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Helping the Helpers: State-Supported Services For Family Caregivers

by

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The Public Policy Institute, formed in 1985, is part of the Research Group of the AARP. One of the missions of the Institute is to foster research and analysis on public policy issues of interest to older Americans. This paper represents part of that effort.

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Foreword

Many older people who need long-term care in America today can remain in their homes and maintain their independence only because of the assistance they receive from family caregivers. Families are the mainstay of the country's long-term care system with nearly one in four U.S. households containing at least one caregiver in 1997.

Many family caregivers, particularly people who provide around-the-clock care, face emotional, physical, and financial problems. A number of states have developed caregiver support programs to try to relieve some of the pressures on family caregivers. State officials believe that helping caregivers to cope with their responsibilities is not only a compassionate response but also a practical policy approach to forestall or prevent the need for institutional care. Paying for long-term care, particularly nursing home care, is costly for states today. Several tax credit and other caregiver support initiatives also have been proposed at the federal level.

AARP hopes to contribute to the current national debate about assisting family caregivers by providing this report on comprehensive and innovative state caregiver programs. The report draws on two 1999 national surveys of caregiver support services, and describes the methods states are using to reach caregiver families. This information can provide useful models for policymakers in their efforts to support the backbone of long-term care, the family caregiver.

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HELPING THE HELPERS: STATE SERVICES FOR FAMILY CAREGIVERS

Executive Summary

Background. Nearly one in four U.S. households was involved in caring for an older family member or friend in 1997. These "informal" (unpaid) caregivers are the backbone of the long-term care system in America today, providing much of the assistance to people who need help with daily activities to remain in their homes. Without the assistance of these family caregivers, many older people with disabilities would be forced to enter institutions for their care.

Policymakers recognize the savings in public dollars when family caregivers help their relatives stay at home. As a result, many states have developed programs to help caregivers with information and referral to resources, education, and training on caring for a person with disabilities, and respite services to provide time off from care responsibilities.

Purpose. The purpose of this report is to provide policymakers and advocates with an overview of a range of state programs to support family caregivers, from statewide comprehensive service programs to smaller, innovative outreach programs that focus on overcoming barriers to assistance faced by many caregivers. These programs suggest some of the approaches states can adopt to help family caregivers enable a relative to live at home.

Methodology. The paper draws on findings from two 1999 surveys: (1) a survey of 33 caregiver support programs in 15 states selected by the California Family Caregiver Alliance (FCA) on the basis of large population of older people and state support for caregiver programs, and (2) a survey by the National Association of State Units on Aging (NASUA) for AARP of smaller-scale innovative caregiver support programs in 10 other states.

After providing an overview of the surveys' findings, the author reviews the statewide comprehensive caregiver support programs of California, Pennsylvania, New Jersey, and Florida that were included in the FCA survey. The author also chose Georgia, Nevada, and South Carolina from among the 10 states in the NASUA survey to review for their unique outreach strategies for reaching caregivers with information and support.

Findings. The FCA and NASUA surveys reveal a wide range of caregiver support programs in the 25 states covered. The survey findings include the following:

- States fund specific programs for caregivers through general revenue funds. Single-purpose caregiver services such as respite care are funded through state

general revenues or as part of a multipurpose publicly funded home and community-based care program that serves both the care recipient and the family caregiver.

- Comprehensive state caregiver programs generally offer respite care and four or more other services, including specialized information and referral, family consultation or care planning, support groups, care management, and education and training.

- While respite care is offered in most states, the states vary considerably in how they define eligibility for services, deliver services, and fund the programs.

- The NASUA survey identified several strategies used by states to reach caregivers with assistance, such as statewide toll-free “helpline” services, mobile adult day care services for rural areas, cash vouchers, and networks of aging and community health organizations to expand services to people with low incomes.

Summary and Conclusion. Caregivers differ in regard to the type of disability affecting their family member, the amount of time they devote to caregiving, and their financial resources and support network. These factors affect the caregiver’s level of stress and burden, and the response of the caregiver to supportive services. The value of these services to the caregiver is diminished, for example, if the programs are not easily accessible because of time or location.

Many state caregiver support programs have limited budgets and can serve only a small number of caregivers. Increased funding could make these services available to many more people trying to keep family members at home. But policymakers also need to consider designing flexible services so that the diverse needs of caregivers will be met.

For example, Pennsylvania and Georgia offer families cash or vouchers to purchase the services or supplies most appropriate to each family’s needs. California provides respite services in emergencies or overnight. These states and others involve family caregivers in the design of caregiver support programs so that the services will be truly useful to the caregiver.

HELPING THE HELPERS: STATE SERVICES FOR FAMILY CAREGIVERS

Introduction

Millions of American households include at least one family member who is caring for an older relative. This assistance ranges from occasional help in paying bills, buying groceries, and cleaning the house to more intense daily assistance with bathing, dressing, and cooking for the care recipient. These family caregivers are called "informal" or unpaid caregivers in contrast to "formal" (paid) personal care or home care workers.

A 1997 National Alliance for Caregiving/AARP Survey reported that nearly one in four U.S. households (22.4 million) was involved in family caregiving. The survey noted that the average family caregiver devotes 18 hours per week to caregiving activities; however, close to one in five caregivers (18 percent) provides at least 40 hours of care per week (NAC/AARP 1997).

