DOCUMENT RESUME

ED 216 275

CG 015 '889

AUTHOR

Hofer, Andrew

TITLE

The Family Support System: Comparative Analysis of Research Projects Funded by the Administration on

SPONS AGENCY

Congress of the U.S., Washington, D.C. Senate Special Committed on Aging.

PUB DATE

Nov 80

NOTE

14p.; Paper presented at the Joint Annual Meeting of the Scientific Gerontological Society (34th) and the Scientific & Educational Canadian Association on Gerontology (10th), (Toronto, Ontario, Canada, November 8-12, 1981).

EDRS PRICE DESCRIPTORS ?

MF01/PC01 Plus Postage.
Administrators; *Aging (Individuals); Comparative
Analysis; *Family Relationship; *Family Role;
*Helping Relationship; Individual Needs; Older
Adults; Program Descriptions; Program Evaluation;
Service Workers; Sociocultural Patterns; Trend
Analysis

IDENTIFIERS

*Caregivers

ABSTRACT

This paper presents a comparative analysis of eight research projects funded by the Administration on Aging during the 1970s which focused on the family as caregivers and support systems for elderly relatives brief description is provided for each project analyzed in this report as well as highlights of major findings, including that the family remains the primary provider of support to the elderly members in time of illness, emergency, or crisis and the primary caregiver for emotional, psychological, and other dependency needs. Documentation of the extent and scope of care is provided and cultural, racial, and ethnic factors which help to shape the family role are discussed. Results are presented which dispel several myths about the demise of the family support system and which suggest a close connection between conjugal families, made viable by mutuality of relationships and reciprocity. Findings from two studies are presented that explore the types of assistance families prefer to enable them to provide better care for their elderly. Implications for policymakers and service providers are also discussed. (NRB)

THE FAMILY SUPPORT SYSTEM: COMPARATIVE ANALYSIS OF

RESEARCH PROJECTS FUNDED BY THE ADMINISTRATION ON AGING

BY
 Andrew Ho∉er

Prepared for the Special Committee on Aging
United States Senate
November 1980

U.S. DEPARTMENT OF EDUCATION
NATIONAL INSTITUTE OF EDUCATION
EDUCATIONAL RESOURCES INFORMATION
CENTER (ERIC)

- This document has been reproduced as received from the person or organization onginating it.
- Minor changes have been made to improve reproduction quality
- Points of view or opinions stated in this document do not necessarily represent official NIE position or policy.

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

ERIC

Full Text Provided by ERIC

2

Introduction

The advent of Medicare, Medicaid, SSI, the Older Americans Act and a host of other programs established for the benefit of the elderly undoubtedly reflected a shift in public policy to assume greater responsibility for certain segments of the population. They also signaled the recognition that there are certain basic rights which have to be guaranteed to everyone, regardless of social status, race, or income. Subsequent to, but not necessarily as a consequence of these new public programs, the belief in the slowly eroding role of the family as a caretaker gained increasingly more and more currency. Additional support for this emerging viewpoint was provided by major shifts in the work force, in geographic mobility, and the demographic composition of society which in one way or another may have contributed toward restricting the family's caretaker ability. The level of existing knowledge, however, is uneven, and there is scant hard data to assess the impact these new programs may have had on the family.

With a few exceptions, it was only in the late sventies that the Administration on Aging began to focus its research efforts on the family. In fiscal years 1979-80, the AoA awarded close to \$3.9 million for 16 research projects, running from one to three years, which are addressing various aspects of the family support system. Most of these however, will not be completed until next year. This paper presents a comparative analysis of those studies which had been completed, or published major reports to date.

Although limited in scope and time allotted, this analysis does attempt to highlight certain findings and trends, some of them supported at high confidence levels in each one of the studies. Further documentation is needed, however, to clearly define the level and direction of trends and to substantiate the generalizability of any findings.

