

FAMILY CAREGIVERS IN CALIFORNIA:
NEEDS, INTERVENTIONS AND MODEL PROGRAMS

December 31, 2001

Andrew Scharlach, Teresa Dal Santo, Jill Greenlee, Stephanie Whittier, David Coon,
Kathryn Kietzman, Kelly Mills-Dick, Pat Fox, and Jolyn Aaker

Center for the Advanced Study of Aging Services

University of California at Berkeley

Berkeley, CA

ACKNOWLEDGEMENTS

This report was made possible through funding from the California Department of Aging (CDA) to the Center for the Advanced Study of Aging Services (Center) at the University of California, Berkeley, as part of an Interagency Agreement between the CDA and the University. The goal of the Interagency Agreement is to provide assistance to CDA in the implementation and evaluation of the new federal National Family Caregiver Support Program (Older Americans Act Amendment of 2000, Title III-E). Specifically, we would like to thank CDA Director Lynda Terry, Deputy Director Joyce Fukui, and Policy Manager Edmond Long for their commitment to improving services for California's caregivers, as well as their detailed knowledge of the program specifics.

We also would like to thank a number of individuals for their specific contributions to this report. Undergraduate Research Apprentice, Joshua Hill, and Senior Clerk, Jhiah Chang, performed many important tasks throughout the project, including checking references, conducting library searches, obtaining library materials and preparing manuscripts. Also, Mia Reiser, Account Manager, provided invaluable support with regard to the Interagency Agreement.

TABLE OF CONTENTS

EXECUTIVE SUMMARY	1
CAREGIVERS' CHARACTERISTICS & NEEDS.....	7
INTRODUCTION	7
BACKGROUND	9
CHARACTERISTICS OF CAREGIVERS.....	10
CARE RESPONSIBILITIES.....	15
IMPACT ON THE CAREGIVER.....	20
IMPACT ON WORK.....	26
CAREGIVING CONTEXT.....	29
SUMMARY	32
REFERENCES.....	35
CAREGIVER SUPPORT INTERVENTIONS.....	49
INTRODUCTION.....	49
EFFECTIVENESS OF CAREGIVER INTERVENTIONS BY CATEGORIES.....	50
SUMMARY AND CONCLUSIONS.....	63
REFERENCES.....	67
MODEL PROGRAMS.....	75
INTRODUCTION.....	75
INFORMATION.....	76
ACCESS.....	78
COUNSELING, SUPPORT GROUPS, EDUCATION, AND TRAINING.....	82
RESPITE SERVICES.....	87

SUPPLEMENTAL SERVICES.....	92
MULTI-COMPONENT SERVICES.....	95
NATIONAL RESOURCES.....	101
PROGRAM DIRECTORY.....	105
REFERENCES.....	110

EXECUTIVE SUMMARY

INTRODUCTION

This report provides a comprehensive review of current knowledge regarding (1) the characteristics and needs of family caregivers; (2) caregiver support interventions and their outcomes, particularly regarding the five service areas identified in the NFCSP and (3) model programs for supporting caregivers. It is hoped that this report will provide the California Department of Aging and local Area Agencies on Aging with a foundation for developing service programs to assist family members in maintaining their caregiver roles for their older family members who are ill or who have disabilities

Caregiver Characteristics and Needs

This section of the report provides a review of several general areas of family caregiving research, including: (1) the prevalence of caregiving and characteristics of caregivers, (2) the impact of caregiving, (3) caregiver needs, and (4) trends in family caregiving that have been identified over time.

By some estimates, nearly one out of every six households gives care nationwide, equating to 2.9 million households in California alone (NAC/AARP, 1997; Scharlach, 2001). Most caregivers are female (Montgomery & Kosloski, 1999; NAC/AARP, 1997; Stone et al., 1987; Wagner, 1997); and, there are slightly higher frequencies of caregiving among minority ethnic groups than among Caucasians (NAC/AARP, 1997). Almost half of all caregivers nationwide are employed (NAC/AARP, 1997), suggesting that approximately 1.8 million caregivers in California balance care duties with work. The care given ranges significantly, based upon the needs of the care recipient; however, 98% of caregivers assist with at least one IADL, and 81% assist with three or more (NAC/AARP, 1997). Individuals who care for someone with a dementia-related illness

2 Family Caregivers in California

provide more care, measured by both the number of hours of care given and the number of IADLs or ADLs with which the care recipient needs assistance (Ory et al., 1999).

The demands of providing care to an ill or disabled family member or friend can impact the health and well-being of the caregiver, at times resulting in high levels of stress that can lead to depression or burnout (Moen et al., 1995). They may also experience a loss of social roles (Skaff & Pearlin, 1992). Physically, caregiving can take a toll on individuals; female caregivers particularly tend to report more physical ailments than do non-caregiving females (Pruchno & Postashnik, 1989; Scharlach et al., 1997; Schulz et al., 1995). Indeed, there is some evidence that mortality rates may be higher for caregivers than non-caregivers (Schulz & Beach, 1999). Yet despite these increased emotional and physical health risks, family caregivers do not tend to seek out health services at higher rates than do non-caregivers (Pruchno & Postashnik, 1989; Scharlach et al., 1994).

Certain individuals are more vulnerable to the deleterious effects of caregiving. Those who care for someone with problematic behaviors, dementia, or a high level of daily dependency are at greater risk for negative outcomes (Bourgeois & Schulz, 1996; Fox et al., 2001; Mittelman et al., 1995; Ory et al, 1999; Pruchno & Potashnik, 1989; Schulz et al., 1995). Caregivers who experience family conflict, financial hardships, or loss of social roles are also at particular risk (Mittelman et al., 1995; Skaff & Pearlin, 1992). Other vulnerable caregivers include those who care for persons with Alzheimer's Disease, have health problems of their own, share a home with the care recipient, have conflictual familial relations, experience occupational conflicts or strains, or are socially isolated (Bourgeois & Schulz, 1996; Fox, Kohatsu, Max, & Arnsberger, 2001; Mittelman et al., 1995; Ory et al, 1999; Pearlin, Mullan, Semple, & Skaff, 1990; Pruchno &

Potashnik, 1989; Schulz et al., 1995; Skaff & Pearlin, 1992). These characteristics help to identify those caregivers who are at greatest risk for deleterious impacts of family caregiving, for whom formal supports may be particularly beneficial.

Finally, the current state of knowledge of family caregiving has implications for program development as well as research. Caregiver needs may be mediated through a complex network of characteristics, including gender, ethnicity, the caregiver-care recipient relationship, and employment status. Understanding how those characteristics interact is essential for identifying how best to meet caregivers' unique needs. Moreover, caregiver needs transform over time, as a caregiver moves through the care trajectory (Montgomery & Kosloski, 1999). Focusing on the intersection of individual characteristics and environmental or time-dependent circumstances may produce important insight into how caregivers might best be served during each phase of their caregiving experience.

The emerging complexities and characteristics of the changing nature of family life are particularly relevant to the development of caregiver support programs in California. Demographic shifts make it apparent that family caregivers are a growing segment of the population; moreover, caregiving contexts are likely to grow more diverse as well. As single parent households, blended families, grandparents raising grandchildren, gay and lesbian homes, and other nontraditional family structures become more common, new complexities within family caregiving arise. Researchers and service providers face the challenge of expanding their conceptual models of caregiving to better meet the needs of California's changing families (Fredriksen-Goldsen & Scharlach, 2001).

4 Family Caregivers in California

Caregiving Support Interventions

The second section of this report examines existing knowledge regarding the effectiveness of interventions in the five service areas identified in the National Family Caregiver Support Program (Older Americans Act Amendment of 2000, Title III-E). In general, we find that a variety of caregiver support services are useful in alleviating caregiver strain and helping caregivers to provide care. Especially effective are individual and family counseling, culturally-targeted education and training interventions, and in-home and adult day care respite services. Less evidence exists for the effectiveness of information-only services, and support groups. Programs utilizing more than one intervention generally are more effective than those in just one service area.

Future program design and implementation would benefit from consideration of the following: (1) interventions should be geared to the specific needs of particular caregiver populations; (2) appropriate and realistic outcome measures are needed in order to evaluate the effectiveness of caregiver programs; (3) most intervention research fails to examine the possible ramifications of caregiver programs for the care recipient and for the caregiver/care-recipient dyad; (4) caregiver stress and burden may be counterbalanced, in part, by the positive aspects of caregiving; (5) it is unknown how technological advances in providing caregiver support services may improve caregiver outcomes.

Model Programs

The third section provides examples of model programs for supporting caregivers in five service areas: (1) information, (2) access, (3) counseling, education and training (4) respite and (5) supplemental. For each model program example listed, there is a brief

description of the program, including whom they serve and the number served, funding sources, the reason for inclusion, and contact information. Local non-profit service providers, state programs, and national programs have been included to illustrate the breadth of imaginative ways systems can be enhanced to serve caregivers better. These programs provide examples of the kinds of programs and services that AAAs may wish to consider in their efforts to respond to the unique needs of their local caregiver populations.

SUMMARY

This report examines the characteristics of caregivers and their care responsibilities, the impact that those duties have on personal and family well-being, the effectiveness of existing caregiver support interventions, and innovative programs that may serve as models to local and statewide efforts to better meet the needs of California's family caregivers. Research to date has captured the broad landscape of family caregiving nationally. Further data collection on the nuances of caregiving in California's racially and ethnically diverse context will serve to clarify and enrich that picture. As research proceeds at both a national and state level, the complexities of family care can be unraveled, and intervention programs to support family caregivers can be based on stronger empirical and theoretical foundations.

CAREGIVERS' CHARACTERISTICS AND NEEDS

Jill Greenlee & Andrew Scharlach

INTRODUCTION

This section provides a comprehensive review of current knowledge regarding the characteristics, needs, and vulnerabilities of family caregivers. While existing data primarily are national in scope, they provide a general framework for developing effective caregiver support programs to meet the particular needs of family caregivers in California. This review is by no means exhaustive, but rather is intended to address several general areas of family caregiving research, including: the prevalence of caregiving, characteristics of caregivers, care responsibilities, the impact of caregiving, caregiver needs, and trends in family caregiving that have been identified over time.

Defining "Caregiver"

The term "caregiver" encompasses a wide range of experiences and situations. Caregiving may include caring for a loved one in the caregiver's home, the care recipient's home or in an institutional setting. It may include attending to an individual's emotional well-being and/or physical health. It may involve long-term caregiving for an individual with a chronic illness or physical disability, or may be intermittent and sporadic as in the case of caring for someone with an acute illness or an acute episode of a chronic illness.

While experts from varied fields agree that family care responsibilities encompass a variety of situations and experiences, it is often necessary to delineate the concept of "caregiver" when conducting research, making policy, or delivering services. The 1982 National Long Term Care Survey (Stone, Cafferata, & Sangl, 1987), for example, classifies caregivers into one of three categories: 1) primary caregivers who have complete responsibility for the care recipient, 2) primary caregivers whose efforts

are supplemented by either informal or formal assistance, and 3) secondary caregivers who do not have primary responsibility for the care recipient. Caregiving scenarios also may be differentiated in terms of the age of the care recipient, the level of the care recipient's impairment, the intensity of caregiving duties, and the duration of the caregiving relationship. Some nationwide surveys on caregiving, for example, have focused on individuals who provide unpaid care for a relative or friend who is over the age of 50 (NAC/AARP, 1997). Narrower definitions also have been used, describing a caregiver as an adult who provides assistance with at least two instrumental activities of daily living (IADL) or at least one activity of daily living (ADL) to an individual who is at least 50 years of age (AARP/Travelers, 1987). Essential to understanding the body of literature on family caregiving is that different definitions of the term caregiver can significantly impact research findings. For example, variations in estimates of the number family caregivers in the U.S. are due in large part to different methods of operationalizing the concept of "caregiver."

Title III-E of the Older Americans Act Amendments of 2000, the National Family Caregiver Support Program, defines caregiver as "an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual"(Public Law 106-501, 2000). This "older individual" is identified in the Older Americans Act as a person over the age of 60, the age group to whom most Older Americans Act programs are directed. This definition of "caregiver" provides descriptive boundaries as to who is eligible to receive services under the National Family Caregiver

Support Program. Moreover, it guides the assessment of caregiver needs, program planning and program implementation.¹

BACKGROUND

Need for Care

Estimates suggest that more than 1.5 million adults in California have physical or mental disabilities necessitating ongoing assistance with day-to-day activities (GAO, 1995). Nationally, approximately 6.4% of community-dwelling elderly Americans (ages 70 or older) are functionally disabled, requiring assistance with one or more activities of daily living (ADLs), such as bathing, eating, walking, or dressing (Crimmins, Saito, & Reynold, 1997; Katz, Ford, Moskowitz, Jackson, & Jafee, 1963). Another 13.8% need assistance with instrumental activities of daily living (IADLs), such as using the telephone, shopping, cooking, laundry, driving, taking medications, or budgeting (Doty, 1986; Lawton & Brody, 1969). Approximately 75% of these frail or disabled elderly adults are cared for at home or in the community by family members or other informal care providers (Bengtson, Rosenthal & Blum, 1996; Liu & Manton, 1994;). Indeed, the availability of family members to provide care has been found to be a major factor predicting whether or not a disabled elderly person can remain at home rather than being institutionalized.

It is estimated that the number of persons requiring long-term care nationwide may nearly double in the next 25 years, as the baby boom generation grows older (GAO,

¹ Title III-E also permits up to 10% of all state funds to be used to assist grandparents or older individuals who are relative caregivers. These individuals are defined as “a grandparent or stepgrandparent of a child, or a relative of a child by blood or marriage, who is 60 years of age or older” and who “lives with the child, is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child; and has a legal relationship to the child, as such legal custody or guardianship, or is raising the child informally” (Public Law 106-501, 2000).

1995). By 2040, California will experience a 200% increase in the number of persons 85 years and older, more than 50% of whom can be expected to require care (Lee & Villa, 2001; Scharlach, Torres-Gil, & Kaskie, 2001). Despite this, the availability of family members or friends to offer that assistance is expected to decrease. The ratio of working age adults to older adults is anticipated to decline, leaving fewer family members to assist in the care of a growing number of older individuals. Additionally, kinship forecasts show that by 2030 there will be a sizeable portion of the older adult population with no biological or step-children (Wachter, 1998). Smaller family size, greater geographic dispersion of family members, increasing numbers of women in the workforce, and the prevalence of divorce and remarriage all contribute to an expected decline in availability of family caregivers (Ory, 2000).

Prevalence of Caregiving

A 1996 telephone survey of 1,509 randomly selected English-speaking individuals conducted for the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP) reported that 16.8 million households, slightly more than 17% of all U.S. households, contained at least one person who was providing unpaid care for a relative or friend over the age of 50 (NAC/AARP, 1997). A 1996 survey by the National Council on Aging found that 25 million Americans had provided or managed care for an individual aged 55 or older within the past year (NCOA, 1997). This is the equivalent of an estimated 2.9 million Californians (Scharlach, 2001).

CHARACTERISTICS OF CAREGIVERS

While the characteristics of caregivers vary tremendously, survey research findings have been used to create a profile of the “typical” American caregiver. This caregiver has been described as a married Caucasian woman, age 46, working full-time

while caring for her 77 year old mother, mother-in-law or grandmother. She is a high school graduate and has an average household income of \$35,000 per year. This caregiver provides care for an average of 18 hours per week for approximately 4.5 years (NAC/AARP, 1997). While this profile describes a likely caregiving scenario, it does not illuminate other important insights about the caregiving population. Indeed, the prevalence of family caregiving in minority communities is higher than among the non-Hispanic Caucasian population (NAC/AARP, 1997). In addition, men increasingly fill caregiving roles, and family caregivers can be found across the spectrum of household incomes. Therefore, such an illustration of the “average” caregiver should not be the driving force behind program development. Rather, more nuanced assessments of the caregiving population should be taken into account.

There appears to be a predictable order in the selection of a primary caregiver for frail elders (Doty, Jackson & Crown., 1998; Seltzer & Li, 2000; Tennstedt, 1999). If married, the care recipient is likely to be cared for primarily by his or her spouse. If the spouse is unable to fulfill that role, children most frequently become caregivers. Among children, daughters and daughters-in-law tend to serve as the primary caregivers (Montgomery & Kosloski, 1999). Spouses, therefore, serve as the first line of defense.

Gender

Three key findings have materialized from the body of literature that explores issues of gender. First, most caregivers are female. Second, there are differences in the way that men and women fill caregiving roles. Third, female caregivers tend to report greater levels of stress or strain than do males (Neal, Ingersoll-Dayton, & Starrels, 1997).

Most reports indicate that women make up about three quarters of all primary caregivers (Montgomery & Kosloski, 1999; Wagner, 1997; NAC/AARP, 1997; Stone et

al., 1987). However, the number of male caregivers appears to be rising, and a survey conducted by the National Family Caregiver Association (NFCA) in 2000 found that 44% of the caregivers interviewed were male (NFCA, 2000). Moreover, among spousal caregivers, men are as likely to be the primary caregiver as are women (Tennstedt, 1999).

Less conclusive are findings on caregiver gender differences in the amount and type of care given. Studies have found that women provide more intensive care than do men (NAC/AARP, 1997); male spousal caregivers are more likely than female spousal caregivers to obtain in-home services to aid in their responsibilities (Tennstedt, 1999; Abel, 1991); and sons and daughters tend to choose different solutions when caregiving situations arise (Abel, 1991). For example, women are more likely to perform tasks such as cooking and cleaning, which often require more time or more frequent contact than do the tasks that males are more apt to perform, such as financial management and home repairs (Tennstedt, 1999). However, a meta-analysis of gender differences in caregiving suggests that differences in caregiver involvement, while statistically significant, are small and communicate little substantive difference between how men and women give care (Miller & Cafasso, 1992).

Distinct from gender differences in the delivery of care, are gender differences regarding the impact of family caregiving. Studies show that women experience greater caregiver strain than do men, regardless of the level of disability of the care recipient (Neal et al., 1997; Young & Kahana, 1989). Daughters and wives in particular experience greater strain than do other relative caregivers (Young & Kahana, 1989; Neal et al, 1997).

Race/Ethnicity

Although the evidence is somewhat equivocal, there seems to be a slightly higher prevalence of caregiving among Asian Americans (31.7%), African Americans (29.4%) and Latinos (26.8%) than among non-Hispanic Caucasians (24%) (NAC/AARP, 1997). Moreover, when controlling for the level of disability, minority caregivers tend to provide more care than do Caucasian caregivers (Tennstedt & Chang, 1998). Latino elderly are more likely than their non-Latino Caucasian counterparts to live in multigenerational households, and have multiple family members involved in providing care (Feinberg, Pilisuk & Kelly, 1999). Of the three racial/ethnic groups, Caucasian caregivers are the most likely to provide care for a spouse; Latinos are the most likely to provide care for a parent; and African Americans are the most likely to be caring for other family members or unrelated individuals (NAAS, 2000; Burton et al., 1995).

A higher proportion of African American and Caucasian caregivers care for dementia victims than do Asian American or Latino caregivers. Indeed, African-American caregivers are one-and-a-half times as likely to care for someone who is demented rather than cognitively intact, whereas Asian American caregivers are nearly twice as likely to care for someone who is not demented (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Among caregivers for persons with dementia, non-Caucasian caregivers are more likely than Caucasian caregivers to be younger and employed. Thus, the design of support services and programs should consider those factors, particularly in communities with large minority populations (Janevic & Connell, 2001).

Differing levels of stress, psychosocial outcomes and levels of service utilization among caregivers of different racial, ethnic, and national origins have also been observed. For example, multiple studies have found that African American caregivers report lower

levels of caregiving-related stress than do Caucasian caregivers (Connell & Gibson, 1997; Hinrichsen & Ramirez, 1992; Lawton, Rajagopal, Brody, & Kleban, 1992; Macera et al., 1992; Miller, Campbell, Farran, Kaufman, & Davis, 1995; Mui, 1992; White, Townsend, & Stephens, 2000). However, it is unclear whether these differences are due to levels of religiosity, values or beliefs about aging, role expectations, social support or other factors (White, Townsend & Stephens, 2000). Moreover, socio-economic status, cultural differences and within-group variability may confound research findings, making it more difficult to determine if and how ethnicity differentially impacts the caregiving experience. Indeed, some scholars have suggested that race may function as a proxy variable for other important factors that are more likely to impact caregiving experiences, such as income, health, and family structure (Young & Kahana, 1995).

Employment

It is estimated that 11.7 million full-time and 2.7 million part-time U.S. employees balance their work obligations with caregiving duties (NAC/AARP, 1997); this equates to approximately 1.5 million full-time and 300,000 part-time California workers. The relationship between employment and caregiving is difficult to clearly discern; however, employment does appear to impact individuals giving care. Research reveals that frequently working heaps additional demands onto already burdened caregivers. Despite this, working outside of the home may also serve as a social outlet, a source of self-confidence for individual caregivers, or a “break” from caregiving tasks.

