

Viewing the National Family Caregiver Support Program through The Family Impact Lens

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ABSTRACT. Families are the major provider of long-term care and support for the functionally dependent elderly. The provision of this care, however, can exact an emotional, physical, and financial toll. The National Family Caregiver Support Program (NFCSP), established in amending the Older American Act in 2000, provides grants to states and territories to fund a range of supports that assist families in caring for dependent elderly persons at home for as long as possible. A family impact analysis of NFCSP provides several lessons and implications for those who design, implement, and study family caregiving. An analysis of this legislation using the family impact lens provides evidence, albeit indirect, that support services funded under the NFCSP can reduce caregiver depression, anxiety, and stress and enables them to provide care longer, thereby avoiding or delaying the need for costly institutional care.

Keywords: family policy, family impact lens, family caregiving, National Family Caregiver Support Program

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Bogenschneider and colleagues recently challenged family professionals to “raise consciousness about... the family impact lens when laws are drafted, programs designed, and services implemented” (Bogenschneider et al., 2012, p. 516). The rationale undergirding this challenge was that decision makers do not have the time or resources to keep up to date on all the changes occurring in contemporary family life. When family professionals provide information

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based on an analysis using the family impact lens, decision makers can have more confidence in ensuring that their decisions strengthen and support family well-being across the lifespan (Bogenschneider & Corbett, 2010).

This paper responds to the challenge issued by Bogenschneider and colleagues by using the family impact lens to analyze the National Family Caregiver Support Program (NFCSP), a federally funded program created when the Older Americans Act was amended in 2000. The NFCSP is intended to help families in fulfilling the function caring for elderly persons who are frail and dependent. The value of such an analysis resides in one of the benefits of using the family impact lens; namely, when policies or programs are implemented, the analysis ascertains whether the intended family outcomes of legislated policy are realized in implementation and whether the services and supported are provided in a way that strengthens family functioning (Bogenschneider et al., 2012).

This analysis will be of particular interest to (a) policymakers involved in reauthorizing the Older Americans Act (which includes the NFCSP) and designing legislation to support families providing care for the frail and dependent elderly, (b) professionals working in the aging network and charged with establishing, providing, or overseeing services offered under the auspices of the National Family Caregiver Support Program, and (c) researchers and evaluators as they conceptualize studies, select measures, and examine the effectiveness of policies and programs that support family caregiving.

The paper is organized in five sections. The first serves as a preface by providing background information on (a) the centrality of family as a primary source of care and support for older persons who are frail and dependent, (b) the prevalence, composition, and economic value of family caregiving, and (c) a description of salient trends in family caregiving. The second section addresses federal policy supporting family caregiving, with a focus on the National Family Caregiver Support Program. The third section lists the family impact principles on which the analysis is predicated. The fourth section uses these principles to conduct a family impact analysis of the National Family Caregiver Support Program. The fifth and final section describes some of the lessons learned from the analysis, and discusses implications for the target audiences.

Background

The Centrality of Family in Eldercare

In commenting on family support of the elderly in later life, Fingerman, Miller and Seidel (2009) observe that “family members do not suddenly arise like a phoenix at the end of life with outstretched arms” (pg. 27). Instead, there are a variety of support and exchange patterns that characterize intergenerational family relations throughout the life course (Fingerman & Burditt, 2011). Although these patterns are complex and often difficult to identify in detail, a common theme discernible in research published over the past four decades is that families play a central role in caring for the dependent elderly. In the 1970s, for example, the classic Cleveland study

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conducted by the U.S. General Accounting Office found that families provided between 80-90% of household maintenance and other instrumental services on behalf of older persons (Comptroller General, 1977). Similarly, findings from the National Long-Term Care Surveys conducted between 1984 and 1999 revealed that two-thirds of care recipients rely entirely on their informal family caregivers (Spillman & Black, 2005). More recently, data collected in the 2009 wave of the national survey of caregivers indicates that family caregivers, particularly women, provide over 75% of caregiving support for persons age 50 or older (National Alliance for Caregiving, 2009a).

Based on two years of field work in Massachusetts, Bookman and Harrington (2007) found that families caring for the frail and dependent elderly often provide support that extends far beyond care rendered in the home. In what Bookman and Harrington characterize as an uncoordinated, fragmented, bureaucratic and sometimes depersonalized system of community health care services, that found that families perform a variety of “shadow workforce” functions, including acting as geriatric case managers, medical record keepers, service providers, and patient advocates; and this they do despite lack of training and education.

Prevalence, Composition, and Economic Value of Family Caregiving

Because of differences in defining caregivers and care recipients, estimates regarding the prevalence of family caregiving vary considerably (Family Caregiver Alliance, 2010). Most frequently mentioned in the current literature is that, at any given point in time, between 41 and 44 million Americans (approximately 1 in 5 adults) provide unpaid care for adults age 50 or older who have chronic illnesses and conditions that hinder the ability to perform activities of daily living (Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009). Of these family caregivers, 24% care for two individuals, and 10% care for three or more persons (National Alliance for Caregiving & AARP, 2009a).

