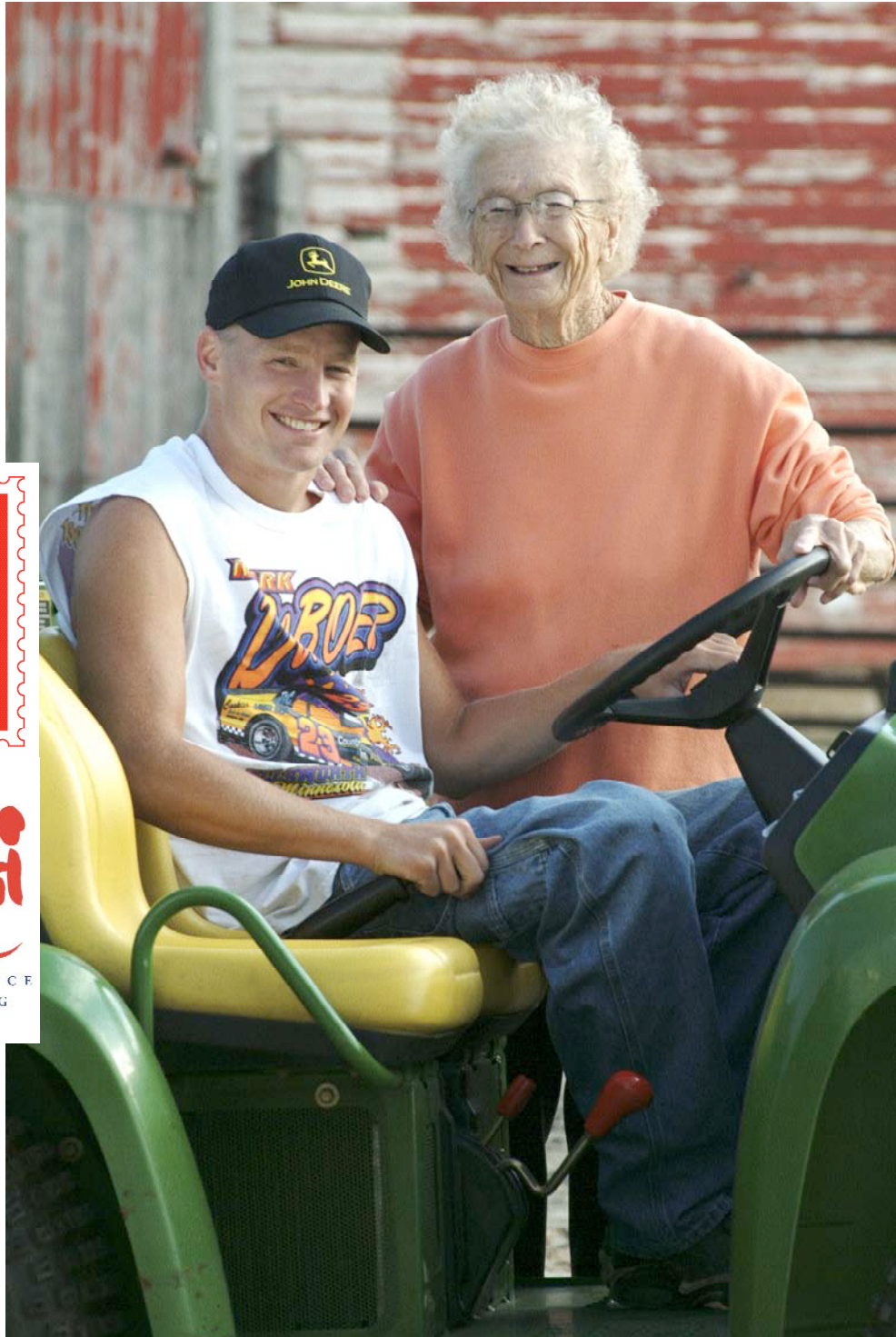


CAREGIVING IN RURAL AMERICA



PREFACE

Easter Seals has been helping individuals with disabilities and special needs, and their families, live better lives for more than 85 years. Easter Seals assists over 15 million children and adults with disabilities and their families annually through a nationwide network of more than 450 service sites. Each center provides top-quality, family-focused, and innovative services tailored to meet the specific needs of the particular community it serves. Primary Easter Seals services include: medical rehabilitation, early intervention and child care, adult day services, workforce development, and camping and recreation. Easter Seals also advocates for the passage of legislation, including the Americans with Disabilities Act (ADA), to help people with disabilities achieve independence. At the core of the Easter Seals organization is a common passion for caring, shared by its 13,000 staff members and thousands of volunteers and by those who support its mission.



The National Alliance for Caregiving is a nonprofit coalition of more than 40 national organizations. The Alliance focuses on issues of family caregiving across the lifespan. Established in 1996 by founding members AARP, the American Society on Aging, n4a, the National Council on the Aging, and the U.S. Department of Veterans' Affairs, the Alliance was created to conduct research, do policy analysis, develop national programs, and increase public awareness of family caregiving issues. Recognizing that family caregivers make important societal and financial contributions toward maintaining the well-being of those for whom they care, the Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients.

