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Pennsylvania's Family Caregiver Support Program: A Demonstration Project

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ABSTRACT

The physical, emotional, and economic burdens of family caregiving can present a serious threat to the stability and continuity of a caregiving situation. Public policymakers, aware of the high costs of replacing such voluntary efforts with publicly funded institutional care, are becoming more and more concerned about the needs of caregivers and possible intervention strategies to meet those needs.

This article begins with a description of Pennsylvania's new policy initiative for caregivers, the Family Caregiver Support Program (FCSP). Following is a discussion of the evaluation of the program's demonstration phase by the Human Organization Science Institute of Villanova University. The evaluation concluded that the FCSP has a significant positive impact on the lives and abilities of caregivers, including the reduction of caregiver stress and burden. The concluding summary of program results seeks to sharpen the reader's interest in the potential benefits of an intervention strategy such as this and suggests a need for additional research for the benefit of those concerned about health care cost containment.

Introduction

An informal support system consisting primarily of family caregivers provides the care for approximately eighty percent of older persons in America with long-term care needs (U.S. House of Representatives Select Committee on Aging, 1987). For every one elderly resident in a nursing home, there are two individuals in the community with similar disabilities being cared for by relatives (Shanas, 1979). Furthermore, families have been noted as a critical factor in delaying or preventing the institutionalization of elderly family members (Brody, et al, 1978).

Providing care for an impaired family member is associated with a fair degree of stress, often referred to as "caregiver burden." The closer the bond between the caregiver and the carereceiver, the more stressful the caregiving role (Anthony-Bergstone, et al., 1988; Brody, 1981 and 1985; Brody, et al., 1978; Cantor, 1983; Zarit, et al., 1980). The amount and type of care and the frequency of contact also compound the impact on the caregiver (Horowitz, 1985; Pearson, et al., 1988; Silliman and Sternberg, 1988; Stephens and Christianson, 1986). A caregiver who resides with a carereceiver is especially at risk for increased stress because of the close proximity and because, in many instances, the carereceiver has a high level of disability (Stephens and Christianson, 1986).

According to some estimates, there are already about 4.2 million Americans providing care to an impaired spouse or parent and over half of these are the primary caregiver (Stone and Kemper, 1989). These numbers can be expected to increase significantly in the years ahead as the United States population ages, bringing with it a growing incidence of chronic illness and functional impairment requiring the support of caregivers. In addition, social and economic changes have been identified which may impinge upon caregivers' continued ability to provide such a high level of care to elderly relatives (Treas, 1977; Ward, 1985).

Public policymakers, aware of the high costs of replacing such voluntary efforts with publicly funded institutional care, are becoming more concerned about the needs of caregivers and intervention strategies which may be available to meet those needs (Greene and Coleman, 1990).

This paper begins with a description of Pennsylvania's new policy initiative for caregivers, the Family Caregiver Support Program. This is followed by a discussion of some of the findings from the evaluation of the program's two-and-a-half-year demonstration phase by the Human Organization Science Institute of Villanova University. The concluding summary of program results seeks to sharpen the reader's interest in the

potential benefits of an intervention strategy such as this and suggests a need for additional research for the benefit of those especially concerned about health care cost containment.

The Family Caregiver Support Program

In the mid-1980s, the Pennsylvania Department of Aging clearly recognized the need to provide support for caregivers. A generalized concern that something be done to bolster family support systems had begun to be widely articulated by advocacy organizations, service providers, and departmental staff. This concern grew out of needs perceived at the grass roots level and was supported by a variety of national research studies which showed that, contrary to popular belief, most of the care provided to dependent elderly persons is provided by family members—not by nursing homes or formal agencies.