Using estimates based on the National Alliance for Caregiving/AARP 2009 national survey of individuals caring for loved ones age 50 and older, a composite profile of caregivers can be drawn. In terms of gender and ethnicity, two-thirds of all informal family caregivers are female, and three-quarters are White; one in ten is Hispanic and another one in ten is African American; and two percent are Asian American (National Alliance for Caregiving and AARP, 2009b). In terms of age, family caregivers can be categorized into two groups: Younger and middle-aged persons providing care for a parent, parent-in-law, or grandparent, and comparatively older caregivers who provide support for a spouse, sibling, or non-relative friend (National Alliance for Caregiving and AARP, 2009a).

Based on replacement costs of paid services, the economic value of family caregivers' support of elderly loved ones (defined as any relative, partner, friend, or neighbor aged 18 and over) was estimated to be at least \$450 billion in 2009 (Feinberg, Reinhard, Houser, & Choula, 2011). Importantly, this figure does not include persons caring for older adults with chronic health conditions or disabilities, but who do not provide assistance with any activities of daily living (such as bathing or dressing) or instrumental activities of daily living (such as managing

medications or finances). Significantly, the amount of economic support contributed by families is more than total Medicaid spending in 2009, including both federal and state contributions for both health care and LTSS (\$361 billion), and nearly four times the Medicaid LTSS spending in 2009 (\$119 billion) (Eiken, Sredl, Burwell, & Gold, 2010; Kasten, Eiken, & Burwell, 2011). If government had to replace these caregiving functions that families provide, the costs would be astronomical. Government cannot afford to – nor would they want to – replace the contributions that family members make to the long-term care of their elderly loved ones (Bogenschneider, in press).

Trends in Family Caregiving

In partnership with AARP, the National Alliance for Caregiving has conducted three national surveys focusing on informal caregiving: the first in 1997, a second in 2003, and a third in 2009 (National Alliance for Caregiving and AARP, 2009a). Comparing the 2009 findings with those reported in 2003 reveals two trends worthy of note because they illustrate the continuing investment of families in eldercare. First, although there has been a decrease in the number of hours of care provided in a given week, a higher proportion of family caregivers (up from 50% in 2003 to 58% in 2009) report helping a loved one with activities of daily living, such as getting into and out of bed, assisting with housework, and preparing meals. Second, since 2003, the proportion of caregivers who simultaneously juggle work and caregiving has remained fairly constant at 75%, yet there has been an increase in the proportion of employed caregivers who indicate they have had to make workplace accommodations, such as having to work late, leave early, or take time off during the day to fulfill caregiving responsibilities (up from 58% in 2003 to 65% in 2009). The cost of caregiving to U.S. employers in 2004 was an estimated \$33.6 billion, or approximately \$2,110 per employed caregiver. In addition, employers are estimated to pay about 8% more in health care costs for employees with eldercare responsibilities to treat depression, diabetes, hypertension, pulmonary disease, and so forth (Feinberg et al., 2011).

Federal Policy Supporting Family Caregiving

Federal policy makers have enacted and implemented several important initiatives designed to support family caregivers and family members receiving care. Some of these initiatives were spawned by the U.S. Congress, whereas others were the product of advocacy efforts by leaders of federal agencies. The most significant direct care service initiatives have included the Lifespan Respite Care Act, the establishment of Aging and Disability Resource Centers, and the creation of the National Family Caregiver Support Program (Elmore & Talley, 2007). The focus of this paper is on the National Family Caregiver Support Program.

2000 Amendments to the Older Americans Act

The Older Americans Act (OAA) was signed into law in 1965, and represents a watershed moment in terms of services for older Americans and their families. Even after nearly

forty years, the OAA remains the primary means for delivering both nutritional and social services to older Americans. In 2000, amendments to the Older Americans Act created a new federal program entitled the National Family Caregiver Support Program (NFCSP). Administered by the Administration on Aging, the NFCSP (Title III-E of the OAA 2000 Reauthorization) represents the federal government's most significant recognition of and commitment to providing direct services to family caregivers.

Importantly, the NFCSP legislation was passed at a time when policy was moving in a direction emphasizing community-based in contrast to institutional care. Established by executive order, the federal government's New Freedom Initiative outlined a plan to assist states and local communities in responding to the U.S. Supreme Court's 1999 decision in *Olmstead v. L.C.*, wherein the Court ruled that states must provide community-based services rather than institutional settings for persons with disabilities who receive assistance in publicly funded programs (Teitlebaum, Burke, & Rosenbaum, 2004). The New Freedom Initiative identified the paucity of family support as a major barrier to community living for persons with disabilities, and underscored the need for greater assistance to informal caregivers (Feinberg & Newman, 2006; Teitelbaum, Burke, & Rosenbaum, 2004).

