often precludes access to community-based assistance programs, most rural communities are limited in fiscal resources and infrastructure (program planners, trained workers, transportation) necessary to develop their own community-based programs (Lemke, et. al., 2001). This often results in barriers characterized as lack of: awareness, availability, access, affordability, adequacy, appropriateness and acceptability (Krout, 1994; Williams, Ebrite & Redford, 1991). Rural residents may be unaware of services in their area or, the lack of specific service availability in the community may decrease service affordability and increase the time required to access those services. Locally available services may be fragmented or of lesser quality (adequacy) or may not have the necessary articulation with urban referral centers. Further, services may not target the health care needs of residents (appropriateness) or be acceptable to the cultural norms and ethnic beliefs of community residents. Connell et al., (1996) noted that even when transportation was available, caregivers in their focus group interviews reported that "the need to travel long distances effectively eliminated the intended benefit of support services (e.g. respite/adult day care, support groups) because the free time caregiver's gained was spent in the car" (p.23).

An investigation of the needs, resources and responses of n=107 rural caregivers of persons with Alzheimer's disease (Buckwalter et al., 1994) revealed that only 51% of caregivers used ANY community-based services, with costs ranging from $16-$850 per month and averaging $73. The majority of costs for services was borne by the caregivers themselves, who reported that cost was a major barrier to service utilization, and that they were "saving their money to buy care in a good nursing home". Another reason given for low service utilization was that respondents were concerned that confidentiality might be a problem. Others stated they would not use any service where they accepted aid from agencies because they felt this was "too close to charity" and that "people should be self-sufficient" and "take care of their own problems" (p. 312).

In Iowa's Mental Health of the Rural Elderly Outreach Project, many rural elders and their caregivers believed that they should be able to handle problems themselves and

viewed mental health assistance as a sign of personal weakness, if not defeat (Smith, Buckwalter, & DeCroix-Bane, 1997). Similar attitudinal barriers were reported by Connell et al., (1996, p. 23), who noted that rural family caregivers in focus group interviews expressed reluctance to seek community-based services because they were seen as "hand-outs" or "welfare". These caregivers felt they should be self-reliant and solely responsible for the care of their older family members. These values and beliefs, and the stigma associated particularly with the use of mental health or counseling services, accounted in large part for the low use of formal services in this rural population. Other program-related barriers reported included poorly publicized programs, those perceived as having "too much red-tape", and programs with certain restrictions such as those that are means-tested. These barriers are consistent with those reported by Collins and colleagues (1991) who noted that denial of symptoms and reluctance to seek help can be attributed to feelings of shame, stigma, fear of institutionalization and suspicion of the health care and service systems. Ageism and misconceptions about illnesses, especially dementia, among rural health care professionals also diminishes the likelihood that caregivers will receive adequate information and referral for needed services (Connell et al., 1996).

Despite these acknowledged barriers, rural caregivers in the Buckwalter et al. survey (1994) were highly motivated to undertake a difficult and burdensome role, and many reported a deep sense of personal satisfaction and growth from the caregiving experience. Data from the Caregiver Burden Scale indicated a strong sense of moral obligation and personal desire as primary motivations for becoming a caregiver, and reflected cultural and religious values of the region. For example 92% of respondents indicated that "Caring is the Christian thing to do" and a similar percentage reported that "God helps them in their caregiving efforts". These findings are supported by more recent research conducted by Martinez (1999) and Davis and Magilvy (2000), who found that rural elders felt they had a responsibility to help themselves, and also felt, that along with God's help, they could survive life's challenges.

These attitudes may explain, in part, the reluctance of many rural caregivers to seek help. Robinson (1988; 1990) has developed a successful social skills training model for caregivers that enables them to learn specific skills they need in order to mobilize help from their social networks. The training program focuses on assertive social skills such as how to give instructions when help is offered, how to make a request for help, how to express appreciation for support, as well as how to say "no". Individual counseling sessions are augmented by written materials reinforcing key points covered during the counseling sessions. Acquisition of these skills yields increased social support and lowered caregiving burden.