The profile of working caregivers is slightly different than that of caregivers who are not employed outside of the home. According to a 1988 survey by the AARP and The Travelers Foundation, caregivers who were employed full-time were on average younger than non-working caregivers; they also were more likely to be college educated,

have higher incomes, be male, and care for a family member who was less disabled (AARP & Travelers, 1988). Employed caregivers are especially likely to experience additional strain when a job is very demanding and there is little flexibility or support (Scharlach, Sobel, & Roberts, 1991). However, employed caregivers may be able to take steps to ease stress that non-employed caregivers cannot afford to take. For example, employed female caregivers, when compared to non-employed female caregivers, tend to use more hours of paid and unpaid assistance to help manage work-related time constraints (Doty et al., 1998).

At the aggregate level, it is unclear how employment impacts caregiving trends, particularly those involving gender-related patterns in caregiving. Concern exists that increased female participation in the labor force will preclude women from filling caregiving roles, and there is evidence that women are more apt to relinquish family care roles than employment (Moen, Robinson, & Dempster-McClain, 1995). However, employment does not necessarily prevent women from functioning as caregivers. An analysis of female primary caregivers revealed that employed caregivers often make use of informal support networks (including friends, spouses and other relatives) to assist in the provision of care (Velkoff & Lawson, 1998; Doty et al., 1998). Furthermore, many caregivers do not face major eldercare-employment conflicts, and a large number of primary caregivers take on their care duties after having left the workforce (Doty et al., 1998).

CARE RESPONSIBILITIES

Care Recipient Characteristics

The 1997 NAC/AARP survey reports that the typical care receiver is someone over the age of 80; indeed, almost two-thirds of care recipients are over age 75.

Approximately 40% of caregivers provide assistance to a parent, and 5% care for a spouse. The remaining 55% of caregivers care for grandparents, parents-in-law, other relatives, or neighbors or friends (NAC/AARP, 1997).

One-fifth of caregivers (21%) provide assistance to someone who lives with them; by comparison, 37% of caregivers lived with their care recipient ten years ago. One quarter (24%) of caregivers live more than 20 minutes away from the person for whom they provide care, up from 16% ten years ago. Approximately one-half (55%) of caregivers live within 20 minutes of their loved one, but not together (NAC/AARP, 1997).

The level of informal care that an older adult receives is directly related to the level of his or her disability (Branch and Jette, 1983; Horowitz and Dobrof, 1982; Sherwood, Morris, & Gutkin, 1981; Tennstedt, 1999). As the level of disability increases, so does the amount of unpaid care that families provide. This holds true even when the care recipient uses formal care. A 1999 report notes that this reflects the importance of informal family care, as families contribute a great deal of care despite the fact that highly disabled care recipients may utilize formal services (Tennstedt, 1999).

Types and Amounts of Assistance Provided

Ninety eight percent of caregivers assist their care recipients with at least one IADL and 81% assist with three or more IADLs, including transportation (79%), household chores (74%), and grocery shopping (77%) (NAC/AARP, 1997). More than one-third of employed caregivers assist with home maintenance activities and repairs, and more than one-fourth do housecleaning, make phone calls for care recipients and/or manage the care recipient's finances (Wagner, 1997). About 15% of caregivers provide

direct hands-on care with intensive personal needs such as bathing, toileting, and dressing.

There appear to be slight gender differences in the type of care that care recipients receive. While women are more likely than men to receive assistance from families, men receive higher levels of care (Tennstedt, 1999). Regardless of functional status, men tend to receive help with more time consuming activities such as personal care, meal preparation and housekeeping chores. Women, on the other hand, frequently receive assistance with activities that require less time, such as transportation, home repairs and shopping. Differences in the type and amount of care received by men and women may, in part, be due to the perception of gender roles and the likelihood that older adults will continue to perform those daily tasks with which they are familiar (Tennstedt, 1999). As a result, men and women may be more likely to receive help with those daily activities that are less familiar to them.

National data indicate that the average caregiver in the U.S. provides care for 18 hours per week. Close to one in five provides either “constant care” or at least 40 hours of care per week, with the caregivers of highly disabled individuals providing an average of 56.5 hours (NAC/AARP, 1997). Smaller studies have found that frequently even more care is provided when the caregiver and care recipient share a residence. Care recipients living with caregiver spouses receive an average of 78 hours per week of informal care, and elders who live with a non-spousal caregiver receive an average of 66 hours/week of care (Tennstedt, 1999; Tennstedt, McKinlay & Sullivan, 1989). Additionally, caregivers who care for elderly individuals with dementia spend, on average, a greater number of hours giving care than do caregivers caring for elderly with normal cognitive status (Langa, et al., 2001).

Based on these national estimates of the number of hours that families and other informal care providers spend giving care, the economic value of caregiving has been estimated at \$196 billion annually (Arno, Levine, & Memmott, 1999). The economic value of care in California alone is more than \$20 billion.

Direct vs. Indirect Services

Caregiver utilization of formal care services, such as home health care, housework and adult day care, has increased dramatically in the past decade, from 22% in 1987 to 38% in 1996 (Wagner, 1997). Indeed, analyses of National Long Term Care Survey data show that, whereas family members and other informal care providers were the sole source of assistance to 67% of community-dwelling disabled elderly in 1982, by 1994 this percentage had dropped to 58% (Lui, Manton & Aragon, 2000). At the same time, the percentage of disabled elderly receiving assistance from both formal (paid) and informal (unpaid) sources climbed from 19% in 1982 to 25% in 1994.

As indicated earlier, within the provision of informal care, women are more likely than men to provide direct care, including laundry, shopping, cooking, feeding, dressing, and bathing, whereas men are more likely to manage care, including arranging services. In addition, male caregivers receive more help from their wives than female caregivers receive from their husbands. Not only do women have more caregiving responsibilities and less help from their spouses, but they also have more trouble than men affording or finding outside resources to help alleviate role strain (Scharlach, 2001). Older adults who are unmarried and live alone in public housing are less likely to receive care from informal caregivers and more likely to utilize services (Tennstedt, 1999). Indeed researchers have found that living alone means that an older adult is twice as likely to use formal, paid services (Tennstedt, Crawford, & McKinlay, 1993). Additionally, African

Americans, Latinos and Asian Americans are more likely to provide direct care than Caucasians, resulting in part from cultural values about family care as well as the lack of affordability of support services (Scharlach, 2001).

Direct and Imputed Economic Support

Almost 40% of long-term care costs are paid directly by individuals and their families (U.S. General Accounting Office, 1995). Families with a care recipient have an average of about \$171 a month in extra expenses, contributing to a total of \$1.5 billion per month spent by caregivers nationwide (NAC/AARP, 1997). California caregivers alone pay an estimated \$203 million per month. Out-of-pocket expenses for caregiving are greatest for those who care for the most disabled care recipients. For example, caregivers for persons who need assistance with at least two ADLs spend an average of \$357 per month (27% of their monthly income) on caregiving-related expenses, whereas those who care for persons who require minimal help spend an average of only \$95 per month (NAC/AARP, 1997).

When examining formal and informal care costs only for people with Alzheimer's disease in California, the 1990 total direct and imputed costs of caring for a person with the disease were \$47,083 per year for patients in the community and \$47,591 per year for institutionalized patients. However, the distribution of costs for formal and informal care for the two groups is quite different. For institutionalized patients, informal care services comprise 12% of the total costs of care while 88% is attributable to formal services. Conversely, for patients residing in the community 73% of the total cost of care is for assistance provided informally while 2% is for formal services (Rice et al., 1993). Combining these estimates with Alzheimer's disease prevalence and population projections, costs for California's community-resident dementia patients are expected to

increase 83% in the period 2000 (\$23.4 billion) to 2020 (\$42.8 billion), and an additional 59% from 2020 to 2040 (\$68.1 billion). Costs for California's institutionalized Alzheimer's disease patients are expected to increase 84% from 2000 (\$2.5 billion) to 2020 (\$4.6 billion), and 61% from 2020 to 2040 (\$7.4 billion), assuming the supply of nursing home beds meets projected demand. Total costs of caring for Alzheimer's disease patients in California will nearly triple between 2000 and 2040 (Fox et al., 2001).

IMPACT ON THE CAREGIVER

Caregiving Stress

The contributions of family caregivers are not made without taking a toll on the mental and physical health of the individuals who provide care. Caring for disabled elderly relatives can negatively impact both physical and emotional well-being (Schulz & Beach, 1999; Schulz, O'Brian, Bookwala, & Fleissner, 1995). However, caregiving may also have beneficial elements for the caregiver. Indeed, research on caregiver stress has resulted in two broad conclusions about the mental health of caregivers. First, caregivers can experience high levels of stress and overload, contributing to symptoms of depression and burnout (Moen et al., 1995). Second, caregivers frequently report that their caregiving role is a positive one, contributing to a sense of personal and familial well-being (Moen et al., 1995; Noonan & Tennstedt, 1997).

While all caregivers may experience some deleterious impacts associated with caregiving, some groups of caregivers are particularly at risk for negative outcomes. For example, primary caregivers of Alzheimer's disease sufferers commonly experience higher levels of depression, anxiety and greater utilization of psychotropic drugs than the general population (Ory et al, 1999; Pruchno & Postashnik, 1989; Fox et al., 2001; Bourgeois & Schulz, 1996; Schulz et al., 1995). Factors associated with high levels of

caregiver stress include the health status of the care recipient and advancement of the debilitating illness; the existence of any problematic behavior from the care recipient; the level of daily dependency of the care recipient; sharing a home with the care recipient; conflictual familial relations; occupational conflicts or strains; financial hardships; and the constriction of social and recreational roles in the caregiver's life (Pearlin et al., 1990; Mittelman et al., 1995; Mittelman et al., 1996). Fluctuating levels of stress experienced by caregivers can result from changes in any of these variables (Pearlin et al., 1990). Broadly speaking, the risk for caregiver depression rises as the length of the caregiving relationship increases, the health status of the care recipient declines, and the emotional well being of the care recipient declines (Schulz et al, 1995).

Many caregivers also experience threats to personal identity and a loss of social roles when they take on caregiving responsibilities (Skaff & Pearlin, 1992). Female caregivers, younger caregivers and caregivers who do not have a spouse tend to have a greater sense of self-loss. Similarly, individuals who care for someone who is despondent or has behavior problems may also experience greater self-loss.

Caregivers also frequently report that their caregiving experience has positive aspects (Moen et al., 1995; Scharlach, 1994). These include feelings of satisfaction in helping a loved one, repaying the care recipient for past activities, spending time together with the care recipient, feeling closer to the care recipient, and the satisfaction of knowing that their loved one is receiving good care. Caregivers also often appreciate the opportunity to express feelings of empathy and love to the care recipient. They may experience greater self-respect and altruistic feelings, knowing that they play an important role in the life of their loved one (Toseland, 2001). Additional benefits include

assistance the care recipient may provide with childcare, household work or finances (Scharlach, 1994).

It appears that positive beliefs about caregiving can have an important impact on the mental health of caregivers. Regardless of the level of demand placed on caregivers, individuals who find meaning in their role and those who are searching for meaning express fewer depressive symptoms and greater self esteem than caregivers who do not find meaning in their caregiving role (Noonan & Tennstedt, 1997). Among female caregivers, individuals with higher levels of education and greater emotional health experience less stress and are more likely to report that they have benefited from their caregiving role (Moen et al., 1995).

Other factors associated with positive caregiving experiences include a caregiver's access to effective coping strategies and coping resources (Nolan, Gordon, & Keady, 1996). Coping refers to the efforts made by an individual to overcome demands or challenges that are perceived as taxing or stressful (Folkman & Monat, 1991). A coping style refers to the general approach an individual takes to stressful situations and is generally seen to fall into one of two broad categories: problem-focused coping and emotion-focused coping. Problem-focused coping refers to an individual's efforts to improve a stressful situation through action. Examples of this include seeking information when confronted with a new situation or resisting an impulsive action in favor of more thoughtful action. Emotion-focused coping refers to thoughts or actions taken in an effort to reduce the impact of a stressful situation. Examples of this are crying, detaching oneself from the situation, or finding ways to relax (Folkman & Monat, 1991). For each style of coping, many different coping strategies may emerge; some of these may have positive outcomes for the individual (meditating, learning more about an

illness), and others may have negative side effects (drug or alcohol use, problem avoidance). Certain situations are more amenable to one style of coping over another. For example, when a situation calls for direct and immediate action, emotion-focused coping may be detrimental. However, in other situations when it enables a person to maintain a sense of well-being, emotion can be useful and healthy (Folkman & Monat, 1991). Finally, it should be noted that individuals do not employ one style or another exclusively, but usually combine complex combinations of both in different situations (Folkman & Monat, 1991).

Researchers have found that an individual caregiver's coping style may be mitigated or influenced by ethnic or cultural background (Aranda & Knight., 1997; ; Knight, Silverstein, McCallum, & Fox, 2001; Young & Kahana, 1995). Caucasian caregivers typically employ problem-solving and avoidance strategies more frequently than do African American caregivers, perhaps because Caucasians perceive caregiving situations as a greater threat or stressor than do African Americans. Moreover, African American caregivers are more likely to view their situation in more positive terms, and draw upon religious faith and social networks to mitigate caregiving stress. Latino caregivers also are more likely to pray or draw upon their own religiosity when faced with caregiving stress. They are less likely, however, to express their feelings or obtain professional help than are Caucasians or African Americans. As a result, Latino caregivers may be at higher risk of depressive outcomes than caregivers of other cultural backgrounds (Adams et al., 2001; Aranda & Knight., 1997; Knight et al., 2000; Young & Kahana, 1995).

Impact on Caregiver Health

Caring for a disabled family member or friend also can affect caregivers' health and physical well-being. Caregivers tend to report more physical ailments than do non-caregivers, including arthritis, back trouble, hearing problems, insomnia, rectal problems and diabetes (Pruchno & Postashnik, 1989; Scharlach, Runkle, Midanik, & Soghikian, 1994; Schulz et al., 1995). Some groups of caregivers have been found to exhibit poorer immune function, more respiratory tract infections, lower antibody and virus-specific T-cell responses to influenza, and slower rates of wound healing than do non-caregivers (Vitaliano, Schulz, R., Kiecolt-Glaser, J., & Grant, 1997). Spousal caregivers for Alzheimer's disease victims report higher rates of diabetes, arthritis, ulcers and anemia than the general population (Pruchno & Postashnik, 1989). Women caregivers tend to experience more health problems than do their male counterparts (NAC/AARP, 1997). Male caregivers experience higher lipoprotein cholesterol levels, greater triglycerides, and more problems with obesity than do non-caregiving males, whereas women caregivers have more problems with weight gain and obesity than do non-caregiving women (Vitaliano et al., 1997).

Spouses, more broadly, tend to mirror one another in terms of their reported physical health status (Satariano, Minkler, & Langhauser, 1984). Individuals who report that their spouse has been ill within the previous six months are more likely to report that they themselves are in poor physical health. Among the possible reasons cited for this covariance is the deleterious impact of spousal caregiving (Satariano et al., 1984).

Among elderly persons caring for a disabled spouse, those who experienced strain as a result of their caregiving role were 63% more likely to die within four years than non-caregiving individuals in one study (Schulz & Beach, 1999). Caregivers who were

not experiencing strain had mortality rates at the same level as non-caregivers.

Caregivers who were at the greatest risk for negative health outcomes included individuals with very demanding caregiving responsibilities, chronic stress as a result of their caregiving role, and negative psychological outcomes such as depression (Schulz & Beach, 1999). A Kaiser Health Plan study found that poor health practices were more common among caregivers who were non-Caucasian, employed part time, low income or in poor health. The researchers concluded that caregivers, if given access to preventative health care services, may not suffer negative health effects due to their caregiving role (Scharlach, Midanik, Runkle, & Soghikian, 1997).

Despite increased health risks, caregivers do not seek medical services for themselves at higher rates than non-caregivers. Caregiving members of the Kaiser Foundation Health Plan in Northern California, for example, were more likely than noncaregivers to report stress-related health problems, when controlling for age, gender, and race; however, they were not more likely to seek health services (Scharlach et al, 1994). One interpretation of these results has been that caregivers often do not find time to address their own health care needs (Pruchno & Postashnik, 1989). For example, even though female caregivers are more likely than other women to report that they suffer from hypertension or heart problems, they use medical services at similar or lower rates. The National Center for Health Statistics found that caregivers reported spending less sick time in bed than the general population. Moreover, caregivers reported fewer visits to a physician than did the general population (National Center for Health Statistics, 1986).

Findings such as these have led researchers to recommend that practitioners treating both the caregiver and care recipient consider the health status of both

individuals when discussing the caregiving situation and future caregiving options (Pruchno & Postashnik, 1989; Schulz & Beach, 1999). Specifically, recommendations include the examination of elderly couples by physicians as a unit, in order to assess if the caregiving spouse is at risk (Schulz & Beach, 1999). Interventions that decrease the level of stress caregivers experience may also improve their physical well-being.

IMPACT ON WORK

As a result of their caregiving responsibilities, employed caregivers frequently are forced to make substantial accommodations in their work activities, so as to balance most effectively the potentially competing demands of work and family roles. Juggling caregiving duties and employment can lead to a decrease in productivity. Moreover, some caregivers may find it necessary to leave the workforce altogether in order to care for a loved one.

Effects on Productivity

More than half of respondents to a 1996 national survey of family caregivers reported losing time from work as a result of their caregiving duties, up from only about one-third in 1987 (NAC/AARP, 1997; AARP, 1988). In the 1996 study, 49% of caregivers reported that they went to work late, left early or took time off during the day to meet caregiving obligations (NAC/AARP, 1997). In a 1997 study of only employed caregivers, 84% reported that caregiving duties caused them to make personal phone calls during the workday; 69% arrived late or left work early; and 67% took time off during the workday to attend to caregiving duties (Metropolitan Life Insurance Company, 1997). Research on Australian caregivers found similar patterns of disruption in the workplace, with 20% reporting that they had to decrease the numbers of hours that they worked (Schofield & Herrman, 1993). While there are diffuse reasons for missed time at work,

generally speaking a caregiver's employment is more likely to be disrupted when the care recipient is more disabled and when the caregiver feels that he or she has a lack of support in providing care (Scharlach, Sobel, & Roberts, 1991).

These disruptions are believed to contribute to significant losses in productivity. A 1997 study estimated that U.S. employers lost between \$11.4 (full time) and \$29 billion dollars (full time and part time) each year in productivity because of work disruptions experienced by employees with caregiving. This suggests an estimate of \$1.7 billion lost in California due to productivity losses for full time employees. Caregiving crises and employee turnover also contribute to a decrease in productivity (Metropolitan Life Insurance Company, 1997).

Impact on Working Caregivers.

Juggling work and family care responsibilities also can impact caregivers' careers. Some employees are forced to take a temporary leave of absence or quit work altogether to accommodate their caregiving responsibilities. A national survey of family caregiving found that 20% of all caregivers left their jobs either temporarily or permanently because of care responsibilities: 11% took a leave of absence, 4% took early retirement, and 6% gave up work entirely (NAC/AARP, 1997). An Australian study found that 28% of the caregivers surveyed responded that they took leaves of absence in order to tend to caregiving duties (Schofield & Herrman, 1993). The intensity of caregiving duties may also play a role in defining a caregiver's professional path. For example, caregivers of dementia patients report more frequently than non-dementia caregivers having to take less demanding jobs, turn down promotions, retire early, or leave the workforce altogether (Ory et al., 1999).

Disruptions in workforce participation may also impact a caregiver's economic circumstances. Women who leave employment for a caregiving role make \$3,965 less per year than those who retire for other reasons. Lost wages and lost opportunities for promotion detrimentally affect women caregivers' financial situation as they themselves grow older, resulting in reduced Social Security benefits (Kingson & O'Grady-LeShane, 1993). An analysis of data from the National Longitudinal Caregiver Study, a survey of spousal caregivers for elderly male U.S. military veterans diagnosed with dementia, found that caregivers lost an average of \$10,709 in earnings annually due to a reduction in hours of work or early retirement necessitated by caregiving responsibilities (Moore, Zhu, & Clipp, 2001).

For those caregivers who remain in the workforce, employment can have a positive impact, providing them with financial, social and psychological resources (Fredriksen-Goldsen & Scharlach, 2001). Paid employment can offer caregivers a much-needed break from their care duties, access to social support through co-worker relationships, and improved relations with the person for whom they provide care (Fredriksen-Goldsen & Scharlach, 2001; Schofield & Herrman, 1993). Employed caregivers are less likely to be depressed than nonworking caregivers, and they express higher levels of life satisfaction and self-esteem (Tennstedt, Cafferata & Sullivan 1992; Moen et al., 1995). Moreover, caregiving can have positive impacts on work performance. Employed caregivers may be more effective and compassionate during customer interactions, may demonstrate greater self-confidence, and may have enhanced feelings of job competence as a result of their caregiving experiences (Scharlach, 1994).