The National Family Caregiver Support Program

Based on the proportion of the population age 70 and over, the NFCSP provides grants to states and territories to fund a range of supportive services designed to help families and informal caregivers care for their loved ones at home and/or in the community for as long as possible. In order to receive federal funding, there is a 25% match from state and/or local sources. Working in collaboration with area agencies on aging and local service providers, the NFCSP calls for states to develop and implement multifaceted systems of support for family and informal caregivers. Federal NFCSP funds are not earmarked or targeted for any specific service. Rather, states are afforded wide latitude in determining the funding allocations for five service categories: (a) information to caregivers about available services; (b) assistance to caregivers in gaining access to supportive services; (c) individual counseling, support groups and caregiver training; (d) respite care; and (e) supplemental services (e.g., emergency response systems, home modifications) to complement the care provided by caregivers.

The initial appropriation by Congress was \$125 million for fiscal year 2001. For fiscal year 2009, NFCSP formula grants to the states totaled \$153 million, ranging from a high of almost \$15.5 million in California to a low of \$766,000 in twelve states (Alaska, Delaware, Hawaii, Idaho, Maine, Montana, New Hampshire, North Dakota, Rhode Island, South Dakota, Vermont, and Wyoming) and the District of Columbia.

Under the NFCSP, states use federal funds to offer direct support services to family caregivers of persons age 60 and older, and can also allocate up to 10% of their funding for support services addressing the needs of grandparents and relative caregivers of children age 18 and younger. Although there is no means test for service eligibility, states must give priority to

persons providing care to older individuals in the greatest social or economic need, with particular attention to low-income individuals and older relatives caring for children with developmental disabilities. Criteria regarding functional ability vary by type of service. For example, to be eligible for respite or supplemental services, individuals 60 years and older must have two or more limitations in activities of daily living or a documented cognitive impairment.

Output data indicate that the services caregivers received from NFCSP helped families manage caregiving responsibilities (Administration on Aging, 2011). For example, Access Assistance Services provided approximately 1.3 million contacts to caregivers, assisting them in locating services from a variety of private and voluntary agencies. Counseling and Training Services provided over 141,000 caregivers with counseling, peer support groups, and training to help them cope with the stresses associated with caregiving. Respite Care Services provided more than 73,000 caregivers with 9.8 million hours with temporary relief – at home, or in an adult day care or institutional setting – from their caregiving responsibilities.

An extensive evaluation of the NFCS was conducted in 2003 under the *State of the States* survey, which involved 150 caregiver support programs nationwide. The survey provided valuable profiles of publicly funded caregiver support programs in all 50 states and the District of Columbia (see Feinberg & Newman, 2006, Feinberg et al., 2004). In 2009, Giunta (2010) used data from *State of the States* survey, demographic data from the 2000 U.S. Census, historical records from Internet searches, and service utilization data from the U.S. Administration of Aging, to conduct a secondary analysis of the National Family Caregiver Support Program. Both the *State of the States* survey reported by Feinberg and colleagues, and the secondary analysis by Giunta, found considerable variability in services and service options available to caregivers across states, and even within states. This variability was partly a product of the different ways in which states frame caregiver services. Some states view caregiver support as an integral part of a system designed to support the frail elderly and/or adults with disabilities. Other states have approached the provision of supportive services for caregivers as a separate program with distinct criteria for eligibility.

But what is probably the most important finding in the aforementioned analyses is that NFCSP funding reached its goal of increasing supportive services for families who care for the frail and dependent elderly. Prior to the enactment of the NFCSP in 2000, only 32 states offered some support for family caregivers; often indirectly as part of state-funded Home and Community-Based Services (HCBS) programs. Very few offered direct services for caregiver support (e.g. California, New Jersey, Pennsylvania, and Wisconsin). As a result of NFCSP funding, however, ALL states now offer direct caregiver services, with one-third providing direct support to family caregivers *for the first time* (Feinberg & Newman, 2006).

Family Impact Analysis

This section of the paper analyzes the NFCSP using the family impact lens analysis initially described by Ooms and Preister (1988), and subsequently revised by the Family Impact

Institute (Bogenschneider, Little, Ooms, Benning, & Cadigan, 2012a; 2012b). The family impact analysis differs from an evaluation that examines whether or not the intended goals of a policy or program were met. The family impact analysis examines whether these goals or their implementation have advertent or inadvertent effects on family well-being. Family impact analysis is not intended to advocate for or against a policy or program, but rather to raise implications for stakeholders to consider (Bogenschneider, Little, Ooms, Benning & Cadigan (2012a).