Connell et al., (1996, pp.19-22) developed a Community Outreach Education Model Program (COEP) for dementia caregivers in rural Michigan. Using focus group interviews with family caregivers and service providers, they identified a number of structural and attitudinal barriers to effective service delivery. Many of these same issues plague programs within the Aging Network. Structural barriers affected help-seeking behavior and the experience of being a caregiver. These barriers included: 1)

Lack of coordination in the service delivery system; 2) Cost of services; 3) Service agencies that are overburdened, understaffed, or unavailable; 4) Distance and transportation; 5) Reimbursement policies for services are too restrictive; 6) Lack of access to comprehensive diagnostic and assessment services; and 7) Family physicians do not always make referrals for services. Caregivers also reported frustrations related to the utilization of needed services, such as being put on a waiting list for services that were needed immediately, and difficulty understanding complex reimbursement policies. Attitudinal barriers included: 1) Stigma and guilt about seeking help and receiving services; 2) Value of self-reliance; 3) Belief that family members should be responsible for care; 4) Reluctance to seek services until a crisis occurs; 5) Denial of symptoms; and 6) Ageism. This same team also noted a number of community strengths to build upon in designing services for rural caregivers, including: 1) Community action and cooperation; 2) Close knit ties and long-established roots; 3) Dedication and caring for residents in rural areas; and 4) Strong cultural identity.

Issues in Rural Case Management

Case management is designed to help clients find the least costly and most appropriate services that will meet their needs. Parker and colleagues (1992) published an extensive review of the issues and challenges related to providing case management services to families living in rural areas. They detail the most critical health care delivery and financing problems faced by rural communities, including third-party payer restrictions, reimbursement levels, provider recruitment and retention, competition with urban providers, emergency medical services, and regulations and paperwork. Additionally, differences between rural and urban case management are highlighted, focusing on lack of available and accessible services, financial constraints, staffing issues, poor discharge planning, and turf issues. These same themes are echoed throughout the rural case management literature. Indeed, Krout (1993) has cogently argued that case management is a process that can play an important role in overcoming many of the service delivery barriers cited above by containing costs, increasing awareness of and access to in-home services, targeting resources, preventing costly and unneeded institutionalization, coordinating various aging services, and, importantly for this paper, supporting family caregivers.

More recently (1997) he analyzed data from a national sample of n=356 agencies regarding barriers to providing case management services to rural older persons. To obtain the sample, a list of 1,201 rural case management providers was developed through phone calls to state health and social service departments and state units on aging officials nationwide, who were read the definitions of case management and rural, and who were then asked to provide contact information for agencies meeting those definitions within their state. For purposes of this research, only agencies that identified a primary service area as rural, open country, small town, or village, or some combination of those settings were included in the final sample (Krout, 1997, p. 144). Several areas were consistently reported by respondents as problematic, including lack of resources to pay for case management and services, a lack of services, lack of transportation, and too many regulations. Demand for documentation made by various

government agencies is an issue that plagues rural health care and service providers, whether it be for purposes of claims submission, quality assurance, or accreditation. Providers are generally not reimbursed for these paperwork demands, and must absorb the cost of maintaining staff to provide the necessary documentation (Parker et al., 1992, p. 48). Rural providers also complain that federal and state regulators as well as peer review organizations fail to adequately consider the applicability of various regulations to rural areas when implementing policies. Finally, many rural providers suggest that not only are the regulations imposing, but the rules change so frequently that it is difficult to keep track of them (Parker et al., 1992, p. 48).

Review of the Literature on What Supports Rural Caregivers

Caregiver Assistance Programs
Informal caregiving for a frail elder typically lasts for eight years or more (MetLife, 1999), and the toll of caregiving has been well documented. Numerous studies indicate informal caregivers experience role strain, negative mood and greater physical health declines than age-matched non-caregivers, as well as more marital discord, family dysfunction and social isolation and loneliness (c.f., Aneshensel, Pearlin & Schuleer, 1993; Gwyther, 1995; Johnson, 1998; Lieberman & Fisher, 1995; Vedhara et al., 2000). These adverse outcomes are compounded by losses from the social support network, and limited knowledge of local resources (Maglivy & Congdon, 2000). Indeed, caregiver strain is a major precipitant of premature and inappropriate institutionalization among rural elders, especially those who perceive they have no alternative care options (Congdon & Magilvy, 1998).