CAREGIVING CONTEXT

Caregivers' experiences providing care and their resulting need for assistance are affected by the context within which caregiving occurs. While each caregiving situation is unique, a number of broad patterns of caregiver needs have been identified. These shared characteristics contribute to a better understanding of how programmatic efforts to assist caregivers might be structured. Of particular interest are the developmental phase of the caregiving process, the caregiver-care recipient relationship, the cultural context, and family relationships.

Researchers have found that caregiving activities change over time in a relatively predictable developmental progression, in accordance with the care recipient's increasing need for care and caregiver role expectations. Montgomery and Kosloski outline this trajectory of caregiving with seven benchmarks: 1) performing caregiving tasks, 2) defining self as a caregiver, 3) providing personal care, 4) seeking out or using assistive services, 5) considering institutionalization, 6) placing the care recipient in a nursing home, and 7) the termination of the caregiving role (Montgomery & Kosloski, 1999). Not all caregivers will move sequentially through all of the markers, and in fact, the order of the markers may vary for different types of caregivers. Nonetheless, each point signifies the further development of the caregiving process and the subsequent changes in caregiver needs that accompany such development.

In order to best meet caregiver needs, services need to be matched with caregivers' position in their developmental trajectory. For example, typically in the early stages of their caregiving experience individuals are more likely to seek information than services, while those individuals who are long-term caregivers may be more inclined to seek respite care (Montgomery & Kosloski, 1999). Caregivers will not use services that

they perceive as inappropriate for their circumstances; thus, the proper targeting and marketing of services to caregivers should contribute significantly to their success in assisting caregivers.

One benchmark not included in the Montgomery-Kosloski model is a phase that precedes all of the others, a phase that is defined by the disabled individuals' ability to maintain their own care with little or no assistance from would-be caregivers. This phase can be described from the potential caregivers' perspective as "watchful waiting." It encompasses the period of self-care wherein disabled older adults are able to coordinate and manage their care and largely meet their own needs with minimal reliance on informal supports. Recognizing this phase in the caregiving trajectory is crucial because with appropriate interventions and formal supports that facilitate self-care for disabled adults, the period of "watchful waiting" may be lengthened and the period of active caregiving shortened. Bolstering the ability of individuals to manage their own needs can thereby delay or decrease the care obligations that family caregivers face.

The relationship between the caregiver and the care recipient also can impact a caregiver's needs and decision to seek services (Montgomery & Kosloski, 1999). For example, differing caregiving trajectories have been identified among spousal caregivers and children. Spousal caregivers tend not to identify themselves as caregivers until they have begun to provide hands-on assistance, making it unlikely they will seek assistance during the first stages of their caregiving experience. Conversely, adult children are more apt to identify themselves as caregivers when the care recipient first becomes disabled, so they are more likely to seek information and outside assistance early on (Montgomery & Kosloski, 1999).

Cultural norms also may play a role in caregiver needs and service utilization. For example, among racial and ethnic minority groups, nearly 75% of caregivers are children—notably higher than the 40% to 60% estimations that have been found among Caucasian populations (Montgomery & Kosloski, 1999). Non-white and Hispanic daughters also tend to provide more personal and household care than do Caucasian daughters (Montgomery & Kosloski, 1999). Moreover, though kin and non-kin social networks are generally larger for Latina and African-American caregivers, the benefits of social support are often accompanied by additional stressors and/or conflicts with familial obligations (Aranda & Knight, 1997; Connell & Gibson, 1997). Thus, programs that are constructed to primarily serve minority caregivers should take into account the high prevalence of daughters as caregivers, who though often surrounded by sources of informal support, may still desire access to formal services as a means of minimizing familial conflict. For example, while African-American caregivers report that they receive more informal assistance from family and friends than do Caucasian caregivers, they also express a greater need for services. When factors such as these are taken into account, effective interventions can be tailored to cultural norms among minority caregivers.

Fourth, while caregiving may impact families in important ways, family dynamics, in turn, may impact the caregiving experience. Families particularly at risk for negative impacts are those that have poor communication, greater demands on limited resources and time, familial conflict, poor parent-child relationships, and greater resistance to change (Toseland, 2000). Open communication can prevent or minimize familial conflict, and thereby reduce some of the psychological stress that caregivers may

experience, while also facilitating the sharing and coordination of caregiving responsibilities among family members (Toseland, 2000).

SUMMARY

Essential to ascertaining what needs caregivers have is understanding who gives care, what kinds of care they give, and to whom it is given. The research findings highlighted in this paper can, in part, aid in answering those questions. First, survey research has offered evidence that caregiving is widespread. By some estimates, nearly one out of every six households gives care nationwide, equating to 2.9 million households in California alone (NAC/AARP, 1997; Scharlach, 2001). Most caregivers are female (Montgomery & Kosloski, 1999; NAC/AARP, 1997; Stone et al., 1987; Wagner, 1997); and, there are slightly higher frequencies of caregiving among minority ethnic groups than among Caucasians (NAC/AARP, 1997). Almost half of all caregivers nationwide are employed (NAC/AARP, 1997), suggesting that approximately 1.8 million caregivers in California balance care duties with work. The care given ranges significantly, based upon the needs of the care recipient; however, 98% of caregivers assist with at least one IADL, and 81% assist with three or more (NAC/AARP, 1997). Individuals who care for someone with a dementia-related illness provide more care, measured by both the number of hours of care given and the number of IADLs or ADLs with which the care recipient needs assistance (Ory et al., 1999).

Second, while caregiving can prove to be a positive experience for some individuals, it frequently has negative impacts on the health and well-being of the caregiver. Caregivers can experience high levels of stress that lead to burnout or depression (Moen et al., 1995). They may also experience a loss of social roles (Skaff & Pearlin, 1992). Physically, caregiving can take a toll on individuals; female caregivers

particularly tend to report more physical ailments than do non-caregiving females (Pruchno & Postashnik, 1989; Scharlach et al., 1997; Schulz et al., 1995). Indeed, there is some evidence that mortality rates may be higher for caregivers than non-caregivers (Schulz & Beach, 1999). Yet despite these increased emotional and physical health risks, family caregivers do not tend to seek out health services at higher rates than do non-caregivers (Pruchno & Postashnik, 1989; Scharlach et al., 1994).

Third, certain individuals are more vulnerable to the deleterious effects of caregiving. Those who care for someone with problematic behaviors, dementia, or a high level of daily dependency are at greater risk for negative outcomes (Bourgeois & Schulz, 1996; Fox et al., 2001; Mittelman et al., 1995; Ory et al., 1999; Pruchno & Potashnik, 1989; Schulz et al., 1995). Caregivers who experience family conflict, financial hardships, or loss of social roles are also at particular risk (Mittelman et al., 1995; Skaff & Pearlin, 1992). Other vulnerable caregivers include those who care for persons with Alzheimer's Disease, have health problems of their own, share a home with the care recipient, have conflictual familial relations, experience occupational conflicts or strains, or are socially isolated (Bourgeois & Schulz, 1996; Fox, Kohatsu, Max, & Arnsberger, 2001; Mittelman et al., 1995; Ory et al., 1999; Pearlin, Mullan, Semple, & Skaff, 1990; Pruchno & Postashnik, 1989; Schulz et al., 1995; Skaff & Pearlin, 1992). These characteristics help to identify those caregivers who are at greatest risk for deleterious impacts of family caregiving, for whom formal supports may be particularly beneficial.

Finally, the current state of knowledge of family caregiving has implications for program development as well as research. Caregiver needs may be mediated through a complex network of characteristics, including gender, ethnicity, the caregiver-care recipient relationship, and employment status. Understanding how those characteristics

interact is essential for identifying how best to meet caregivers' unique needs. Moreover, caregiver needs transform over time, as a caregiver moves through the care trajectory (Montgomery & Kosloski, 1999). Focusing on the intersection of individual characteristics and environmental or time-dependent circumstances may produce important insight into how caregivers might best be served during each phase of their caregiving experience.

The emerging complexities and characteristics of the changing nature of family life are particularly relevant to the development of caregiver support programs in California. Demographic shifts make it apparent that family caregivers are a growing segment of the population; moreover, caregiving contexts are likely to grow more diverse as well. As single parent households, blended families, grandparents raising grandchildren, gay and lesbian homes, and other nontraditional family structures become more common, new complexities within family caregiving arise. Researchers and service providers face the challenge of expanding their conceptual models of caregiving to encompass these changes in California's families and their caregiving needs (Fredriksen-Goldsen & Scharlach, 2001).

Understanding the characteristics of caregivers, the care responsibilities that they take on, and the impact that those duties have on their well-being all contribute to a clearer picture of caregiver needs. Research to date has captured the broad landscape of family caregiving nationally. Further data collection on the nuances of caregiving in California's racially and ethnically diverse context will serve to clarify and enrich that picture. As research proceeds at both a national and state level, the complexities of family care can be unraveled, and programs to support family caregivers can be based on stronger empirical and theoretical foundations.

REFERENCES

Abel, E. (1991). Who cares for the elderly? Public policy and the experiences of adult daughters. Philadelphia, PA: Temple University Press.

Adams, B., Aranda, M., Kemp, B., & Takagi, K. (in press). Ethnic and gender differences in coping. Journal of Clinical Geropsychology.

Alzheimer's Association & National Alliance for Caregivers. (1999). Who cares? Families caring for persons with Alzheimer's disease. Washington, DC: Authors.

American Association of Retired Persons & The Travelers Foundation. (1988). A national survey of caregivers. Washington, DC: Opinion Research Corporation.

Aranda, M., & Knight, B. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. The Gerontologist, 37, 342-354.

Arno, P., Levine, C., & Memmott, M. (1999). Economic value of caregiving in the United States. Health Affairs, 18, 182-188.

Arnsberger, P., Fox, P., Zhang, X., & Gui, S. (2000). Global aging of the population and the need for long term care: A comparison of the United States and the People's Republic of China. Journal of Cross-Cultural Gerontology, 21, 1-21.

Barer, B., & Johnson, C. (1990). A critique of the caregiving literature. The Gerontologist, 30, 26-29.

Barusch, A. (1993). Increasing family care through mandates, incentives and service rationing: An international perspective. Paper prepared for the 46th Annual Scientific Meeting Gerontological Society of America, New Orleans, LA.

Bengtson, V., Rosenthal, C., & Burton, L. (1996). Paradoxes of families and aging. In R. Binstock and L. George (Eds.), Handbook of Aging and the Social

Sciences (4th ed., pp. 254-282). New York: Academic Press.

Biegel, D., & Schulz, R. (1999). Caregiving and caregiver interventions in aging and mental illness. Family Relations, 48, 345-354.

Bourgeois, M., & Schulz, R. (1996). Interventions for caregivers of patients with Alzheimer's disease: A review and analysis of content, process, and outcomes.

International Journal of Aging and Human Development, 43, 35-92.

Branch, L., & Jette, A. (1983). Elders' use of informal long-term care assistance. The Gerontologist, 23, 51-56.

Burton, L., Kasper, J., Shore, A., Cagney, K., LaVeist, T., Cubbin, C., & German, P. (1995). The structure of informal care: Are there differences by race? The Gerontologist, 35, 744-752.

Connell, C., & Gibson, G. (1997). Racial, ethnic and cultural differences in dementia caregiving: Review and analysis. The Gerontologist, 37, 355-364.

Creedon, M., & Tiven, M. (1989). Eldercare in the workplace. Washington, DC: National Council on the Aging and National Association of State Units on Aging.

Crimmins, E., Saito, Y., & Reynolds, S. (1997). Further evidence on recent trends in the prevalence and incidence of disability among older Americans from two sources: The LSOA and the NHIS. Journal of Gerontology B: Psychological Sciences and Social Sciences, 52, 59-71.

Doty, P., Jackson, M., & Crown, W. (1998). The impact of female caregivers' employment status on patterns of formal and informal eldercare. The Gerontologist, 38, 331-341.

Family Caregiver Alliance. (1999). Survey of fifteen states' caregiver support programs: Final report. [On-line], Available:

http://caregiver.org/publications/pub_execsum9910.html

Family Caregiver Alliance. (2001). Who's taking care? Profile of family caregivers and care recipients served by California CRCs. [On-line]. Available:

http://www.caregiver.org/newsletters/winter2001/whos_taking_care.html

Family Circle & Kaiser Family Foundation. (2000). National survey on health care and other elder care issues: Summary of finds and chart pack (Publication #1603).

Washington, DC: Author.

Feinberg, L. (1997). Options for supporting informal and family caregiving: A policy paper. Paper prepared for The American Society on Aging, San Francisco, CA.

Feinberg, L., Pilisuk, T., & Kelly, K. (1999). Report on family caregiver support in California's publicly funded programs. San Francisco, CA: Family Caregiver Alliance.

Folkman, S., Lazarus, R., Pimley, S., & Novacek, J. (1987). Age differences in stress and coping processes. Psychology and Aging, 2, 171-184.

Folkman, S., & Monat, A. (1991). Stress and coping: An anthology. New York, NY: Columbia University Press.

Fox, P., Kohatsu, N., Max, W., & Arnsberger, P. (2001). Estimating the costs of caring for people with Alzheimer's disease in California: 2000-2040. Journal of Public Health Policy, 22, 88-97.

Fredriksen-Goldsen, K., & Scharlach, A. (2001). Families and work: New directions in the 21st century. New York, NY: Oxford University Press.

Fuller-Thomson, E., & Minkler, M. (2001). American grandparents providing extensive child care to their grandchildren: Prevalence and profile. The Gerontologist, 41, 201-209.

General Accounting Office. (1999). Assisted living: Quality-of-care and consumer protection issues in four states (GAO/HEHS-99-27, Apr. 26, 1999).

Washington, DC: Author.

Harris, P. (1998). Listening to caregiving sons: Misunderstood realities. The Gerontologist, 38, 342-352.

Herrman, H., Singh, B., Schofield, H., Eastwood, R., Burgess, P., Lewis, V., & Scotton, R. (1993). The health and well-being of informal caregivers: A review and study program. Australian and New Zealand Journal of Public Health, 17, 261-266.

Hinrichsen, G., & Ramirez, M. (1992). Black and white dementia caregivers: A comparison of their adaptation, adjustment, and service utilization. The Gerontologist, 32, 375-381.

Hooyman N., & Gonyea, J. (1995). Feminist perspectives on family care: Policies for gender justice. Family Caregiver Application Series, 6. Thousand Oaks, London, New Delhi: Sage Publications.

Horowitz, A. (1978). Families who care: A study of families in providing long-term care to the frail and chronically ill elderly living in the community. Final report submitted to Health Care Financing Administration USDHHS (Grant No. 18-P-97541/2-02). Washington, DC: U.S. Department of Health and Human Services.

Horowitz, A., & Dobrof, R. (1982). The role of families in providing long-term care to the frail and chronically ill elderly living in the community. Final report submitted to the Health Care Financing Administration. Washington, DC: Department of Health and Human Services.

Howe, A., Schofield, H., & Herrman, H. (1997). Caregiving: A common or uncommon experience? Social Science and Medicine, 45, 1017-1029.

Janevic, M., & Connell, C. (2001). Racial, ethnic, and cultural differences in the dementia caregiving experience: Recent findings. The Gerontologist, 41, 334-347.

Jegermalm, M. (2001). Direct and indirect support for carers: patterns of support services in informal caregivers to elderly in Sweden. Unpublished manuscript, Stockholm, Sweden: Stockholm University, Department of Social Work.

Jette, A. (1996). Disability trends and transitions. In R. Binstock and L. George (Eds.), Handbook of Aging and the Social Sciences (4th ed., pp. 94-116). New York: Academic Press.

John, R., Hennessy, H., Dyeson, T., & Garrett, M. (2001). Toward the conceptualization and measurement of caregiver burden among Pueblo Indian family caregivers. The Gerontologist, 41, 210-219.

Katz, S., Ford, A., Moskowitz, R., Jackson, B., & Jaffee, M. (1963). Studies of illness in the aged. The index of ADL: A standardized measure of biological and psychological function. Journal of the American Medical Association, 185, 914-919.

Kingson, E., & O'Grady-LeShane, R. (1993). The effects of caregiving on women's social security benefits. The Gerontologist, 33, 230-239.

Knight, B., Lutzky, S., & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: Recommendations for future research. The Gerontologist, 33, 240-248.

Knight, B., Silverstein, M., McCallum, T., & Fox, L. (2000). A sociocultural stress and coping model for mental health outcomes among African-American caregivers in southern California. Journal of Gerontology: Psychological Sciences, 55B, 142-150.

Langa, K., Chernew, M., Kabeto, M., Herzog, R., Ofstedal, M., Willis, R.,

Wallace, R., Mucha, L., Straus, W., & Fendrick, M. (2001). National estimates of the quantity and cost of informal caregiving for the elderly with dementia. Journal of General Internal Medicine, 16, 770-778.

Lawton M., Rajagopal, D., Brody, E., & Kleban, M. (1992). The dynamics of caregiving for a demented elder among black and white families. Journal of Gerontology: Social Sciences, 47, S156-S164.

Lazarus, R., & Folkman, S. (1984). Stress, Appraisal and Coping. New York: Springer Publishing Company.

Lee, R. (2001). The fiscal impact of population aging. Testimony prepared for the Senate Budget Committee, Washington, DC: Author.

Lee, R., & Villa, V. (2001). Population aging in California. SB-910 report, Berkeley, CA: University of California, California Policy Research Center.

Levine, C. (1998). Rough crossings: Family caregivers' odysseys through the health care system. New York, NY: United Hospital Fund.

Levine, C. (1999). Home sweet hospital: The nature and limits of private responsibilities for home health care. Reprinted from Journal of Aging and Health, 11, 341-359.

Levine, C. (1999). The loneliness of the long-term caregiver. New England Journal of Medicine, 340, 1587-1590.

Levine, C., & Zuckerman, C. (1999). The trouble with families: Toward an ethic of accommodation. Annals of Internal Medicine, 130, 148-152.

Levine, C., & Zuckerman, C. (2000). Hands on/hands off: Why health care professionals depend on families to keep them at arm's length. The Journal of Law, Medicine & Ethics, 28, 5-18.

Lui, K., Manton K., & Aragon, C. (2000). Changes in home care use by disabled elderly persons: 1982-1994. Journal of Gerontology: Social Sciences, 55B, S245-S253.

Macera, C., Eaker, E., Goslar, P., Deandrade, S., Williamson, J., Cornman, C., & Jannarone, R. (1992). Ethnic differences in the burden of caregiving. American Journal of Alzheimer's Disease, September/October, 4-7.

McCann, J. (1991). Effects of stress on spouse caregivers' psychological health and cellular immunity. Paper presented at the Gerontological Society of America Conference, San Francisco, CA.

Metropolitan Life Insurance Company. (1997). Metlife study of employment status on patterns of formal and informal care. Metlife Mature Market Group, Westport, CT: Author.

Metropolitan Life Insurance Company. (1999). The MetLife Juggling Act study. Metlife Mature Market Group, Westport, CT: Author.

Miller, B., & Cafasso, L. (1992). Gender differences in caregiving: Fact or artifact? The Gerontologist, 32, 498-507.

Miller, B., Campbell, R., Farran, C., Kaufman, J., & Davis, L. (1995). Race, control, mastery, and caregiving distress. Journal of Gerontology: Social Sciences, 50B, S374-S382.

Mintz, S. (2001, May 17). Family caregiving and the Older Americans Act: Caring for the caregiver. Testimony presented before the United States Senate Special Committee on Aging, Washington, DC.

Mittelman, M., Ferris, S., Shulman, E., Steinberg, G., Ambinder, A., Mackell, J., & Cohen, J. (1995). A comprehensive support program: Effect on depression in spouse-caregivers of AD patients. The Gerontologist, 35, 792-802.

Moen, P., Robinson, J., & Dempster-McClain, D. (1995). Caregiving and women's well-being: A life course approach. Journal of Health and Social Behavior, 36, 259-273.

Moore M., Zhu C., & Clipp, E. (2001). Informal costs of dementia care: estimates from the National Longitudinal Caregiver study. Journal of Gerontology: Social Sciences, 56B, S219-S228.

Montgomery, R., & Kosloski, K. (1999). Family caregiving: Change, continuity, and diversity. In R. Rubinstein & P. Lawton (Eds.), Alzheimer's Disease and Related Dementias: Strategies in Care and Research. New York, NY: Springer Publishing Company.

Mui, A. (1992). Caregiver strain among black and white daughter caregivers: A role theory perspective. The Gerontologist, 32, 203-212.

National Academy on an Aging Society. (2000). Challenges for the 21st century: Chronic and disabling conditions. Washington, DC: Author.

National Alliance for Caregiving & the American Association of Retired Persons. (1997, June). Family caregiving in the U.S.: Findings from a national survey. Washington, DC: Authors.