Family impact analysis embodies five principles: family responsibility, family stability, family relationships, family diversity, and family engagement. Not all principles and questions apply to every topic, so as recommended by Bogenschneider and colleagues (2012a), the family impact principles most relevant to the NFCSP program are considered here: family responsibility, family diversity, and family engagement. Because it most closely maps with services offered under the National Family Caregiver Support Program, more attention is devoted to the principle of family responsibility than to diversity and engagement.

Family Impact Principle: Family Responsibility

The principle of family responsibility states that policies and programs should support and empower the functions that families perform for society—family formation, economic support, childbearing, and caregiving. The primary question guiding an analysis centered on this principle is: Does the program support and supplement family members' ability to carry out their responsibilities? This analysis examines who provides the care, what impacts there are for the caregiver, and how caregiving affects those who receive the care.

Beginning with who provides the care, much of the responsibility for married older persons who cannot perform activities of daily living falls on spouses, who are generally old themselves and trying to cope with their own health problems (Bookwala, 2012). Despite concern about the geographic dispersion of family generations in the United States, data from the Health and Retirement Study (HRS) indicate that almost 63% of frail older adults have at least one adult child living within 10 miles, and that more than half of frail elders who are *unmarried* receive help from daughters (Johnson & Wiener, 2006). Adult children, mostly women, who help aging parents are often employed outside the home, forcing them to juggle family responsibilities with work demands (AARP, 2013; National Alliance for Caregiving & AARP, 2009a).

Because it can be physically, emotionally, and financially demanding, providing help to older family members who are frail and dependent often poses challenges for both spousal and filial caregivers (Qualls & Zarit, 2009). Family caregivers—men and women as well as spouses and adult children—can also feel isolated from their friends and overwhelmed by their responsibilities, leading to high levels of stress, depression, and physical health problems (Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009). Although there are many qualifiers, the preponderance of evidence indicates that families caregivers generally derive benefit from community-based supports (Fortinsky, Tennen, Frank, & Affleck, 2007; Lantz, 2004; Pinquart & Sörensen, 2003; Salva, Almeida, Davey, & Zarit, 2008). Without this support, Robison et al.

(2009) emphasized that: “Caregivers who do not have the support they need from the community-based, formal long-term care system miss work and feel depressed and isolated, which may lead, in turn, to caregiver burnout and institutionalization of the care recipient” (Robison et al., 2009, pg. 795). In addition, data from the Fifth National Survey of Older American Act (OAA) Program Participants conducted in 2009 included reports from 1,793 caregivers who had received NFCSP services. More than four in ten, (41%) of these caregivers indicated that without the supportive services offered under the NFCSP, the elderly person receiving family support would not be able to co-reside in the same household, and almost one-third reported that the care recipient would be in a nursing home or assisted living facilities (Mathematica Policy Institute Issue Report, 2010)

Importantly, difficulties faced by caregiving families have the potential of reducing the amount (or diluting the quality) of care provided to frail elderly loved ones, as well as increasing the probability of institutionalization (Spillman & Long, 2009). According to national survey data recently collected by the Administration on Aging (2011), 77% of caregivers report that NFCSP services definitely enabled them to provide care longer than otherwise would have been possible, and 89% report that these services helped them to be a better family caregiver. Nearly half the caregivers of nursing home eligible care recipients indicated that the care recipient would be unable to remain at home without the support services. The following sections identify specific types of supportive services offered under the NFCSP, and describe research related to the extent to which each service category enables family caregivers to fulfill caregiving responsibilities.

Respite services. The purpose of respite programs is to periodically or temporarily relieve family caregivers from the continuous responsibility of providing day-to-day care for one or more elderly family members. The rest afforded by respite care gives family caregivers time to be alone, to carry out other activities, or respond to other obligations. In their comprehensive national survey of the NFCSP, Feinberg and Newman (2006) report that respite care is the most uniformly offered service for caregivers. In fact, some level of respite care for family caregivers is now provided by all 50 states and the District of Columbia. In 2008 respite care funded by NFCSP provided more than 73,000 caregivers with 9.8 million hours with temporary relief – at home, or in an adult day care or institutional setting—from their caregiving responsibilities (Administration on Aging, 2011). Overall there is evidence indicating that use of respite services alleviates caregiver burden, and enables families to continue providing care in the home and avoiding or delaying institutionalization (Shaw, et al., 2009; Spillman & Long, 2009; Whittier, Coon, & Aaker, 2002). Yet the research also indicates that the relation between respite services and family impacts varies depending on the health status of the care recipient, the type of respite provided, what benefits it provides for the caregiver, and when it is provided.

The family impact of respite care varies according to the health status of the care recipient. The need for and value of respite services resides in the fact that caring for an elderly loved one who is functionally dependent often requires continuous vigilance. Respite services are particularly helpful to families caring for elderly loved ones suffering from a dementia such

as Alzheimer's disease (Etters & Harrison, 2008), or for relatives who have experienced a stroke (Cameron & Gignac, 2008).