Description of Projects

Three of the projects covered in this report were funded in the early nineteen-seventies:

- 'The Elderly in the Inner City" awarded to the New York Office for the Aging, a study of persons 60 and older in New York City, claimed to be the largest cross-ethnic urban elderly study to 1970, based on a representative sample of over 1,500 respondents of the inner city. Investigator: Marjorie Cantor, AoA Grant No. AA-4-70-089. Consists of a number of reports.
- "Social and Economic Supports and Family Environment for the Elderly ", awarded to Bowman Gray School of Medicine, Wake Forest University. The study examined the preferences and acceptability of incentives families need to enable them to take care of older members; it is based on two studies of families, care-takers and older persons conducted in Cleveland and Winston-Salem. Investigator: Marvin B. Sussman. AoA Grant No. 90-A-316, report dated January 1979:

"The National Survey of the Aged", awarded to the University of Chicago, describes the elderly population in 1962 and 1975, and measures the changes in their situation. The data is based on two national samples of the 65 and older, non-institutionalized population; the oldest and sickest members however are underepresented. The surveys used comparable questions. AoA Grant No. 90-A-369 Investigator: Ethel Shanas:

The 1977 research guidelines solicited proposals to investigate ways to assist persons to function in caretaker roles. As a result, 9 projects were funded by AoA to last for up to 3 years in the amount of \$2.7 million. The following were available for this analysis:

- Informal and Formal Support Systems and Their Effect on the Lives of the Elderly in Selected Ethnic Communities ", awarded to Catholic University of America. This is a study of 8 white ethnic groups of European origin in the Washington-Baltimore area; the sample includes both the 'elderly and their spokespersons. Investigator: David Guttmann, Acad Grant No. 90-A-1007.
- "Three Generations of Women: Comparisons of Attitudes and Preférences for Stvice Providers "a paper presented by Elaine Brody et al at 32nd annual meeting of Gerontological Society, Washington, D.C., in November 1979. Paper is based on research supported by AoA Grant No 90-A-1277, "The Dependent Elderly and Women,s Changing Roles" conducted by the Philadelphia Geriatric Center.
- "With a Little Help from my Friends", a grant to the American Institute of Research. The study is based on a nationally representative sample of elderly in their seventies who do not suffer severe physical or mental impairement (minority populations underrepresented), and a sample of those who assist the elderly in a regular, informal way; AoA Grant No. 90-A-1320, report dated January 1980. Investigator: Sara E. Rix.
- "The Role of Caregivers in the Black Community ", grant to the Institute for the Study of Human Systems, Inc. A 2-year study in 5 Black communities of a sample of elderly, the informal caregivers, and the formal agencies. Investigators: Brin Hawkins and Solomon Jacobson. AoA Grant No. 90-A-1375. Report undated.
- Preliminary Executive Summary for AoA Grant No. 96-A-1681, "Long-Term Care Decision Making: Institutionalized Elderly", dated March 1980.

 A grant to Georgetown University for a secondary analysis of the 1976
 Survey of Institutionalized Persons conducted by Census Bureau for DHEW.
 Respondents include a nationally representative sample of LTC institutions, (including penal), the residents of these institutions, and a subsample of families of the residents, based on follow-up interviews. Investigator:

 Beth Soldo.

The 1978 guidelines announced only a limited area that relates to the family support system: the decision-making process. However, seven additional projects were funded as a result of the 1979 guidelines; these projects, funded at \$1.1 million, focus on the experiences and problems of caretaker families. The attachment lists the projects funded as a result of these announcements.

Myth of the Demise of the Family Support System

The family is and remains a major provider of assistance and support to the elderly member. This is the most consistent finding brought to light in each one of the studies covered in this report. Documentation of the extent and scope of care is also provided. The extended family still exists, especially in the Spanish and Black communities, and in a modified version in others (Cantor, Hawkins).

The emrging structure of the family is shown by the disappearance of the twoand three-generation families under one roof and the appearance of what Litwak
calls the modified extended family: separately housed but partly dependent nuclear
families which help each other (Cantor). This reduction in structure and physical
isolation does not seem to alter the close familial ties and the the supporting
role that usually characterized the family network; although they are living apart,
half of the elderly parents live within 30 minutes of their children, close enough
for personal interaction. The clearest indication of the emerging structure is shown
by the fact that the number of parents who lived with children or non-relatives
declined for both groups by 50% between 1962 and 1975 (Shanas).

The related myth that the dissolution of the traditional family also brought decrease in interaction is also dispelled: Shanas found that 67% of those 75 and over and severely disabled had seen a child in 24 hours; 3/5 of the elderly in Guttman's study relied on the informal and family network; 81% of the New York Inner City elderly have one easily accessible child and a majority see the nearest child at least once a week (Cantor). The notion that government programs encourage the shirking of family responsibility (what Brody calls the myth of service substitution) does not seem to have much foundation (Brody).