In his fiscal 2001 budget plan, President Clinton proposed a $3,000 tax credit to assist Americans who have long-term care needs and the family members who care for them. The White House estimated that about 2 million Americans would be eligible for the tax credit, which would be phased in beginning with $1,000 in 2001 and rise in increments until reaching $3,000 in 2005.

The president's budget also included funding for services under the Older Americans Act such as respite care to assist family caregivers of older persons. This program would cost about $1.25 billion over 10 years, according to White House estimates.

Many states have created and expanded caregiver support programs in recent years, ranging from comprehensive packages of services that are available statewide to smaller, localized, single-service programs. Caregiver support services include respite, care planning, education and training, legal and financial counseling, information and referral services, and support groups. Some states have also enacted cash allowance or tax credit programs for family caregivers and family and medical leave programs that require employers to offer unpaid family leave for employees with caregiver responsibilities.

The pivotal role of family caregivers in helping older people with disabilities to remain in their homes has prompted many state policymakers to review their state's efforts at caregiver support. Policymakers have noted that family caregiving that helps people with disabilities remain at home can save public dollars that might otherwise be spent on that individual in a nursing home.

A recent report concludes that “caregiver support has become a salient policy issue …on Capitol Hill, in state legislatures, and in workplaces across the country” (Family Caregiver Alliance 1999b). Thus, state and federal policymakers are looking for effective models in existing state caregiver support programs.

To put state efforts to assist family caregivers in context, the paper begins with a discussion of research findings about whether support programs for caregivers have proved to be effective in relieving stress and depression. Then the paper provides an overview of current public caregiver support programs throughout the country and describes several state programs in depth.

The information on state caregiver support programs draws on two 1999 state surveys — a 15-state survey conducted by the California Family Caregiver Alliance and a 10-state survey by the National Association of State Units on Aging. The author selected several states from the surveys to provide examples of comprehensive statewide efforts for caregivers or to suggest innovative state outreach activities to assist caregivers.

Appendix A discusses the most prevalent form of state caregiver support, respite services. Appendix B summarizes other types of state support for caregivers, such as family and medical leave laws and tax incentive programs.

Background

Informal caregiving plays a major role in providing long-term care services in the United States. The availability of family supports makes it possible for many individuals with disabilities to remain in their homes, rather than being forced to enter an institution for their care. The presence of a family or other unpaid caregiver may obviate the need for paid services or may complement paid services.

One study has estimated the national economic value of informal caregiving in 1997 at $196 billion. The study used survey figures on average number of hours of caregiving and a midrange market wage rate to estimate the cost of replacing informal caregiving with paid home care workers (Arno et al. 1999).

Another study indicates that family caregivers continue to provide care for their relatives even if other publicly or privately paid resources are available. This study’s analysis of data from the 1982, 1989, and 1994 National Long-Term Care Surveys shows that while the use of paid help increased over the survey years, informal caregivers did not cut back their assistance (Liu et al. 2000).

The research literature is replete with studies reporting significant rates of stress and depression among caregivers who provide extensive support for family members, particularly when they are caring for relatives suffering from dementia (Schulz et al. 1995). Researchers have also noted that caregivers in general “often face practical problems of lack of knowledge regarding caregiving technique, community resource utilization, and simple stress management" (Greene and Monahan 1989).

The research literature suggests that services and support for caregivers can help alleviate stress and depression. For example, Greene and Monahan (1989) found statistically significant reductions in anxiety, depression, and sense of burden among caregivers who completed an eight-week professionally guided support group program.

In another study, Mittleman and her colleagues examined the effects of a comprehensive support program on depression in caregivers whose spouses suffered from Alzheimer's disease. The caregivers participated in individual and family counseling sessions and in weekly support groups. The researchers reported significantly less depression among program participants than among a control group of caregivers who received no services (Mittelman et al. 1995). Other researchers say that support groups can help caregivers by providing information about various disabilities and sharing information about effective coping strategies (Toseland and Rossiter 1989, Zarit 1990).

Studies have also been conducted on the impact on caregivers of adult day care, respite, and educational services (Montgomery and Borgatta 1989, Zarit 1990, Zarit and Teri 1992, Knight et al. 1993, Bourgeois et al. 1996, and Zarit et al. 1998). Although researchers generally report positive outcomes for caregivers from this variety of supports, policymakers and researchers continue to explore the most effective ways to assist family caregivers. This paper, therefore, reviews several types of caregiver support programs that states have developed.

Methodology

The information in this paper on state caregiver support programs comes largely from surveys conducted in 1999 by the California Family Caregiver Alliance (FCA) and the National Association of State Units on Aging (NASUA).

The California Family Caregiver Alliance conducted its 15-state survey from April through August 1999 in preparing for a national invitational state policy conference on caregiving in San Francisco in October 1999. The FCA sought to identify "best practices to serve as useful models for other states."