Easter Seals services include: medical rehabilitation, early intervention and child care, adult day services, workforce development, and camping and recreation.

The plan and completion of this report were undertaken by staff from both organizations. Easter Seals staff included Jed Johnson, Assistant Vice President for Adult and Senior Services; Carol Maus, Director of Rural Solutions; Jennifer Dexter, Assistant Vice President for Government Relations, Office of Public Affairs; and Kristi Martin, Marketing and Communications Specialist, National AgrAbility Project. The National Alliance for Caregiving staff included Gail Gibson Hunt, President and CEO, and Mary Brugger Murphy, health writer and consultant to the Alliance. Additional advisors

included: Rick Greene, Program Specialist, Administration on Aging; Dennis Dudley, Program Specialist, Administration on Aging; Donna Wagner, Ph.D., Director of Gerontology, Towson University; and Kathy Kelly, Executive Director, Family Caregiver Alliance.

We would also like to acknowledge David Weakliem, Ph.D., Professor of Sociology and Interim Director, Roper Center for Public Opinion Research, University of Connecticut, for his assistance with the analysis of the 2004 Alliance/AARP survey data on rural caregivers and care recipients.

INTRODUCTION

Family caregiving in the United States today is emerging as a major policy issue. A staggering \$306 billion per year is the estimated economic value placed on the care provided by family and friends of children and adults with chronic health conditions and disabilities (Arno, 2006). More than one in five adults, which is 44.4 million people, in the U.S. provide unpaid care to another adult age 18 or older (National Alliance for Caregiving and AARP, 2004). And another 6 million provide care to a child with a disability. These family caregivers live in urban, suburban, and rural areas of the country. Although many of their needs are similar, those caregivers living in rural areas face unique challenges whether they are providing assistance for a parent, a spouse, or other loved one, or a friend or neighbor.

In order to address the unique needs of rural caregivers, we must have a clearer picture of just who they are, for whom they are caring, and how they are managing their lives. This report provides new data that begin to answer those questions. Like so many reports that begin to illuminate an area of unmet need, it may also raise more questions than it answers. Together, the National Alliance for Caregiving (the Alliance) and Easter Seals produced this report to bring to light and support the demand to address the ever-increasing numbers and unmet needs of rural caregivers. Both organizations have a strong interest in caregiving, in the well-being of caregivers and care recipients, and in the challenges of providing care in special situations. In addition, both organizations have a commitment to exploring and addressing the unique needs and issues of rural Americans.

Based on that mutual interest, the Alliance and Easter Seals began to examine the available data and identified the need for further exploration of the current state of rural caregiving. Using information collected in the 2004 national caregiver survey conducted by the Alliance in collaboration with AARP and published in *Caregiving in the U.S.* (2004), they found interesting distinctions between urban and rural caregiving. They also, however, recognized the need for further study. This report is a summary of findings from the 2004 survey related to caregiving in rural America, but is also a statement of the need for additional information and action. Unless otherwise cited, all data presented in this report are from the 2004 survey.

A staggering \$306 billion per year is the estimated economic value placed on the care provided by family and friends of children and adults with chronic health conditions and disabilities

– Arno, 2006

This report includes:

- A brief description of the state of caregiving in the United States.
- An overview of rural caregiving in the United States that highlights both similarities and differences between rural caregiving and that in urban and suburban settings.
- Profiles of rural caregivers meeting caregiving challenges head on.
- A Call to Action! Next steps to address specific rural caregiving needs.
- Examples of programs in place to serve rural caregivers.
- References and resources.



THE STATE OF CAREGIVING IN THE UNITED STATES

In order to put the entire discussion of rural caregiving in perspective, it is useful to consider why caregiving is important. Here are a few of the facts.

- Eighty percent of the long-term care services provided to older people is unpaid care by family and friends (Shirey, 2003).
- The economic value of caregiving in the U.S. was estimated for 2004 to be \$306 billion (Arno, 2006).
- Fifteen to twenty percent of the workforce in the U.S. is engaged in caregiving at any one time (MetLife Mature Market Institute, 2003).
- The average out-of-pocket cost for a caregiver is \$200/month (National Alliance for Caregiving and AARP, 2004).
- According to 2006 data, employer costs for working caregivers totaled between \$13 billion and \$33.6 billion per year (MetLife Mature Market Institute and National Alliance for Caregiving, 2006).
- An employed caregiver providing personal care can lose on average about \$659,000 in wages, pension, and Social Security benefits over a “career” of caregiving (MetLife Mature Market Institute, National Alliance for Caregiving, and National Center on Women and Aging, 1999).



More than one in five adults in the U.S. (44.4 million people) provide unpaid care to another adult age 18 or older.

In 2004 the National Alliance for Caregiving, in collaboration with AARP and with support from MetLife Foundation, produced the report, *Caregiving in the U.S.* (2004). Several key findings of that study follow.