In the three-generational study of women, 80% of the respondents reiterated the myth that today's children do not take care of their elderly as in the past - yet, these same women strongly endorsed the proposition that children should help their own elderly (Brody).

This apparent disparity between perceived public practice and individual behavior seems to underscore the persistance of the traditional value system which guides the family's interaction. Insistance that that their own case is the exception reveals that inpsite of the prevailing public trend as they see it, the family remains a cohesive and resilient unit. Its role continues as it adjusts to emerging trends and pressures and adopts variations to function as needed. In a sense this attitude also implies a rejection of substitute services.

Consonant with the above data is the willingness of the majority of families to take in the elderly, should the need arise; 80% expressed such willingness and 5.6% said they would actually perform that function (Sussman). Paralleling the families'

wiflingness to help the elderly is the elderly's own preference to have the child and the family as primary caretaker (Cantor, Guttman). The nature and extent of family interaction, as will be shown later, also indicates that the family is a viable caretaker unit.

Popular belief to the contrary, filial responsibility is strong. The studies underscore the significance and durability of the emotional bond and intimate ties between parents and children. Both the children and grandchildren put special emphasis on closeness to parent/grandparent (confidant role-Brody). Filial responsibility is recognized by children and is a motivating force for help, especially in ethnic communities (90% of white ethnics had a confident, mostly sons and daughters -Guttman; sense of responsibility and loyalty motivates caregiving in the Black community-Hawkins). For women, the traditional value of family care is linked with the new value emanating from women's increasingly greater work role. Inspite of the "overload" they still feel a sense of obligation to their parents (Brody). The strongest expression of filial responsibility comes from grand-children (Brody).

As long as the myths about the erosion of family ties prevail, and selfless devotion and anonymity of the family's role remains unrecognized, the development of a responsive public policy is hampered. Whatever the reason for the myths, the role of families needs to be portayed in its true dimension and presented forcefully to influence public opinion and decision-making.

Independence and Living Arrangements

The desire to be independent comes through in various ways and is expressed by all the generations. The push for independence is revealed in the emerging family structure (modified extended family) and reflects new lifestyles in housing and living arrangements. Living alone becomes an acceptable lifestyle - the number of married couples living by themselves rose from 79% in 1962 to 84% in 1975; parallel to this was the substantial decline in the number of old living with children or non-relative, noted earlier (Shanas). In the Black community in New York, the number of women living with children is three times higher than in others (Cantor). There is one alarming trend, however: in 1975 34% of the elderly lived alone, and they also had high incapacity scores, as compared to 25% in 1962 (Shanas).

However, living alone is not concomittant of isolation, nor is living arrangement the determining factor of loneliness and the extent of interaction with others. Those in poor health and living with others were nine times as likely as those in good health to report loneliness - those alone and in poor health were twice as likely than those in good health to feel lonely. Loneliness is not necessarily the absence of others, however Feelings of loneliness and the extent of interaction seem more important than living arrangements (Shanas). "Intimacy at a distance" is still a powerful force.

Although not under one roof, the modified extended family lives close to each other and the distance decreases as they become older (Shanas). Interestingly, while the majority live close, 74% of all the generations expressed the belief that adult children should not live close to their parents (Brody) However,

proximity may not be the major determinant of the functionality of relationships - the extent of contact and expressed preferences of both elderly and the children as to who the caretaker should be appear equally important.

Related to the wish to be on their own is the desire not to be a burden to the child, and the reluctance to ask for help(Brody, Cantor); in the Rix study, 1/3 of the elderly felt it difficult to ask for assistance; other family members, especially those in the middle generation, feel that government could replace especially those in the middle generation, feel that government could replace certain type of family help, and actually prefer purchase of service (Brody).