The FCA selected the states[1] largely on the basis of number of people age 65 and older in 1995, geographic representation, high level of expenditures on caregiver programs, and a mix of target populations. The FCA sent a written questionnaire to the program administrators or state department representatives who were responsible for the programs identified in the states. Then the FCA made follow-up calls to the officials to expand or clarify information on the questionnaire, and sent each state a copy of the data for verification.[2]

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[1] California, Florida, Illinois, Iowa, Michigan, New Jersey, New York, North Dakota, Ohio, Oregon, Pennsylvania, Texas, Virginia, Washington, and Wisconsin.

[2] FCA published the survey results in its 1999 report, "Survey of Fifteen States' Caregiver Support Programs: Final Report."

To supplement the findings from the FCA survey, AARP contracted with the National Association of State Units on Aging (NASUA) to identify other states with programs that offer new or different outreach approaches to caregiver families. Based on telephone interviews with key informants from national organizations, aging and disability groups, and state officials, NASUA staff selected states[3] with caregiver projects considered innovative by the key informants. NASUA staff then gathered written material on the programs and conducted telephone interviews with state program officials.

The author has selected material from the two surveys to provide an overview of state caregiver support programs throughout the country. First, the author summarizes general findings from the two surveys that help to illustrate the types of services states are providing and the population they are serving. The author then highlights the programs of four FCA-surveyed states — California, Florida, New Jersey, and Pennsylvania. Three of the four states (California, Florida, and Pennsylvania) had the best financed, most comprehensive statewide caregiver support programs in 1999. New Jersey had the best financed and most extensive respite care program, and is launching two new statewide caregiver programs.[4]

Finally, the author describes the efforts of three states from the NASUA survey (Georgia, Nevada, and South Carolina) that illustrate the techniques some states have developed to finance or deliver services to hard-to-reach caregiver families, particularly in rural areas.

The term “family caregiver” is used in this paper because many state programs restrict eligibility for caregiver services to family members**,** although informal (unpaid) caregivers might also be friends or other non-related individuals.[5] Also, some state programs use a narrow definition of “family caregiver” to mean specific family members (e.g., spouses) for purposes of eligibility for a service such as respite.

This report reviews state-funded supportive services that are intended *specifically* for caregivers, such as respite, education and training, counseling, support groups, and information and referral. However, many states fund a limited amount of home health care or personal care services through general revenues for people with disabilities. Many of these publicly funded services also provide support indirectly for the caregiver since the availability of a paid worker gives the caregiver time to rest or to attend to other tasks.

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[3] Connecticut, Georgia, Kansas, Kentucky, Maryland, New Hampshire, Nevada, South Carolina, Utah, and Vermont.

[4] The FCA survey covered 33 programs in the 15 states, many of which provide services *primarily* for a person with disabilities but also include a service such as respite for a family caregiver. The author chose states that had comprehensive and well-financed programs that focus mainly on the caregiver.

[5] This paper discusses programs for family caregivers of people with developmental disabilities, adults with cognitive impairments, and adults with functional impairments, but *not* programs for family caregivers of children under the age of 18.

FCA and NASUA Surveys:

Findings from the surveys include the following:

- Most state caregiver support programs serve families caring for persons with functional impairments, cognitive impairments (especially Alzheimer's disease), or adults with developmental disabilities.

- States typically fund caregiver support programs with general revenues. However, states often offer respite care as a specific service within a Medicaid or state-funded home and community-based care package of services or as a separate state-funded program of respite services only.

- Most state programs for family caregivers offer respite and four or more services, including specialized information and referral, family consultation, care management, support groups, and education and training. Eligibility, funding, and service delivery for respite care vary considerably across programs and states. (See box below for list of typical state services for caregivers. Appendix A describes respite services in greater detail; Appendix B discusses state tax credit and family leave programs for caregivers.)

- Eleven of the 15 FCA-surveyed states have identified and defined family caregivers in statute or through administrative or programmatic definitions.

- Eligibility criteria vary by diagnostic or functional level, age, and income. Most of the services intended primarily for the family caregiver have no income requirements, operating through a sliding fee scale or other cost-sharing mechanism.

- State officials believe that the most beneficial aspects of their programs include flexibility of program services, broad income eligibility to serve middle-income families, and a focus on consumer-directed care. Their biggest problems include inadequate funding, limited services or program scope, and lack of awareness of program services.

TYPICAL STATE CAREGIVER SUPPORT SERVICES

- Respite care: Temporary break from caregiving responsibilities.

- Adult day services: Structured and rehabilitative services for older adults that also provide a respite for caregivers.

- Information and referral: Assistance in finding services for the care recipient or the caregiver.

- Education and training: Information on specific diseases and dementias and assistance in learning how to provide hands-on care.

- Financial support: Vouchers or cash to purchase services or equipment.

- Family consultation/care planning: Assistance in making a care plan and exploring care options.

- Legal and financial consultation: Consultation on issues related to caregiving.

- Counseling/support groups: Emotional support to caregivers coping with the strain of the caregiving role.

- Tax assistance: State tax deductions or credits.

- Nearly two-thirds of the FCA-surveyed programs have developed educational materials for families as part of their programs (fact sheets, training materials, booklets, and videotapes). The California Caregiver Resource Centers and Regional Centers and the Wisconsin Alzheimer’s Family Caregiver Support Program have their own websites.