National Alliance for Caregiving & the American Association of Retired Persons, & The Equitable Foundation. (1998). The caregiving boom: Baby boomer women giving care. Washington, DC: Authors.

National Center for Health Statistics. (1983). Disability days: United States, 1980 (Series 10, Number 143). National Center for Health Statistics.

National Center for Health Statistics. (1986). Current estimates from the National Health Interview Survey, United States, 1986 (Series 10, Number 164).

National Center for Health Statistics.

National Council on Aging. (1997). Caregiving across the miles: Findings of a survey of long-distance caregivers. Washington, DC: NCOA.

National Family Caregiver Association. (2000). Caregiver survey-2000. Kensington, MD: Author.

Neal, M., Ingeroll-Dayton B., & Starrels M. (1997). Gender and relationship differences in caregiving patterns and consequences among employed caregivers. The Gerontologist, 37, 804-816.

Nolan, M., Gordon G., & Keady, J. (1996). Understanding family care. Buckingham and Philadelphia: Open University Press.

Noonan, A., & Tennstedt, L. (1997). Meaning in caregiving and its contribution to caregiving well-being. The Gerontologist, 37, 785-794.

Ory, M., Hoffman, R., Yee, J., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. The Gerontologist, 39, 177-183.

Ory, M., Yee, J., Tennstedt, S., & Schulz, R. (2000). The extent and impact of dementia care: Unique challenges experienced by family caregivers. In Schulz, R. (Ed.), Handbook on Dementia Caregiving: Evidence-based interventions for family caregivers. New York: Springer.

P. L. 106-501, 106th Cong., 2nd Sess., 316th Sec., Statute 2226, Page 114 (2000).

Pearlin, L., Mullan, J., Semple S., & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist, 30, 583-591.

Peters-Davis, N., Moss, M., & Pruchno, R. (1999). Children-in-law in caregiving families. The Gerontologist, *39*, 66-75.

Pruchno, R., Burant, C., & Peters, N. (1997). Typologies of caregiving families: Family congruence and individual well-being. The Gerontologist, *37*, 157-167.

Pruchno, R., & Postashnik, S. (1998). Caregiving spouses: Physical and mental health in perspective. Journal of the American Geriatrics Society, *37*, 697-705.

Satariano, W., Minkler, M., & Langhauser, C. (1984). The significance of an ill spouse for assessing health differences in an elderly population. Journal of the American Geriatrics Society, *32*, 187-190.

Scharlach, A. (1994). Caregiving and employment: Competing or complementary roles? The Gerontologist, *34*, 378-385.

Scharlach, A. (2001). Family caregiving. SB-910 report, Berkeley, CA: University of California, California Policy Research Center.

Scharlach, A. (2001). Family caregiving for older Californians. Berkeley, CA: University of California, California Policy Research Center.

Scharlach, A., Lowe B., & Schneider, E. (1990). Elder care and the work force: Blueprint for action. Lexington, MA: Lexington Books.

Scharlach, A., Midanik, L., Runkle, C., & Soghikian, K. (1997). Health practices in adults with elder care responsibilities. Preventative Medicine *26*, 155-161.

Scharlach, A., Runkle, C., Midanik, L., & Soghikian, K. (1994). Health conditions and service utilizations of adults with elder care responsibilities. Journal of Aging and Health, *6*, 336-352.

Scharlach, A., Sobel, E., & Roberts, E. (1991). Employment and caregiver strain: An integrative model. The Gerontologist, *31*, 778-787.

Scharlach, A., Torres-Gil, F., & Kaskie, B. (2001). Strategic planning framework for an aging population. SB-910 report, Berkeley, CA: University of California, California Policy Research Center.

Schofield, H., Bloch, S., Nankervis, J., Murphy, B., Singh, B., & Herrman, H. (1999). Health and well-being of women family carers: A comparative study with a generic focus. Australian and New Zealand Journal of Public Health, *23*, 585-589.

Schofield, H., & Herrman, H. (1993). Characteristics of carers in Victoria. Family Matters, *34*, 21-26.

Schulz, R., & Beach, S. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. Journal of the American Medical Association, *282*, 2215-2219.

Schulz, R., O'Brian A., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. The Gerontologist, *35*, 771-791.

Seltzer, M., & Li, L. (2000). The dynamics of caregiving: Transitions during a three-year prospective study. The Gerontologist, *40*, 165-178.

Sherwood, S., Morris J., & Gutkin, C. (1981). Meeting the needs of the impaired elderly: The power and resiliency of the informal support system. Final report to the Administration on Aging (Grant No. 90-A-1292), Boston, MA: Hebrew Rehabilitation Center for the Aged.

Shifren, K. (2001). Early caregiving and adult depression: Good news for young caregivers. The Gerontologist, *41*, 188-190.

Skaff, M., & Pearlin, L. (1992). Caregiving: Role engulfment and the loss of self. The Gerontologist, *32*, 656-664.

Stone, R., Cafferata, G., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. The Gerontologist, *27*, 616-626.

Tennstedt, S. (1999). Family caregiving in an aging society. Paper presented at the U.S. Administration on Aging Symposium: Longevity in the New American Century, Baltimore, MD.

Tennstedt, S., Cafferata, G., & Sullivan, L. (1992). Depression among caregivers of impaired elders. Journal of Aging and Health, *4*, 58-76.

Tennstedt, S., & Chang, B. (1998). The relative contribution of ethnicity vs. socioeconomic status in explaining differences in disability and receipt of national care. Journal of Gerontology: Social Sciences, *53B(2)*, 861-870.

Tennstedt, S., Crawford, S., & McKinlay, J. (1999). Determining the pattern of community care: Is coresidence more important than caregiver relationship? Journal of Gerontology: Social Sciences, *48(2)*, S74-S83.

Tennstedt, S., McKinlay, J., & Sullivan, L. (1989). Informal care for frail elders: The role of secondary caregivers. The Gerontologist, *29*, 667-683.

Toseland, R., Smith, G., & McCallion, P. (2001). Family caregivers of the frail elderly. In Gitterman (Ed.), Handbook of social work with vulnerable and resilient populations. New York, NY: Columbia University Press.

Velkoff, V., & Lawson, V. (1998). International Brief. Gender and aging: Caregiving. U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census.

Vitaliano, P., Schulz, R., Kiecolt-Glaser, J., & Grant, I. (1997). Research on physiological and physical concomitants of caregiving: Where do we go from here? Annals of Behavioral Medicine, *19*, 117-123.

Wachter, K. (1998). Kinship resources for the elderly: An update. Berkeley, CA: University of California at Berkeley, Department of Demography.

Wagner, D. (1997). Comparative analysis of caregiver data for caregivers to the elderly 1987 and 1997. National Alliance for Caregiving.

White, T., Townsend, A., & Stephens, M. (2000). Comparisons of African-American and white women in the parent care role. The Gerontologist, 40, 718-728.

Whitlatch, C., & Friss Feinberg, L. (1998). The use of informal networks in the provision of in-home respite for caregivers of cognitively impaired adults. Paper presented at the 1998 Annual Meeting of the Gerontological Society of America, Philadelphia, PA.

Whitlatch, C., Zarit, S., & von Eye, A. (1991). Efficacy of interventions with caregivers: A reanalysis. The Gerontologist, 31, 9-14.

Yee, J., & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: A review and analysis. The Gerontologist, 40, 147-164.

Young, R., & Kahana, E. (1995). The context of caregiving and well-being outcomes among African and Caucasian Americans. The Gerontologist, 35, 225-232.

Young, R., & Kahana, E. (1989). Specifying caregiver outcomes: Gender and relationship aspects of caregiving strain. The Gerontologist, 29, 660-666.

CAREGIVER SUPPORT INTERVENTIONS

Stephanie Whittier, David Coon, & Jolyn Aaker

INTRODUCTION

Caring for a disabled family member can be challenging, potentially impacting caregivers' health, mental health, work, social relationships, and quality of life. To alleviate caregiver stress, enable caregivers to better cope with the demands of caring for a loved one, and improve caregiver and care recipient outcomes, many interventions have been developed. However, although programs supporting caregivers have proliferated, there exists limited research regarding their effectiveness.

In this section, we examine what is known about caregiver interventions and their outcomes. In particular, we examine existing knowledge regarding the five service areas identified in the National Family Caregiver Support Program (Older Americans Act Amendment of 2000, Title III-E):

1. Information to caregivers about available services;
2. Assistance to caregivers in gaining access to these services;
3. Individual counseling, organization of support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their caregiving roles;
4. Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
5. Supplemental services, on a limited basis, to complement the care provided by caregivers.

In general, we find that a variety of caregiver support services are useful in alleviating caregiver strain and helping caregivers to provide care. The magnitude of their utility, however, is impacted by a variety of factors: the outcome chosen for measurement; the caregiver's background characteristics, including their psychosocial strengths and vulnerabilities; and the care recipient's type and level of impairment. Interventions in one service area, though useful, have not been found to be as effective as programs utilizing more than one intervention. The success of these multi-component caregiver interventions may be associated with services that address a wider variety of caregiver concerns for diverse groups of caregivers. The key is to find the best combination of services to meet the diverse nature of caregiver needs and experiences.

EFFECTIVENESS OF CAREGIVER INTERVENTIONS BY NFCSP SUPPORT CATEGORIES

Information

One cannot make meaningful decisions about one's caregiving situation unless adequate and complete information is available. Indeed, some consider information, advice, and referral to be the most needed caregiver services (Friss, 1990), for even when services are available, many caregivers remain unaware of them (Maslow & Selstad, 2001). However, it is important to note that the need for information goes beyond how and where to get help. Information regarding health conditions and their implications, care needs, costs of care, and how to plan for future care needs also is important for caregivers (Feinberg, 1997). As a result, most caregiving interventions strive to increase the caregiver's knowledge of available services, the recipient's disease, and caregiver challenges and solutions (Kennet, Burgio, & Schulz, 2000). However, studies that have been done on the effects of information-only services have not shown evidence of

positive mental or physical health-related outcomes (Kennet et al., 2000). Indeed, intervention studies that use information-only as the “usual care” or control condition, suggest that while increasing caregiver’s knowledge is important, it is not a sufficient intervention in and of itself.

Assistance Gaining Access to Services

Information about available services does not necessarily translate into caregiver service utilization. Program and service planners, along with policy-makers, must consider five key elements when analyzing why caregivers may not be using services: availability, accessibility, appropriateness, acceptability, and affordability. First, services needed by family caregivers must be available in their community. Second, these services must be accessible. A caregiver may find difficulty arranging for respite care if the respite worker must commute an hour, or if the nearest adult day care center increases the caregiver’s daily commute to work by an additional hour. Support groups or counseling services must be located conveniently enough for the caregiver to arrange for a respite worker and make the appointment within a reasonable amount of time. Service accessibility applies not only to physical location of services, but to the structure of service delivery as well. Working hours must be such that the caregiver can reasonably utilize the formal support network.

Third, offered services must be appropriate to the caregiver’s needs. There may be a plethora of counseling and support group services in a particular locale, though caregivers may have a more dire need for education and training relating to their relatives’ mental or physical limitations.

Fourth, services must be culturally appropriate and acceptable to the caregiver. Service providers must understand that the cultural position towards familial

responsibility and requesting help from those outside the family can be dramatically different from culture to culture. Cultures hold differing expectations about family responsibilities and appropriate sources of support for caregivers. The value placed on individuality as compared with familial consensus or elder/leader authority varies across cultures (Gallagher-Thompson, Arean, et al., 2000). This can result in differing perceptions regarding the utilization of formal services. Furthermore, services must be linguistically accessible in terms of native language, as well as in terms of level of education within that native language.

Fifth, services must be affordable to caregivers. Caregiver consideration of the affordability of services will not only include financial costs, but also costs in terms of time, effort, potential loss of confidentiality, and potential family conflict. Service utilization and behavior change recommended by service providers, or expected by agencies in order to receive services, have direct and indirect costs. Caregivers must be able to reconcile the perceived costs of service utilization with the perceived benefits. Services with narrow selection criteria or high costs/co-pays significantly undermine the availability and accessibility of formal services for many caregivers. Minimizing such costs increases the likelihood of caregiver service utilization.

It is important to note that simply being provided a brochure or phone number may not be as beneficial as actual linkages to services (Cole, Griffin, & Ruiz, 1986). In a study by Weuve, Boult, and Morishita (2000), caregivers who were provided a detailed care management plan and linked directly to services reported less caregiver burden than a control group, which was only provided written information and service referrals. In fact, though the control group was provided detailed literature, many in the control group could not recall that they received any information or could not find the literature.

Another study by Braun and Rose (1994) evaluated the impact of case-managed in-home care on caregivers, which included the direct linking to, or providing of, services to the experimental group. Caregivers receiving the services reported a decrease in time caregiving, a decrease in burden from caregiving, and a decrease in time-off from work for caregiving duties.

Though there is little research evaluating how effectively caregivers are assisted in utilizing services, there exists a strong implication from these two studies that directly linking clients to services, either through on-going case management or as a “linkage” activity, increases the utilization of services and has a positive impact on caregivers. Additionally, caregiver and family needs typically vary across the course of a disease as well as in response to life changes. Information and services useful at one point may not be helpful at another; further suggesting that periodic or ongoing assistance is often warranted.

Counseling, Support Groups and Training

Counseling

Counseling services offered to caregivers vary greatly. Counseling may include, but is not limited to, traditional psychotherapy, individual problem-solving, couples counseling, group counseling, and family treatment. Counseling, whether conducted in an individual, group, or family format, typically strives to relieve caregiver depression and/or anxiety, resolve pre-existing personal problems which complicate caregiving, mollify conflicts between the caregiver and recipient, and/or improve family functioning.

Many studies have examined the effectiveness of these various types of counseling services. In 1996, Bourgeois, Schulz, and Burgio did a comprehensive review of over 100 Alzheimer’s disease caregiver intervention studies and found that individual

counseling interventions have shown positive outcomes for narrowly defined problems. Group counseling, however, failed to yield a similar magnitude of effects. These differences between individual and group counseling were related to variations in individual caregiver goals and needs. Daughters and daughters-in-law of frail elderly parents have been found to make greater gains in psychological functioning and well-being when receiving individual counseling than group counseling; group interventions, however, produced greater improvements in caregivers' social supports (Toseland, Rossiter, Peak, & Smith, 1990). These results suggest that the types of problems and issues specific to an individual caregiver might be the most appropriate intervention determinant (Toseland et al., 1990).

Other studies have looked at family counseling approaches with caregivers. The effectiveness of family counseling is being evaluated currently in Miami with Cuban American and Caucasian caregivers. This program, the Family-Based Structural Multisystem In-Home Intervention, provides family counseling that tries to identify existing problems in communication and to produce changes in interaction patterns that allow the caregiver to harness available family and community resources. The focus of change is not just the individual or the environment, but rather the transaction between the two, which is viewed as embedded within larger social and cultural systems (Coon, Schulz, & Ory, 1999). Preliminary data suggest that this intervention, when combined with technological support that links family caregivers to other family members and community resources, yields positive mental health outcomes, especially for Cuban American caregivers (Czaja & Rubert, in press).

Other researchers have looked at the relative effectiveness of psychotherapy or counseling based on different theoretical orientations, finding that caregivers with

particularly high levels of emotional distress, depression or anxiety can benefit from various approaches. For example, Gallagher-Thompson and Steffen (1994) found that psychodynamic therapy and cognitive behavioral therapy were effective in significantly reducing clinical levels of depression in a sample of 60 family caregivers caring for a person with dementia. This same study also found that psychodynamic counseling proved to be more effective with caregivers who had more recently become caregivers, but cognitive behavioral counseling therapy was more effective with those who had been caregivers for a longer period of time.

Support Groups

Support groups are among the most popular and most prevalent interventions available to caregivers. In general, support groups are designed to provide informal peer support, information about diseases and disability, and referrals for caregiver support services. Support groups often are affiliated with a social service or non-profit agency targeted to help older adults and their families, and frequently are led by peers or paraprofessionals. Many support groups include periodic speakers as part of a forum that addresses issues and concerns relevant to caregivers, although the actual structure and content can vary substantially.

Studies have shown that participants in support groups typically evaluate these programs as quite useful and helpful (Gonyea, 1989; Toseland, Rossiter & Labrecque, 1989). In addition, there is some evidence that they provide knowledge and enhance informal support networks (Bourgeois, Schulz, and Burgio, 1996). However, there is much less evidence of their effectiveness in improving caregiver mental and physical health or ability to manage their caregiving situation (Dura, Stukenberg, & Kiecolt-

Glaser, 1991; Monahan, Greene, & Coleman, 1992; Russo, Vitaliano, Brewer, Katon, & Becker, 1995; Toseland et al., 1989).

Education and Training Programs

Education and training programs strive to help caregivers by educating them about resources and by teaching specific problem solving and coping techniques (Toseland & Smith, 2001). Studies assessing the effectiveness of skills training have produced equivocal and, at times, contradictory results. However, teaching specific caregiver skills that are clearly operationalized, practiced, and used to resolve real-life problems have been found to produce significant changes in outcome measures directly related to those skills (Bourgeois, et al., 1996).

Problem-solving and behavior management interventions have been found to demonstrate the greatest effectiveness (Pusey & Richards, 2001). For example, Teri, Logsdon, and Uomoto (1997) found that a nine-week behavior treatment program teaching caregivers skills to manage care recipient depression effectively (increasing pleasant events and problem-solving strategies) decreased depressive symptoms in caregivers. Gallagher-Thompson, Lovett, et al. (2000) found that psycho-educational interventions teaching either mood management skills or problem-solving skills were effective in reducing depression, reducing burden, and increasing coping.

Researchers have begun investigating culturally-targeted education and training interventions. Recent work by Gallagher-Thompson and colleagues (2001), Gallagher-Thompson, Coon, et al. (under review), and Gallagher-Thompson, Solano, et al. (under review) suggest that culturally-tailored skills programs can be more effective with Latinas and Caucasian women than a traditional support group in reducing caregiver depression, increasing positive coping, and fostering aspects of social support. The

REACH Skill Training intervention in Alabama found that behavior management skills training with care-recipients and problem-solving training with caregivers (Coon et al., 1999) resulted in a lower frequency of care recipient behavioral problems, reduced caregiver appraisals of bother, and increased caregiver leisure activities. However, there was some evidence that interventions had differential impacts by race. African-American caregivers showed the greatest reductions in stressfulness appraisal following behavioral skills training, while white caregivers showed greater improvement after receiving only educational support. Results suggest that further work attending to the special needs of minority caregivers is important (Burgio, Stevens, Guy, Roth, & Haley, under review).

Multi-Component Counseling Programs

Programs which offer a combination of counseling, support, and education services have been found to be especially effective. Mittelman, Ferris, Shulman, Steinberg, & Levin (1996) looked at the long-term effectiveness of a comprehensive support and counseling program for spouses and family members of patients with Alzheimer disease in postponing or preventing nursing home placement. The researchers found that a program of counseling and support not only can help prevent increased caregiver depression but it can also substantially increase by up to 326 days the time spouses are able to care for Alzheimer's patients at home, particularly during the early and middle stages of dementia when nursing home placement is generally least appropriate. The latter finding was particularly true for caregiving husbands.

Health Education (HEP) Group Intervention Programs combine multiple aspects of support, counseling, and training services, including emotion-focused and problem-focused coping strategies, education, and support. Members of Kaiser Permanente-Northeast, a regional HMO, were recruited to participate in a study comparing outcomes

of HEP and the staff model of “usual care” offered to caregivers in health maintenance organizations. Participants in this study have been found to have lower rates of depression, greater social integration, increased effectiveness in solving pressing problems, increased knowledge of community services and how to access them, improved feelings of competence, and enhanced responses to the caregiving situation. However, the intervention was not associated with changes in caregiver burden, role strain, or the physical and emotional demands of caregiving (Toseland et al., 2001). A recent multi-component psychoeducational intervention that included education, skills training, and family support significantly reduced caregivers’ negative reactions to disruptive behaviors and caregiver burden over time (Ostwald, Hepburn, Caron, Burns, & Mantell, 1999).

Respite

Respite care programs are designed to offer temporary or periodic relief from the time demands of caregiving by providing care for care recipients who are unable to remain alone due to mental or physical impairment. Respite is a secondary benefit received by the caregiver of a service provided to the care recipient. This relief affords the caregiver the opportunity to attend to other tasks, such as shopping, running errands, visiting the doctor, relaxing, or socializing.