Oldest and youngest generations of women prefer children to be service providers. On the other hand, women in the middle generation would opt for private pay to meet their own needs in old age which indicates a conflict between the emerging norms and value system of the working women and their wish to be independent. They hold on to the view that children should help their parents (the traditional role of family), but they themselves do not want such help the traditional role overload, the wish to spate and to avoid the burden of help pressure of "role overload", the wish to spate and to avoid the burden of help on their own children, and their greater willingness to accept government financial support may partially explain this attitude (Brody). Consonant with these is the middle generation's reluctance (90%) to rely on their children as these is the middle generation's reluctance (90%) to rely on their children as a source of money, in case they need help. The elderly also express a particularly "fierce desire" to remain financially independent - only one-third would turn to their kin, one-third to no-one (Gantor); only 3-4% received money regularly, and 2% had their medical bills paid by the children (Shanas).

Whenever studied, attitudes toward welfare also play a role in the pattern of service provision and the drive toward independence. The nature and saliency of these attitudes have not been explored in these studies, and it is not explored how cognitive and affective factors shape and infuence opinions. In general, non-family help is viewed by the elderly as welfare (Brody); it is considered as a handout; nor are elderly whites and some of the ethnic groups is considered as a handout; nor are elderly whites and some of the ethnic groups willing to accept welfare (Cantor, Guttman). Countering the notion that non-willing to accept welfare, is the belief that the government should provide family services are welfare, is the belief that the government should provide services since they are paying for it through taxes; close to one-half of the services since they are paying for it through taxes; close to one-half of the services since they are paying for it through taxes; close to one-half of the services over ethnic services for this reason; elderly preferred government services over ethnic services for the elderly (Guttman).

The family life cycle also increased, as almost 50% of the elderly were members of four-generation families in 1975, up from 40% in 1962; three out of four were members of multi-generation families, and four out of five had at least one sibling (Shanas). This widening of the family base may have a significant impact on the caretaker function. On the surface, it appears that almost half impact on the caretaker function. On the surface, it appears that almost half impact on the elderly can count on a liger pool of potential resource for assistance of the other hand, the provision of assistance appears to be on an intimate on the other hand, the provision of assistance appears to be on an intimate basis. Shanas found that the presence of more than one child and at least one basis. Shanas found that the presence of more than one child and at least one helping network. On this basis, most of the elderly who have at least one sur-

viving child (60% of the total) can count on such intimate care.

Some 40% of the elderly were widowed, separated, or divorced, and 3% were without family but may have collateral kin. As far as marriage is concerned, men are more likely to be married than women and, as they grow old, men stay married longer.

The proximity of the caretaker is one of the common finding of these studies; as noted earlier, 50% with at least one child had also own household but lived within 30 minutes journey (Shanas); in New York, 63% of the Black children lived within city limits, 30% being in the same household or in the immediate neighborhood (in sharp contrast to the South were 50% of children lived out-of-State - Cantor); about half of these children are seen by their mothers at least weekly; however, 40% of the women have not had a surviving child. This seems to run contrary to the myth that Black women abandon their children. The interaction between Black children and their mothers in support of each others seems to be extensive, and, as Canter opines, suggests that the Northern ghetto life marked by crowded conditions and proximity may be more conducive to familial interdependence than in Southern cities.

In addition to the drive for independence, all generations express the need for love, intimacy, solidarity and close personal relationships; matching this feeling about the viability of familial ties are the salient attitudes and preferences expressed by both groups regarding the primary source of help: the children. The presistance of the emotional bond and sense of interdependence seems to override the rise in the physical separation of the extended family. Thus, Sussman maintains that it is precisely the exchange and the reciprocity of these relationships which serve as a "...major dose of preventive medicine..", contributing to life satisfaction and the genfal well-being of all concerned.

Cultural, racial and ethnic factors play unique parts in shaping the family role. Certain ethnic groups (Italians, for one) maintain close family ties, regardless of differences in attitudes, or in social, economic and educational status between parents and children; in other groups (notably Eastern European Jews), these differences and the desire for independence may override the family bond, and may trigger a preference for formal services rather than reliance on the family (Brody).

The changing or transitional structure of the family, the various normative prescriptions and role expectations of society, undoubtedly affect the emiging pattern of family relationships. So are, also, the major shifts in longevity and the growing number of of the old and old-old, the rise in employment of women of middle age, and the graying of the adult child. What is the nature and impact of these forces needs further study.