Family impact also depends on the type of respite care services being provided. One of the complicating factors in the research investigating the impacts of respite on caregiving families is that this service category is offered in a variety of forms: home help, day centers, and temporary institutionalization, including residential or night-time respite (Garcés, et al., 2009). The latter form of respite has been least studied, and its impact on families remains unclear. Most frequently investigated have been the effects of in-home respite. Caregivers who use in-home respite services report lower levels of stress, burden, anxiety and depression, fewer somatic illnesses, less anger, and more positive feelings (Hawranik, & Strain, 2000). The same appears to be true for families who utilize day centers.

The family impact of respite care also depends on what benefits this service provides to the caregiver. The problematic aspect of this research is that the link between use of respite as a category of supportive services for caregiving families and outcomes is complex. As an illustration of this complexity, Garcés, et al (2009) observe that the use of formal respite services has been linked in some studies to higher levels of caregiver tension and depression and more family conflict as a result of disagreements about the use of respite services. When comparing family caregivers who used respite services over a period of 3 months with those who did not, Zarit (1996) found that there was a significant decrease in caregiver burden, but that primary stressors such as role captivity (i.e. restrictions in social activity) did not change.

Finally, the timing of respite care also has proven to be critical (Zarit, 2001). For example, Knight and colleagues (1993) reported that the use of respite care had only a moderate effect on caregiver burden. They propose that one reason for this finding was that the usefulness of respite services is greatest when used *before* the stresses of caregiving accumulate and precipitate a crisis. Family caregivers who wait too long before accessing respite care and utilize it only when the older family member is in an advanced stage of a progressive illness may not benefit as much as those who seek it early in the trajectory of caregiving. Like other community-based services for caregivers, the benefit of respite care is likely to be greatest when used to prevent the depletion of a caregiver's resources and collapse of capacity instead of being used as an emergency response once a caregiver's capacity has been exhausted. Perhaps this is an explanation for why the results of early intervention to support family caregivers have been shown to result in greater alleviation of the negative outcomes of caregiving (Lyons & Zarit, 1999).

Although respite care is the only NFCSP support service uniformly offered by all states under the NFCSP, other services related to family caregiving needs and responsibilities are offered by many states. These services include providing information and assistance in gaining access to services, care management, education and training, support groups, and family consultations (Feinberg & Newman, 2006). While it is difficult to find studies investigating the impact of these services in the context support from the NFCSP, there is research indicating that

some of the types of services offered under NFCSP are helpful to caregiving families. Several of these services are discussed below.

Counseling, support groups, and training. Psychosocial programs for caregivers include counseling, support groups, and training; the overarching goal of which is to improve or increase the family's skills and abilities for coping with caregiving. The general objectives are to reduce caregiver burden and stress, and improve the quality of care rendered to elderly family members. Not surprisingly, there is a wide range of intervention strategies and formats in this service area. Strategies and formats associated with psychological intervention focus on self-care, family communication and interpersonal relations, stress-management and relaxation techniques. Educational intervention strategies emphasize home care skills, problem-solving, behavioral techniques, and financial and legal planning.

A number of studies have examined the effectiveness of different types of counseling services for family caregivers. In reviewing 100 interventions for families caring for family members with Alzheimer's disease, Bourgeois, Schulz, and Burgio (1996) found that individual counseling services resulted in positive outcomes, but only for narrowly defined problems. Group counseling for those caring for dementia patients failed to yield a similar magnitude of effects. Importantly, 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 reported greater gains in psychological functioning and well-being when receiving individual counseling. Group counseling, however, produced greater improvements in caregivers' social supports (Toseland, McCallion, Smith, & Banks, 2004). These findings suggest that the benefit of counseling services may be linked to certain types of problems and issues specific to individual caregivers.

In spite of the fact that caregiving occurs in a family context, there have been few studies focusing on the benefits of family counseling services. But the findings of studies that have been conducted indicate that such counseling results in increases in a variety of measures of caregiver well-being and perceived social support, and in reductions in burden and depression (Qualls & Noecker, 2009). Middleman and colleagues at the New York University School of Medicine's Alzheimer's Disease Center have conducted the longest continual study of counseling intervention, including a combination of individual and family counseling and continuous availability, by telephone, of counselors to caregivers and families to help them deal with crises and the changing nature of the patient's symptoms over the course of the disease (Drentea, Clay, Roth, & Mittelman, 2006). The result of this intervention is approximately a 1-year delay in the institutionalization of the family member with dementia, in addition to improvement in the well-being of family members involved in caregiving.