A nationwide study of family caregiver incentive policies completed for the department (Biegel, et al., 1986) influenced the initial conceptualization of a policy initiative to provide stronger incentives to family members to assume or maintain the role of caregiver to a functionally dependent older relative. An early decision was made to develop a demonstration program which would explore the local coordination of service incentives with financial incentives. It was also decided that, since the state constitution prevented the department from providing cash grants, a reimbursement approach to financial assistance would be tried. This later proved to be important from the perspective of caregiver taxable income. Additional program design utilized valuable input from a focus group of representatives of caregivers on caregiver issues. In 1987, the department initiated the Family Caregiver Support Program (FCSP) as a demonstration project in four sites competitively selected from Pennsylvania's 52 area agencies on aging. The four sites, representing different kinds of communities and geographical areas, were:

Bucks County Area Agency on Aging, Doylestown, PA
North Central Human Services, Inc., Ridgway, PA
 (Cameron, Elk, and McKean Counties)

Philadelphia Corporation for the Aging, Philadelphia, PA
Southwestern PA Area Agency on Aging, Monessen, PA
 (Washington, Fayette, and Greene Counties)

The Family Caregiver Support Program is designed to reduce caregiver burden and reinforce the care being provided to older persons at home. Focusing on the needs of caregivers, the program provides a combination of services and financial assistance to families caring for a functionally dependent older relative who is living with them. The program is currently being implemented throughout the state under recently enacted legislation which slightly expands the client group to include the caregivers of adults of any age with Alzheimer's Disease or other chronic dementia. Locally, the program is administered by Pennsylvania's 52 area agencies on aging.

The basic components of the program are:

- a comprehensive assessment of the needs of the caregiver, the care-receiver, and the caregiving environment;
- benefits counseling;
- caregiver training and education; and
- financial assistance with ongoing caregiving expenses, home modifications, and assistive devices.

Financial assistance is in the form of reimbursement for expenses incurred. Depending upon need, income, and expenditures, caregivers may be reimbursed for up to \$200 per month for services and supplies (e.g., respite care, incontinence supplies, etc.); and up to \$2000 for home modifications and assistive devices. Families with incomes of up to 200 percent of poverty level are eligible for 100 percent of the maximum financial benefit available. As income increases by 20 percent beyond this level, the benefits decrease by 10 percent, until they phase out at 380 percent of poverty level.

The principal goals of the FCSP are:

- To reduce caregiver burden.
- To enable caregivers to provide effective and appropriate care through benefits counseling and caregiver education.
- To empower caregivers, through expense reimbursement, to choose respite care options and other supports as they determine most appropriate.
- To extend the benefits of the FCSP to middle income families through the use of income-related cost sharing.

In two respects, the FCSP design represents a significant departure from traditional social service delivery. First, there is a focus on the family as the client and manager of the older person's care. Second, the program

includes direct reimbursement of caregivers for out-of-pocket expenditures of their own choosing. Social agencies often view clients as people whom they need to “care for” and “cases” which they need to “manage.” This conceptualization subtly pervades many aspects of the human service delivery system and may explain why some families do not seek help even when they need it. The department saw this attitude as an obstacle to the successful implementation of an effective caregiver support program. Thus, the FCSP was intentionally designed to reinforce the caregivers’ ability to manage the care needed by their relatives.

The department believed that if the program effectively targeted the caregiver, it would be possible to reach a different service population than that currently being reached by other programs for the elderly. The demonstration sites were skeptical about this. They believed that they would not discover many families whose older functionally dependent relative was not already known to the area agency on aging. The “unlearning” was achieved through the persistence of the department, the cooperation of the four demonstration sites and the program experience which eventually showed that a large percentage of the FCSP client families were not previously known to the AAA. Data from the *Final Evaluation Report* indicate that 48.5 percent of the carereceivers in families served during the demonstration were new to the agencies (Kelley, et al., 1990).

The area agency on aging sites also did not initially believe that their County Commissioners or Boards of Directors would allow them to make direct payments to clients. All, however, have been able to implement direct reimbursement procedures using some system of invoicing which provides adequate documentation for agency payments. The integration and local coordination of service and financial program benefits is an essential factor in the FCSP model and contributes to an expansion of local service options for caregivers. It also allows the agencies to work in partnership with caregivers to provide a more holistic approach to family support—making them more capable of looking beyond the needs of the older dependent relative to see other kinds of family intervention needs.

Evaluation of the Demonstration

Villanova University’s Human Organization Science Institute was selected from among five bidders as the project evaluator for the FCSP in November 1987. The methodology utilized to evaluate the program was a longitudinal design which included both quantitative and qualitative methods, including

descriptive statistics, process documentation, pre- and post-correlational analysis, and analysis of variance. Significance of correlations was determined at .05 level of significance.