- The NASUA survey identified several strategies for reaching caregiver families, particularly families with low incomes living in rural areas: mobile adult day care services, vouchers to pay for services, partnership arrangements among the aging and mental health networks and community health centers, and statewide toll-free “Helpline” services.

State Program Summaries

California Caregiver Resource Centers

California has developed a statewide network of Caregiver Resource Centers that provide information, education, and support to caregivers of adults with brain disorders (e.g., Alzheimer's disease, stroke, Parkinson's disease). The program developed out of the work of the Family Survival Project, organized in the 1970s by family members whose relatives suffered from a variety of brain disorders. With the help of an attorney, psychotherapist, and psychiatrist, the group sponsored community meetings in 1977. In 1978, the California Department of Mental Health provided a grant to the Family Survival Project to determine the number of individuals with adult-onset brain damage and the availability of services for these individuals and their caregivers.

The legislature approved funds in 1980 for a pilot project to develop a package of support services for family caregivers of adults with brain damage or neurological disease (e.g., Alzheimer's disease, stroke, traumatic brain injury). The pilot was awarded to the Family Caregiver Alliance (formerly the Family Survival Project), and was tested for three years across the state. In 1984, the legislature authorized a statewide system of Caregiver Resource Centers (CRCs) to be phased in over four years, and designated the Family Caregiver Alliance as Statewide Resources Consultant under contract with the California Department of Mental Health to oversee statewide activities created by the legislation (Kelly 1998). Eleven nonprofit centers have been operating since 1989.

In fiscal 1998-99, the budget for the statewide system was $9.247 million, placing California second to Pennsylvania in the level of funding for caregiver support services. Another $2 million was authorized for expanding adult day health care programs and the Alzheimer's Day Care Resources Centers through the Department of Aging. In fiscal 1998-99, the program served a total of about 11,600 caregivers through a range of support services (see page 8).

The program operates on a consumer-directed care model. Families are given information, support, and skills to become their own care managers. One of the biggest problems for the program, according to state administrators, is the heavy demand for respite care services, which has limited funding. In fiscal 1998-99, about 2,500 families were on a waiting list for respite care.

CALIFORNIA CAREGIVER RESOURCE CENTERS

California Resource Centers offer a range of services, including:

- Information, advice, and referrals — Specialized information on adult-onset brain disease/disorders, caregiving issues, and functional and behavioral problems, and basic information on legal and financial issues and community resources.

- Assessment — An in-home assessment of the caregiver to identify caregiver needs and problems. Using the assessment, CRC staff work with the caregiver to develop a care plan of support services. Caregivers are reassessed at six-month intervals as long as the need for assistance continues.

- Education and Training — Training events are sponsored regionally to educate families and service providers about topics such as care techniques, current research, and self-care and stress reduction strategies.

- Support Groups — CRCs sponsor support groups for families and caregivers and adults with brain impairments. The Family Caregiver Alliance website has also created an on-line caregiver support group.

- Respite Care — This program offers financial assistance for a range of respite service options. Families may choose a voucher program or a direct pay option. The vouchers can be used with home care agencies, adult day programs, or facilities offering overnight respite. The direct pay option allows a family to hire an independent provider for in-home respite care. Each CRC can authorize up to $425 per month for respite per family client. (In practice, CRCs cap this service at $250-$350 per month to serve more caregivers.) The program also includes short-term options: respite camps, caregiver retreats, emergency respite, and transportation.

Pennsylvania Family Caregiver Support Program

The Pennsylvania Family Caregiver Support Program began as a demonstration project in 1987 at eight Area Agencies on Aging with $200,000 in funding. The state legislature enacted the program in 1990; it was implemented statewide in 1992. Expenditures totaled $10.2 million in 1998.

The program is administered and operated locally by the state's 52 Area Agencies on Aging (AAAs) in all 67 counties. In 1998, the program served a total of about 6,700 caregivers, with about 3,500 caregivers enrolled in the program at any given time during the year.

The Pennsylvania caregiver support program consists of four main components: (1) financial assistance to a household to purchase services or supplies that assist in caring for a family member; (2) initial and ongoing assessment of needs plus developing and monitoring a care plan; (3) benefits and community resource counseling; and (4) caregiver education and support.

The program reimburses family caregivers for expenses they incur caring for a functionally dependent relative 60 years of age or older who lives with the caregiver. (Caregivers who reside with younger relatives with dementia may also be eligible for the program.) Examples of reimbursable expenses include adult day care or a personal care aide, transportation, nutritional supplements, over-the-counter drugs, lift chairs, or grab bars.

Caregivers can be reimbursed for up to $200 per month for services and supplies. The amount of reimbursement depends on need, household size, household income, and expenditures. There are no time limits on how long a family can remain in the program. The average monthly expenditure is $149. Families may also be eligible for a one-time grant of up to $2,000 to modify the home or purchase assistive devices for the family member.

To be eligible for the program, household income cannot exceed 380 percent of the federal poverty level ($2,550 per month for an individual in 1999). At income of 200 percent of poverty or less ($1,342 per month for an individual in 1999), the caregiver is eligible to receive the maximum grant of $200. As income rises from 200 to 380 percent of poverty, the amount of the grant becomes smaller.