Under the NFCSP, support groups are among the most popular and most prevalent community-based services available to families. They are designed to provide informal peer support, information about diseases and disability, and referrals for caregiver support services. Although family caregivers who participate in support groups often describe them as helpful, there is not strong evidence indicating that they are effective in improving the mental or

physical health of family caregivers, or the ability of families to fulfill caregiving responsibilities (Scharlach, et al., 2001).

Psycho-educational services that provide family caregivers with training have proven effective. This is particularly true of training that is clearly focused on a limited set of outcomes. One example is a study by Coon and colleagues (2003) wherein two psycho-educational training programs were compared: one centered on teaching family caregivers of dementia patients the skills involved in anger management, and another where the focus was on strategies for managing depressive feelings. When compared to a wait-list control group, both interventions resulted in significant reductions of the respective targets: anger and depression.

One limitation in assessing the impacts of psycho-educational services for caregivers is that the benefits may not accrue immediately after training. In training that focuses on skill-building (e.g. communication among family members), benefits may emerge over time; after families have had an opportunity to gain more experience in applying the strategies and techniques they were taught. One example of this is found in the work by Ostwald and colleagues (1999) where training centered on teaching management skills and helping build family support. Although there were no immediate differences in comparison to a wait-list control group, such differences did emerge 2 months later. Family caregivers who had received the training reported comparatively lower levels of burden and depression.

Information, service access assistance, and care management. In order to fulfill caregiving responsibilities, families need information regarding health conditions and available community services. Importantly, studies on the effects of information-only services have not demonstrated an appreciable, positive impact on mental or physical health-related outcomes of caregivers. Needed in addition to information is assistance in accessing and managing services. In 2008, the access assistance services funded by the NFCSP provided approximately 1.3 million contacts to caregivers nationwide; enabling them to locate and utilize services from a variety of private and voluntary agencies. The value of this service to caregivers is illustrated in a study by Weuve, Boult, and Morishita (2000) wherein family caregivers who not only received information, but also benefited from a care management plan and help with directly linking to services, reported less burden than did a control group who only received written information and service referrals. Similarly, a study by Braun and Rose (1994) found that caregivers who received case-managed home care for an elderly loved one reported lower levels of caregiver burden and less time-off from work to fulfill caregiving duties than did a control group of caregivers who did not receive case management help.

Multidimensional services and timing. Services that appear to hold the most promise in helping family caregivers are those that use a variety of interventions and address multiple points in the caregiving process that produce family stress (Pinquart & Sörensen, 2006; Gallagher-Thompson & Coon, 2007). A good example is a randomized, controlled trial of an intervention for family caregivers that combined both counseling and support groups for family caregivers of loved ones with Alzheimer's disease (Gaugler, Roth, Haley, & Mittelman, 2008). The authors of this study report that burden and depressive symptoms were significantly lower in the treatment group.

Other empirically-based treatments (EBTs) have been shown to alleviate the stresses experienced by family caregivers. In a careful review of EBTs, Coon and Evans (2009) identified three that are effective: psycho-educational skill building, psychotherapy (cognitive-behavioral focus), and multi-component interventions that combine two approaches, such as education, family meetings, and skill building.

As was mentioned in an earlier section of this paper, the timing of services for family caregivers is also important. Using data from a 3-year prospective study of dementia caregivers at sites in eight states, Gaugler, Kane, Kane, and Newcomer (2007) found that the timing of service delivery was important, and that early utilization of community-based services helped delay nursing home placement of a loved one suffering from dementia. For family caregivers in the early stages of caring for a loved one with dementia, the utilization of such in-home services such as personal care or chore help was helpful in minimizing the accumulation of stress and in delaying nursing home placement.

Family Impact Principle: Family Diversity

The principle of family diversity recognizes that policies and programs can have varied effects on different types of families, and claims that there should be an acknowledgement and value of diversity in family life. An impact analysis aligned with this principle assesses the extent to which policies and programs discriminate against or penalize families solely based on their cultural, racial, or ethnic background; economic situation; family structure; geographic location; presence of special needs; religious affiliation; or stage of life. The key question addressed is: How does the policy or program affect various types of families?

The *NFCSP Resource Guide* (Administration on Aging, no date) stresses the importance of knowing and understanding the characteristics of the population being served and emphasizes that delivering population-based services are important methods for developing effective caregiver support programs. The *Guide* emphasizes that an essential step in delivering population-based services is creating or using model burden assessments tailored to evaluate the needs of specific minority groups. Yet, ironically, neither of the major evaluation studies of the program collected data on the Native American Caregiver Support Program, support programs for persons with developmental disabilities, or grandparents caring for grandchildren.

Building on contingency theory, a model of family caregiving proposed by Fingerman and Birditt (2011) maintains that family support is a product of both structural factors, such as resources and demands associated with family members' needs, and intra-psycho factors, such as cultural beliefs about support and rewards of providing everyday support. Support for this model is found in the results of a recent multigenerational study of Black and White families reported by Fingerman, VanderDrift, Dotterer, Birditt, and Zarit (2011) wherein racial differences in supporting elderly parents was explained by intra-psycho factors. Middle-aged Black children provided more support to elderly parents than did middle-aged White children, and this difference was a function of the stronger adherence to cultural beliefs among Black

families regarding support for parents and the personal rewards derived from providing such support.