All caregivers participated in a 2-4 hour interview in the caregiver's home. The interview was structured by a standardized multidimensional assessment instrument which contained a mix of scale items, and fixed choice and open-ended questions. The interviews were conducted by case managers in the four demonstration sites. All caregivers remaining in the program long enough were interviewed again at 6-month intervals using the same assessment instrument.

The key study questions discussed in the *Final Evaluation Report* (Kelley, et al., 1990) address the following concerns:

- Social, demographic, and functional characteristics of program participants.
- Discernible differences in caregiver well-being, stress, and ability to function in the caregiving role.
- Facilitators and barriers to program implementation and operation.
- Procedures used by the agencies to manage program funding and cost-sharing responsibilities.
- Family satisfaction with the program's services.

The evaluation study period extended from December 1987 to February 1990. The study was designed to gather data on each enrolled caregiving family for a period of at least six months. Data was collected for initial assessments between December 1987 and August 1989. Data for six-month reassessments were collected until February 1990. Service data were collected for the entire study period. While attrition decreased the number of participating families, a majority of enrolled families (480) were reassessed after six months, and a substantial number (200) were reassessed again after twelve months. A smaller number of families (58) were reassessed for a third time after eighteen months. The data presented in this paper reflect information gathered on each client family at the initial assessment and again at the 6-month reassessment.

Caregiver/Carereceiver Characteristics

Between December 1987 and August 1989, a total of 833 caregiving families (833 caregivers and 842 carereceivers) were assessed and admitted to the FCSP. The caregivers and their carereceivers were representative of

TABLE 1
Selected Characteristics of Caregivers and Carereceivers

Category	Caregiver	Carereceiver
Admissions		
Total	833	842
Carereceivers previously unknown to Area Agency on Aging		48.5 %
Terminations (entire study period)	466	—
Demographics		
Females	74.8%	58.4%
Average Age	62.2 yrs	77.2 yrs
Average Highest Grade Completed	11.0 yrs	9.3 yrs
Employed Full-Time	10.5%	0.0%
Veteran	9.6%	15.5%
Racial Identity		
Asian	0.2%	0.4%
Black	20.8%	20.2%
Hispanic	1.7%	1.8%
White	77.3%	77.7%
Relationships		
Mothers	0.4%	31.2%
Wives	32.7%	17.2%
Daughters	30.6%	0.0%
Fathers	0.0%	5.9%
Husbands	17.7%	32.4%
Sons	5.9%	0.4%
Siblings	3.6%	3.7%
In-Laws	3.6%	3.7%
Other	4.9%	4.9%
Physical Health		
Average Physical Health Problems	2.1	3.5
Average Medications	2.2	4.7
Average Visits to Health Care		
Professional (in prior six months)	3.7	6.8
Average Hospitalizations (in prior six months)	0.2	0.9
Continent of Bladder	—	57.7%
Continent of Bowel	—	69.0%
Average ADL Needs (of 8 possible)	0.1	5.3
Average IADL Needs (of 12 possible)	1.6	10.6

(continued on next page)

TABLE 1 (cont.)
Selected Characteristics of Caregivers and Carereceivers

Category	Caregiver	Carereceiver
Mental Health		
Average Mental Status Quotient (MSQ) Score (of 9 possible)	—	4.2
Carereceivers with mild to severe cognitive impairment	—	31.9%
Carereceivers unable to respond to MSQ cognitive ability test	—	23.5%
Average Zarit Score (of 88 possible)	32.9	—
Caregiver participation in Support Group	9.6%	—

the national profile of caregivers, in that the majority were female, predominantly wives and daughters (see Table 1). However, some men did act as caregivers (25 percent) and at one rural demonstration site thirty-seven percent of the caregivers were male. The percentage of caregivers working full-time was only 10 percent but an additional 12 percent stated that they left employment to become a caregiver.

The participants in the demonstration program represented a previously underserved population group, characterized by ill health, moderate stress, and long hours of care provision with little opportunity for relaxation or respite. They were financially needy, having limited incomes and high expenses. Caregivers consistently reported that they were never out of their caregiving roles. Caregivers were found, on average, to be active in the role of caregiver for eighteen hours a day, and many stated that they were required to be with the carereceiver twenty-four hours a day. The fear that these caregivers are stressed and nearing a time when they will no longer be able to offer care for their dependent relative is legitimate.