U.S. Family Caregivers

More than one in five adults in the U.S. (44.4 million people) provide unpaid care to another adult age 18 or older. The “typical” caregiver is 46 years old, female, has some college education, works, and spends more than 20 hours a week caring for her mother. More women are caregivers (61%) than men; more are between 18 and 49 years of age (58%) than 50 or older (42%). Many (59%) work either full-time or part-time while providing care. On average, most provide 21 hours of care each week. For information they turn

most often to the Internet (29%) and second most often to doctors (28%). For support, they turn mostly to prayer (73%), friends or relatives (61%), and books or other materials (44%).

U.S. Care Recipients

More care recipients are female (65%) than male, and many are widowed (42%). More are older (80% are 50 or older) rather than younger. More than half (53%) live alone. And, among those who do not live with their caregiver, more than half (55%) live in their own home. Caregivers helping those between 18 and 49 say the main problem or illness of their care recipient is mental illness or depression (23%). Most care recipients are likely to be the caregiver’s mother (34%), grandmother (11%), or father (10%).

Unmet Caregiver Needs

Caregivers reported the following unmet needs: finding time for oneself (35%), managing emotional and physical stress (29%), and balancing work and family responsibilities (29%). They also reported needing help keeping the person cared for safe (30%), finding easy activities to do with them (27%), talking with doctors and other healthcare professionals (22%), or making end-of-life decisions (20%).

CAREGIVING IN RURAL AMERICA

When considering what the advantages and challenges are for caregivers in rural America, it is important to begin by defining what it means to be “rural.” Although most people have a general idea about what it means, their perception may not fit the specific definitions that agencies responsible for counting, analyzing, or distributing community resources use. The U.S. Census Bureau defines rural areas as territory, population, and housing units located outside of urbanized areas (densely-settled areas with a Census population of at least 50,000) or urban clusters (densely settled areas with a Census population of 2,500 to 49,999) with fewer than 2,500 people or areas where people live in open country. The areas designated as rural in the 2000 Census cover 3,444,930 square miles, which is more than 97% of the total U.S. land mass, and 59,061,367 people, which is 21% of the total U.S. population.

Generally, Americans living in rural areas find themselves with fewer financial resources, business opportunities, health and social services, public transportation options, and young people living in their midst than their urban and suburban counterparts.

Generally, Americans living in rural areas find themselves with fewer financial resources, business opportunities, health and social services, public transportation options, and young people living in their midst than their urban and suburban counterparts. Rural Americans also find greater distances between themselves and the services they need and those who provide them than their urban and suburban counterparts. When it comes to caregiving, these differences make an activity that can be challenging in the most resource-rich urban and suburban environments even more complex.

Rural Healthy People 2010 (RHP 2010) provides a description of the state of health care in rural America (Gamm, Hutchison, Dabney & Dorsey, 2003). The document outlines health providers’ and decision makers’ concerns related to the overall issue of health care. It was created as a companion to the original Healthy People 2010 in recognition of the fact that rural areas frequently pose different and often greater challenges than urban and suburban areas do when it comes to addressing health care needs and goals. Rural-urban/suburban

disparities in health conditions associated with particular preventable or chronic diseases and disparities in infrastructure or professional capacity to address health needs are highlighted in the publication. RHP 2010 identifies the top priority for keeping rural people healthy as access to quality health care, with access to insurance, primary care, and emergency medical services also being at the head of the list (Gamm et al., 2003). For caregivers and care recipients, not only is limited access to primary and emergency health care a problem, but it is compounded by limited access to other services that could be of help to both parties, including the entire array of social, volunteer, and in-home supportive services, and accessible transportation.



The following information, which is drawn from data collected in the 2004 national caregiver survey of 1,247 caregivers provides a summary of these data from the perspective of the rural caregiver and rural care recipient. In this study, 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). A chart comparing demographic data among rural, suburban, and urban caregivers is provided at the end of this section for a more comprehensive comparison. Below are highlights from it.



U.S. RURAL FAMILY CAREGIVERS: DEMOGRAPHIC HIGHLIGHTS

For caregivers and care recipients, not only is limited access to primary and emergency health care a problem, but it is compounded by limited access to other services that could be of help to both parties, including the entire array of social, volunteer, and in-home supportive services, and accessible transportation.

- Sixty-four percent of rural caregivers are currently married; 6% report living with a partner; 6% are widowed; 14% are separated or divorced; and 11% were never married.
- Eighty-six percent of rural caregivers identified themselves as White, 7% Hispanic, 6% Black, and 1% Asian.
- Just over 25% of rural caregivers live in the same household as the care recipient; 60% live within a one-hour drive; 4% live between a one- and two-hour drive away; and 11% live more than a two-hour drive away.
- Forty-one percent of rural caregivers have children or grandchildren living with them.
- Fourteen percent of rural caregivers have provided care for 10 years or more, about 45% between 1 and 9 years, 18% between 1 year and 6 months, and about 23% for less than 6 months.
- Rural caregivers spend an average of 21 hours per week caregiving but 19% of them spend more than 40 hours per week caregiving.
- Fourteen percent of rural caregivers and nearly 20% of their care recipients are veterans.

- About 11% of rural caregivers report annual incomes under \$15,000; 17% had incomes between \$15,000 and \$29,000; 34% between \$30,000 and \$49,000; 18% between \$50,000 and \$74,000; 8% between \$75,000 and \$99,000; and 11% report annual incomes over \$100,000.
- Twenty-seven percent of rural caregivers are college graduates, and an additional 29% completed some college or technical schooling. Thirty-six percent are high school graduates or have their GED and 8% did not complete high school.