Respite services are categorized into three main forms: in-home care, adult day care, and overnight respite. In-home respite consists of someone providing care at periodic intervals in the care recipient’s home for a specified amount of time while the primary caregiver is away or occupied by other activities. Forms of in-home respite may include assistance with household chores, physical care, or care recipient companionship and supervision (Kropf, 2000; Zarit, Gaugler, & Jarrot, 1999). Adult day care consists of

care during daytime hours for individuals with dementia or other disabilities in a supervised, structured, congregate environment; care may be medical, social, and/or behavioral (Gelfand, 1999; Kropf, 2000; Zarit et al., 1999). Finally, overnight respite consists of 24-hour care in a nursing home, hospital, or other extended care facility. Stays range from one night to two or more weeks, depending on the needs of the caregiving family. The type of care that is most useful to the caregiver will depend on the caregiver's and care receiver's needs (Administration on Aging, 2001; Bourgeois et al., 1996; Kropf, 2000; Toner, 1993; Toseland & Smith, 2001; Zarit et al., 1999).

Respite services, mainly in the form of in-home and adult day care, have been shown to contribute to decreases in caregivers' perceived stress, burden, anxiety, and somatic complaints, and an increase in caregiver morale, although respite use does not necessarily relieve caregiver depression (Biegel & Schultz, 1998; Bourgeois et al., 1996; Lyons & Zarit, 1999; Zarit, Stephens, Townsend, & Green, 1998; Zarit et al., 1999). Caregivers using respite care also tend to report reduced social and emotional isolation, and increased self-esteem, assertiveness, and control over their lives (Bourgeois et al., 1996). Caregivers typically report being "satisfied" to "highly satisfied" with the benefits of respite care to themselves and to the care recipient (Bourgeois et al., 1996; Feinberg & Whitlatch, 1997; Toseland et al., 2001; Zarit et al., 1999).

Early use of respite care is especially important if caregivers are to receive the greatest positive impact. Early intervention has been shown to relieve more caregiver stress and other negative outcomes than respite services offered after the caregiver has been providing care for many years (Lyons & Zarit, 1999). Moreover, research indicates that regular, on-going use of respite services, in contrast to intermittent, inconsistent use, can result in lower levels of caregiving-related stress, reduced feelings of overload and

burden, and better psychological well-being (Bourgeois et al., 1996, Toseland et al., 2001; Zarit et al., 1998).

A 1997 study conducted by Feinberg and Whitlatch compared the use of two different auspices under which in-home respite care could be provided: agency-based respite services and “direct pay” respite services using vouchers. Interestingly, the study found the direct pay voucher system to be more cost-effective than the agency-based model. Users in both groups spent approximately \$282 per month on respite care, yet direct pay users received 36.6 hours of respite care while agency based users received 28.1 hours of respite per month. The principal reason for this difference is that direct pay users hired family and friends as respite aides at lower rates (an average of \$7.70 per hour) than agency respite workers were paid (an average of \$10.10 per hour), and thus were able to receive more hours of respite care per dollar spent than agency-based users.

Few studies investigate the impact of respite care on care receivers. However, there is some evidence that dementia patients receiving respite care show improvement in reported problem behaviors (Burdz, Eaton, and Bond, 1988, in Bourgeois et al., 1996), although this may not be associated with changes in caregiver burden. Adult day care programs are especially likely to have salutary effects for participants, which may increase with continued use (Gilleard, Belford, Gilleard, Whittick, & Gledhill, 1984, in Bourgeois et al., 1996). Generally, care recipients appear to experience decreased confusion, improved mood and life satisfaction, and improved well-being as a result of adult day care attendance (Zarit et al., 1999).

The benefits of overnight respite use for the caregiver and the care receiver are less clear. Although overnight respite can reduce caregivers’ physical and mental strain (Burdz et al., 1988; Scharlach & Frenzel, 1986;), this relief may only be temporary (Zarit

et al., 1999). In fact, elders placed in overnight respite frequently are institutionalized at higher rates than are other elder care recipients, with increases of 12% (Foundation for Long-Term Care, 1983) to 29% (Larkin & Hopcroft, 1993). One possibility for this increased rate of institutionalization may be that overnight respite acts as a bridge to placement for caregivers, helping accustom them to relinquishing care of their care recipient (Zarit et al., 1999).

Supplementary Services

Supplementary services encompass other services which complement the care provided by caregivers. The area of supplementary services is loosely defined, as each state is afforded the opportunity to develop creative supports for its caregivers. For example, by using Medicaid waivers, states have the flexibility to offer home and vehicle modification programs, as well as assistive devices. The California Department of Aging includes home modification, home security and safety assistance, assistive devices, personal care, chores/homemaker services, home delivered meals, legal assistance, visiting caregiver, and assistance with placement in an appropriate living arrangement as examples of supplementary services. The assumption is that by providing these benefits, informal caregiving is strengthened by making it less taxing for caregivers to assist the care recipient (Smith, Doty, & O'Keefe, 2000).

A review of research supports the use of supplementary services. For example, supplemental services such as the installation of emergency alarms, provision of meals, and minor home modifications, when coupled with case management, can result in positive outcomes overall for caregivers (Braun & Rose, 1994).

Multi-Component Programs

Most programs offer more than one service to better meet the needs of individual caregivers, as they face different challenges during various stages of their caring careers. These multi-component programs may include two or more of the five service areas outlined in Title III-E of the Older Americans Act. For example, the Brooklyn Hospital Center's program, Supporting Family Caregivers of Neurologically Impaired Patients, offers individual counseling, home visits, information, as well as support groups. The state of Pennsylvania also offers various caregiver services, including information and referral, family consultation, care management, legal consultation, respite care, home modifications, emergency response, support groups, caregiver education and training, counseling, and financial assistance (Feinberg & Pilisuk, 1999).

Research has shown that multi-component interventions, especially those that contain a skill training component, generate larger effects than narrowly-focused interventions (Kennet et al., 2000). Multi-component programs have been found to have positive effects on caregivers in areas such as subjective burden, caregiver depression, service utilization, stress levels, and perceived quality of life (Kosloski and Montgomery, 1993; Mittleman et al., 1996; Mohide et al., 1990; Montgomery & Borgatta, 1989; Ostwald et al., 1999; Seltzer, Ivry, & Litchfield, 1987; Zarit et. al, 1998). However, studies done on multi-component programs offer little insight into the relative effectiveness of specific program components (Bourgeois et al., 1996; Zarit et al., 1998), making it difficult to determine which specific interventions are most helpful and how to create cost-effective treatments that maximize potential benefits to caregivers.

SUMMARY AND CONCLUSIONS

Caregivers typically grapple with more than one caregiving concern. A review of current literature demonstrates that programs flexible enough to meet the unique needs of different caregivers can be most successful. Programs which incorporate multiple aspects of the service areas discussed are better positioned to affect positive outcomes for caregivers. Despite what is known about interventions in these five caregiver service areas, future program design and implementation would benefit from further investigation. The following section outlines some of the implications and limitations of current research, and suggests new directions for caregiver services.

Implications

Interventions should be geared to the specific needs of particular caregiver populations. The needs of caregivers of demented individuals differ substantially from the needs of other caregivers, for example. A study by Ory, Hoffman, Yee, Tennstedt, and Schulz (1999) found that the two groups differ not only with regard to stressors and perceived stress, but also with regard to the type and amount of long-term care and caregiver support services needed.

Culture and ethnicity also need to be considered in designing services for caregivers. Although a number of recent studies have included greater sensitivity to racial, ethnic, and other cultural features, most intervention research has been done exclusively on Caucasians (Burgio et al., under review; Czaja & Rubert, in press; Gallagher-Thompson, Arean, et al., 2000; Gallagher-Thompson, Coon, et al., under review; Gallagher-Thompson et al., 2001; Hersen & Van Hasset, 1998; Janevic & Connell, 2001). More intervention studies culturally tailored to specific groups are

needed to enhance our knowledge of how to develop more culturally competent caregiver programs and to better address individual differences and needs.

Secondly, appropriate and realistic outcome measures are needed in order to evaluate the effectiveness of caregiver programs (Bourgeois et al., 1996). Too often interventions fail to assess relevant proximal outcomes, making it difficult to understand how and why an intervention did or did not work (Schulz, 2000). More attention needs to be given to using general outcome measures that facilitate comparisons with non-caregiver groups; also needed are outcome measures that are sensitive to change and that have good test-retest reliability, so that effects are not underestimated (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991).

A third important limitation of most intervention research is the failure to examine the possible ramifications of caregiver programs for the care recipient and for the caregiver/care-recipient dyad. Unfortunately, most programs and studies are concerned only with caregiver needs and outcomes. Little is known about the ways in which caregiver interventions may impact the care received by care recipients, or the quality of the caregiver-recipient relationship. Yet, there is some beginning evidence to suggest that important synergies may be achieved by simultaneously treating the caregiver and care recipient and/or altering the social and physical environment of the caregiver/care-recipient dyad (Schulz, 2000). For example, services that provide respite to family caregivers may allow them to provide higher-quality care for a longer period of time, and services that benefit patients may ease some of the demands of caregiving for the care provider (Zarit et al., 1999).

Fourth, although the vast majority of research delineates negative effects of caregiving, an emerging literature suggests that caregiver stress and burden may be

counterbalanced, in part, by the positive aspects of caregiving (Kramer, 1993a, 1997; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Lawton, Rajagopal, Brody, & Kleban, 1992; Miller & Goldman, 1989). This relatively new caregiver literature provides increasing support for the 'gains' perspective as a potentially meaningful arena for program development. A number of studies have suggested that the decision to become or remain a caregiver over an extended period of time may be associated with positive motivations such as: the opportunity to give back to the care recipient; an improved relationship with care recipient or other family members; prevention of further care recipient deterioration or feeling good about the quality of care provided; the opportunity to serve as a role model; increased self-esteem; feeling appreciated; an enhanced sense of meaning or purpose; and feelings of pleasure (Farran et al., 1991; Harris, 1998; Kramer 1993a, 1993b; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; NAC/AARP, 1997). Such positive aspects of caregiving may have beneficial effects for caregivers and care-receivers alike (Miller & Lawton, 1997). Moreover, interventions that enhance positive aspects of the caregiving experience may be more acceptable than those focused on alleviating strain.

A fifth issue which merits additional attention is how technological advances may improve caregiver outcomes. Home videos, computer programs, telephone services, and online education and support are just a few of the many ways technology may enhance services. The few studies to date that have looked at the effectiveness of technological programs have found generally positive results. For example, a study conducted by Leirer, Morrow, Tanke and Pareante (1991) found that a computer network enhanced the instrumental and emotional support provided by nurses to caregivers. A current study is looking at the effects on caregiver stress of a Telephone-Linked Care (TLC) program,

which provides a 24-hour automated telecommunication system through a computer-controlled human voice system that speaks with caregivers at home (Coon et al., 1999). Programs such as these are on the rise and it is important to understand the value of the various types of technological interventions in order to utilize them appropriately for the development of future interventions.

Lastly, the importance of creating and sustaining partnerships is a central issue in the development of successful caregiver interventions. Improving caregiver well-being requires moving beyond the individual caregiver to the organizational, community, and policy levels. Tomorrow's interventions should be directed at enhancing coordination among employer health care systems, churches, senior centers, and other community based organizations (the organizational level), within the context of retirement communities, cities, counties, and service regions (the community level), as well as the broader-based policy level, in order to more effectively assist our increasingly diverse population of family caregivers (Coon & Thompson, in press).

REFERENCES

- Administration on Aging. (n.d.). Respite: What caregivers need most-administration on aging fact sheet [On-line]. Available: <http://www.aoa.gov/factsheets/Respite.html>
- Biegel, D., & Schulz, R. (1998). Caregiving and caregiver interventions in aging and mental illness. Family Relations, 48, 345-354.
- Bourgeois, M., Schulz, R., & Burgio, L. (1996). Interventions for caregivers of patients with Alzheimer's disease: A review and analysis of content, process, and outcomes. International Journal on Aging and Human Development, 43, 35-92.
- Braun, K., & Rose, C. (1994). Testing the impact of a case management program on caregiver appraisal. Journal of Gerontological Social Work 21(3/4), 51-69.
- Burgio, L., Stevens, A., Guy, D., Roth, D., & Haley, W. (under review). Impact of two psychosocial interventions on white and African American family caregivers of individuals with dementia.
- Cole, L., Griffin, K., & Ruiz, B. (1986). A comprehensive approach to working with families of Alzheimer's patients. In R. Dobrof (Ed.), Social Work and Alzheimer's Disease (pp. 27-39). New York: Haworth.
- Cooke, D., McNally, L., Mulligan, K., Harrison, M., & Newman, S. (2001). Psychosocial interventions for caregivers of people with dementia: Systematic review. Aging & Mental Health, 5, 120-135.
- Coon, D., & Thompson, L. (in press). Family caregiving for older adults: Emergent and ongoing themes for the behavior therapist. The Behavior Therapist.

Coon, D., Schulz, R., & Ory, M. (1999). Innovative intervention approaches with Alzheimer's disease caregivers. In D. Biegel & A. Blum (Eds.), Innovations in practice and service delivery across the lifespan (pp. 295-325). New York: Oxford University Press.

Czaja, S., & Rubert, M. (in press). Telecommunications technology as an aid to family caregivers of persons with dementia. Psychosomatic Medicine.

Dura, J., Stukenberg, K., & Kiecolt-Glaser, J. (1991). Anxiety and depressive disorders in adult children caring for demented parents. Psychology and Aging, 6, 467-473.

Farran, C., Keane-Hagerty, E., Salloway, S., Kupferer, S., & Wilken, C. (1991). Finding meaning: An alternative paradigm for Alzheimer's disease family caregivers. The Gerontologist, 31, 483-489.

Feinberg, L., & Whitlatch, C. (1997). Family Caregivers and consumer choice: options for in-home respite care: executive summary [On-line]. Available: <http://caregiver.org/research/respite.html>.

Feinberg, L. (1997). Options for supporting informal and family caregivers: A policy paper. San Francisco, CA: The American Society on Aging.

Feinberg, L., & Pilisuk, T. (1999). Survey of fifteen states' caregiver support programs. San Francisco, CA: Family Caregiver Alliance.

Foundation for Long-Term Care. (1983). Respite care for the frail elderly. Albany, NY: Center for the Study of Aging

Friss, L. (1990). A model state-level approach to family survival for caregivers of brain-impaired adults. The Gerontologist, 30, 121-125.

Gallagher-Thompson, D., & Steffen, A. (1994). Comparative effects of cognitive-behavioral and brief psychodynamic psychotherapies for depressed family caregivers. Journal of Consulting and Clinical Psychology, *62*, 543-549.

Gallagher-Thompson, D., Árean, P., Coon, D., Menéndez, A., Takagi, K., Haley, W., Argüelles, T., Rubert, M., Loewenstein, D., & Szapocznik, J. (2000). Development and implementation of intervention strategies for culturally diverse caregiving populations. In R. Schulz, et al. (Eds.), Handbook of dementia caregiving intervention research (pp. 151-185). New York: Springer.

Gallagher-Thompson, D., Arean, P., Rivera, P., & Thompson, L. (2001). Reducing distress in Hispanic family caregivers using a psychoeducational intervention. Clinical Gerontologist, *23*, 17-32.

Gallagher-Thompson, D., Coon, D., Solano, N., Ambler, C., Rabinowitz, R., and Thompson, L. (under review). Distress among Caucasian and Hispanic/Latina caregivers of elderly relatives with dementia: Site specific results from the REACH national collaborative.

Gallagher-Thompson, D., Lovett, S., Rose, J., McKibbin, C., Coon, D., Futterman, A., & Thompson, L. (2000). Impact of psychoeducational interventions on distressed family caregivers. Journal of Clinical Geropsychology, *6*, 91-110.

Gallagher-Thompson, D., Solano, N., Coon, D., & Arean, P. (under review) Recruitment and retention of Latina dementia family caregivers in intervention research: Issues to face, lessons to learn.

Gelfand, D. (1999) The aging network: programs and services (5th ed.). New York: Springer.

Gonyea, J. (1989). Alzheimer's disease support groups: An analysis of their structure, format and perceived benefits. Social Work in Health Care 14(1), 61-72.

Harris, P. (1998). Listening to caregiving sons: Misunderstood realities. The Gerontologist, 38, 342-352.

Hersen, M., & Van Hasset, V. (1998) Handbook of Clinical Geropsychology. New York: Plenum Press.

Janevic, M., & Connell, C. (2001). Racial, ethnic and cultural differences in the dementia caregiving experience: Recent findings. The Gerontologist, 41, 334-347.

Kennet, J., Burgio, L., & Schulz, R. (2000). Interventions for In-Home Caregivers: A Review of Research 1990 to present. In R. Schulz (Ed.), Handbook of Dementia Caregiving (pp. 61-125). New York: Springer.

Kosloski, K., & Montgomery, R. (1993). Perceptions of respite services as predictors of utilization. Research on Aging, 15, 399 - 314.

Kramer, B. (1993a). Marital history and the prior relationship as predictors of positive and negative outcomes among wife caregivers. Family Relations, 42, 367-375.

Kramer, B. (1993b). Expanding the conceptualization of caregiver coping: The importance of relationship-focused strategies. Family Relations, 42, 383-391.

Kramer, B. (1997). Gain in the caregiving experience: Where are we? What next? The Gerontologist, 37, 218-232.

Kropf, N. (2000). Home health and community services. In R.L. Schneider, L. Robert, N.P.Kropf, and A.J. Kisor (Eds.) Gerontological Social Work (2nd ed.) (pp. 167-190). Belmont, CA: Wadsworth.

Larkin, J., & Hopcroft, B. (1993) In-hospital respite as a moderator of caregiver stress. Health and Social Work, 18(2), 132-139.

- Lawton, M., Kleban, M., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. Journal of Gerontology, *44*, P61-71.
- Lawton, M., Moss, M., Kleban, M., Glicksman, A., & Rovine, M. (1991). A two-factor model of caregiving appraisal and psychological well-being. Journal of Gerontology, *46*, P181-189.
- Lawton, M., Rajagopal, D., Brody, E., & Kleban, M. (1992). The dynamics of caregiving for a demented elder among black and white families. Journal of Gerontology: Social Sciences, *47*, S156-S164.
- Leirer, V., Morrow, D., Tanke, E., & Pareante, G. (1991). Elders won adherence: Its assessment and medication reminding by voice mail. The Gerontologist, *31*, 514-520.
- Lund, D., Hill, R., Caserta, M., & Wright, S. (1995). Video Respite™: An innovative resource for family, professional caregivers, and persons with dementia. The Gerontologist, *35*, 683 – 687.
- Lyons, K., & Zarit, S. (1999). Formal and informal support: The great divide. International Journal of Geriatric Psychiatry, *14*, 183-196.
- Maslow, K., & Selstad, J. (2001). Chronic Care Networks for Alzheimer's disease: Approaches for involving and supporting family caregivers in an innovative model of dementia care. Alzheimer's Care Quarterly, *2*, 33-46.
- Miller, D., & Goldman, L. (1989). Perceptions of caregivers about special respite services for the elderly. The Gerontologist *29*, 408-411.
- Miller, B., & Lawton, M. (1997). Symposium: Positive aspects of caregiving. The Gerontologist, *37*, 216-217.

Mittelman, M., Ferris, S., Shulman, E., Steinberg, G., & Levin, B. (1996) Family intervention to delay nursing home placement of patients with Alzheimer's disease.

Journal of the American Medical Association, 276, 1725-1731.

Mohide, E., Pringle, D., Streiner, D., Gilbert, J., Muir, G., & Tew, M. (1990). A randomized trial of family caregiver support in the home management of dementia.

Journal of the American Geriatrics Society, 38, 446-454.

Monahan, D., Greene, V., & Coleman, P. (1992). Caregiver support groups: Factors affecting service use. Social Work, 37, 254-260.

Montgomery, R., & Borgatta, E. (1989). The effects of alternative support strategies on family caregiving. The Gerontologist, 29, 457-464.

National Alliance for Caregiving & AARP. (1997). Family caregiving in the U.S.: Findings from a national survey. Washington, DC.

Ory, M., Hoffman, R. R. III, Yee, J., Tennstedt, S., & Schulz, R. (1999) Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. The Gerontologist, 39, 177-185.

Ostwald, S., Hepburn, K., Caron, W., Burns, T., & Mantell, R. (1999). Reducing caregiver burden: A randomized psychoeducational intervention for caregivers of persons with dementia. The Gerontologist, 39, 299-309.

Pusey, H., & Richards, D. (2001). A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia. Aging & Mental Health, 5, 107-119.

Russo, J., Vitaliano, P., Brewer, D., Katon, W., & Becker, J. (1995). Psychiatric disorders in spouse caregivers of care-recipients with Alzheimer's disease and matched

controls: A diathesis-stress model of psychopathology. Journal of Abnormal Psychology, *194*, 197-204.

Scharlach, A., & Fenzel, C. (1986). An evaluation of institution-based respite care. The Gerontologist, *29*, 77-82.

Schulz, R. (2000). Handbook of Dementia Caregiving. New York: Springer.

Seltzer, M., Ivry, J., & Litchfield, L. (1987). Family members as case managers: Partnership between the formal and informal support networks. The Gerontologist, *27*, 722-728.