Regardless of whether they provide indirect or direct care, informal caregivers of elders in rural communities need a core set of skills that will enable them to accurately monitor and interpret symptoms, successfully manage medical regimens, provide hands-on care, find and utilize appropriate resources and make sound caregiving decisions, all while providing affective support and encouragement to the chronically-ill or disabled person (Schmall, 1995; Schumaker, Stewart, Archbold, Dodd & Dibble, 2000). Thus, caregiver assistance programs traditionally combine information on aging and chronic illness with skill training on providing home care, as well as affective support, counseling and periodic respite for the caregiver (c.f., Toseland, Smith & McCallion, 2001, for a discussion of the content of caregiver training programs). Caregiver assistance programs may be delivered through individual, group and/ or family counseling sessions, in-home caregiver skill training sessions and / or various technology-based mediums (e.g. telephone contacts, computerized training programs, 2-way video interaction systems). Technology innovations for rural case management and service delivery are therefore briefly discussed in the next section.

The Role of Technology in Delivering Services to Rural Caregivers
Redford and Parkins (1997) provide an excellent review of the promise of communication and information technologies to expand the reach of case managers

and improve the coordination, access to, and quality of care in rural communities. Due to increasing pressures on service infrastructures, case managers face constant challenges in finding, getting and monitoring services for rural clients, and educating caregivers to improve their care decisions. Redford and Parkins (1997) suggest that telecommunications and information technologies may be one answer to these access challenges and the effects of geographic isolation. They list the following benefits of telehealth technologies for Case Managers (p. 156):

- Reductions in travel time to adequately assess and monitor clients;
- Increases in the numbers of clients that can be effectively monitored;
- Opportunities to more frequently conduct educational sessions and provide technical and emotional support to homebound care recipients and their caregivers; and
- The ability to readily access through the Internet, client records, educational and informational materials, communications with colleagues, and other activities that decease isolation.

And benefits for Consumers, which, for purposes of this paper are caregivers:

- Closer contact with case managers;
- Opportunities for interaction with others in similar circumstances;
- Timely access to face-to-face contact when needed for assistance or support;
- Reductions in time and energy needed to travel for health monitoring;
- Assistance with the supervision and monitoring of in-home workers; and
- More opportunities to attain information and education to manage their own and another's care.

Two examples of successful technology-based interventions are briefly described next. Brennan and colleagues (1995) established and evaluated a computer network (ComputerLink) to meet the educational and support needs of in-home caregivers of persons with dementia. The computer network provided information (e.g. a self-care encyclopedia), communication (e.g. an anonymous question and answer segment and a public bulletin board forum); and decision-support functions (among caregivers and a clinical expert). Outcomes included a significant increase in caregiver confidence in decision-making and social support.

Preliminary data from in-home telemedicine demonstration projects in rural Kansas (Lindberg, 1997) suggest they can effectively provide health care for elderly and disabled persons, and assist their caregivers. As the literature indicates that rural elders are less likely than urban elders to use formal, in-home long term care services (Kenney, 1993), innovative technology-based service delivery models like the Kansas project, may be particularly important service delivery mechanisms for rural care providers. The next section of this paper briefly reviews some of the approaches and programs that

have been effective, or show promise of being effective, in delivering needed services to rural caregivers.