Care managers at Area Agencies on Aging complete an assessment of the care recipient and the caregiver, using a Comprehensive Options Form. The assessment helps the family and the care manager to determine the most appropriate package of benefits to meet the needs of the caregiver and the older person receiving care.

CAREGIVERS PRACTICAL HELP

The Pennsylvania Department of Aging publishes a 75-page guide for family caregivers called *Caregivers Practical Help*.[6] The guide was originally designed by the New York State Office for the Aging as a course for trainers, but was later modified by New York and Pennsylvania so that family caregivers could use the information without having to attend a formal training course. The following is a description of the material in the guide:

- **Psychological Aspects of Caregiving**

Examines the psychological problems associated with caregiving, including stress, burnout, emotional exhaustion, and social withdrawal. Describes ways families can work together to relieve some of these problems.

- **Medical Problems of Aging**

Basic information about common chronic illnesses, such as cardiovascular disease and organic brain syndromes.

- **Age-Related Changes in Vision, Hearing, and Speech**

Discussion of vision, hearing, and speech changes associated with aging and communication problems that arise. Suggestions on how to deal with these problems.

- **Finding and Using Community Resources**

Information on available services (national, state, and local). Discussion of home service options, transportation resources, adult day care services, and housing options.

- **Personal Care Skill Development**

Guidance in helping an older person with personal care and homemaker tasks. Ways to change the environment to improve an older person’s functioning.

- **What Does the Future Hold?**

Possible strategies for the caregiver, such as supplemental help from service providers, informal support groups, and advocacy for unavailable services.

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[6] Pennsylvania Department of Aging. *Caregivers Practical Help: A Guide for Family Caregivers of Older Pennsylvanians.* Harrisburg, PA. 1998.

New Jersey Caregiver Assistance Program and Statewide Respite Care

In her annual State of the State address to the New Jersey Legislature in January 1999, Gov. Christine Whitman announced that she was allocating almost $6 million for two new caregiver support programs in fiscal year 2000, and providing increased funding for a statewide respite program. The new initiatives are the Caregiver Assistance Program (CAP) for family caregivers of Medicaid beneficiaries ($2.3 million), and Jersey Assistance for Community Caregivers (JACC) for the caregivers of persons not eligible for Medicaid services ($2.5 million). An additional $1 million in state revenues was budgeted for the state's existing respite program for caregivers.

Under the Caregiver Assistance Program, county care managers authorize payments to help family caregivers purchase goods and services for their Medicaid-eligible relative. Certain people whose incomes are too high to qualify them for the Medicaid-funded services may be eligible for the Jersey Assistance for Community Caregivers program, through which they and their family caregivers will be able to use medical day care, meals on wheels, and other services. In 1999, persons age 65 and older with annual incomes above the state's $18,000 Medicaid limit but below $29,300 qualified for the JACC program. Eligible recipients are expected to help pay for services on a sliding fee schedule based on their income.

The governor's plan called for the Caregiver Assistance and the Jersey Assistance for Community Caregivers programs to begin operating in the first four counties that implemented the state's new single-point-of-entry system, called NJ EASE (Easy Access Single Entry). This system provides one-stop shopping for information and assistance, outreach, benefits screening and assessment, and care planning for older people. The four counties are Atlantic, Ocean, Morris, and Union. The caregiver programs will expand statewide in future years.

New Jersey's Statewide Respite Program has been operating since 1988, supported almost entirely by state casino revenues, although some funds also come from county providers and contributions from participants. With a budget of almost $5 million in fiscal 1998, the program served 2,250 participants. The additional $1 million budgeted by the governor brought the fiscal 1999-2000 total to about $6 million.

The program is administered at 21 sites across the state by "sponsor" agencies — county offices on aging, county-level human service agencies, home care agencies, and hospitals. Services are available for emergency and crisis situations, as well as for routine respite for caregivers.

To be eligible for the program, a care recipient's income cannot exceed $1,500 per month; total assets cannot exceed $40,000. Families may receive up to $3,000 per year for a variety of respite care options that include in-home respite and adult day services.

Florida Alzheimer's Disease Initiative and Respite Program

Florida's Alzheimer's Disease Initiative was established in 1985 to provide services to people with Alzheimer's disease or a related dementia and their family caregivers. The program includes a governor-appointed state advisory council with consumer representation.

Operating in 68 respite sites and four model day care sites[7] throughout the state, the program served over 3,200 people in fiscal 1999 with a budget of $6.3 million in state funds. The program imposes no income limits or caps on services. While families can remain in the program as long as they like, the average length of stay is between nine and ten months. Twenty-five percent of the clients stayed in the program for four months or fewer. Services include respite, day care, and a memory disorders clinic.

Another respite program in Florida is called RELIEF (Respite for Elders Living in Everyday Families). This program, which was enacted in 1997, provides in-home assistance from volunteers to allow the family caregiver time to take care of other responsibilities. The program offsets volunteer expenses to provide evening and weekend respite in the home. For fiscal year 2000, the program has a budget of $1.3 million. Program sponsors hope to reach families who do not quality for other programs or who are on waiting lists for other programs.