Initial attrition rates demonstrate the frailty of the carereceiver population. Of the 466 terminations, 45 percent were due to carereceiver death and 23 percent were as a result of nursing home placement. The average time in the program for families whose service was terminated was just over six months.

Caregiver Burden

One of the primary objectives of the FCSP is to provide support to the caregiving situation, thereby reducing the caregivers' burden. The evaluators

considered changes in caregiver burden to be one of the major measurements of program impact.

Care managers administered a validated twenty-two question survey known as the Zarit Caregiver Burden Scale (Zarit, et al., 1980). This scale uses a five point (0-4) rating system to measure caregiver burden and stress, with a possible total score of 88. Overall, caregiver Zarit scores were well within the mild-to-moderate range (mean = 32.9), with many caregivers (45.7 percent) falling within this rating. Caregivers scoring within the little-to-no-burden range (24.1 percent) and the moderate-to-severe range (24.5 percent) were roughly equivalent. Few caregivers scored within the severe burden range (5.7 percent).

Caregiving Tasks

Twenty-two caregiving tasks were reviewed. Some were not applicable to all caregiving situations. Caregivers, for the most part, tended to perform tasks themselves (mean = 9.7 tasks) rather than supervising the activities of the carereceiver (mean = 3.1 tasks). The large number of tasks being performed also indicated the level of carereceiver need for care.(See Table 2.)

These same twenty-two tasks were reviewed to identify three other factors of caregiving: those items the caregivers felt cause stress, those items the caregivers wanted help with, and those items the caregivers preferred to do themselves. Maintaining the carereceivers' personal hygiene was reported most frequently as the task causing stress (25.8 percent) and as the task caregivers wanted help with (31.1 percent). Similar consistency was found in the area of providing constant supervision and companionship, with nearly one-quarter of caregivers finding this stressful (22.4 percent) and wanting help with the task (22.2 percent). Assisting with ambulation or lifting the carereceiver caused stress for approximately the same number (19.3 percent) as those wanting help (16.5 percent) with the task. Tending incontinence or assisting with toileting found similarity between stress (13.1 percent) and wanting help (10.8 percent). The relative ranking of tasks causing stress and tasks where help was wanted was identical for these four tasks. In terms of the tasks caregivers preferred to do themselves, performing other caregiving tasks (29.4 percent), providing basic medical care (20.7 percent), and maintaining nutrition (19.5 percent) ranked first, second, and third, respectively. It should be noted that some caregivers preferred to perform the tasks of maintaining personal hygiene (12.8 percent) and providing the necessary supervision and companionship (8.6 percent).

TABLE 2
Description of Caregiver Needs by Site

		n = 833
<u>Caregiver Activity</u>		
Mean Items Caregiver Does		9.7
Mean Items Caregiver Supervises		3.1
<u>Item Causing Caregiver Stress</u>		<u>Responses *</u>
Personal Hygiene		454
Toileting/Incontinence		231
Ambulation/Lifting		339
Medical Care		49
Nutrition		117
Supervision/Companionship		393
Other		172
<u>Items Primary Caregiver Wants Help With</u>		
Personal Hygiene		593
Toileting/Incontinence		206
Ambulation/Lifting		314
Medical Care		40
Nutrition		104
Supervision/Companionship		423
Other		209

*Caregivers were able to respond to more than one item.

Caregiving Supports

While caregivers performed a variety of tasks and provided the vast majority of care required by their dependents, most were not entirely alone in their caregiving endeavors at the time of assessment. Informal support, provided without compensation by other family members, friends, and neighbors, was evident in the majority of homes, with only a few caregivers (9.2 percent) reporting no such support. Overall, most caregiving families received informal support from several sources (mean = 2.4 informal supports), and over one-third (38.5 percent) reported support from at least three informal sources.

In addition to informal supports, families availed themselves of the formal support network. Formal supports are classified as persons providing care in exchange for compensation, and are typically available through an

agency or organization. While some use of formal supports was reported, it was at a much lower rate than the use of informal supports, with most families identifying only one formal support (mean = 1.2). Almost one-third of all families (31.9 percent) reported having no formal supports prior to admission into the FCSP.