Promising Practices

Mobile Outreach Programs

In 1978, the President's Commission on Mental Health noted, "Rural communities tend to be characterized by higher than average rates of psychiatric disorders, particularly depression, by severe intergenerational conflicts, by an exodus of individuals who might serve as effective role models for coping, by an acceptance of fatalistic attitudes and minimal subscription to the idea that change is possible" (p.1164). Regrettably, not much has changed over the past 23 years. Together with the often-fierce sense of self-determination, independence, dignity, privacy, and hardiness characteristic of many rural Americans (Lee, 1993), access issues, and the pronounced stigma associated with mental illness, elders most at risk do not present themselves for traditional mental health services. Fear of being labeled as crazy, of being shunned by friends and neighbors, or being "put away" in an institution prevents many rural residents and their caregivers from receiving needed mental health services and supportive assistance. Thus psychiatric problems among rural residents often go undiagnosed and untreated (Abraham, Buckwalter, Snustad, Smullen, Thompson-Heisterman, Neese, & Smith, 1993; Neese et. al., 1999), putting a tremendous strain on their caregivers.

Interdisciplinary psychogeriatric outreach models in rural Iowa and Virginia have been shown to be effective (as well as cost-effective) in delivering services to geographically and socially isolated elders and their caregivers (Abraham et al., 1993; Buckwalter, Smith, Zevenbergen, & Russell, 1991; Smith & Buckwalter, 1999). Both programs are community partnerships involving the local Area Agency on Aging and the community mental health system. (For a detailed description of the key components and a comparison of these outreach models, see Abraham et al., 1993, p. 206. For more information on the structure of the Mental Health of the Rural Elderly Outreach Project see Smith & Buckwalter, 1999, and for data on outcomes of the project see Buckwalter et al., 1991).

These models also emphasize the need for strong coordination and cooperation among mental health, medical and social service providers; maximizing limited resources; assuring continuity of care; and using professional, paraprofessional, and lay personnel. The mismatch between the needs of caregivers of the mentally ill rural elderly and the services available to them will not disappear in the foreseeable future, raising the short-term service issue regarding improvement of accessibility to local and regional resources, and the long-term policy issue of determination of reasonable levels of resource development, allocation, and equity.

The problems of transportation, poverty, lack of trained personnel, low population density, and the large catchment areas will continue to make the delivery of mental health services more difficult in rural areas. Outreach models can make substantial gains in overcoming these problems and providing needed services to rural elders and their caregivers. Individualizing these programs to reflect local culture, geography, need and resources improves both the delivery of care and the ability of programs to be sustained over the long term (Abraham et al., 1993, p 210).

An option for caregiver support in rural settings often comes from faith-based initiatives. Under the leadership of Dr. Karen Robinson, the University of Louisville School of Nursing developed a successful dementia-specific **Volunteer Caregivers Program** (VCP) that is an outgrowth of the Volunteer Interfaith Caregivers of Kentuckiana. The idea for this support program began when representatives from various religious congregations and a local Alzheimer's disease chapter joined together and developed a vision to train volunteers to provide in-home respite to keep caregivers connected to their support groups. Since 1994 the VCP has provided support services to more than 100 caregivers at no charge. Program services include assessment, care planning, education, evaluation, information and referral, and volunteer support. The VCP also provides free public services such as memory screening and community education programs. (See Resources section for contact information)

Building a Seamless Delivery Dementia Care System in Rural Iowa (Dr. Janet Specht, PI, Dr. Geri Hall, Co-PI and Ann Bossen, Project Director) is a collaborative project between the Iowa Department of Elder Affairs, the University of Iowa's College of Nursing and Center on Aging, Area Agencies on Aging, Alzheimer's Association chapters and ResourceLink of Iowa. The three-year (2000-2003) Administration On Aging funded project (grant # 90AZ2366) is designed to provide expanded in-home services to rural Iowans and their caregivers who are affected by Alzheimer's disease and related disorders (ADRD). The project uses a community organization model, developed by the Big Sioux chapter of the Alzheimer's Association, to help rural communities develop care systems that meet their unique needs in eight rural counties throughout Iowa.