U.S. RURAL CARE RECIPIENTS: DEMOGRAPHIC HIGHLIGHTS

- 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, with 27% of the total between 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.
- Rural caregivers themselves report that 13% of their rural care recipients' main problems or illnesses were the "results of old age", 8% of diabetes, 7% of cancer, and 7% of Alzheimer's/dementia.

AREAS OF CONCERN UNIQUE TO RURAL CAREGIVING

After the data from the 2004 survey were analyzed to identify areas of concern that were statistically significant and unique to rural caregiving, the results were compared with other sources of information related to rural health and caregiving. Several themes emerged, including:

- the limited use and availability of services in rural areas,
- the significant impact of caregiving on rural workplaces,
- the financial hardships rural caregivers with low incomes face,
- the stress of rural caregiving and related coping mechanisms,
- the level of availability and concerns regarding use of the Internet,
- the prevalence of disability related to incidents in farming and ranching operations, and
- the current and increasing number of veterans in need of care in rural areas.

Nationwide, approximately 288,000 agricultural workers between the ages of 15 and 79 have a disability that affects their ability to perform one or more essential tasks – Bureau of Labor Statistics, 1999



Following are specific facts drawn from the 2004 survey data that expand on each theme and its implications (National Alliance for Caregiving and AARP, 2004).

LIMITED USE AND AVAILABILITY OF SERVICES

Rural caregivers are less likely to use most formal services that might support them in their caregiving efforts. Twenty-two percent of rural caregivers report using an aide or nurse through an agency or service, while 25% of urban and 24% of suburban caregivers do so. Only 8%

of rural caregivers report using other paid help (i.e., besides an aide, housekeeper, or nurse), while 16% of urban and 13% of suburban caregivers do so. Only 29% of rural caregivers are likely to use transportation services, while 38% of urban and 34% of suburban caregivers do so.



Just 6% of rural caregivers take part in a support group, while 9% of urban and 8% of suburban caregivers do so. These data are consistent with other findings on this topic and speak to the lack of services in rural areas. Not surprising then is the fact that only 4% of rural caregivers make use of respite services and 3% of rural caregivers make use of adult day centers, both lower than their urban (5% and 8%, respectively) and suburban (5% and 6%, respectively) counterparts.

Further, 17% of rural caregivers are likely to say that they need help or information in knowing how to talk to doctors, while 28% of urban and 20% of suburban caregivers do so. This finding may speak to the fact that there are simply fewer physicians and educational health care services in rural areas, thus giving rural residents limited opportunities to interact and become comfortable in communicating with medical staff. Alternatively, this lower figure could be due to the fact that in small communities people may have a personal relationship with the local physician and find it easy to talk with him or her. Further exploration of this topic is necessary.

Rural caregivers are less likely to use most formal services that might support them in their caregiving efforts.

These facts support the overall observation that services are less available in rural areas (i.e., caregivers cannot use what is nonexistent). A variety of other factors, (e.g., higher levels of self-reliance, lower incomes, and larger financial burden among rural caregivers than among urban caregivers), however, may contribute to rural caregivers' limited use of services. Clearly, additional research is needed in this specific area to determine, for example, whether adult day services or support groups are available in rural areas, and if they are, whether caregivers use them or not, and why.

IMPACT OF CAREGIVING ON THE RURAL WORKPLACE

Although they are less likely to be employed than their urban (57% employed) or suburban (62% employed) counterparts, 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, 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.

This reflects the significant workplace impact caregivers living in rural areas experience, one which is only slightly less severe than that of their urban counterparts.

LOWER INCOME LEVELS AMONG RURAL CAREGIVERS

Over 11% of rural caregivers report household incomes of under \$15,000, which is the highest percentage of caregivers in that category; 9% urban and 4% suburban caregivers make under \$15,000. At the other end of the scale, rural caregivers have the smallest percentage in each of the top three income categories. Only 18% have incomes between \$50,000 and \$74,000, with 21% of both urban and suburban having incomes at this level. Eight percent have income between \$75,000 and \$99,000 while 9% of urban and 12% of suburban caregivers have this level of income. Finally, 11% of caregivers with household incomes over \$100,000 are found in rural areas – 14% of urban and 22% of suburban caregivers reported incomes in this range.

Only 27% of rural caregivers report graduation from college or graduate school while 37% of urban and 42% of suburban caregivers do so. Eight percent of rural caregivers did not complete high school compared with 6% of urban and 2% of suburban caregivers. In light of a number of studies that have found a correlation between college graduation and earning potential, this lower level of education among rural caregivers may be one of the factors that contributes to their lower level of income.

Rural caregivers (27%) report experiencing a moderate to high level of financial hardship, while just 23% of urban and 19% of suburban caregivers expressed a high level of financial hardship.