Ancentives |

The two studies reported by Sussman focus on finding out what types of assistance or help families prefer to enable them to provide better care for the elderly, and whether they would participate in government programs providing help to caretaker families. The respondents were older persons and their caretakers. Two types of supports were presented - financial and service programsfor selection and ranking. The monthly check (\$200-400) proved to be the most popular financial support (45 to 61% in Winston Salem (WS) and 68% in Cleveland) Least popular were the rental allowance/tax deduction and the low cost home improvement loan. Preference for food stamps was low for the groups, and uneven among the various samples - it was rated last witherent allowance/tax deduction by one of the samples in WS, while in Cleveland it was fourth out of the five items presented; when asked about the least liked supports, food stamps were rated last by four samples and renallowance/tax deduction was last for one sample.

The preference for medical care was the clear-cut first choice of all of the samples in both studies over three other choices of service programs (67% in Cleveland and a range from 23 to 26% in WS); homemaker service was the second most liked in all, except one sample group in WS, followed by the social center as third choice; conversely, least preference was given to the social center among all but one of the samples.

Considered together, the two top ranked choices among the financial and service support programs were the monthly check and medical care. The combined results of the studies show a slight preference for social programs in WS and for financial support in Cleveland. The modest number of service agencies in WS, contrasted with an abundant number in Cleveland may partly explain the difference.

Those who had actually cared for the elderly emphasized quality medical care and the social center as the most desirable support programs - only 11% of them voted for the monthly check - a clear indication that relief for and help with caring represent the kind of help that would maximize caretaker ability; they also expressed a desire to reduce "their psychic input "to make their lives less harried.

Willingness to participate in government programs to help families take care of their old members was overwhelmingly endorsed (over 90%) in both studies, and .56% in fact indicated that they would participate in such programs. Those who completed at least high-school and who had no religious preference, as well as Black persons were more likely to see the government take responsibility for the elderly; Catholics and Protestants felt strongly that that responsibility belongs to the family. The preference for government intervention was also expressed by the ethnic groups studied by Guttman; half of them voted for such help.

ERIC Full Text Provided by ERIC

- 8

Another area explored by the two studies was willingness to take in the older person. Over 80% in both studies expressed such willingness under some circumstances. Those saying "no", favored government programs first, stating that only as the last resort should families care for their elderly. Willingness is further conditioned on perceived difficulties and the feeling of the spouse. Duration of marriage and age are two other variables, but they affect willingness negatively - the loger married and the older, the least likely to be willing to take in older persons. Background, income and other socio-demographic variables do not seem to have perceptive influence. Another finding is the difference in willingness expressed by men, women and couples: women are lowest in unwillingness, followed by men and couples; the ranking is the same for the highest level of willingness. These variables which influence willingness should receive commesurate consideration in designing programs and in involving the family and relatives in caretaking activities.

As far as costs are concerned, the two studies reveal a progression in expenses starting with home care and leading to private or public institutions. It is cheaper to care for a person who lives with family than one who lives in the neighborhood; most costly is hospitalization; costs however do not take into account any value that may be associated with intangible benefits flowing from love, intimacy, solidarity and enhanced quality of life. Yet, although not measured, these intangible benefits do produce definite economic savings (Sussman).

Nature of Contacts and Help

Most older persons in their seventies and even in their eighties are coping with basic life management tasks with only minor assistance from others - the help they received was mainly to enhance the quality of life - most would rely on the family network for help if needed (Rix, Shanas, Cantor, Guttman, Sussman, Hawkins, Brody).

Family contacts increase with need and age - 67% of those 75 and older with high incapacity scores had seen a child in the last 24 hours, compared to 36% of those 65-69; the rate for those 80 and over was 79%. The majority of the 6 elderly are in daily/weekly contact with at least one child; the purpose of contact is to visit, share activities and help (Shanas). In New York City 87% of those who had at least one child reported one or more type of help from them (Cantor). Household and maintenance tasks compose the major areas of help by relatives - 85% cook, 69% do laundry, 65% shop, 62% clean (Rix) - the other studies quote similar findings. Children of Black women in New York gave gifts to 80% to and helped 75% of their elderly mothers who were ill or needed shopping (Cantor). In five Black communities, over 50% of the caretakers did shopping, cooking, escort and visitation (Hawkins). In general, women are the major providers of help, with spouses and daughters providing the most.