Two assumptions underlie this approach: 1) If services are to be accepted within rural communities, they must be designed by the community; and 2) If the community values the services, they will refer neighbors to them. Other successful outreach programs have also been based on a community development model (see The Community Outreach Education Program, as described by Connell et al., 1996), which is a process of working collaboratively with community members "to assess the collective needs and desires for healthful change and to address these priority needs through problem solving, utilization of local talent, resource development and management" (Lassister, 1992, p. 30). Lassiter (1992, pp. 30-31) sets forth five tenets of community development that are of special importance in rural areas: 1) Citizen participation and partnership are essential for community improvement and growth; 2) The focus of work will be on local concerns; 3) Citizen groups are utilized in community development; 4) Implementation

is suitable to the locality; and 5) Process outcomes for the community are as important as task undertakings.

The "Seamless Delivery System" project is also designed to demonstrate the effects of an in-home nurse care managed delivery system on care recipient and caregiver well being. Four (experimental) of the 8 counties receive nurse care managers (NCM) who are specially trained to provide in-home services, education and support to persons with ADRD and their caregivers, with a particular emphasis on building capacity in the caregiver by focusing on the well-being and stressors clients identify. The NCMs work with the local case management system to coordinate available services, refer clients to funding sources, assist with community development programs and report to the AAAs. There is also a telecommunications back up system, ResourceLink of Iowa, available for both control and experimental counties. Individualized services are offered to both persons with dementia and their caregivers, and dementia-trained nurses work with care recipients and caregivers. The four control counties have a local project facilitator (LPF) who is the referral point for services, who completes intake forms, and refers clients to the existing Case Management System. Caregiver outcomes include: Caregiver well being, endurance, and stress. (See Appendix for Client Intake Forms for this project, especially Part 2: Information about the caregiver). The investigators have identified a number of structural and philosophical barriers to implementation, including reticence to allocate services to caregivers assessed as having too many resources or too much income. At present only baseline quantitative data has been analyzed, so comparisons between control and experimental counties are premature. However, several unique observations have emerged that may prove useful in future programming efforts. Project implementers and evaluators report that:

1. When the NCM is from the area she/he serves, the project is more successful. In many cases, the nurse has become a bit of a local celebrity, achieving the status one aging network professional described as "a trusted relative", and has been easily integrated into the community's perception as a "helping professional". This integration has fostered referrals from sources such as the local bank, churches, service and social clubs, and people in the rural town.

2. Several of the counties have enthusiastically embraced the community action programming. The fact that it was developed within and by their community exclusively has become a real source of pride. Programs that are clearly identified with community needs are more aggressively pursued than those that are developed by "outsiders" and "imposed" on consumers in the rural communities.

3. An unanticipated problem that has emerged in this project has to do with devaluation of the younger working caregiver. Some members of the community and the aging network have expressed concerns over providing services to someone who "works and has a salary", feeling younger, working caregivers aren't "justified" in receiving help. Clearly more education aimed at changing these attitudes is required-education illuminating the adverse psychosocial and financial consequences that may ensue should the caregiver be forced to quit employment in order to be eligible for services.

One approach that was effective was to emphasize to members of the Aging Network that should the working caregiver have to resign, he/she would no longer be contributing to the county tax base and might also have to forfeit retirement earnings, but attitudes denying services to employed caregivers in rural areas persist.

In-Home Caregiver Support Programs

A number of in-home caregiver support programs have demonstrated an array of positive outcomes for caregivers. Buckwalter and colleagues (NINR, 1992) conducted a 4 year multi-site rural caregiver study to test the effectiveness of an in-home caregiver training intervention based on the Progressively Lowered Stress Threshold (PLST) Model. The intervention provided 5 hours of training to facilitate caregivers' knowledge of dementia and development of competence in problematic behavior management. Caregivers in both the experimental and control groups also received referrals for support groups and case management services. Findings revealed that caregivers who received the in-home training intervention felt better about their situation, had more satisfaction with the caregiving experience, an increased sense of mastery, as well as decreased levels of burden, uncertainty and depression. They were also less bothered or upset by behaviors of the care recipient. Of note is that the "Seamless Delivery System" project discussed above uses elements of the PLST model as part of the in-home service provided by NCMs.