Rural caregivers tended to spend either the least or the most out-of-pocket dollars for medications, groceries, and the like on behalf of their care recipients. Compared to 34% urban and 39% suburban caregivers, 43% of rural caregivers spent nothing on their rural care recipients. Of those caregivers who spent more than \$500 per month on their care recipient, 6% were rural, 4% were urban, and 2% were suburban.

Rural caregivers (41%) are also much more likely than their urban counterparts (28%) to have children or grandchildren residing with them. Forty percent of suburban caregivers report having children under age 18 in their household. The need to support these children in addition to the care recipient may also contribute to levels of financial hardship.

Although they are less likely to be employed than their urban counterparts, more than half of rural caregivers (54%) reported working full-time or part-time during the period in which they were providing care.

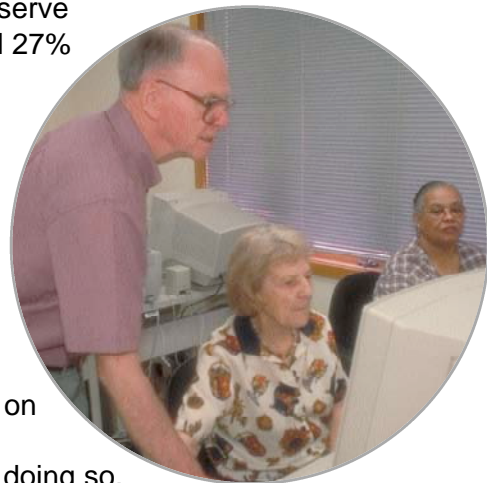
STRESS AND COPING MECHANISMS RELATED TO RURAL CAREGIVING

Rural caregivers (78%) were statistically more likely to turn to prayer as a means of support than were their urban (71%) or suburban (70%) counterparts. This fact needs further examination to determine what role the church or clergy could play in supporting caregivers or how interventions or services could best be structured to support rural caregivers.

Caregivers reported stress levels associated with providing care at opposite ends of a continuum. At one end, rural



caregivers (30%) reported it was not stressful at all to serve as a caregiver, as compared to 25% of their urban and 27% of their suburban counterparts who said it was not stressful. At the other end, however, 21% of rural caregivers reported that it was very stressful to be a caregiver while only 18% of their urban and 17% of their suburban counterparts so reported.



USE OF THE INTERNET

Although many rural caregivers-support and service-delivery organizations and systems are relying heavily on the Internet to provide information and assistance, this research suggests that caution should be exercised in doing so.

One of the most interesting responses in this survey was that a mere 25% of rural caregivers reported using the Internet to find information, while 37% of both urban and suburban caregivers reported using it. This likely reflects such issues as lack of access to broadband connections in rural areas; many rural caregivers' limited skills, knowledge, and comfort level with using computers; limited financial capacity to purchase a computer or pay for high-speed connections, and limited access to computers that could be used outside the caregivers' homes (e.g., in a local institution, such as a library, within quick and easy access of the caregiver).

Rural caregivers tended to spend either the least or the most out-of-pocket dollars for medications, groceries, and the like on behalf of their care recipients.

HAZARDOUS NATURE OF FARMING AND RANCHING

Agricultural production is one of the most hazardous occupations. Over 700 farmers and ranchers die in work-related incidents yearly and another 120,000 workers sustain disabling injuries from work-related incidents (National Safety Council, 2006). In addition, the USDA National Agricultural Statistics Service estimates that more than 200,000 farmers, ranchers, and other agricultural workers experience lost-work-time injuries and occupational illnesses every year, approximately 5% of which have serious and permanent results. Off-the-farm incidents; health conditions, such as heart disease, arthritis, or cancer; and aging disable tens of thousands more. Nationwide, approximately 288,000 agricultural workers between the ages of 15 and 79 have a disability that affects their ability to perform one or more essential tasks (Bureau of Labor Statistics, 1999).

When a member of a farm or ranch family needs part-time or full-time care, that need is usually filled by a family member. For those individuals and families affected by disability and chronic health conditions, finding affordable and appropriate care is a serious issue. Rural isolation, limited personal resources, and limitations in rural health delivery systems all contribute to the challenges that family members of the many farmers and ranchers with disabilities and chronic health conditions face when seeking a caregiver for their loved one. How to provide care and simultaneously keep the farm operation running smoothly is a question to which farm families often find no satisfactory answer. For an example of one farm family's story, see the section in this report titled Profiles of Two Caregivers in Rural Areas.

VETERANS LIVING IN AND RETURNING TO RURAL AREAS

Another unique characteristic of rural areas is the high number of men and women living there who are or have been members of the military. Almost one quarter of all veterans live in rural areas (U.S. Senators Salazar and Thune, 2006). In some states (e.g., Vermont and Iowa), however, more than half of the state's veterans live in rural areas. Frail, rural older veterans may be at particular risk because options for care (both VA and non-VA health and social services) are less available or nonexistent in rural areas.

Compounding this situation is the increasing number of veterans with serious injuries and disabilities returning to their homes in rural America following their military service in the Middle East. An increase in rural veterans means an increased need for services to support their caregivers. In the 2004 National Alliance for Caregiving and AARP survey, just over 14% of rural caregivers and nearly 20% of their rural care recipients were veterans.

Almost one quarter of all veterans live in rural areas.