A similar finding was reported by Barber and Vega (2004) in a study of middle-aged Hispanic and Non-Hispanic White children caring for elder parents. The Mexican-American caregivers in their study reported deriving more satisfaction and personal gains from caregiving than did their Non-Hispanic White counter-parts, leading them to echo an observation and challenge issued by Gallagher-Thompson, Coon, Rivera, and Zeiss (1998):

...minority caregivers' values and beliefs, along with their life experiences, create a powerful variable which impacts appraisal and coping, so that for many, caregiving is almost automatically less stressful than for Anglo counterparts. Thus, they may not need or want the same kinds of services that have been developed to serve the more well-characterized needs of Anglo caregivers... (p. 484).

Because the focus of many of the services funded under the National Family Caregiver Support Program are targeted at structural factors, such as demands and resources associated with family caregiving needs, it is likely that the intra-psychic factors associated with cultural beliefs are ignored, or not given sufficient attention. That such might be the case is implied in a study of the availability of caregiver support services under the NFCSP implemented by area agencies on aging in California (Whittier, Scharlach, & Dal Santo, 2005). The most frequently identified gap with regard to services for family caregivers was that the lack of availability of multilingual and culturally- appropriate caregiver support services for Hispanic families. Importantly, this gap was identified in every category of Title III-E services (e.g. Information, Access, Caregiver Support, Respite, and Supplemental Services).

Although the cultural focus in the study by Whittier, Scharlach, and Dal Santo (2005) was on Hispanic caregivers, the findings of their study likely apply to other ethnic groups as well. Hasnain and Rana (2010), for example, observe that little research is available on the caregiving needs and circumstances of Muslim families who immigrate to the United States from South Asia, the Arab world, and the Middle East, and they remind readers via several case studies that Muslim families encounter cultural issues and barriers in the context of support services for caregivers (e.g. difficulties in language, service bias geared toward a White majority).

Family Impact Principle: Family Engagement

The third and final family impact principle used in this analysis – family engagement – states that policies and programs must encourage partnerships between program professionals and families. Organizational culture, policy, and practice should include relational and participatory practices that respect family autonomy and preserve family dignity. A question guiding an analysis of impact according to this principle is: In what specific ways does the policy or program respect family autonomy and allow families to make their own decisions?

An important feature of the NFCSP is that states are given the flexibility of embracing consumer-directed options; that is, to allow direct payments to family caregivers, or to provide either a voucher or budget for goods and services. The objective of consumer-directed options is to empower families. They may decide how, when and to whom respite is to be provided, or they may opt to directly purchase goods or services to meet their needs and/or those of the older person receiving care.

In their national survey, Feinberg and Newman (2006) reported that 44 states indicated that services offered under the NFCSP were consumer-directed. Most commonly, 34 state NFCSPs give the family a choice of respite providers (e.g., between contract agencies such as home care agencies or independent providers); 26 states offer a voucher or budget for respite care and supplemental services (e.g., consumable supplies, assistive devices, yard maintenance); and 25 states provide caregivers with a menu to choose those services that best fit their needs. Only 15 states and the District of Columbia permit direct payments to family members to buy goods or services.

Under the NFCSP, states have the option of paying family caregivers. In the Feinberg and Newman (2006) survey, over half of the states reported that family members are permitted to be paid under the NFCSP. Of those states, respite care is the service that family members most typically can be paid to provide (28 states), although some states allowed payment to families to provide personal care (14 states) or other services (4 states) and, in Pennsylvania, “any service” needed by the family.

Summary: Lessons Learned

The National Family Caregiver Support Program (NFCSP), funded under Title III-E of the 2000 reauthorization of the Older Americans Act, provides states with funds to offer community-based support services for families caring for elderly loved ones who are frail and dependent. One of the general benefits derived from the NFCSP has been an increased awareness of family caregivers (as opposed to a more limited focus on care recipients) as legitimate consumers of community services (Feinberg & Newman, 2004). But identifying specific and direct impacts on families of services funded under the NFCSP is somewhat difficult. Part of this difficulty is a product of the considerable variability in service delivery across and even within states. Assessing impacts is also difficult because there is no mandated assessment of families using NFCSP services. This forces a family impact analysis to rely primarily on studies discerning the effectiveness of specific community-based interventions targeted at limited populations of caregivers who provide assistance to individuals with a specific disease or debilitating condition (Brouwer et al., 2004; Han & Haley, 1999; Harding & Higginson, 2003; Schulz et al., 2002). Assessing direct impacts of the NFCSP on families is also complicated by the Program’s fragmented financing, multiple points of entry, variable service offerings, and lack of a standardized approach to caregiver assessment.