Archbold and associates (1995) tested the Preparedness, Enrichment, Predictability (PREP) system for in-home family caregivers of elders. Through a Medicare waiver provision, families in the experimental PREP group received 3-6 months of care from PREP nurses, including systematic assessment, family focus, local and cosmopolitan knowledge, individualized interventions using multiple strategies, therapeutic relationships and transitions. Subjects in the control group received standard HMO and in-home health agency care. Caregivers who received the PREP system reported higher care effectiveness and overall usefulness of the in-home staff. Hospital costs for the PREP group were also lower ($6929 vs. $2775).

National Family Caregiver Support Program

As a result of the National Family Caregiver Support Program (NFCSP) initiative funded by the Administration on Aging, a number of programs targeting both middle age rural caregivers in the workforce as well as older spouses are in development, or currently underway. In Iowa, under the leadership of the Iowa Association of Area Agencies on Aging (with Betty Grandquist, Coordinator), a new, multi-faceted project is underway to assist caregivers in rural settings. This project is a collaborative effort between AAAs, the Iowa Association of AAAs and the State Unit on Aging. It combines a case management approach with screening and referral to the nearest AAA where a Family Caregiver Expert takes over. This expert has a background in human services and aging issues, and is knowledgeable about resources in the communities served. A software program (ESP) developed by the Atlanta Regional Commission has been purchased which will provide a standard information and assistance network, a directory of resources, and match caregiver needs to available options. Data will be collected statewide at the Association office, although each AAA will develop support services

responsive to the needs of caregivers in their area. The Family Caregiver Expert may need to take special classes on how to effectively use this software. In addition, a toll-free number has been established to create a single point of entry for services. An Iowa Family Caregiver Project web page has been developed and a marketing and education plan is being established to provide consistency across the network.

The final "Promising Practice" to be highlighted is *The Family Caregiver Support Program*, funded by the Heritage Area Agency and operated by Elder Services Incorporated, Iowa City, Iowa. It serves family caregivers in a seven county region and is comprised of two primary components: Information and Assistance (I & A), and Family Caregiver Counseling. The I & A Specialist receives inquiries from a nationwide toll free telephone number and provides callers with information about appropriate state or local caregiver resources. The Family Caregiver Counseling Specialist works one on one with family caregivers in their home to assess their needs, develop a plan to address problems, and enable caregivers to successfully maintain their role. Typically, a short-term counseling model (usually 1-6 meetings) supports caregivers during times of transition, and assists them in making important decisions, although crisis intervention services are also available. The Counseling Specialist may provide assistance in the form of I & A, skill building (e.g. communication, caregiving skills), short term counseling, family mediation, and arrangement of appropriate community services and resources. Information is targeted to each caregiver's unique needs, and help is provided to alleviate their sense of isolation and to feel supported in their role. Family Caregiver Support services are funded by the NFCSP and are provided free of charge. The majority of referrals come from case managers who oversee services to clients involved in the Case Management Program for the Frail Elderly. The Counseling Specialist addresses caregiver needs, which may go unnoticed in the case management program. Other referral sources include health care centers, aging service providers and members of the community at large.

Practice Implications for the Aging Network

The R.U.R.A.L Model

Based on the diverse needs of rural caregivers and the characteristics of their social networks, successful caregiver support, and training programs will:
· Offer programs suitable for both non-kin as well as kin caregivers (e.g., "How to start a Neighborhood Friendly Visitor Program")

· Provide a variety of informational programs for caregivers on topics such as healthy aging, symptoms and management of common chronic diseases, managing medical

and drug regimens, emergency care, marital and family issues around long-term caregiving;

· Offer preventive counseling as well as supportive counseling services for distressed and depressed caregivers;

· Offer community programs that avoid labels that may make them socially unacceptable or stigmatizing for caregivers in a rural community (e.g., "Adult Day Care," "Respite Care" or Caregiver "Support" Group);

· Provide access to transportation services to community-based programs offerings, as well as home visitation services for individual caregivers;

· Offer caregiver "health promotion" programs e.g., blood pressure checks, pap smears, mammograms, during weekday, daytime hours so busy caregivers can combine self-care activities for themselves with a doctor's appointment for the elder during a trip into town;

· Provide telephone contact and referral service for urban-dwelling family members who are "long-distance" caregivers for elders in the rural community;

· Make annual fund-raising activities a regular part of program so as to insure local investment/ownership in the project, which is critical to its success; and

· Staff programs with professional, paraprofessional and volunteer personnel who are both knowledgeable about and sensitive to community culture and traditions as well as health care problems and service needs.