The Department of Veterans Affairs (VA) has begun to recognize the issues of family caregivers because it cannot meet the long-term care needs of all veterans in VA facilities. Therefore, the VA is beginning to help veterans' family caregivers address their needs for access to support services both inside the VA and in the Community. The VA, however, will need authorization from Congress in order to offer more support services to family caregivers.

**Comparison of Selected Statistics Among
Caregivers-Rural, Suburban, and Urban**
From the 2004 National Alliance for Caregiving and AARP Survey
(Single decimals rounded to the nearest whole number.)

CHARACTERISTIC	RURAL	SUBURB	URBAN
<u>Marital and military status</u>			
Married	64%	56%	50%
Living with a partner	6%	6%	6%
Never married	11%	17%	26%
Widowed	6%	7%	5%
Divorced/separated	14%	15%	14%
Veteran	14%	15%	13%
<u>Employment and income</u>			
Working full-time or part-time during the period in which they provided care	54%	62%	57%
Had to take time off and/or leave job early to provide care	56%	54%	62%
Had to take leave of absence to provide care	18%	15%	18%
Went from fulltime to part-time job to provide care	8%	9%	12%
Turned down promotion to provide care	4%	5%	5%
Took early retirement to provide care	3%	3%	3%
Lost some job benefits to provide care	6%	4%	5%
Gave up job entirely to provide care	8%	4%	8%
Has an annual income under \$15,000	11%	4%	9%
Has an annual income over \$110,000	11%	22%	14%
Caregiving presents a moderate to great financial hardship	27%	19%	23%
<u>Amount of care provided</u>			
Provided care for 10 years or more	14%	14%	14%
Provided care for 1-9 years	45%	44%	51%
Provided care for 1 year - 6 months	18%	18%	17%
Provided care for less than 6 months	23%	23%	18%
Spends an average of 21 hours/week providing care	21%	24%	26%
Spends more than 40 Hours/week providing care	19%	16%	0%
<u>Education</u>			
Report graduation from college or graduate school	27%	42%	37%
<u>Living & care service arrangements</u>			
Has children/grandchildren under 18 living with them	41%	40%	28%
Lives in same household as care recipient	25%	22%	25%
Uses an aide or nurse through an agency or service	22%	24%	25%
Uses other paid help (i.e., not an aide, nurse, or housekeeper)	8%	13%	16%
Uses transportation services	29%	34%	38%
Uses an outside service to deliver meals	13%	11%	10%
Finds providing care not stressful	30%	27%	25%
Finds providing care very stressful	21%	17%	18%
<u>Personal supports</u>			
Needs more help or information in balancing work and family responsibilities	26%	28%	33%
Turns to prayer as means of support	78%	70%	71%
Takes part in a support group	6%	8%	9%
Makes use of respite services	4%	5%	5%
Makes use of adult day centers	3%	6%	8%
Needs help in or information about knowing how to talk to doctors	17%	20%	28%
Uses the Internet to gather information	25%	37%	37%

PROFILES OF TWO CAREGIVERS IN RURAL AREAS

A Native American Caregiver on a Reservation

Loretta participates in the Rosebud Reservation Native American Caregiver Support Program in South Dakota. She is 81 years old and is caring full time for four of her five grandchildren. Four years ago she adopted her eldest grandson through the Indian Child Welfare Act Program.

She faces many challenges daily. Never having learned to drive, she walks everywhere. Walking five miles to accomplish a task is not unusual for her. She says this keeps her healthy. She takes her grandchildren along and teaches them their native language along the way. She wants them to know the values and traditions of their culture and to carry it on. The National Family Caregiver Support Program has delivered services and resources to assist in caring for her grandchildren, including respite and a support group. These have provided much-needed emotional support for Loretta.

In many ways Jean is a typical farm wife. She raised the seven children (four of whom were adopted and have special needs), runs the household, assists with farm finances, keeps the family connected to the community, and helps out with seasonal farm chores. She and her husband Don have operated, essentially by themselves, a 40-head dairy farm with 2000 acres of pasture and cropland in Colorado for 30 years.

Life changed when Don and one of the children were injured in a car accident. Their daughter, unconscious for three months, sustained a severe traumatic brain injury and became legally blind. Don also sustained a brain injury; although it was less severe than their child's, it left him with short-term memory loss.

Jean carried on her normal activities but added new responsibilities, providing emotional support and hands-on assistance for Don in running the farm. She also provided intensive caregiving, home-schooling, and coordination of educational and medical services for their daughter. She became overwhelmed by the details and changes in rules and regulations affecting her daughter's education. The County Extension Agent referred her to the AgrAbility project staff at Easter Seals. The staff supported her in her role as caregiver, providing insight and direct help on working with all of the providers and agencies involved. The AgrAbility staff also suggested that she may benefit from counseling services and referred her to a mental health center. Jean worked with a counselor and found it extremely helpful.

A Farm Wife Coping with Stress

CALL TO ACTION!