Men seem to get considerably more help than women - Rix found that five times as many women as men did not get help with cleaning, and four times as many did not get help with cooking.

In ethnic communities 3/5 of the elderly relied on the informal and family support system, and 80% who had children frequented them often; life satisfaction was tied closely to family life, and for one-third of them good family life meant happiness (Guttman). Benefits of multi-generational households were even more pronounced in the Black communities - it offered, besides help, a reassuring, psychologically supporting environment (Cantor). Contrary to stereotypes, Black women do get help from children and augmented family - 86% received help from their offspring, and 80% of the children gave gifts and 75% helped in

In case of illness, emergency, or crisis, the family is the major provider of help (Cantor, Hawkins, Shanas). In the two national surveys by Shanas, 67% reported help from children. The family also attends regularly to personal care needs, household tasks required to keep the elderly in the community. Regularity of contact, intimacy, emotional interdependence, and the idiosyncratic and personal nature of tasks and help are key features of the family caretaker function.

illness and with other chores (Cantor).

In meeting the prolonged needs of the seriously impaired, the family is motivated by a sense of responsibility (Hawkins). In many instances, the family is also the last resort for those who no longer can be kept in institutions. Spouse was the major help to the bedfast. Help by children, however, declined, some of it being replaced by paid helpers. This trend was the result of several factors: bedfast likely to be older, and caring children also older; they may be physically less able to help; more middle aged women took jobs (Shanas). Younger children believed that responsibility should be shared more equally between sons and daughters, and younger women are more likely to believe that adult children with own families should do household tasks for their elder parents (Brody). "Intimacy at a distance" seems very much alive.

That there is a limit as to the type and duration of the help families can provide is shown by the fact that incontinence is a deciding factor in institutionalizing the elderly parent - the family does not seem to be equipped to cope with such problems; regardless of the functional ability of the older person, in case of incontinence the family is likely to opt for institutional placement (Shanas). The decision to institutionalize the elderly person seems to be a family affair: in 41% of the cases it was the older person or the spouse who made the decision, and in 47% of the cases the family member, excluding spouse decided the placement; only 12% of admissions were non-family. The referral network which recommends the long-term care facility is also dominated by the informal-system; only 46% of the referrals are by the formal network (Soldo).

Assistance is not a one way street. There is considerable reciprocity among the elderly and their offsprings and relatives. Help by parents increased from 60 % to 71% between 1962 and 1975, and so did help to grandchildren (Shanas). In New York City, 62% of the parents gave gifts, 52% intervened in illness or crisis, 34% took care of grandchildren; in all 80% of Black women provided one or more instrumental and affective help to their children (Cantor). Steady exchange of help was also characteristic in white ethnic communities (Guttman).

Discussion

Although not conclusive, the findings of this small-scale study are strongly suggestive of the family's current caretaker role. The major consistent finding is that the family is and remains the primary and major provider of support to the elderly mebers in times of illness, emergency, or crisis as well as for help with emotional, psychological and other dependency needs. This is even more! remarkable in view of the enormity of the social, economic demographic and technological changes which brought about the disappearance of the extended family, the graying of America, the rise in women's employment, and the correlated or concomitant changes in attitudes, lifestyles and values. In fact, the constancy of the familial bond does not seem to be affected by the emerging normative values and roles which, as perceived or expressed by the public at large, run counter to actual family behavior. The family seems to have enormous potential to be flexible and to adjust its behavior to carry out its mission in a vastly changing environment: caretaking seems no longer to be solely a function of living tagether but on living nearby; intimacy at a distance, frequency of contacts and mutual expectations are at the core of caretaker activity.

The results also dispell a number of widely held myths about the demise of the family support system: the erosion of filial responsibility, the thankless child syndrome, and the break up of the family as a social and caretaker unit. However, as long as these myths prevail, and selfless devotion and anonymity, the family's role remain unrecognized, the development of a responsive public policy is virtually impossible. The role of families needs to be portrayed in its true dimension and presented forcefully to influence public opinion and decision-making.

Another finding is the close connection between conjugal families, composed of old and young, interacting and supporting each other. Mutuality of relationships and reciprocity make the connection viable. The emergenyce of the four-generation family creates both an additional burden and enlarged roles, and seems to extend the potential pool of available help for about 50% of the elderly.