Based on the descriptive studies and projects highlighted in this paper, Table 2 lists program characteristics and persons to involve for planning successful rural caregiver assistance programs.

	Desired Program Characteristic	Program planners must ensure rural caregiver assistance programs:
R.	Relevance	Involve caregivers in identifying program service needs and program relevance
U.	Unity	Integrate new program offerings with existing community services to insure the new program does not compete with or duplicate existing programs
R.	Responsiveness	Are responsive to the ethnic and cultural identity and traditions of elders/ caregivers/ residents in the community
A.	Access	Enhance program access for caregivers through timing, location, transportation and publicizing new services
L.	Local leadership	Include local leadership (nurses, social workers,

		physicians, ministers, church groups, civic leaders, other community service workers) in supporting and publicizing the program

Using an ecological model of adaptation and aging to view competencies within an environmental context, Lee (1993, pp 225-227) proposed a number of individual and community-based nursing care approaches. For purposes of this paper they have been modified by the authors to be more germane to service providers in the rural Aging Network, and are set forth in Table 3.

Individual Strategies	Community-Based Strategies
1. Because of the heterogeneity of rural environments and the homogeneity of the many subcultures of elderly persons living within those environments, service providers should develop a working knowledge of the characteristics of the local rural environment, the competencies of the elderly persons living there, and the available health and social resources	1. Consolidate programs in multi-purpose packages that can serve the broadest possible population. For example, mobile units designed for a specific purpose such as immunizations, could be expanded to also provide assessment and referral services for elders and their caregivers.
2. Beyond information on specific physical and mental health conditions, assessment strategies should include information about functional status, individual characteristics, members of kin and non-kin support network, the community environment, and access to transportation. Preferred methods for obtaining information should also be assessed.	2. Use of existing structures, services or providers as the foundation for developing programs and services for rural caregivers will enhance the acceptability of the programs and increase the longevity of the services.
3. A home visit should be part of the assessment process, to alert providers to the potential of substandard housing and safety standards that need to be addressed (e.g., a new home safety assessment scale developed by Dr. Louise Poulin de Courval, McGill University: www.clscote-des-neiges.qc.ca/sas).	3. Linkages between programs need to be formed so that coordination instead of duplication exists at the local level.
4. Health maintenance and promotion goals should be developed WITH instead of FOR rural elders and their caregivers. Ask what strategies work for them.	4. Primary care providers (i.e., physicians, nurses, physician's assistants should always be included in the service plan.

5. Encourage caregivers to use local resources (such as homemaker services) to reduce fatigue secondary to the demands of the caregiving situation. Because asking for and receiving help is not the norm in many rural areas, assist the elder and their caregiver to problem solve while maintaining autonomy, dignity, and privacy. This may require both time and diplomacy.	
6. Use of control-enhancing interventions may benefit older rural adults and their caregivers. Classes aimed at providing knowledge and skill development (i.e., stress management) may assist caregivers to more adequately master the environment and improve quality of life.	

Betty Grandquist, current Coordinator of the NFCSP in Iowa and former director of the Iowa Department of Elder Affairs, has shared recommendations from her experiences in the Aging Network, and with rural caregiver support programs in particular. These are:
1. Include volunteers in your program development and implementation efforts. Bring them to the table, as they challenge professionals and offer a fresh and realistic perspective.

2. Be sensitive to how the caregiver wants to be perceived…some may reject the "caregiver" label, even though it makes them eligible for services, as they believe being categorized as "caregiver-care recipient" adversely changes the spouse-spouse or adult child-parent relationship.

3. Use a variety of approaches to alert rural caregivers to available services, including brochures, radio and TV spots, educational programs, web sites etc. A multi-media consumer publicity "blitz" is a good way to kick off new programs or projects.