Smith, G., Doty, P., & O'Keefe, J. (2000). Supporting informal caregiving. In G. Smith, J. O'Keefe, L. Carpenter, P. Doty, G. Kennedy, B. Burwell, R. Mollica, & L. Williams (Eds.), Understanding medicaid home and community services: A primer. Washington, DC: Office of Disability, Aging and Long-Term Care Policy. [On-line]. Available at the HHS/ASPE website:
<http://aspe.hhs.gov/daltcp/reports/primerpt.htm#Chap8>.

Teri, L., Logsdon, R., & Uomoto, J., et al. (1997). Behavioral treatment of depression in dementia patients: A controlled clinical trial. Journal of Gerontology B: Psychological Science and Social Science, *52*, 159-166.

Toner, J. (1993). Concepts of respite care: A gerontologist's perspective. In L. Tepper & J. Toner (Eds.), Respite care: Programs, problems, and solutions (pp. 123-131). Philadelphia: Charles Press Publishers.

Toseland, R., & Smith, T. (2001). Supporting caregivers through education and training [On-line]. Available from the Administration on Aging at:
<http://aoa.gov/carenetwork/Fin-Toseland.html>.

Toseland, R., Rossiter, C., Peak, T., & Smith, G. (1990). Comparative effectiveness of individual and group interventions to support family caregivers. Social Work, 35, 209-217.

Toseland, R., Rossiter, C., & Labrecque, M. (1989). The effectiveness of peer-led and professionally led groups to support family caregivers. The Gerontologist, 29, 465-471.

Toseland, R., Smith, G., & McCallion, P. (2001). Family caregivers of the frail elderly. In A. Guttermann (Ed.), Handbook of social work practice with vulnerable and resilient populations (pp. 548-581). New York: Columbia University Press.

Weuve, J., Boulton, C., & Morishita, L. (2000). The effects of outpatient geriatric evaluation and management on caregiver burden. The Gerontologist, 40, 429-436.

Zarit, S., Gaugler, J., & Jarrot, S. (1999). Useful services for families: Research findings and directions. International Journal of Geriatric Psychiatry, 14, 165-181.

Zarit, S., & Leitsch, S. (2001). Developing and evaluating community based intervention programs for Alzheimer's patients and their caregivers. Aging & Mental Health, 5, S84-S98.

Zarit, S., Stephens, M., Townsend, A., & Greene, R. (1998). Stress reduction for family caregivers: Effects of adult day care use. Journal of Gerontology: Social Sciences, 53B, S267-S277.

MODEL PROGRAMS

Stephanie Whittier, Jolyn Aaker, Kathryn Kietzman, & Teresa Dal Santo

INTRODUCTION

The previous two chapters detailed what is known about caregiver characteristics and the evidence supporting differing approaches to providing caregiver services. This chapter provides examples of model programs for supporting caregivers. The search was not constructed on measurements of program effectiveness but rather looked for innovative and creative models for serving caregivers. Local non-profit service providers, state programs, and national programs all have been included to illustrate the breadth of imaginative ways systems can be enhanced to serve caregivers better. It is hoped that these sections together will provide the reader with the foundation for developing service programs responsive to the needs of family caregivers.

Information on these model programs was collected through the Internet, foundation reports, and literature reviews. Once a program was identified for inclusion, contact was made with program directors to verify and update the information. Programs were selected because of their uniqueness in the areas of target population, funding sources, or service provision. Each entry has a brief description of the program, including whom they serve and the number served (if available), funding sources, and the reason for inclusion (“innovation”). All programs replied to the request for updated information regarding their program. A program directory alphabetizes all entries and specifies under which section they can be located (Information; Access; Counseling, Support, and Education; Respite; Supplemental Services; and Multi-Component Programs). Program descriptions are organized according to service area.

INFORMATION

Care Choice Ohioⁱ

Care Choice Ohio (CCO) provides early-intervention to help families plan for long-term care needs. CCO, a component of Ohio's PASSPORT program, offers individualized consultation with staff from the PASSPORT Administrative Agencies (PAA) about long-term care planning, regardless of the source and amount of the person's income. Services address a gap in services to a population often missed by other funding sources. Services include specialized information and referral, family caregiver assessment of need, and family consultation and care planning.

Funding: State General Fund

Innovation: Offers advanced planning for long-term care needs to ensure families know what options are available to them.

Contact:

Sheri Kiser, Manager of Clinical Services
Ohio Department Of Aging
50 West Broad Street, 9th Floor
Columbus, OH 43215
Phone: (614) 644-5455
Fax: (614) 466-5741
Web: <http://www.state.oh.us/age/planassess.html>

Eldercare Locatorⁱⁱ

Eldercare Locator is a free nationwide assistance service designed to help older persons and their caregivers locate local support resources or give information about long-term care planning. Eldercare Locator links caregivers with state and local resources that enable older persons to remain independent in their own homes. Information provided includes how to locate services for elders living in the community as well as the names, addresses, and phone numbers of organizations in the desired location. It has a message recorder for after-hours calls with a policy to return calls the following business day. Eldercare Locator is a public service of the Administration on Aging, and is administered by the National Association of Area Agencies on Aging.

Funding: Federal Funds; the Administration on Aging

Innovation: Recognizes the needs of long-distance caregivers. Acts as a preliminary information clearinghouse for people needing local resource information. This model would be well-suited for duplication at the state or county level, with more specific listings of community resources.

Contact:

Eldercare Locator

Phone: (800) 677-1116

TDD/TTY: (202) 855-1234

Web: www.eldercare.gov**Long Distance Caregiver Project**ⁱⁱⁱ

When caregivers live apart from their relatives, they often are not aware of the services needed by their relative or what resources are available. This program furnishes people with dementia in the Los Angeles area and their long-distance caregivers with information and referral. The family consultants make home visits to seniors to assess the elder's living environment, care, and needs and then consult with the caregiver and elder on the assessment and care planning. Legal consultations by phone at reduced rates are offered to long-distance caregivers to familiarize them with California-specific legal and financial planning tools and strategies. A Caregiver Resource Guide aids caregivers in locating appropriate resources and long-distance caregivers can access a website with service and resource information.

Funding: Archstone Foundation*Innovation:* Addresses the growing population of long-distance caregivers and their unique needs.*Contact:*

Judith Delaney

Alzheimer's Association of LA

5900 Wilshire Boulevard

Los Angeles, CA 90036

Phone: (323) 930-6251

ACCESS

Caregiver Assistance Network^{iv}

Founded in 1996 as a project of Catholic Social Services of Southwestern Ohio, this program offers a central access point for information about caregiving. The Caregiver Careline, staffed by trained volunteers, offers moral support, provides specific, practical suggestions, and identifies appropriate community resources. Caregiver Assistance Network also offers a newsletter, educational programs, support groups, and a limited respite program.

Funding: Some of these programs are partially funded by the United Way and Community Chest, and the Ohio Department of Aging, through the Council on Aging of the Cincinnati Area, Inc.

Innovation: Provides assistance and access to programs and services through a peer network of volunteers.

Contact:

The Caregiver Assistance Network

100 East Eighth Street, 6th Floor

Cincinnati, OH 45202

Phone: (513) 929-4483

Fax: (513) 241-4333

Web: <http://www.cssdoorway.org/>

Email: cssfamily@queencity.com

Family Caregiver Self-Awareness Project^v

A comprehensive communication campaign designed to reach out to help family caregivers identify and address their own needs. This nationwide, public education campaign incorporates messages and recommended interventions that can change the way family caregivers perceive themselves and behave in their roles as caregivers.

The Family Caregiver Self-Awareness Project focuses on the family caregiver as the recipient of its efforts. The overall objectives are to: ensure that family caregivers understand that caregiving can go over and above their traditional roles as spouse, child, or parent, acknowledge their changing situation, reach out for help, and become their own advocates.

Funding: \$200,000 in grants from The Retirement Research Foundation, Janssen Pharmaceutical, and CareThere.com.

Innovation: Recognizes that help for family caregivers does not always mean formal services. The program aims to help caregivers recognize that they can set up informal support networks to help in their caregiving tasks. The project is focused on helping

caregivers understand that it is all right to reach out for assistance, from either informal or formal helpers.

Contact:

Melanie Kinney Hoffmann
National Family Caregivers Association
Phone: (301) 972-6430
Web: www.nfcacares.org

Georgia Mobile Day Care Program^{vi}

This program brings day care to rural communities, allowing caregivers a chance to obtain respite from their daily caregiving responsibilities. Mobile Day Care offers caregivers respite, support, care management, and help identifying other resources. Using sites such as churches and community centers, staff travels between locations bringing the materials and supplies needed for that day. Depending on the needs of the community, each site is open for five or six hours per day, one to three days each week. This mobile day care model spreads staff costs among sites, thereby increasing the program's efficiency.

Originally developed for caregivers of persons with Alzheimer's disease, mobile day care is a program that can serve all caregivers of older persons, irrespective of impairment. It is also a viable service option whether serving a rural area or the borough of a larger metropolitan area.

Currently, an eight-minute video of the program may be obtained at no charge.

Funding: Initially funded by the Administration on Aging's Alzheimer's Demonstration Grants to the States program.

Innovation: Allows rural or urban communities to establish day care programs where none currently exist. This program brings resources to consumers who are otherwise unable to avail themselves of these services. The practice of sharing staff helps to address difficulties of low enrollment and the high costs associated with the day care program sustainability.

Contact:

Cliff Burt
Aging Services Coordinator
Georgia Department of Resources
Division of Aging Services
Two Peachtree Street, NW; Suite 9-470
Atlanta, Georgia 30303-3142
Phone: (404) 657-5336
Email: gcburt@dhr.state.ga.us

The Milwaukee Community Service Bank^{vii}

This program was developed in response to waiting lists of up to three years for services related to daily living tasks. By mobilizing a pool of community agencies that donate services, the Milwaukee Community Service Bank is able to assure that elderly people with no access to other services get the services they need. Following an assessment, individuals are matched with services. These services are provided on a temporary basis until appropriate funding or other resources become available and a permanent solution can be found.

Both older persons and their caregivers benefit from obtaining assistance with daily living tasks. Services include: day care, case management, companions, legal services, housekeeping, counseling, personal care, shopping, meals, medical equipment, chore service, and delivery of emergency goods.

The Dementia Service Bank was created in 1999 as the service component of a grant received from the Administration on Aging by the Bureau of Aging and Long Term Care Resources—The Wisconsin Dementia Service Network. The Dementia Service Bank purchases services for persons with dementia in the following service categories: home health, personal care, companions, day care and respite care—at home or at a facility. \$175,000 per year has been allocated for these services.

Funding: Faye McBeath Foundation, Helen Bader Foundation, Greater Milwaukee Foundation

Innovation: Offers a broad range of temporary services to older adults and their caregivers until a more appropriate and permanent solution can be found.

Contact:

Phyllis Blackburn
St. Ann Center for Intergenerational Care
2801 E. Morgan Avenue
Milwaukee, WI 53207
Phone: (414) 977-5013

New Jersey Easy Access, Single Entry (NJ EASE)^{viii}

NJ EASE is a consumer-focused statewide system that aids access to services for seniors by providing a new and easy way for seniors and their families to learn about and obtain needed services. In each NJ EASE county, seniors and their families have the opportunity to call one toll-free telephone number to learn about and access important services.

NJ EASE provides: information on services and programs; referrals to other agencies and help contacting them; assistance completing applications for services; one-stop benefits counseling; home visits to help with paperwork or check in on people having trouble taking care of themselves; in-home comprehensive assessments to determine need for supportive services; development of a care plan to identify and arrange for services; and

the assistance of care managers to obtain and monitor services. As of November, 2000 more than 200,000 seniors and their families had been helped by this program.

Funding: NJ EASE was originally funded in 1994 by a \$238,251 planning grant from the Robert Wood Johnson Foundation that was matched by State funds in the amount of \$400,592.

Innovation: This program offers a multi-component plan of access for seniors and their families. Using a single point of entry, consumers are able to learn about and access a broad range of financial, medical and social services. The phone number is nationwide, allowing out-of-state family members to assist in caring for their loved ones.

Contact:

Barbara Fuller, Supervisor

NJ Division of Senior Affairs

PO Box 807

Trenton, NJ 08625-0807

Phone: (609) 943-3463

NJ EASE: (877) 222-3737

Web: <http://www.state.nj.us/health/senior/sanjease.htm>

COUNSELING, SUPPORT GROUPS, EDUCATION, AND TRAINING

ASPECT - A Support Program for the Elderly (and their caregivers) during Crisis Times^{ix}

This program provides in-home counseling support to older persons and caregivers when unexpected, upsetting or sudden changes in life occur. Without in-home service, these people often are unable to access such support. When situations are identified as stressful, agencies refer to ASPECT. A trained counselor supports older persons and caregivers in dealing with practical and emotional issues. Resource information is provided as well as encouragement in facing difficult decisions. Clients can continue ASPECT participation in order to help prevent future crises. Grant funding and agency scholarships reduce the cost of this program to a reasonable amount. There is a sliding scale depending upon income.

Funding: Pew Charitable Trusts.

Innovation: This program offers crisis intervention for caregivers who are experiencing extreme levels of stress. This type of intervention may be instrumental both in preventing more serious problems from developing, and in helping caregivers make informed decisions about their loved one's care.

Contact:

Fred DeLong, Ph.D.
The Lincoln Center for Family and Youth
201 Union Avenue
Bridgeport, PA 19405
Phone: (610) 277-3715 x 243
Email: fdelong@thelincolncenter.com

Alzheimer's Disease Knowledge Building Program^x

This program gives information and advice about coping with the challenges that are commonly seen in the early stages of Alzheimer's disease. Increased public awareness and the advent of newer treatments result in people coming for help earlier in the progression of the disease than typically seen in the past. However, few resources are available regarding the early stages of the disease that balance help and hope for individuals and families. This program was designed to help increase knowledge about Alzheimer's disease among family members and friends of people in the early stages of the disease and assist them in adjusting their attitudes and behaviors to their changing roles and responsibilities. The program provides written materials for participants and includes five weekly evening sessions in a community setting that focus on issues associated with the early stages of the disease. Evaluation demonstrates increased knowledge, improved coping skills, and increased self-efficacy of participants. A train-the-trainer program is currently under development in cooperation with the Greater Illinois Chapter of the Alzheimer's Association.

Funding: Helen Bader Foundation, HCR ManorCare Foundation, and Eisai Inc.

Ongoing Funding: Mather LifeWays

Innovation: This program specifically targets family members and friends of persons in the early stages of Alzheimer's. By offering information about the challenges of caring for persons in the early stages of Alzheimer's, the program offers a proactive and preventive approach to adapting to the caregiver experience. This program may work well as an adjunct to support groups for persons in the early stages of the disease or as a stand alone program for family members and friends.

Contact:

Daniel Kuhn, MSW, Director of Education
Mather Institute on Aging, Mather LifeWays
1603 Orrington Avenue, Suite 1800
Evanston, IL 60201
Phone: (847) 492-6813
Email: dkuhn@matherlifeways.com

As Families Grow Older^{xi}

This program assists faith-based organizations and other community providers in their efforts to help family caregivers and their relatives to plan together for the care that may be needed. It enhances the supportive capacities of other family members, neighbors, friends, congregations and community service providers. The program includes a training kit to be used by community service providers with everything they need to conduct a six module educational program for older adults and their families, including planning and program guide, participant work book and materials for six module workshops. Workshop topics include: an introduction to family dynamics; the roles and resources of caregiving; challenging health issues of aging; making choices about living arrangements; exploring the financial and legal issues of aging; and living and dying in your faith.

Funding: Winter Park Foundation

Innovation: This program provides a curriculum tool – a training kit - that makes it possible for community organizations to conduct a quality educational program for caregivers without having to design their own curriculum.

Contact:

Cathy Michaelson Lieblich
Winter Park Health Foundation
Miller Center for Older Adult Services
2010 Mizell Avenue
Winter Park, FL 32792
Phone: (407) 629-5771 x 2227
Fax: (407) 647-4028
Email: clieblich@wphf.org

At Home with the A.R.T.S. (Alzheimer Recreation Therapy Services)^{xii}

This program is unique because it brings music and therapeutic recreation activities to Alzheimer's individuals in their own homes. Active intervention through therapeutic activities can improve the Alzheimer's individual's mood, behavior and family life. The program includes an in-home assessment of activity abilities and needs, weekly visits from an activities therapist; visits include a 1 hour activity session with the Alzheimer's individual and ½ hour training session with the caregiver in techniques of music, movement and therapeutic recreation activities so they can develop and implement in-home activities.

Funding: Grotta Foundation, Robert Wood Johnson Foundation, Krol Foundation, Sandy Hill Foundation, Traveler's Foundation Westfield Foundation, James C. Jarvie Commonwealth Service, Health Care Foundation of New Jersey, and The Rothman Foundation.

Innovation: In addition to benefiting the individual with Alzheimer's, this program offers the caregiver new skills and ways to communicate and have fun despite the barriers of Alzheimer's Disease.

Contact:

Laura Holly Dierbach
Alzheimer's Association, Greater New Jersey Chapter
400 Morris Avenue #251
Denville, NJ 07834
Phone: (973) 586-4300
Email: laura.dierbach@alz.org

Caregiver Tip Cards^{xiii}

Caregiver Tip Cards were designed to offer information and tips for the informal caregiver of older adults. They are a series of quick-reference cards involving four common activities: Bathing, Communication, Feeding, and Toileting. Each set of cards is available in one of four languages: English, Spanish, Hmong, and Russian, and comes with supplies that give the caregiver a choice of display options. The cards are laminated and are approximately 5"X 8".

Funding: Pfizer, Inc.

Innovation: This program offers a non-intrusive, culturally responsive, easy to use educational intervention for caregivers who are increasingly assuming responsibilities with daily life tasks.

Contact:

Stacy Barnes
 Wisconsin Geriatric Education Center
 Marquette University
 P.O. Box 1881
 Milwaukee, WI 53201
 Phone: (414) 288-3712 or (800) 799-7878

Eldercare in the Workplace^{xiv}

This program is the first of its kind to target the small and mid-sized business and non-profit sector, and to tailor educational and informational materials and services to their caregiving workforce. Working caregivers have special needs and problems that not only impact upon their own family's quality of life but also affect their co-workers and employers. The specific activities of this program focus on (1) sensitizing employers to the magnitude of caregiving and its impact on the workplace; (2) identifying and implementing model workplace policies, education and caregiver support services suitable for the small business environment; and (3) training local AAA staff in outreach to local businesses on eldercare issues in the workplace, and in partnering with employers to provide a package of services for their employee caregivers. The project is a collaborative team effort bringing together the expertise and influence of the statewide business trade association, State Department of Health and Senior Services, the Geriatric Education Center of the University of Medicine and Dentistry of New Jersey, and the National Alliance for Caregiving.

Funding: Grotta Foundation

Innovation: This program raises awareness of caregiver issues in the workplace and forges a unique collaboration between the State, Area Agencies on Aging, small and mid-sized businesses and the non-profit sector.

Contact:

Rick Greene
 New Jersey Department of Health and Senior Services
 P.O. Box 807
 Trenton, NJ 08625
 Phone: (609) 588-3169

S.O.S. (Speaking of Seniors)^{xv}

The program focuses exclusively on spousal caregivers, providing services tailored specifically to their special needs. The goals of this program are to relieve the stress, guilt, and depression often experienced by spousal caregivers, and to help older couples address the challenges that arise because of changing roles and responsibilities. Specific program services include: outreach through educational workshops, marital counseling, group and individual therapy and home visits. In many cases, the care recipient spouse

also receives individual therapeutic intervention. The program operates on a sliding scale, targeting those who are not eligible for publicly reimbursed therapy.

Funding: Grotta Foundation, Wallerstein Foundation

Innovation: This program is unique in that it exclusively serves spousal caregivers and addresses their special needs. The provision of home visits enables the caregiver to obtain services that may otherwise be difficult to access.

Contact:

Lynn Hanson
Main St. Counseling Center
8 Marcella Avenue
West Orange, NJ 07052
Phone: (973) 736-2041

RESPIRE SERVICES

Camp for Caring^{xvi}

Camp for Caring is a weekend retreat for individuals with Alzheimer's disease, stroke, Parkinson's disease, or a related disorder. Offered by the Family Caregiver Alliance, caregivers of adults with cognitive impairment are given the opportunity to have 48 hours of respite while their loved one enjoys a 2-night stay with trained staff and volunteers in a one-on-one non-institutional, scenic Bay Area setting. The impaired adult receives 6 home cooked meals and snacks and may participate in a variety of structured activities offered including arts and crafts, singing, dancing, low-impact exercises, group activities and games and socializing. Persons who are frail, incontinent, non-communicative or non-ambulatory are welcome to participate. A nurse is available around the clock and night attendants are also on duty to assist those who have needs during the night.