Still, it is possible to identify some lessons learned and implications of this family impact analysis for policymakers, professionals who work with caregivers, and researchers.

Policymakers and professionals should consider the following as they enact, establish, and implement caregiving programs:

- The most promising services for supporting family caregivers and reducing institutionalization use a variety of interventions provided at multiple points in the caregiving process.
- If resources are limited, respite services may be more valuable to chronic conditions that require more intensive caregiving such as dementia, stroke, etc.
- Respite services are most effective if provided early on before the strains of caregiving deplete the caregivers' reserves and resources.
- Based on emerging evidence, family counseling may be more effective than group counseling or peer-to-peer support in improving the quality of care and delays in institutionalization.
- Psychological and educational services can help family caregivers deal with anger, depression, the burden of caregiving, and so forth. As stated earlier, there appears to be clear evidence that such services result in significant decreases in anger and depression experienced by family caregivers.
- Directing resources to case management has proven more effective in reducing caregiver burden than providing only information.
- Providing a menu of services that provides families with choices helps target the unique needs of families, which vary according to several dimensions including the cultural values and beliefs of racially and ethnically diverse families.

The family impact analysis of the NFCSP also raises a number of implications for researchers and evaluators. First, knowledge about how community-based support services affect family interactions, and particularly the quality of the caregiver-recipient relationship, appears scant. There is, however, some evidence indicating that interventions addressing the needs of both caregivers and care recipients are beneficial for families. One example is a study by Lyons, Zarit, Sayer, & Whitlatch (2002) wherein the focus was the caregiving dyad as a unit rather than as individual members. Findings regarding dyadic congruence underscored the need to include both caregivers and care receivers when addressing issues related to relationship quality. As the authors of this study observe, interventions targeting the caregiving relationship have the potential for offsetting some of the disagreement over the caregiving situation and related strain, particularly those that promote communication between care recipient and caregiver about the caregiving situation and their respective needs.

Second, research on the effectiveness of interventions designed to support families involved in caregiving reveals "no one size that fits all". There is, in fact, little consensus regarding how to best support family caregivers. Community-based caregiver interventions have cumulatively failed to generate a strong evidence base about how to best train and support family caregivers in their diverse roles (Knight, Lutzky, & Macofsky-Urban, 1993; Zarit, Gaugler, & Jarrott, 1999). Importantly, the most frequently used caregiver support services offered under the NFCSP (respite services, support groups, case management, etc.) did not qualify as empirically-based treatments in the review by Coon and Evans (2009). The translation of EBTs

into community settings in the future will require “strategic partnership among researchers, practitioners, and policymakers to bridge the research-community gap, effectively deliver interventions, and maximize effective and sustainable translations” (Coon & Evans, 2009, pg. 432).

Third, cultural and ethnicity cannot be ignored in providing community-based services to family caregivers. One of the key caregiver supports offered under the National Family Caregiver Support Program is assistance in gaining access to and utilizing services. But simply providing information about what services are available does not ensure that they will be used. Intra-psychic factors associated with culture and ethnicity may prove to be barriers for service utilization if services are not offered in a way that is culturally appropriate and acceptable to the caregiver (Radina & Barber, 2004). Although a number of caregiving studies have included greater sensitivity to racial, ethnic, and other cultural features, most intervention research has been done exclusively on Caucasians (Burgio et al., 2003; Gallagher-Thompson et al., 2003). More intervention studies culturally tailored to specific groups are needed to enhance our knowledge of how to develop more culturally competent caregiver support services under the NFCSP in order to effectively address cultural/ethnic differences and needs.

Conclusion

The National Family Caregiver Support Program has increased awareness of families as a primary source of long-term care and support for older persons. The community-based services offered under the NFCSP help families fulfill caregiving responsibilities, and delay nursing home placement. But the efficacy of community-based services and interventions—particularly for caregiving families representing a wide range of ethnic and cultural backgrounds—is difficult to discern. Gaps exist in linguistically and culturally appropriate caregiver services offered under the NFCSP. As observed by Whittier, Scharlach, and Dal Santo (2005), overcoming these “gaps and establishing a comprehensive caregiver service network will require collaboration and coordination among formal and informal networks, public and private entities, and local and state systems” (pg. 60).

Decision makers have long endorsed the many contributions that families make to their members and society. Family impact analysis is one tool that professionals can use to incorporate the lens of family impact in policy and program design, development, implementation, and evaluation. The task now is to communicate the results of such an analysis to policymakers and those who teach about or work with family. The hope is that this paper serves as an effective means of communicating the results of a family impact analysis for those involved in supporting families in fulfilling the important function of caring for elderly loved ones who are frail and dependent.

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