Georgia Outreach to Rural and Low-Income Caregiver Families[8]

Georgia comprises 159 rural counties, areas that typically have few resources for caregivers. The situation can be particularly acute for caregivers of family members with Alzheimer's disease, who need the respite that adult day care services can provide. Adult day centers do not often locate in rural areas because the number of potential participants is too small to cover the cost of services.

In 1995, the Central Savannah River Area Agency on Aging contracted with the Augusta Area Chapter of the Alzheimer's Association to provide mobile day care in McDuffie and Burke counties. In 1998, the Athens Community Council on Aging, Inc. opened sites in Elbert and Greene counties, and the McIntosh Trail/Mental Health/Mental Retardation Community Service Board opened two sites in Butts and Upson counties.

In a mobile day care program, the staff and supplies move from a central (usually urban) location to sites in rural counties, often a church or senior center. Two to three days a week, the mobile day care staff travel as far as 50 miles each way to specific sites to provide services. Two or three counties share the cost of the staff and supplies. Like their stationery counterparts, mobile adult day care providers must meet state standards for staffing, facilities, and accessibility.

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[7] The model day care sites are designed as a source of research on innovative therapeutic services for people with Alzheimer's disease.

[8] The Georgia programs are funded through the U.S. Administration on Aging Alzheimer's disease Demonstration Grant Program, which has awarded grants to 15 states since 1992 to develop educational and service programs for people with Alzheimer's Disease, their families, and caregivers.

The fiscal year 2000 funding for the Central Savannah River and McIntosh Trail mobile day care projects totaled over $88,000 in federal and state Alzheimer's Demonstration Grant funds, with additional local support totaling $37,000. The Athens project received a total of $62,000 in state and local funds.

Another Georgia caregiver project is administered by Legacy Link, Inc., an Area Agency on Aging (AAA) that serves 13 counties near Gainesville, Georgia. Since July 1997, the agency has operated a self-directed care demonstration program called "Legacy Express" that provides vouchers to caregivers to purchase services or supplies. Caregivers are given a handbook on using program services, a list of approved providers, and a voucher book with which to purchase services.

Vouchers are provided in $50, $20, and $10 denominations. Caregivers may select from an array of services and supplies, such as respite, day care, personal support aides, medications, pharmacy supplies, adult diapers, or even lawn care. The caregiver arranges the service with the provider and pays with the voucher; the provider redeems the voucher through the AAA. If the cost of the service is less than the face amount of the voucher, the AAA credits the "change" to the caregiver's account.

Percent of Services Used by Legacy Express Clients

Personal care	**50%**
Respite	**23%**
Home care supplies (pharmaceuticals, medications)	**11%**
Adult day care	**8%**
Home modifications, lawn care, emergency response	**6%**
Other	**2%**

Source: Georgia Division of Aging Services
January 2000

Each participating family is given a total of $500 upon entering the program, but the family may request additional funds when the $500 is exhausted. Families are given considerable flexibility in how and when they spend the money; they can choose to make periodic payments (say, weekly or monthly) for a specific service such as respite, or they can spend the money to purchase supplies or medications whenever they need. One family was given about $2,000 over two years to install a bathroom.

Program officials estimate that caregivers spend on average $100 a month, with some families not spending anything during a given month and others spending more than $100. At the end of calendar 1999, 46 families were participating. The voucher program has a budget of about $100,000 in fiscal 2000, which consists of about $86,000 in federal-state funds under the Alzheimer's Demonstration Grant and about $12,000 contributed by the AAA.

South Carolina Project COPE (Care Options and Public Education)

Project COPE began in 1992 as a means to expand services to low-income and minority families in rural areas of the state that lacked services for caregivers of people with Alzheimer's disease and related dementias. For fiscal year 2000, the program has Alzheimer's Demonstration grant funds of $700,000 in federal and state funds. Since its inception, more than 2,800 families have contacted Project COPE for information and referral or for services.

The program began operating in the Trident region in the southeastern part of the state (consisting of three counties that are a mix of urban and rural areas), in the barrier islands near Charleston, and in the Pee Dee region (six rural counties in the upper part of the state). Three additional regions (Catawaba, Lower Savannah, and Waccamaw) are now receiving education and training grants.

Project COPE involves a partnership of three networks: aging, mental health, and community health centers. In the Trident region, a nurse hired by the Area Agency on Aging coordinates the project. In the Pee Dee region, a social worker is employed jointly by the project and the community health center and housed at the AAA to manage the project.

Two main services are offered through Project COPE sites: a telephone helpline and respite care services. In the one-year period from July 1, 1998 through June 30, 1999, 255 families contacted Project COPE helplines or respite sites for information or services, 166 families received adult day services, and 119 families received in-home respite services.

Northern Nevada Eldercare Website

The Nevada Division for Aging Services contracted with The Continuum of Reno to build and maintain an eldercare website for northern Nevada. The Continuum is a for- profit intergenerational center that provides adult and child care rehabilitation and training.

The website, which opened in July 1999, recorded 535 visitors by October 20, 1999. The site provides the following types of information: 1) announcements of classes, workshops, and forums on caregiving; 2) local resources, such as providers of respite care; 3) links to national websites for caregivers; 4) a bulletin board where caregivers can post messages; and 5) a discussion group called "Topic of the Month," that allows caregivers to exchange messages with experts in gerontology and caregiving. (The listing of local resources is limited to northern Nevada.)