Although this report provides many insights into rural caregiving, one thing is abundantly clear – more research is needed on caregiving in rural America. Some of the significant questions yet to be answered include:



- Are rural caregivers aware of and taking advantage of all of the services and benefits to which they are entitled? For example, are they accessing those resources made available through the National Family Caregiver Support Program, or are veterans using Department of Veterans' Affairs services?
- As the makeup of rural America becomes increasingly diverse, what are the unique needs of the rural caregivers and the culturally relevant approaches to providing them services?
- How can rural communities assess their existing environment using approaches with a focus on strengthening their infrastructure and expanding the services available to assist caregivers?
- What are the specific impediments to rural caregivers using the World Wide Web and other emerging internet-based technologies? What changes are necessary in the electronic infrastructure of rural America in order to make Internet resources accessible to caregivers? Is there a role that rural caregivers can play in advocating for changes to be made?

If rural caregivers, like their urban and suburban counterparts, are expected to continue serving as the backbone of the long-term care system in the United States, they need information, education, support and services to help them do so.

- What are the effective strategies that rural elders use to stay connected to their adult children who have moved away and are caring from a distance? Conversely, what strategies do adult children use when they function as long-distance caregivers?
- What are the policy barriers and gaps in public services that need to be addressed so that our public systems better serve caregivers? Congress and the federal government have begun to address this question through the creation and expansion of the National Family Caregiver Support Program in the Older Americans Act and the passage of the Lifespan Respite Care Act, but is there more that can be done?
- Can the Veteran's Administration mandate to care for veterans only be expanded to include support for family caregivers of veterans?

If rural caregivers, like their urban and suburban counterparts, are expected to continue serving as the backbone of the long-term care system in the United States, they need information, education, support, and services to help them do so. The data in this report make clear the urgent need for development of specialized services and approaches in order to meet the unique needs of rural caregivers. Expansion of consumer-directed models of support may be one answer. Further, in-depth research on the current and future needs of rural caregivers should to be conducted.

Demonstrations of innovative, replicable models of service delivery to support caregivers are needed. As such service models are developed and evaluated, they need to be disseminated widely across rural America.

While this report highlights some of the unique needs of rural caregivers and aspects of rural caregiving, there are some key points that are universal. All caregivers, in all locations, need basic support information and education and services, such as respite care and a comprehensive, coordinated long term care system that acknowledges the significant role of the family caregiver. All caregivers could benefit from use of a uniform and valid assessment tool through which information can be collected on the individualized aspects of a caregiver's situation. The results of the assessment could highlight areas of difficulty and be used to identify appropriate types of services and support.

PROGRAM PROFILE

Statewide Services for Caregivers

Family Caregiver Alliance is working in partnership with Mountain and Del Oro Caregiver Resource Center's and the Northern Sierra Rural Health Network (coordinator of an extensive video conferencing and telemedicine network) to test and evaluate three modes of delivery for education and training programs for rural and frontier caregivers throughout a nine-county, 30,000 square-mile area in northern California. A grant from the Bristol-Meyers Squibb Foundation is supporting efforts to build a collaborative network of health, home and community-based service providers, educational institutions, technology networks, community organizations, and caregivers to expand the capacity of existing systems to provide high-quality education and training to underserved rural caregivers. The two-year project (2005-2007) focuses on the improved functioning and well-being of family caregivers. Based on survey responses from 168 rural family caregivers and service providers, the following topics were selected for education programs;

- practical caregiving skills to increase the competency of the caregiver to provide hands-on care to the patient,
- care management skills to increase ability of caregivers to access health and community- based service systems, and
- self-care skills to meet the physical and emotional needs of the caregiver.



Two-way videoconference workshops using telemedicine technology at rural hospitals and clinics, workshops by conference calls, and in-person meetings are being employed to deliver practical caregiver education classes. In addition, a rural caregiver education collaborative is under development that brings together elected officials, service providers, and caregivers in a regional town hall forum and coalition-building effort.

This project also builds upon the 20-year experience of the California Caregiver Resource Center (CRC) system to provide direct services—information and

A two-year project focuses on the improved functioning and well-being of rural family caregivers.

assistance, uniform caregiver assessment and caregiver action planning, respite services, counseling, education, legal consultation and online service delivery to caregivers throughout the state. Over the past two decades, the CRC system has used a wide variety of in-person and technology-assisted strategies to serve caregivers in rural and frontier communities in the state. Examples of these programs include: coordinating teams of staff from Alzheimer's Day Care Resource Centers, Alzheimer's Research Centers, and the CRCs to go to rural communities to offer practical training and consultation; using existing telecommunication systems like satellite, videoconference capabilities within adult education, community colleges, libraries, and health centers to provide training; and development of Link2Care, an online support and education program for caregivers of adults with dementia. All have served to improve the quality of life for family caregivers in remote parts of California.



PROGRAM PROFILE

The National AgrAbility Project

The AgrAbility Project, administered by U. S. Department of Agriculture, Cooperative State Research, Education and Extension Services (CSREES), links land-grant universities with private, non-profit disability service providers, like Easter Seals, to deliver practical education and assistance that will promote independence in production agricultural and rural living for people with disabilities.