Camp for Caring is available four times per calendar year. Each camp accommodates between 15-18 people. Campers must be clients of the Family Caregiver Alliance and have an MD's approval to participate. First priority is given to those families who are already on an agency wait list for respite care. 6 trained staff, a group of about 10 volunteers, and one 24-hour nurse, staff each camp.

Funding: Fees are payable on a sliding scale basis and currently range from \$125 to \$250 per person for the entire weekend. All additional costs are subsidized by Family Caregiver Alliance, foundations, corporations, and individual camp sponsors. Scholarships are also available to those who cannot afford the sliding scale fees. The actual cost of each weekend camp is estimated to range between \$12,000 - \$15,000.

Innovation: A weekend camp, providing 48 hours of respite for caregivers of persons with adult onset brain impairment. Care recipients have a 2-night stay with one-on-one companionship provided by a volunteer or staff member. Structured activities are provided in a scenic, relaxed and non-institutional setting. Nursing care is available around the clock.

Contact:

Jennifer Hull, Senior Program Associate
 Family Caregiver Alliance
 690 Market Street Suite 600
 San Francisco, California 94104
 Phone: (415) 434-3388 or (800) 445-8106
 Fax: (415) 434-3508
 Email: jhull@caregiver.org or info@caregiver.org
 Web: www.caregiver.org

Caregivers Retreat^{xvii}

Caregivers Retreat complements Camp for Caring by offering a weekend retreat for caregivers of cognitively impaired adults. Offered twice a year by Family Caregiver Alliance and held in the same facility as the Camp for Caring, this retreat is available to 24-30 caregivers. Each retreat has a specific theme related to caregiving, and gives caregivers an opportunity to rest and relax, participate in structured activities, and share common experiences with other caregivers. Psychotherapeutic and psychoeducational support groups are part of the retreat's agenda and are facilitated by two staff therapists.

Clients of Family Caregiver Alliance are invited to the Caregivers Retreat, based on referrals made by the Family Consultants, and responses are accommodated on a first come, first serve basis. Family Caregiver Alliance Family Consultants assist the caregiver in attaining respite care for their loved one, as needed. In addition, short-term respite funds are available on an as-needed basis for those caregivers who cannot afford to cover the cost of providing respite care needed in their absence.

Funding: The Caregivers Retreat fees are the same as the fees for Camp for Caring. Payable on a sliding scale basis, the fees currently range from \$125 to \$250 per person for the entire weekend. All additional costs are subsidized by Family Caregiver Alliance, foundations, corporations, and individual camp sponsors. Scholarships are also available to those who cannot afford the sliding scale fees. The estimated cost of each Caregiver Retreat weekend is between \$13,000 and \$15,000.

Innovation: A weekend retreat in a scenic setting that offers caregivers of adults with brain impairment respite in a supportive and therapeutic environment where they can rest, relax and share their caregiving experiences with others who have similar circumstances.

Contact:

Jennifer Hull, Senior Program Associate
Family Caregiver Alliance
690 Market Street Suite 600
San Francisco, California 94104
Phone: (415) 434-3388 or (800) 445-8106
Fax: (415) 434-3508
Email: jhull@caregiver.org or info@caregiver.org
Web: www.caregiver.org

ElderServe at Night^{xviii}

ElderServe at Night provides overnight respite care for people caring for older adults at home who require continuous supervision through the night due to physical or cognitive impairment. Modeled after an adult day care program, a variety of recreational and therapeutic activities are offered throughout the night. The program is available from 7pm to 7am, seven nights a week, 365 days a year. Services are available on a regular schedule, or on an as-needed basis. The program is housed in the Hebrew Home for the

Aged in Riverdale, New York and serves people living in the Bronx, Manhattan, and neighboring Westchester County. Door-to-door transportation is available.

Funding: The program costs \$75.00 a night, which can be paid privately or through Medicaid.

Innovation: The first overnight adult day program in the country, this program provides overnight respite care for caregivers who are caring for their relatives at home. This program is unique in that it offers traditional adult day care services at night, giving caregivers an opportunity to get rest and relief at a time when they may need it most. It also provides a safe and supervised environment to the impaired adult, offering a full range of activities throughout the night, and personal care as needed.

Contact:

David V. Pomeranz
 Hebrew Home for the Aged at Riverdale
 5901 Palisade Ave
 Bronx, NY 10471
 Phone: (718) 581-1780
 Fax: (718) 543-3681
 Web: www.elderserve.org

Faith in Action^{xix}

This nationwide program of The Robert Wood Johnson Foundation supports the development of volunteer caregiving services to the growing number of people with long-term health problems, including those who are frail and elderly, hospice patients, children with disabilities, and people who suffer from such conditions as arthritis, diabetes, cancer, AIDS, multiple sclerosis, and Alzheimer's disease. The Foundation's funding is being used to triple the number of programs from the current 1,000 to 3,000 over six years.

Volunteers come from churches, synagogues, mosques and other houses of worship, as well as the community at large. These volunteers help those in need with many everyday activities, such as providing a ride to the doctor, shopping for groceries, cooking meals or helping with light housework, running errands and simply providing companionship through friendly visiting or telephoning. Volunteers may also provide respite care and relief for family caregivers. With this volunteer assistance, the growing number of people who are aging and chronically ill can maintain their independence for as long as possible.

Funding: The Robert Wood Johnson Foundation: Start-up grants of \$35,000 are being offered to local coalitions as well as on-going technical assistance to help communities organize and sustain their growth through local fundraising. Assistance provided to communities needing guidance in the grant application process.

Innovation: Interfaith volunteer caregiving model helping religious organizations, volunteer organizations, social service, and health agencies form effective coalitions that

provide non-medical volunteer services, care and companionship to individuals with long-term health conditions.

Contact:

Faith in Action

Wake Forest University School of Medicine

Medical Center Boulevard

Winston-Salem, NC 27157-1204

Phone: (877) 324-8411(toll-free) or (336) 716-0101 (local)

Email: info@FIAVolunteers.org

New Jersey Statewide Respite Care Program^{xx}

Since 1988, this statewide respite program has been serving families with adult members who have physical and mental impairments resulting from accidents, illness or the aging process, as well as families with members age 18 and above who are physically or developmentally disabled. Sponsor agencies administer the program on a county level in 21 sites across the state. Crisis and emergency respite are available in addition to routine respite care for caregivers. Services provided include: companions, homemaker/home health aides, medical or social adult day health services, temporary care in licensed medical facilities, camperships, private duty nursing service, alternate family care, and in-home caregiver education and support.

This program generally serves low-income care recipients and their caregivers who are ineligible for Medicaid. Applicants must have an income below \$1,590 per month (\$3,180 for couples) and liquid resources of less than \$40,000. Cost-sharing is assessed for individuals whose income exceeds the federal poverty level. There is a cap of \$3,000 per year on services for each case. The caps and cost-share requirements may be waived on a case-by-case basis. Out-of-home placements are limited to 21 days per year. An estimated 2,800 families receive respite services under this program each year.

Funding: The program is funded by State funds and casino revenues. For the State Fiscal Year 2000, an amount of \$7,000,000 was appropriated. Funding will extend until 2002.

Innovation: The program provides relief and support to uncompensated caregivers of a broad population including younger and older adults with a range of physical and mental disabilities. It leverages most of its funding from State casino revenues.

Contact:

Peri L. Nearon, Administrator
 Statewide Respite Care Program
 Division of Senior Affairs
 PO Box 807
 Trenton, NJ 08625
 Phone: (609) 943-3466
 Email: pnearon@aol.com
 Web: <http://www.state.nj.us/health/senior/benefits/health.htm> - respitcare

Oregon Lifespan Respite^{xxi}

The nation's first statewide system to provide relief to families providing 24-hour care to loved ones at home, this network of community-based organizations serves families and caregivers of persons with any disability: any chronic or terminal physical, emotional or mental health condition requiring ongoing care and/or supervision. This non-categorical program serves persons with no eligibility criteria by diagnosis, age or income.

The four major program components include: information and referral; recruitment and training of providers; access to local respite resources; and formation of community coalitions. Each county has a local phone number where individuals seeking respite care may call to obtain a referral to a trained provider who has undergone a criminal background check. To date, the Lifespan Respite model has been replicated in Wisconsin, Nebraska, and Oklahoma.

Funding: Funded by State General Funds and community partners, the Governor has proposed \$1.2 million for the program during the two-year fiscal period beginning July 1, 2001.

Innovation: It is the only statewide program with no eligibility criteria based on disability, income, or age. This program promotes access to respite by providing a single point of contact where families and caregivers are assisted in finding trained respite providers; by building on the strengths of existing local networks; and by utilizing multiple sources of funding which are population-specific to supplement network capacity.

Contact:

Debbie Bowers, Respite Care Administrator
 Oregon Department of Human Services
 500 Summer Street NE E25
 Salem, OR 97301-1098
 Phone: (503) 945-6815
 Fax: (503) 945-7029
 Email: debbie.bowers@state.or.us
 Web: <http://cpt.hr.state.or.us/respite/welcome.html>

SUPPLEMENTAL SERVICES

Cooperative Caring Network^{xxii}

This program is an intergenerational, regional service credit program that encourages people who receive help to serve others as well. Volunteers receive an exchangeable “service credit” for each hour of service they provide, which they can then use for their own future needs. The program offers older persons assistance with daily living tasks through transportation, friendly visiting, help with yard work or chores, assistance with paperwork, and telephone reassurance.

This program was maintained for six years. However, when the funding ended in 1997, the program was no longer sustainable. It is now no longer in existence.

Funding: The Morris and Gwendolyn Cafritz Foundation, Robert Wood Johnson Foundation, The Pew Charitable Trusts, Public Welfare Foundation

Innovation: This program is built on a principle of reciprocal exchange, where through engaging in volunteer activities, existing community and intergenerational relationships are fostered and enhanced to support care recipients. As a result, the demands on caregivers are reduced.

Contact:

Farrell Didio
United Seniors Health Cooperative
409 Third Street, S.W. #300
Washington, DC 20024
Phone: (202) 479-6692
Email: fdidio@erols.com

Friends for Life^{xxiii}

Friends for Life is a charity that assists the elderly and people with disabilities through legal guardianship, money management, adult day care, and by organizing volunteers who help them live independently. The charity is a registered professional Guardianship agency offering guardianship to incapacitated people in twelve counties in Central Texas. In this capacity the charity insures that each client has a safe place to live, medical care, food, clothes and someone to care for them. As part of the Interfaith Volunteer Caregivers initiative, Friends for Life offers a broad range of volunteer services; last year, 3,442 volunteers gave 38,693 hours assisting 8,403 elderly or disabled people. The program provides: assistance with money management, friendly visits, telephone reassurance, transportation, shopping assistance, errands, respite care, and household repairs and yard work.

The charity is currently building an intergenerational center that will house its adult day care center, a childcare center, intergenerational programs (including music, art, model

trains, exercise, reading and gardening). It will provide significant, unique opportunities for interactions and caregiving between the older adults and the children. The intergenerational vision includes involvement of church youth and senior groups, scouting groups, Boys & Girls Club, nursing homes, retirement centers, senior apartments, day care centers, schools (elementary, junior high, high school and college), and our homebound elderly.

Funding: Robert Wood Johnson Foundation

Innovation: This program offers volunteers the opportunity to choose from an array of support services such as shopping, cooking, accompanying someone to a doctor's appointment, mowing lawns, building wheelchair ramps, or light household repair. When appropriate, clients are given the opportunity to volunteer.

Contact:

Inez Russell

Friends for Life

P.O. Box 23491

Waco, TX 76702-3491

Phone: (254) 772-7600

Fax: (254) 772-3900

Web: <http://friendsforlifeonline.org>

Home Safety Assessment Program^{xxiv}

This program uses a professional care manager who goes into the home to evaluate the safety of the home environment for someone who is being cared for at home. Accidents in the home with older persons, and especially with persons with dementia, are especially stressful for the safety and security of their relatives. Moreover, unsafe home environments can result in premature institutionalization. The program provides: (1) an individualized and customized assessment and care plan for the caregiver; (2) information about available resources and home safety issues; (3) connections to agencies that can assist with any needed home and environmental modifications; (4) some home safety devices at no charge.

Funding: Pfizer, Inc.

Innovation: This program offers home safety evaluations to caregivers, which may help decrease levels of stress and prevent care recipient institutionalization. Issues of access are addressed by this program's use of home visits by care managers who promote caregiver linkages to other appropriate community providers.

Contact:

Susan Alexman
Jewish Family Service of Los Angeles
5700 Wilshire Boulevard
Los Angeles, CA 90036
Phone: (323) 851-8202

Lifetime Support^{xxv}

This program is designed for caregivers of developmentally disabled adults, particularly elderly parents, who have concerns about who will care for their child when they are no longer able to do so. The program offers guardianship, representative payeeship, financial planning, care planning, advocacy, information and referral, a community trust, and visitation.

Funding: Various Foundations, Grants and Fees

Innovation: This program uniquely targets elderly caregivers of developmentally disabled adults to address their concerns about their loved one's future care.

Contact:

Barbara Repetti
Lifetime Support Incorporated
1225 South Avenue
Plainfield, NJ 07062
Phone: (908) 754-5910
Fax: (908) 754-6817
Email: info@arcunion.org
Web: www.arcunion.org/lifetime.html

MULTI-COMPONENT SERVICES

Caregivers and Professionals Partnership (CAPP)^{xxvi}

This multi-faceted, interdisciplinary program was created with the express purpose of strengthening Mount Sinai Hospital and affiliate institutions' responsiveness to the needs of family caregivers of adults. Caregivers and Professional Partnership (CAPP) has three major programmatic components: 1) the CAPP caregiver resource center which provides centralized, accessible information and support to caregivers of adult patients through telephone assistance, a resource library, and website; (2) a performance improvement initiative to increase institutional responsiveness to caregiver issues; and (3) an education program for staff and caregivers to (a) enhance caregivers' ability to manage caring for family members and (b) promote staff sensitivity and training to improve hospital-wide practice with family caregivers.

CAPP's caregiver resource center offers caregivers and providers access to multiple databases, the internet, a fax machine, and a wide range of resources and information. All caregivers who contact the center receive a follow-up phone call. All contacts are recorded in a database and staff has been able to use this information to identify gaps in services, such as Spanish-speaking and bereavement support groups.

CAPP serves family caregivers of adults in the New York Metropolitan area and their health care providers.

Funding: United Hospital Fund Family Caregiving Initiative, The James N. Jarvie Commonwealth Service, The American Express Foundation, and individual donors.

Innovation: Caregivers work closely with a multi-disciplinary team of staff members to oversee and implement CAPP. Caregivers are represented on the Steering Committee, the CAPP Caregiver Resource Advisory Committee, and also function as educators and ad hoc consultants to the program. Services are provided to both consumers and employees of Mount Sinai Hospital.

Contact:

Judy Dobrof, DSW
 Assistant Director
 The Mount Sinai Hospital
 Box 1252
 One Gustave Levy Place
 New York, NY 10029-6574
 Phone: (212) 659-8998

The Club^{xxvii}

The Club serves older persons in early stages of dementia and their caregivers. The Club offers a 3-day a week socialization and recreation program to help elders in the early-stages of dementia with mild to moderate cognitive loss maintain participation at the highest level possible. The Club provides caregivers with education, information, training, support groups, and lecture series about early-stage dementia and the disease process. Furthermore, homebound or working caregivers have access to an on-line server for information and advice.

Funding: Grotta Foundation

Innovation: An early-stage intervention providing socialization and support group for patients and caregivers.

Contact:

Frederick Jenny
Senior Care & Activities Center
46 Park Street
Montclair, NJ 07042
Phone: (973) 783-5589

El Portal^{xxviii}

El Portal offers culturally responsive services to address the multiple barriers that may hinder Latino/Hispanic families from accessing needed services for caregivers of older persons with dementia. By partnering with existing provider networks, El Portal overcomes barriers from differences in language, cultural values or beliefs, or lack of knowledge about appropriate formal and informal support networks. El Portal provides multiple services to caregivers of the Latino/Hispanic community, including a Spanish language telephone help line; respite subsidies for in-home and day respite; scholarships or enrollment in the safe return wanderers registry; linkage to a network of subcontracting agencies that deliver culturally appropriate services; support groups; and direct care providers.

Funding: Everhealth Foundation; Guenther Foundation

Innovation: Provides a culturally sensitive program which promotes and utilizes input from clients and caregivers in the community.

Contact:

Rosa Ramirez
Alzheimer's Association of Los Angeles
5900 Wilshire Boulevard, Suite 1700
Los Angeles, CA 90036
Phone: (323) 938-3379

Family Caregiver Alliance^{xxix}

Family Caregiver Alliance is a non-profit organization that serves as the model for California's statewide system of Caregiver Resource Centers (CRCs). This single-entry network of 11 regional CRCs offers a broad range of services to caregivers of adults with cognitive impairments including: information, advice, and referral; assessment of caregiver needs; long-term care planning and consultation; legal and financial consultation; mental health interventions such as counseling, support groups and psycho-educational groups; education and training programs; and respite care services. The CRCs use a consumer-directed care model, offering a flexible array of services to predominantly middle income families who are ineligible for other public benefits and cannot afford to pay for services out-of-pocket. FCA operates in the Bay Area CRC.

In order to address some of the barriers to access confronted by caregivers, Family Caregiver Alliance recently created Link2Care, an internet program providing online information, services and connections to caregiving families on demand within an existing community-based long-term care service system.

Family Caregiver Alliance also houses the Statewide Resources Consultant (SRC), contracted by the State of California to operate a statewide information clearinghouse on caregiving and brain disorders; conduct education, training and applied research; carry out program and policy development; maintain a statewide database on clients served; and provide technical assistance to the CRC sites.

Funding: The CRC and SRC are administered by the California Department of Mental Health and are funded by State General Funds and client contributions. Link2Care is funded by a grant from The California Endowment. The National Center on Caregiving is funded by the Archstone Foundation.

Innovation: Offers a broad range and an array of flexible and consumer-directed services to caregivers of persons with adult onset brain impairment. Services are targeted to reach middle income families who are not eligible for other public benefits but who can neither afford to privately pay for services.

Contact:

Kathleen Kelly, Executive Director
 Family Caregiver Alliance
 690 Market Street Suite 600
 San Francisco, CA 94104
 Phone: (415) 434-3388 or (800) 445-8106
 Fax: (415) 434-3508
 Email: info@caregiver.org
 Web: www.caregiver.org

Jersey Assistance For Community Caregiving^{xxx}

The Jersey Assistance For Community Caregivers provides a multitude of in-home services for persons who would otherwise not be able to remain in their residences. Though the primary client is the senior, it is believed that by strengthening the elder person's supports, the caregiver's capacity is bolstered. To be eligible, individuals must be over 60; financially ineligible for Medicaid or Medicaid waiver services; have no alternate means to acquire services; and be determined clinically eligible for nursing facility care. By contracting with vendors to provide services, seniors and their caregivers are offered such services as care management, respite care, homemaker services, environmental accessibility modifications, caregiver/recipient training, special medical equipment and supplies, transportation, chore services, and attendant care. The program is funded entirely through state money. Participants (the seniors) have a sliding scale co-pay obligation based on their countable income. Disenrollment from the program occurs when the participant has countable income at 365% of the poverty level. Service limits are \$600 per month, \$7,200 annually.

Funding: State funds

Innovation: Multi-component services offered to caregivers and recipients through state funding, targeting those who are income ineligible for federal support but not financially able to secure needed resources on their own. Opportunity for clients to hire and direct their own caregiver, using a consumer-directed approach.

Contact:

Cheryl S. MacDougall
Supervisor, In-Home Services
Office of Waiver and Program Administration
Division of Consumer Support
P.O. Box 722
Trenton, NJ 08625-0722
Phone: (609) 588-7631
Email: Cheryl.MacDougall@doh.state.nj.us

Pennsylvania Family Caregiver Support Program^{xxxi}

Pennsylvania has provided a statewide system of caregiver services since 1990. The program is administered by the Department of Aging, through the 52 Area Agencies on Aging. The program serves adult primary caregivers of functionally dependent adults age 60 and older, family caregivers of age 18-59 care recipients with dementia, and age 60 and older relatives living with and caring for children age 18 and younger. Caregivers must be low income – at or below 380% of poverty, but nobody is financially ineligible to participate in the program.

The range of services, provided to all enrolled in the program if they so choose, includes: specialized information and referral; assessment of need; family consultation/care

planning; care management; legal consultation; respite care; home modification/repair; emergency response; support groups; caregiver education and training; counseling; and financial help to purchase durable goods and related supplies .

Funding: State General Funds; NFCSP Federal Funds

Innovation: Offers a consumer-driven model of service which allows for more options for respite care and a monthly allowance for service reimbursement (up to \$200/month), and a “lifetime grant” of \$2,000 which may be used for home modifications and assistive devices.