When asked to identify the most important form of support, most caregivers cited the informal sources (44.6 percent). Formal supports were also identified with substantial frequency (34.0 percent), indicating that support, whatever the source, was considered to be important by the caregivers. Over one-tenth of the caregivers (11.7 percent) reported having no important supports, while slightly less (9.7 percent) identified the combination of informal and formal supports as being important.

Service Delivery and Utilization

Services of the FCSP fit into one of five basic categories. *Core services* include the assessment process (initial and subsequent), ongoing care management, benefits counseling, and caregiver education. These services are provided directly by the FCSP at no cost to the caregiver. Caregiver education is a partial exception, since it may, in some cases, be a purchased service also. The other services of the FCSP are provided as a result of caregiver selection and use of the financial reimbursement funds for respite care and other supportive services. These services include: *In-Home Services* (household management, in-home personal care, and general respite care); *Out-of-Home Services* (adult day care and overnight respite care); *Consumable Supplies* (such as incontinence supplies); and *Assistive Devices and Home Modifications*.

Each site was asked to submit a monthly report of services delivered. This report included information on units of service, amounts of reimbursement, and caregiver/program cost-sharing ratios. These data helped to provide some indication of the patterns and costs of service utilization. Table 3 shows the percentage of all enrolled families who used the various services. It should be noted, however, that the apparent low utilization of adult day care and overnight respite care are more related to the limited availability of these services than to caregiver choice. By contrast, in Philadelphia and Bucks County, where adult day care is more accessible, 10.5 percent and 15.4 percent, respectively, of enrolled families used this service.

TABLE 3
Families Receiving Services by Type

Category	Percent of Total (n = 833)
Core Services Rendered	
Assessments	97.1
Consultant Assessments	9.9
Benefits Counseling	74.2
Training/Education	25.6
Family Counseling	9.8
In-Home Services	
Household Management	26.4
In-Home Personal Care	58.1
Out-of-Home Services	
Adult Day Care	7.9
Overnight Respite Care	4.6
Assistive Devices and Home Modifications	
Assistive Devices	20.2
Home Modifications	15.4
Consumable Supplies	34.2

Of the more than eight hundred thousand dollars (\$804,874) spent by the program to reimburse caregivers for the purchase of such services during the total study period (December 1987 to February 1990), the majority (52.5 percent) went toward the purchase of In-Home Personal Care. Considerably less was spent on Household Management (15.4 percent), Home Modifications (11.0 percent), Consumable Supplies (8.2 percent), Adult Day Care (5.9 percent), Assistive Devices (3.6 percent), Overnight Respite (3.2 percent), and Other Services (0.3 percent). Caregiving families spent over one hundred and fifty thousand dollars (\$155,655) in addition to the amount reimbursed by the program, representing less than one-fifth of the total dollars spent (16.2 percent of \$960,529).

Annualized Program Costs

Although the FCSP demonstration contracts officially ended on June 30, 1990, the data collected for the evaluation study only cover the provision of services until February 1990. Consequently, some final cost data was not

TABLE 4
Family Cost-Sharing Data

Category	Cost	Percent of Total Costs	Percent of Costs Paid by Families
Total Reported Costs of			
Purchased Services	\$960,529	100.0	
Total Paid by Families	\$155,655	16.2	
Total Paid by Program	\$804,814	83.8	
In-Home Household Management		15.4	5.7
In-Home Personal Care		52.5	19.2
Out-of-Home Adult Day Care		5.9	21.2
Out-of-Home Overnight Respite Care		3.2	24.8
Assistive Devices		3.6	7.3
Home Modifications		11.0	9.6
Consumable Supplies		8.2	18.0

available to the evaluators for discussion in the evaluation report. Furthermore, various start-up delays prevented optimum caseload levels from being reached until the final contract year. Thus, total program expenditures for the last twelve months of the demonstration (\$1.5 million) were even a little higher than the expenditures during the entire two-year period covered by the evaluation data. The data from this one full year of stabilized and consistent service levels provides us with the best annualized cost data on the demonstration program. The following observations on the final twelve months are noteworthy:

- Total contract expenditures\$1,519,233
(7/1/89 - 6/30/90)
- Total caregiver reimbursements \$882,160
 - 83 percent for ongoing expenses (respite, etc.) ... \$732,680
 - 17 percent for home modifications and assistive devices..... \$149,480
- Unduplicated number of families served
(7/1/89 - 6/30/90).....1,006
- Average total cost per family.....\$1,510
- Average active caseload (est.)..... 675
(based on approx. attrition rate of 33 percent/yr.)
- Average total cost per caseload slot (est.).....\$2,250

Local Program Variations

The qualitative review of the FCSP's local operation established the adaptability of the basic program model to local needs and available service resources. Even though there was extensive inter-agency sharing through frequent networking meetings during the demonstration, the four participating sites developed local programs with some significant differences.