The analysis does not offer insight into the affect public policy may have on the family. The creation of a host of public programs in the last two decades refelected an assumption of more responsibility for certain segments of the population; Some of these such as the freeing of child responsibility, SSI, Medicare, etc. undoubtedly benefited the elderly. However, the majority of families and the elderly studied have not benefited from these, although many express preference for appropriate governmental assistance to help ease the caretaking burden. If policy depends in part on expectations and preferences, than the family ought to be at the center of national policy. Such is not the case, and the present off-hands policy may have had the unintended impact of discouraging this role. The fact that only three States have started programs of their own to support the caretaker family underscores the lack of Federal initiative in this area. Yet the data show preference by families for outside support ! Assistance to cope with incontinence offers perhaps the best example of the need for appropriate intervention consisting of medications, new technological devices, or simply competency building on the part of families. Providing such assistance is likely to prevent unnecessary institutionalization. On balance, it appears that even without outside help, or

with insufficient resources families will continue to care for their elderly members at home as long as they can.

Apart from policy, the analysis also has/implications for service providers: preferences, attitudes and behavior of families may be more important than other demographic data in program planning and development; needs assessment needs to go beyond the routine data to cover all aspects of the family support system. In this way services can be designed to complement the humane, responsive, intimate caring only the family can provide; providers need to work with families to enable them to deal with and use the system, to refine their caretaking role and to recognize their own limitations. The formal and the family support systems need to work in balance, sharing the responsibility for the care provided.

Concurrently, more research is needed to see how incentives work, how to determine and meet family caretaking needs, and to find out about burn-out and tolerance levels beyond which caretaking becomes " maltaking ". Different approaches and techniques need to be developed and tested in large-scale demonstration programs in different parts of the country and with different types of populations.

Finally, it seems the question is no longer whether to support the family but how and through what means and support can the ability of this mediating structure be enhanced to continue its crucial role in keeping elderly members at home and out of institutions. After all, the family may be as much in need of help as the elderly person it is caring for.

ATTACHMENT

List of AoA Research Projects on the Family Support System,
Funded in Fiscal Years 1978-1980

	Organization and Title of Project
Grant No.	
90-A-1007	Catholic University of America; "Informal and Formal Support Systems and Their Effect on the Lives of the Elderly in Selected Ethnic Communities". Completed.
90-A-1277	Philadelphia Geriatric Center; "The Dependent Elderly and Women's Changing Roles ": Preliminary report.
90 - <u>A</u> -1290	National Center on the Black Aged; "Informal Social Networks in Support of Elderly Balcks in the Black Belt of the U.S. ".
90-A-1294	Hebrew Rehabilitation Centerfor Aged; " A Study of the Informal Network of the Needy Elderly".
90-A-1320	American Institutes for Research; "With a Little Help from my Friends". Completed.
90-A-1329	Fordham University at Lincoln Center; "The Impact of the Entry of the Formal Organizations on Existing Networks of Older Americans ".
90-A-1375	The Institute for the Study of Human Systems, Inc., "Case Studies of the Potential of Persons in the Environment of the Min fity Elderly to Act in Supportive Caregiving and Community Integrative Roles"
90-A-1679	Levinson Policy Institute; " Decision-making for Home Care ".
90-A-1681	Georgetown University; "Long Term Care Decision Making: Institutionalized Elderly". Preliminary report.
90-AR-2069	Ohio University; "Kanship and Community Support and Information Systems of the Rural Elderly in Meigs County, Ohio ".
90-AR-2076	Whatcom Counseling and Psychiatric Clinic; "Families as Caretakers of the Elderly: A Comparison of Rural Indian and White Families ".
90-AR-2081	Duke University; " A Survey of Families Providing Home Care to Chronically Ill Elderly Relatives ".
90-AR-2112	Benjamin Rose Institute; "Effects on Families of Caring for Impaired Elderly Residing in Residence".
90-AR-2124	Georgetown University; "Families as Caregivers of the Elderly: Structural and Geographic Variations".
90-AR-2174	Philadelphia Geriatric Center; "Women in the Middle and Care of the . Dependent Elderly ".
90-AR-0014	Asociacion Nacional Pro Persones Mayores; Hispanic Support Systems and the Chronically Ill Older Hispanic ".