Conclusion

"Development and evaluation of interventions for family caregivers is one of the most important challenges in long-term care of the elderly" (Zarit 1990). Caregivers vary in relation to the type of disability affecting their family member, the amount of time they devote to caregiving, and their financial resources and support network, among other things. These factors affect their levels of stress and burden and their responses to programs of information and support.[9]

Researchers have noted that for programs for caregivers to be helpful, the programs must consider this diversity of the caregiver population and the range of problems with which caregivers are dealing. Montgomery and Borgatta (1989) say that caregivers who face large demands on their time and energy are "frequently not receptive to any services that may initially place greater demands on them." For example, researchers have found that many caregivers do not use adult day care services for a period of respite because the programs may not be scheduled at convenient times or locations.

Greene and Coleman say that program officials must not "impose significant new time and care management demands on people already struggling for some order in their lives," (Greene and Coleman 1990). Policymakers need to "reduce the real cost of access to these services by not imposing significant new and trouble costs on people already short on time and long on trouble." Several state models of caregiver support described in this paper have tried to address these access problems by establishing multi-service caregiver centers throughout a state (California), by allowing families to use funds for the specific services the family needs (Pennsylvania), or by bringing services such as adult day care closer to older people and their families (Georgia).

Researchers have also looked at the effectiveness of support groups for helping caregivers. Toseland and Rossiter suggest that more attention be devoted to "the format, content, and approach" of support group strategies. For example, the researchers point out that support groups typically continue only for short periods of time although caregiving is a "long-term proposition, often lasting for years." The researchers believe that caregivers might realize more benefit from being in support groups that last for the duration of the caregiving experience (Toseland and Rossiter 1989).

Yates and her colleagues suggest that efforts on behalf of caregivers should be directed at intervening before problems develop – before the caregiver begins to suffer from overload. Developing strategies to prevent overload, they say, might involve "training caregivers in technical skills or in obtaining emotional support before they actually need it" (Yates et al. 1999). Interventions could include "supportive educational approaches to develop skills, information to empower caregivers, and reaffirmation of their existing skills, abilities, and knowledge" (Yates et al. 1999).

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[9] Based on Zarit (1990), "burden" is defined as the caregivers' appraisal that assisting their relative has had a "detrimental effect on their personal and social life, health, finances, and emotional well-being."

The challenge to policymakers is to determine caregiver needs and then to design the support services that will be most effective in meeting those needs. The key to helping caregivers, many experts agree, is flexibility to help address the diverse needs of a diverse population of caregivers. Flexibility might mean:

- Establishing sliding fee scales for services for people whose incomes exceed Medicaid or state-funded income eligibility criteria such as the Pennsylvania program provides.

- Bringing services to the caregiver and the family as in the case of the mobile day care services in Georgia, rather than asking people to travel long distances to access services.

- Providing overnight and emergency services as do the California Caregiver Resource Centers.

- Offering families cash allowances or vouchers to purchase the type of services or supplies appropriate to each family's needs and situation. The Pennsylvania and Georgia models have these features.

- Involving caregivers in designing caregiver support programs by identifying the types of problems or concerns they would like addressed and the goals or outcomes for the proposed service.

APPENDIX A

RESPITE CARE

> *"Respite care is a temporary break provided to an individual who supplies regular care to a disabled relative or friend."* U.S. Bipartisan Commission on Comprehensive Health Care

Respite care is the most prevalent service provided by states for family caregivers. Respite care is temporary, short-term relief provided to caregivers in or outside the home that is intended to help alleviate the stress associated with constant or frequent caregiving responsibilities. "Respite care changes the focus of who is the primary recipient of services from the patient to the caregiver" (Lindeman and Soos 1991).

Many policymakers also believe that providing respite services for caregivers may help deter or postpone institutionalizing the care recipient. Since most people entering nursing homes either have too little money to pay for their care from the outset or soon exhaust their resources, keeping people out of institutions or delaying their admission saves public dollars. One study estimates that a one-month delay in nursing home placement among Alzheimer's disease and other dementia admissions could save as much as $1.12 billion annually (Leon et al. 1998).

Respite care takes a variety of forms, ranging from in-home respite, institutional respite, daycare, and day health programs. Many respite programs include assessment, care management, counseling, and caregiver education about the purpose of respite and about dementia (if the care recipient has Alzheimer's disease or another form of dementia), and ways of managing patient behavioral problems.

The number of state respite programs has been growing, both as state-funded, single-purpose programs or as a specific benefit in a comprehensive package of services under a Medicaid Home and Community-based Waiver program. A 1997 study of state-funded home and community-based care programs reported that 11 states had respite care programs with funding ranging from $185,000 (Arizona) up to $2.4 million (Washington). Of these 11 states, four states (Alaska, California, Hawaii, and New Jersey) also had state-funded adult day care programs, which provide respite for caregivers while the care recipient is in attendance (Kassner and Williams 1997).