Each site focused its efforts differently on the various aspects and components of the FCSP. One placed a heavy emphasis on benefits counseling. Another stressed home modifications. A third expanded agency core services to provide, at no cost to caregivers, coping skills counseling for all interested client families. Care management staff was structured and utilized differently in all four sites.

All four sites devoted substantial attention to the development of their financial reimbursement system and caregiver cost-sharing protocols. One site instituted a voucher system for the purchase of respite care and other services. In all cases, the sites were able to produce systems that provided the necessary accountability for payments to caregivers without imposing a burden or extensive paperwork requirements on them.

Of the program model variations developed in the four local sites, none emerged as more appropriate or successful than another. This seems to underscore the importance of allowing local agencies flexibility in the local adaptation and implementation of programs they will be expected to operate. It also carries positive implications for the replicability of the FCSP in other communities.

Correlation Analysis of FCSP Participation

Starting with the hypothesis that a low sense of burden, coupled with low-risk behaviors and involvement in activities of interest outside of the home, support continued caregiver functioning, the evaluators used three measures to determine change in caregiver stress and functioning. The first measure was the validated Zarit Scale of Caregiver Burden. This twenty-two item rating scale measured caretakers' perceptions of personal stress and burden using both behavioral and subjective ratings. The evaluators created two additional measures, the Caregiver Well-Being Scale and the Caregiver Social Functioning Scale. The Well-Being Scale measured a series of risk behaviors, such as sleeping patterns, eating patterns, medication misuse, alcohol misuse, and sense of satisfaction. The Social

Functioning Scale assessed the caregivers' involvement in community, social, and personal activities. Each of the three scales provided a numeric score. For the Zarit Scale, a low score indicated a low sense of burden while a high score indicated a high sense of burden. For the Caregiver Well-Being Scale, higher scores indicated healthier behavior. Higher scores on the Social Functioning Scale indicated greater caregiver involvement in activities outside of the home.

The evaluators found significant statistical correlations between the three scales. The Zarit Scale was significantly and negatively related to both the Well-Being and Social Functioning Scales. This indicated that higher stress levels, as measured by the Zarit scale, were statistically related to unhealthier behaviors and limited social activity, as measured by the Well-Being and Social Functioning Scales, respectively.

The evaluators further applied the three different scale scores to a series of correlation tests, seeking to confirm the relationship of: ten variables of caregiver status, such as age, education, physical and emotional health, and ADL and IADL needs; six variables of carereceiver status, such as age, mental competence, ADL and IADL needs, and independence; and ten variables of family status, such as years in a relationship between caregiver and carereceiver, caregiver activities of caregiving, level of paid and unpaid external support, income, and caregiving expenses.

The correlation analyses were performed using the initial assessment scores of the three scales. The Zarit Scale proved to have significant relationships with sixteen of the selected variables. The Social Functioning Scale also proved to be significantly associated with sixteen variables, eleven overlapping with the Zarit Scale. The Well-Being Scale showed twelve significant relationships with the selected variables, six overlapping with both the Zarit and the Social Functioning Scales. The fact that the three scales were statistically related to each other, yet produced different correlation values with the twenty-six caregiving variables, indicated that each scale was identifying different, and significant, aspects of caregiver burden and/or satisfaction.

On a pre-post analysis, changes in perceived caregiver burden, caregiver social functioning, and caregiver well-being were examined by readministering the three interviews (Zarit, Social Functioning, and Well-Being) at six months, twelve months, and eighteen months following the initial assessment. The changes in scores from the initial assessment to subsequent assessments were calculated. These analyses showed that there were significant decreases in the Zarit Scale of Caregiver Burden matched by significant increases in the Caregiver Social Functioning and Well-Being Scales.