4. Many factors are involved in the success or failure of a program in rural settings, such as availability of quality services, transportation, etc.

Ms. Grandquist advises that flexibility and a common sense approach to the allocation of funds are the hallmarks of any successful program for rural caregivers. For example, in one case a care recipient received burns from an old gas stove while the caregiver was bathing. In this case, an appropriate intervention might be one related to adjustment of the home environment; that is, to use available money to assist the caregiver in purchasing a safer appliance and teaching them how to disable the stove when not directly monitoring the care recipient. Finally, she cautions that, to the extent possible, avoid bureaucracies that impede getting the money to where it is needed most.

Dementia-specific recommendations from rural family caregivers in the COEP (Connell et al., 1996, p. 24) included the need to target educational interventions to information and referral agencies (e.g. staff of AAAs), government agencies (e.g. Commission on Aging, law enforcement agencies), and the public using outreach to service clubs, churches, the local business community and community centers. These caregivers also suggested development of a speaker's bureau as a mechanism to disseminate information to the community. Community involvement, a sense of ownership and group identity, and a commitment to the program were viewed as vital to long term change in the response of people to caregivers of persons with dementia in rural communities.

Finally, Parker et al., (1992, p. 57) offer a number of recommendations on ways to develop case management approaches in rural areas. Their suggestions are based on survey results as well as input from rural case managers in Minnesota and Wisconsin, and were designed to reduce the isolation of rural providers and to increase their support and contact with physicians. Recommendations included: 1) Provide outreach education programs to professionals; 2) Use the electronic media to disseminate information; 3) Contact congressional officials to reinforce the need to expand Medicare benefits to rural areas; and 4) Improve interdisciplinary teamwork and relationships.

Conclusions

Rural areas have long been characterized as having a unique set of conditions that make service delivery difficult. These include poverty, isolation, difficulties with transportation, sparse and scattered population, resistance to innovation and too few human service agencies, trained professionals and health care resources. Thus, rural health and human service providers are challenged to "define and creatively meet the service needs" (Bice, 1987, p. 9) of rural caregivers. In order to do this, members of the Aging Network may have to become what Dobkin (2001) has called "social entrepreneurs". That is, persons who "adopt a passion or mission to solve a societal problem" with "continuous creativity, flexibility, and stamina" undeterred by limited resources (Dobkin, 2001, p. 33).

To be successful, service providers must offer rural caregivers better coordination of services, improved communication among local agencies (Connell et al., 1996), consistent relationships with providers they trust, and improved access to information (Davis & Magilvy, 2000). Indeed, in order to overcome the many attitudinal and logistic barriers to service delivery in rural areas, community based outreach efforts must include representation from health care professionals, service providers, staff of community organizations and volunteers. "Cooperative efforts help to develop community competence and empowerment, and provide a greater understanding of cultural values and beliefs" (Connell et al., 1996, p. 16).

Effective rural caregiver support programs must get needed services to often-isolated rural elders WHEN and HOW they need them. Services should be caregiver, not provider, driven, and flexibility should be the watchword. Desired programs are available, accessible, accommodating, acceptable and affordable. Some effective programmatic approaches identified in this chapter include: mobile outreach programs, in-home visitation, satellite clinics, and increased use of telemedicine and information technologies. The RURAL model is set forth as a way to provide caregiver support and training and to meet the diverse needs of rural caregivers while accommodating the characteristics of their social networks.

back to top

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Resources

1. For information on elder care resources, contact:
www.resinets.com/health/elder.htm

2. For information on general health issues in rural America, contact:
www.nrharural.org

3. For activities of all state offices of rural health, contact:
www.rural.center.org/nosorh/

4. For Information Regarding Assessment Issues for Rural Case Management, and How to Blend Extant AAA Data Bases contact:
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5. For Information on Faith-Based Communities, the Volunteer Caregiver Program at the University of Louisville, and Social Skills Training Groups for Caregivers contact:
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6. For Information Regarding the New Home Safety Assessment Scale for People with Dementia Living at Home contact:
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