Contact:

Joan Dougherty
 Pennsylvania Department of Aging
 555 Walnut Street, 5th Floor
 Harrisburg, PA 17101-1919
 Phone: (717) 783-6207
 Fax: (717) 783-6842
 Email: jdougherty@state.pa.us
 Web: www.state.pa.us/PA_Exec/Aging

Wisconsin’s Community Options Program^{xxxii}

Wisconsin’s Community Options Program (COP) provides funding for people over the Medicaid eligibility limit for assessment, care planning, and other support services with the goal of allowing people with disabilities to remain in their homes and out of nursing homes. Family caregivers are offered a full-range of support services through the eligibility of the elder. There are no “disallowed” services (except new building construction) and no per client expenditure caps or service maximums, as long as the county and state stay within the allowable average, meet the needs identified at assessment, include a care plan, and are cost effective. COP employs a mix of funding sources. Medicaid-eligible clients receive waiver-covered services first, but may use state money to cover additional services in the care plan. Examples of services offered to participants are: information and referral; needs assessment; consultation and care planning; care management; legal consultation; respite care; home modifications/repairs; emergency response; support groups; caregiver education and training; and counseling.

Funding: State General Funds; State Waiver Match; Community Aids Fund; Title XIX Medicaid; Targeted Case Management - Federal

Innovation: Caregivers receive a wide range of services simply for being involved in the care of the elder and benefits by having time for him/herself and peace of mind. The program has flexible funding and there are no restrictions with the Community Options money, allowing COP to offer services to meet individual needs and situations.

Contact:

Judy Zitske, COP Coordinator
Wisconsin Department of Health and Family Services
Bureau of Aging and Long Term Care Resources
1 W. Wilson, Rm. 450
P.O. Box 7851
Madison, WI 53707
Phone: (608) 267-9719
Fax: (608) 267-3203

NATIONAL RESOURCES

AARP (formerly known as the American Association of Retired Persons)

AARP is a nonprofit, nonpartisan membership organization for people 50 and over. Originally founded in 1958, AARP currently represents more than 34 million members. AARP provides information and resources; advocates on legislative, consumer, and legal issues; assists members to serve their communities; and offers a wide range of unique benefits, special products, and services.

Many of AARPs' resource materials are specific to caregivers. Numerous fact sheets are available on the AARP Web site covering a broad range of topics such as: stress management; planning for the care of older parents; help to long-distance caregivers; tips for involving others in caregiving; how to provide hands-on care for a loved one; how to communicate with health professionals; and how to balance work and caregiving responsibilities.

Contact:

AARP
601 E Street, NW
Washington, DC 20049
Phone: (800) 424-3410 or (202) 434-2277
Web: www.aarp.org
Email: member@aarp.org

Alzheimer's Association

The Alzheimer's Association, a national network of chapters, is the largest national voluntary health organization committed to finding a cure for Alzheimer's and helping those affected by the disease. The Association ranks as the top private funder of research into the causes, treatments, prevention, and cure of Alzheimer's disease. The Association also provides education and support for people diagnosed with the condition, their families, and caregivers.

Contact:

Alzheimer's Association
919 North Michigan Ave. Suite 1100
Chicago, Illinois 60611-1676
Phone: (800) 272-3900 or (312) 335-8700
Fax: (312) 335-1110
Web: www.alz.org

ARCH National Respite Network and Resource Center

The mission of the ARCH National Respite Network and Resource Center is to assist and promote the development of quality respite and crisis care programs, to help families

locate respite and crisis care services in their communities and to serve as a strong voice for respite in all forums.

ARCH provides training and technical assistance; develops relevant materials in print and electronic media; sponsors the annual Networking Institute on Crisis and Respite Care; operates the National Respite Locator Service; facilitates communication and networking among and between families, social service organizations and programs nationwide; and collects and disseminates information on respite and family support.

The National Respite Locator service helps parents, caregivers, and professionals find respite services in their state and local area. The service is also useful when a family travels or must move to another state.

Contact:

ARCH National Respite Network
800 Eastowne Drive, Suite 105
Chapel Hill, NC 27514
Phone: (800) 604-9655
Fax: (919) 490-4905
Web: www.archrespite.org

BenefitsCheckUp

The National Council on the Aging created this service that identifies federal and state assistance programs for older Americans. After entering simple information, such as age, income and zip code, BenefitsCheckUp explains what benefit programs the inquirer may be eligible for and how to apply for them. The whole process takes less than 15 minutes and is completely confidential; as such, it does not require the user's name, address, phone number, Social Security number, or other information that could be used to identify them.

Contact:

National Council on the Aging
Web: www.benefitscheckup.org

Children of Aging Parents(CAPS)

CAPS is non-profit, charitable organization providing information, referrals, support and resources on caregiving issues. Its mission is to assist caregivers of the elderly and to heighten public awareness that the health of the family caregivers is essential to ensure quality care of the nation's growing elderly population. Currently, CAPS averages about 10,000 requests for assistance each year. CAPS provides educational outreach, supports the development of caregiver support groups, hosts a speaker's bureau and, in partnership with The Caregivers Advisory Panel (TCAP) conducts market research designed to convey the needs and opinions of caregivers to health care product manufacturers, service providers and policy makers.

CAPS is a member of Independent Charities of America.

Contact:

Eldercare

Help Line: (800) 227-7294

Web: www.caps4caregivers.org

National Alliance for Caregiving (NAC)

The National Alliance for Caregiving is a non-profit joint venture, created in 1996 as a coalition to support family caregivers and the professionals who serve them. NAC has 25 members in its coalition, including founding members AARP, American Society on Aging, the Department of Veterans Affairs, Glaxo Wellcome, N4A, National Council on the Aging, and 19 other organizations. The alliance conducts research, develops national projects to reach out to family caregivers, and works to increase awareness of caregiving issues.

The Axa Foundation sponsors the NAC Family Care Resource Connection. This Internet clearinghouse lists professionally rated resources for caregivers. Available resources address topics such as: medical conditions; hands-on skills for caregivers; legal and financial information; coping with caregiving; and community resources.

Contact:

National Alliance for Caregiving

4720 Montgomery Lane, Suite 642

Bethesda, MD 20814

Web: www.caregiving.org

Email: gailhunt.nac@erols.com

National Center on Caregiving(NCC)

A project of Family Caregiver Alliance, the National Center on Caregiving is a central source of information and technical assistance on caregiving and long-term care for policy makers, families, health and service providers, media, program developers and funders. Launched in July of 2001 and funded by the Archstone Foundation, the Center's objectives are to develop and disseminate information about best practices at the state and

national levels; to provide technical assistance to policy makers, business/foundation leaders and program developers on innovative caregiver support programs; to deliver high quality consumer information to caregivers; and to provide quality information for media seeking to cover caregiver issues.

Contact:

National Center on Caregiving

Phone: (800) 445-8106 or (415) 434-3388

Web: www.caregiver.org

Email: info@caregiver.org

National Family Caregivers Association (NFCA)

The National Family Caregivers Association, incorporated in 1993, is a grassroots organization dedicated to supporting and improving the lives of America's family caregivers. NFCA was created to educate support, empower and advocate for the millions of Americans who care for their ill, aged or disabled loved ones. NFCA is the only constituency organization that reaches across the boundaries of different diagnoses, different relationships and different life stages to address the common needs and concerns of all family caregivers.

Contact:

Web: www.nfcacares.org

REFERENCES

- i Feinberg, L., & Pilisuk, T. (1999, October). Survey of Fifteen States' Caregiver Support Programs: Final Report. Family Caregiver Alliance.
- ii Administration on Aging [On-line]. Available: <http://aoa.gov/elerpage/locator.html>
- iii Gutheil, I., & Chernesky, R. Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models.
- iv Caregiver Assistance Network Home Page [On-line]. Available: <http://www.cssdoorway.org/can/>
- v Family Caregiver Self-Awareness Project Program Description [On-line]. Available: <http://www.nfcacares.org/CIPdesc.html>
- vi Georgia Mobile Day Care Program Description. Georgia Department of Human Resources, Division of Aging Services.
- vii Gutheil, I., & Chernesky, R. Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models.
- viii New Jersey Division of Senior Affairs. NJ EASE Fact Sheet [On-line]. Available: <http://www.state.nj.us/health/senior/sanjease.htm>
- ix Gutheil, I., & Chernesky, R. Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models.
- x Gutheil, I., & Chernesky, R. Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models.
- xi Gutheil, I., & Chernesky, R. Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models.
- xii Gutheil, I., & Chernesky, R. Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models.
- xiii Gutheil, I., & Chernesky, R. Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models.
- xiv Gutheil, I., & Chernesky, R. Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models.

-
- xv Gutheil, I., & Chernesky, R. Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models.
- xvi Gutheil, I., & Chernesky, R. Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models.
- xvii Gutheil, I., & Chernesky, R. Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models.
- xviii The Peter F. Drucker Foundation for Nonprofit Management [On-line]. Available: http://www.pfdf.org/innovation/innovation/innovation.asp?innov_id=98
- xix About Faith in Action, a Robert Wood Johnson Foundation Program [On-line]. Available: <http://www.fiavolunteers.org/about/index.htm>
- xx Statewide Respite Care Program, State of New Jersey, Department of Health and Senior Services [On-line]. Available: <http://www.state.nj.us/health>
- xxi Oregon Department of Human Services News Release [On-line]. Available: <http://www.hr.state.or.us/news/2001news/2001-0521.html>
- xxii Gutheil, I., & Chernesky, R. Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models.
- xxiii Gutheil, I., & Chernesky, R. Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models.
- xxiv Gutheil, I., & Chernesky, R. Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models.
- xxv Gutheil, I., & Chernesky, R. Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models.
- xxvi Caregivers and Professionals Partnership (CAPP) fact sheet. Mt. Sinai Hospital [On-line]. Available: <http://www.mssm.edu/capp/index.shtml>
- xxvii Gutheil, I., & Chernesky, R. Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models.
- xxviii Gutheil, I., & Chernesky, R. Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models.
- xxix Feinberg, L., & Pilisuk, T. Survey of Fifteen States' Caregiver Support Programs: Final Report. October 1999 Family Caregiver Alliance [On-line]. Available: <http://www.caregiver.org>

^{xxx} New Jersey Department of Health & Senior Services, Division of Consumer Support [On-line]. Available: <http://www.state.nj.us/health/consumer/jacc.htm>

^{xxxi} Pennsylvania Department of Aging [On-line]. Available: http://sites.state.pa.us/PA_Exec/Aging/srih-ncs.html

^{xxxii} Feinberg, L., & Pilisuk, T. (1999, October). Survey of Fifteen States' Caregiver Support Programs: Final Report. Family Caregiver Alliance.

PROGRAM DIRECTORY

A = Access; C = Counseling, education, & training; I = Information; M = Multi-component; R = Respite; S = Supplemental

Alzheimer's Disease Knowledge Building Program (C)

Daniel Kuhn, MSW, Director of Education
Mather Institute on Aging, Mather LifeWays
1603 Orrington Avenue, Suite 1800
Evanston, IL 60201
Phone: (847) 492-6813
Email: dkuhn@matherlifeways.com

As Families Grow Older (C)

Cathy Michaelson Lieblch
Winter Park Health Foundation
Miller Center for Older Adult Services
2010 Mizell Avenue
Winter Park, FL 32792
Phone: (407) 629-5771 x 2227
Fax: (407) 647-4028
Email: clieblch@wphf.org

ASPECT-A Support Program for the Elderly (and their caregivers) during Crisis Times (C)

Fred DeLong, Ph.D.
The Lincoln Center for Family and Youth
201 Union Avenue
Bridgeport, PA 19405
Phone: (610) 277-3715 x 243
Email: fdelong@thelincolncenter.com

At Home with the A.R.T.S. (Alzheimer Recreation Therapy Services) (C)

Laura Holly Dierbach
Alzheimer's Association, Greater New Jersey Chapter
400 Morris Avenue #251
Phone: (973) 586-4300
Email: laura.dierbach@alz.org

Camp for Caring (R)

Jennifer Hull, Senior Program Associate
Family Caregiver Alliance
690 Market Street Suite 600
San Francisco, California 94104
Phone: (800) 445-8106 or (415) 434-3388
Fax: (415) 434-3508
Email: jhull@caregiver.org
info@caregiver.org
Web: www.caregiver.org

Care Choice Ohio (I)

Sheri Kiser
Ohio Department Of Aging
50 West Broad Street, 9th Floor
Columbus, OH 43215
Phone: (614) 644-5455
Fax: (614) 466-5741

Caregiver Assistance Network (A)

The Caregiver Assistance Network
100 East Eighth Street, 6th Floor
Cincinnati, OH 45202
Phone: (513) 929-4483
Fax: (513) 241-4333
Web: www.archdiocese-cinti.org/carenetw
Email: cssfamily@queencity.com

Caregiver Tip Cards (C)

Stacy Barnes
Wisconsin Geriatric Education Center
Marquette University
P.O. Box 1881
Milwaukee, WI 53201
Phone: (414) 288-3712 or (800) 799-7878
Email: wgecnet@marquette.edu

Caregivers and Professionals

Partnership (CAPP) (M)

Judy Dobrof, DSW
Assistant Director
The Mount Sinai Hospital
Box 1252
One Gustave Levy Place
New York, NY 10029-6574
Phone: (212) 659-8998
Email: judy.dobrof@mountsinai.org

Caregivers Retreat (R)

Jennifer Hull, Senior Program Associate
Family Caregiver Alliance
690 Market Street Suite 600
San Francisco, California 94104
Phone: (800) 445-8106
(415) 434-3388
Fax: (415) 434-3508
Email: jhull@caregiver.org
info@caregiver.org
Web: www.caregiver.org

The Club (M)

Frederick Jenny
Senior Care & Activities Center
46 Park Street
Montclair, NJ 07042
Phone: (973) 783-5589
Email: scac@mail.com

Cooperative Caring Network (S)

Farrell Didio
United Seniors Health Cooperative
409 Third Street, S.W. #300
Washington, DC 20024
Phone: (202) 479-6692
Email: fdidio@erols.com

Eldercare in the Workplace (C)

Rick Greene
New Jersey Department of Health and
Senior Services
P.O. Box 807
Trenton, NJ 08625
Phone: (609) 588-3169

Eldercare Locator (I)

Eldercare Locator, Joanne Balkovich
Phone: (800) 677-1116
TDD/TTY: (202) 855-1234
Fax: (202) 296-8134
Web: www.eldercare.gov

ElderServe at Night (R)

David V. Pomeranz
Executive Vice President
Hebrew Home for the Aged at Riverdale
5901 Palisade Ave
Bronx, NY 10471
Phone: (718) 581-1780
Fax: (718) 543-3681
Web: www.elderserve.org
Email: info@hebrewhome.org

El Portal (M)

Rosa Ramirez
Alzheimer's Association of Los Angeles
5900 Wilshire Boulevard Suite 1700
Los Angeles, CA 90036
Phone: (323) 938-3379
Fax: (323) 938-1036
Email: rosa.ramirez@alz.org

Faith in Action (R)

Sarah B. Cheney
Faith in Action
Wake Forest University School of
Medicine
Medical Center Boulevard
Winston-Salem, NC 27157-1204
Phone: (877) 324-8411 (toll-free)
(336) 716-0101 (local)
Email: info@FIAVolunteers.org
scheney@wfubmc.edu

Family Caregiver Alliance (M)

Kathleen Kelly, Executive Director
 Family Caregiver Alliance
 690 Market Street Suite 600
 San Francisco, CA 94104
 Phone: (800) 445-8106
 (415) 434-3388
 Fax: (415) 434-3508
 Email: info@caregiver.org
 Web: www.caregiver.org

Family Caregiver Self-Awareness Project (A)

Melanie Kinney Hoffmann
 National Family Caregivers Association
 Phone: (301) 972-6430
 Web: www.nfcacares.org
 Email: info@nfcacares.org

Friends for Life (S)

Inez Russell
 Friends for Life
 P.O. Box 23491
 Waco, TX 76702-3491
 Phone: (254) 772-7600
 Fax: (254) 772-3900
 Web: <http://friendsforlifeonline.org>
 Email: inez@texasinternet.com

Georgia Mobile Day Care Program (A)

Cliff Burt
 Aging Services Coordinator
 Georgia Department of Resources
 Division of Aging Services
 Two Peachtree Street, NW
 Suite 9-470
 Atlanta, Georgia 30303-3142
 Phone: (404) 657-5336
 Email: gcburt@dhr.state.ga.us

Home Safety Assessment Program (S)

*This program is no longer in service;
 Susan Alexman may be contacted for
 more information*
 Susan Alexman
 Jewish Family Service of Los Angeles
 5700 Wilshire Boulevard
 Los Angeles, CA 90036
 Phone: (323) 851-8202
 Fax: (323) 876-6140

Jersey Assistance For Community Caregivers (M)

Cheryl S. MacDougall
 Supervisor, In-Home Services
 Office of Waiver and Program
 Administration
 Division of Consumer Support
 P.O. Box 722
 Trenton, NJ 08625-0722
 Phone: (609) 588-7631
 Email: Cheryl.MacDougall@doh.state.nj.us

Lifetime Support (S)

Barbara Repetti
 Lifetime Support Incorporated
 1225 South Avenue
 Plainfield, NJ 07062
 Phone: (908) 754-7052
 Fax: (908) 754-6817
 Web: www.arcunion.org/lifetime.html
 Email: info@arcunion.org

Long Distance Caregiver Project (I)

Judith Delaney
 Alzheimer's Association of LA
 5900 Wilshire Boulevard
 Los Angeles, CA 90036
 Phone: (323) 930-6251
 Fax: (323) 938-1036

The Milwaukee Community Service Bank (A)

Phyllis Blackburn
St. Ann's Center for Intergenerational Care
2801 E. Morgan Avenue
Milwaukee, WI 53207
Phone: (414) 977-5013
Fax: (414) 977-5050

New Jersey Easy Access, Single Entry (NJ EASE) (A)

Barbara Fuller, Supervisor
NJ Division of Senior Affairs
PO Box 807
Trenton, NJ 08625-0807
Phone: (609) 943-3463
NJ EASE: (877) 222-3737
Fax: (609) 943-3467
Email: barbara.fuller@doh.state.nj.us
Web:
www.state.nj.us/health/senior/sanjease.htm

New Jersey Statewide Respite Care Program (R)

Peri L. Nearon, Administrator
Statewide Respite Care Program
Division of Senior Affairs
PO Box 807
Trenton, NJ 08625
Phone: (609) 943-3466
Email: pnearon@aol.com
Web: www.state.nj.us/health

Oregon Lifespan Respite (R)

Debbie Bowers, Respite Care Administrator
Oregon Department of Human Services
500 Summer Street NE E25
Salem, OR 97301-1098
Phone: (503) 945-6815
Fax: (503) 945-7029
Email: debbie.bowers@state.or.us
Web: www.hr.state.or.us/respite

Pennsylvania Family Caregiver Support Program (M)

Joan Dougherty
Pennsylvania Department of Aging
555 Walnut Street, 5th Floor
Harrisburg, PA 17101-1919
Phone: (717) 783-6207
Fax: (717) 783-6842
Email: jdougherty@state.pa.us
Web: www.state.pa.us/PA_Exec/Aging

S.O.S. (Speaking of Seniors) (C)

Lynn Hanson
Main St. Counseling Center
8 Marcella Avenue
West Orange, NJ 07052
Phone: (973) 736-2041

Wisconsin's Community Options Program (M)

Judy Zitske, COP Coordinator
Wisconsin Department of Health and Family Services
Bureau of Aging and Long Term Care Resources
1 W. Wilson, Rm. 450
P.O. Box 7851
Madison, WI 53707
Phone: (608) 267-9719
Fax: (608) 267-3203
Email: zitskjb@dhfs.state.wi.us

NATIONAL RESOURCES

AARP

601 E Street, NW
Washington, DC 20049
Phone: (800) 424-3410
(202) 434-2277
Web: www.aarp.org
Email: member@aarp.org

Alzheimer's Association

919 North Michigan Ave. Suite 1100
Chicago, Illinois 60611-1676
Phone: (800) 272-3900
(312) 335-8700
Fax: (312) 335-1110
Web: www.alz.org

ARCH National Respite Network

800 Eastowne Drive, Suite 105
Chapel Hill, NC 27514
Phone: (800) 604-9655
Fax: (919) 490-4905
Web: www.archrespite.org

National Council on the Aging

Web: ww.benefitscheckup.orgEldercare
Help Line:(800) 227-7294
Web:www.caps4caregivers.org

National Alliance for Caregiving

4720 Montgomery Lane, Suite 642
Bethesda, MD 20814
Web: www.caregiving.org
Email: gailhunt.nac@erols.comNational

Center on Caregiving

Phone: (800) 445-8106
(415) 434-3388
Web: www.caregiver.org
Email: info@caregiver.org

National Family Caregivers Association (NFCA)

Web: www.nfcacares.org