TABLE 5
Matched Pair Analysis

Correlation of Caregiver Variables with Initial Assessment Score			
	Score		
	6 months (n=480)	12 months (200)	18 months (58)
Zarit Scores	-4.14*	-4.03*	-4.66*
Caregiver Social Functioning Scale	3.50*	.66	2.19
Caregiver Well-Being	3.40*	3.50*	2.78*

* p=.05

To determine which of the twenty-six variables had significant relationships with changes in caregiver burden, correlation tests were run using the change in stress level (Zarit) and those variables determined to significantly correlate at the point of initial assessment. Table 6 shows the relationship between the selected variables and the changes in stress at the point of the first reassessments (6th month review). For the combined group, the following results emerge:

- As carereceiver Instrumental Activities of Daily Living (IADL) needs increased, caregiver stress likewise increased and caregiver social functioning decreased;
- As the number of items the caregiver did increased, caregiver social functioning decreased;
- As the number of hours the caregiver was required to provide care increased, social functioning decreased.
- As the family's purchases of caregiving services increased, stress decreased; and,
- As caregiver personal time, visiting activity and hobby activity increased, stress decreased and social functioning increased.

TABLE 6
 Correlations between Change in Zarit Scale and Change in Selected Variables at Six Months (Significance Determined at .05)(n = 492)

	<u>Zarit</u>	
	Corr.	Sig
Caregiver IADL Needs	.021	
Carereceiver IADL Needs	.117	Yes
Number of Items Caregiver Does	.059	
Number of Items Caregiver Supervises	-.060	
Caregiver Hours Caregiving Per Day	.125	
Number of Formal (Paid) Caregiver Supports	.001	
Number of Informal (Unpaid) Caregiver Supports	.026	
Monthly Cost of Caregiving Services (To Family)	-.162	Yes
Monthly Cost of Caregiving Supplies (To Family)	-.014	
Caregiver Personal Time Activity	-.178	Yes
Caregiver Visiting Activity	-.139	Yes
Caregiver Hobby Activity	-.096	Yes

These findings suggest that a caregiver's sense of demands on his or her time was directly related to his or her sense of stress and social isolation. Also, the appropriate intervention of purchased services (with cost-sharing by the FCSP program) to provide respite contributed to an increase of personal time and a reduction of stress, despite the additional costs to caregivers.

Table 7 displays the results of correlation tests of the connection between service variables and selected variables of caregiver need and activity. Tests include all services combined and each of the service categories (In-Home, Out-of-Home, Assistive Devices and Home Modifications, and Consumable Supplies).

TABLE 7
Correlations between Service Variables and Change in Selected Variables
Initial Assessment versus First Reassessment (6 months)
All Services Combined
(Significance Determined at .05)
(n = 488)

Selected Variable	Frequency of <u>Service events</u>		# of <u>Hours</u>		Program <u>Expenses</u>	
	Corr.	Sig.	Corr.	Sig.	Corr.	Sig.
CG Zarit Score	.085	—	-.153	Yes	.131	Yes
CG Social Functioning Scale	.103	—	.070	—	.023	—
CG IADL Needs	.142	Yes	.244	Yes	.157	Yes
CR IADL Needs	-.167	—	-.057	—	-.096	Yes
# of Items						
CG supervises	.120	Yes	.212	Yes	.227	Yes
CG Personal Time Activities	.076	—	.125	Yes	.097	Yes
CG Visiting Activity	.114	Yes	.178	Yes	.158	Yes
CG Hobby Activity	.134	Yes	.134	Yes	.126	Yes

CG = Caregiver
 CR = Carereceiver

These correlation analyses indicate:

- As the level of service hours and program expenses increased, the level of stress decreased.
- As the personal functional needs of the caregiver increased, more services were provided.
- As the level of service events, service hours, and program expenditures increased, the number of caregiving activities the caregiver was able to supervise (as opposed to do) increased.
- As the level of service hours and program expenses increased, the amount of reported caregiver personal time increased.
- As service events, service hours, program expenses, and the number of different services increased, reported caregiver visiting increased.
- As service events, service hours, program expenditures, and family expenses increased, caregiver hobby activity increased.