The National AgrAbility Project is a partnership between Easter Seals and the University of Wisconsin Cooperative Extension Service. National project staff provides training, technical assistance, and information on resources to state AgrAbility project staffs. In 2006, 21 state AgrAbility projects offered an array of services, including:

- on-site technical assistance on adapting and using farm equipment and tools, and on modifying farm operations and buildings;
- development and coordination of peer and family caregiver support networks;
- training to help Extension educators and other rural professionals upgrade their skills in assisting farmers with disabilities; and
- agriculture-based education to help prevent further injury and disability.

Both the national and state projects have directed specific attention to developing resources for the caregivers of farmers and ranchers with disabilities. Those resources are available through the AgrAbility Website at www.agrabilityproject.org.

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CAREGIVING IN RURAL AMERICA

Annotated Resource List

The following resources provide additional information related to many of the topics highlighted and issues raised in this report.

Adult Day Services – A resource that is of special value to caregivers but difficult to provide in rural areas is adult day services. For an example of one state's examination of the need for and availability of the services, see “Adult Day Services in Rural Pennsylvania.” It can be found on the Web site for The Center for Rural Pennsylvania, http://www.ruralpa.org/adult_day_services_melnick04.pdf.

Cash and Counseling – Other approaches include flexible models of care. For example, because of their flexibility, the cash and counseling and consumer-directed models of service delivery are particularly appropriate for rural areas, according to Donna Wagner and Kelly Niles-Yokum in “Caregiving in a Rural Context.” This is a chapter in “Service Delivery to Rural Older Adults: Research, Policy and Practice”, edited by John A. Krout and R. Turner Goins, Springer Publishing, 2006.

Mobile Services – One approach to meeting the challenge of providing adult day services in rural areas is to take the service to those in need rather than have them come to the service. In Georgia, this takes the form of mobile adult day services, using a van to transport staff, materials, and supplies for a day among multiple sites on a rotating basis. For a detailed description, see the Web site for the Georgia Department of Human Resources at <http://dhr.georgia.gov/portal/site/DHR> and search for “mobile day care.”

Rural Older Adults – Kathleen Buckwalter, RN, PhD, FAAN, and Linda Lindsey Davis, RN, PhD, drafted a comprehensive document entitled “Report on Elder Caregiving in Rural Communities” that addresses both strategies for development of caregiver assistance programs and policy implications. The document can be found at <http://www.centeronaging.uiowa.edu/archive/pubs/Elder%20Caregiving%20in%20Rural%20Communities.htm>

Rural Transportation – A new report by the Beverly Foundation and the Community Transportation Association of America examines the importance and challenge of providing transportation services in rural areas. With transportation being key in linking those in need with essential services and being less than readily available in rural areas, the report's focus on innovations is timely. “Transportation Innovations for Seniors: A Report on Rural America” describes the rural environment, transportation challenges and requirements, especially for seniors, and the importance of innovation. Five case studies of innovative rural transportation solutions are included in the report. The report is available on the Beverly Foundation Web site at http://www.beverlyfoundation.org/Resourcestore/Research_and_Reports.html.

Rural Veterans – The Veterans Administration has experimented with outreach efforts to serve rural veterans. The Coordination and Advocacy for Rural Elders (CARE) program was designed to provide case management services to rural veterans who were at risk because of fragmented services and a lack of coordinated efforts. Findings suggest that the model is a feasible approach for screening, assessing, and managing a population of

at-risk elderly veterans living in rural communities. See "Coordination and Advocacy for Rural Elders (CARE): A Model of Rural Case Management with Veterans." Christine Ritchie et al. *The Gerontologist*. Vol.42, No.3, 399-405. 2002.

Additional related Web sites

University of New Hampshire, Carsey Institute – www.carseyinstitute.unh.edu.

A current Carsey Institute Report on Rural America includes a discussion of demographics, population redistribution trends, and policy implications for rural areas.

Federal Office of Rural Health Policy – www.ruralhealth.hrsa.gov.

This site offers a report on informal caregiving in rural areas as well as a report on Telehealth.

Rural Assistance Center – www.raconline.org.

Not only does this site link you to the HRSA site above, it also includes a discussion of broadband access in rural areas.

National Rural Health Association – www.NRHArural.org.

Available now on this site is a report on hospice and palliative care in rural and frontier areas.

Southwest Rural Health Research Center –

www.srph.tamhsc.edu/centers/srhc/default.htm

This site is sponsored by the nation's first School of Rural Public Health, at Texas A&M University. The site has a focus on aging and long-term care and many publications of possible interest. Included is "Access to Quality Health Services in Rural Areas, Long-Term Care," which examines the differences in long term care services delivered in rural versus urban areas. An extensive bibliography is provided for even greater exploration of the topic.

Purdue University's Breaking New Ground Program – www.ruralcare.info.

This site is designed to help bridge the information gap and assist in creating a Web support community for rural caregivers.



Easter Seals
www.easterseals.com
www.agrability.org



National Alliance
for Caregiving
www.caregiving.org

To download an electronic copy of this report, go to
www.easterseals.com

To obtain a copy of this report in an alternative format,
call 202.347.3066.

Front cover photo: Ryan Odens, 2006 Easter Seals National Adult Representative, and his grandmother, Lois Odens.