In 1996, 48 states operated Medicaid waiver programs for older persons with disabilities.[10] Thirty-eight of the 48 states included respite services within the package of services they provided in these waiver programs. Eight of the other states had respite services within their Medicaid waiver programs for mentally retarded/developmentally disabled individuals. Only two States (Oregon and South Dakota) did not include respite services within any of their Medicaid waiver programs.[11]

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[10] Arizona has a statewide capitated managed long-term care program that offers similar services to Medicaid waiver programs. Maryland has a Medicaid waiver program for mentally retarded/developmentally disabled persons.

[11] Oregon has a state-funded "Lifespan Respite Care Program" for caregivers of people of all ages.

A 1992 study of respite programs across the country reported the following findings:

- No consistency existed among federal, state, local, and private providers of respite care in type, eligibility criteria, or funding for respite services.

- Respite care definitions and eligibility varied greatly from state to state and depended on individual state priorities and resources.

- Finding and keeping competent respite care providers was universally difficult.

- Data on the costs and use of respite care were limited (Family Caregiver Alliance 1992).

Twenty of 35 state-sponsored respite programs surveyed in 1991 reported that they are unable to meet the demand for respite services (Lindeman and Soos 1991).

While many states report considerable demand for respite services, a number of research studies have also found significant evidence that caregivers are often reluctant to avail themselves of the services when offered, or drop out of programs after a short period of time (Cox 1997, Montgomery and Borgatta 1989). Caregiver families are "fiercely independent" and reluctant to accept help "until they reach a crisis point," the researchers say (Montgomery and Borgatta 1989). (Of course, many caregivers stop using respite services because their relative enters a nursing home or dies.)

Researchers have also found, however, that participation improves and stress is reduced if caregivers avail themselves of respite services earlier in a relative's illness, the caregiver is given sufficient amounts of respite, and the service is flexible as to hours and location (Blume et al. 1990, Cox 1997). Cox suggests that combining respite with counseling and support groups could help "strengthen the coping mechanisms of caregivers and their willingness to accept services" (1997).

Caregivers who do take advantage of respite services generally report being satisfied with the programs (Lawton et al. 1989, Weissert et al. 1990, and Cox 1997). Researchers who conducted a national survey of 60 adult day care centers in the mid- 1980s reported that adult day care appeared to be "meeting the needs of its clientele, particularly caregivers who are trying to balance family commitments with their own jobs" (Weissert et al. 1990). The more hours the caregiver worked, the more satisfied he or she was with day care services.

A 1998 study compared the experience of caregivers of relatives with dementia who used adult day care with a control group not using this service, and found lower levels of stress and better psychological well-being among the day care users (Zarit et al. 1998). The study focused on caregivers who used adult day care at least two times a week for three months or longer.

APPENDIX B

STATE TAX CREDIT AND FAMILY LEAVE PROGRAMS FOR CAREGIVERS

Two different types of state assistance for family caregivers are tax credit programs and family leave policies. The National Conference of State Legislatures reports that half the states offer a tax break to people who care for a family member in their homes and to businesses that provide dependent care assistance to employees.[12]

State tax credit programs build on the federal tax credit, which reduces the amount of income taxes a family owes. The federal tax credit covers the expenses an employed person incurs to pay for household services or personal aides for a spouse who is disabled or an aging parent who requires daily living assistance.

The amount of the federal credit ranges from 20 percent to 30 percent of qualified expenses, depending on a taxpayer's adjusted gross income (AGI). For claimants whose AGI is $10,000 or less, the credit may be as much as 30 percent. The maximum federal credit is $720 for one qualifying dependent and $1,440 for two or more qualifying dependents.

Most of the state credits conform closely to the federal credit. The states use the federal eligibility rules, and define the state credit as a percentage of the federal credit. For example, Kansas allows 25 percent of the federal credit on the state return, or $180 for one qualifying dependent; Delaware allows 50 percent of the federal credit, or $360 for one dependent.[13]

Tax credit programs usually have requirements that limit the number of people who might benefit, such as a requirement that the caregiver and family member live in the same home, and that the family member be financially dependent on the caregiver. Also, many state tax incentive programs cover only child care, rather than elder care.

The federal Family and Medical Leave Act, which became effective on August 5, 1993, requires businesses with 50 or more employees to allow workers to take up to 12 weeks of unpaid leave in a 12-month period for family care or personal medical reasons. Several states cover more workers and/or require employers to allow workers longer periods of leave than the federal law. For example, the Oregon Family Leave Act covers employers with 25 or more employees and has a broader definition of family member, including parents-in-law. Alaska allows 18 weeks during a 24-month period; Connecticut, 16 weeks during a 24-month period.

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[12] Wendy Fox-Grage and Jennifer Grooters, "Caring for the Caregivers," *State Legislatures,* June 1998.

[13] Jennifer Grooters of the National Conference of State Legislatures provided the information on state tax credits, which is based on January 1998 information.

In Vermont, an employee may take up to four hours of short-term family leave in any 30-day period and up to 24 hours of short-term leave in any 12-month period. These short-term leave periods cannot be subtracted from the federal 12-week allowance. Massachusetts requires employers to allow up to 24 hours leave in a 12-month period for accompanying a spouse or elderly relative to routine medical or dental appointments.

States that extend coverage to employers with fewer than 50 employees include Maine, Minnesota, Oregon, Vermont, and the District of Columbia.

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