Program Results

The results of the FCSP Demonstration can be summarized as follows:

(1) The program reached a highly needy population. Carereceivers had an average of 3.5 distinct physical health problems; took an average of 4.7 different medications; and in over one-third of the cases were not continent of bowel or bladder. At least one-third of the carereceivers were cognitively impaired. The average age of caregivers in the program was 62. Over half of the 833 families participating in the demonstration reported an annual income of \$17,250 or less. Average household size was 2.6.

(2) The program was an effective resource for caregivers. Statistical correlations indicate a reduction in caregiver stress, an increase in caregiver well-being, and an increase in available time for personal activities. Also, over 90 percent of all respondents to a satisfaction questionnaire judged the program as having made positive differences in their lives, lessened their stress, and made it easier for them to care for their relatives.

(*Final Evaluation Report* data covering a two-year period, January 1, 1988 to December 31, 1989.)

(3) Given the amounts available for caregiver reimbursement, overall costs were lower than many anticipated. Data from the last full (12-month) contract year, ending 6/30/90, indicated the following: average total program cost per family = \$1510; average family reimbursements = \$877; average total cost per caseload slot = \$2250; average reimbursements per caseload slot = \$1307.

Note: "Caseload slot" is used to identify one unit of the average daily caseload over a 12-month period. The average cost of a "caseload slot" is determined by dividing the total program expenditures reported by the average daily caseload. One "caseload slot" may, with attrition, be used to serve more than one family in a 12-month period. Due to fixed funding levels, agencies may control expenditures by projecting the number of caseload slots which available funding will sustain. Thus, the importance of distinguishing between the average annual cost of services to one family and the average annual cost of funding one caseload slot.

What the demonstration did not establish is a body of evidence related to its cost effectiveness. It may be presumed that providing support to family caregivers reduces stress-related health problems and avoids or delays the placement of older persons in nursing homes or other institutions. Proof of this, however, would require a sophisticated research design involving a longitudinal study of experimental and control groups. The department may

undertake such an evaluation in the future, but in the meantime, the merits of the program must be couched in humanistic terms. Further data would be needed to demonstrate program effectiveness to those who are principally concerned about cost containment.

The FCSP has enabled the department to get much-needed help to a new group of clients who traditionally have not taken advantage of formal services for impaired older persons. Many of the caregivers served have apparently operated from the assumption that, since they take care of their older relatives, they don't need to depend on formal services to provide that care. Often, they have not absorbed the full depth of their own needs. In the words of the Director of one of the AAA Demonstration sites, "We are discovering some very heroic people through this program."

Because the program is directed to the needs of caregivers, many of these people seem more open to seeking help for themselves than they were to looking for an agency to provide care to their relatives. Because of this achievement, we are also able to provide official acknowledgment of the important role dedicated family caregivers are playing in the provision of long-term care services to impaired older persons.

The FCSP proved to be a viable and beneficial program. It clearly met its primary objective to reduce the stress encountered by caregivers as they provide for the daily needs of their aging, dependent relatives. It demonstrated the viability of new methods of service delivery, the provision of financial assistance, and the ability to successfully empower clients.

The most substantial measure of FCSP impact was on the caregivers' reported levels of stress and burden. In studying the relationship between services delivered and changes in stress, there was indeed a direct and statistically significant relationship between the services caregivers received, their use of reimbursement funds, and changes in their levels of stress. As services and use of reimbursement funds increased, stress decreased. The evaluators can state with confidence that the program achieved its objective of having a beneficial impact on the lives and functioning of the caregivers. Within the limits of the evaluation, no one service type emerged as being more important than others in terms of reducing stress. It appears to be the availability of the program and the combined array of services, in total, that produces a positive impact.

Note

Pennsylvania's Family Caregiver Support Program has now been fully implemented throughout the state through the 52 Area Agencies on Aging. The Program received an appro-

priation of \$8.5 million for State Fiscal Year 1991-92, which ended on June 30, 1992. Of that amount, approximately \$7 million was spent. The appropriation for State Fiscal Year 1992-93 was \$8.55 million. The average cost per family served during 1991-92 was \$1550 and the average cost per caseload slot was \$2500. The program is currently funding approximately 3400 caseload slots which provide services to approximately 5500 families each year. Legislation enacted late in 1990 extended the benefits of the Program to the caregivers of younger adults (under age 60) with chronic dementia, such as Alzheimer's Disease. The impact of that expansion is still being studied.

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