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## Issues in Family Care of the Elderly: Characteristics of Care, Burden on Family Members and Support Programs

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# **Executive Summary**

## **1. Background**

This report addresses the care of elderly persons by their families. The report provides a conceptual framework for examining the system of informal support, and presents selected findings from the international literature on informal support. It also provides information amassed from studies conducted in Israel in recent years concerning the characteristics of people who care for an elderly relative, the types of care they provide, and the burden of care and its effect on the entire family. The report also surveys the entitlements for those who provide support, and describes selected programs in Israel and abroad that demonstrate major trends. These provide background for strategic thinking about this issue in Israel.

### **1.1 Why the Growing Interest in Family Care of the Elderly?**

In recent years, policymakers and service planners have become more interested in finding ways to support informal care providers, for several reasons:

- ◆ Most of the care for the elderly is provided by informal caregivers, most of whom are family. Studies conducted in Israel and elsewhere among disabled elderly reveal that informal care has remained extensive despite the accelerated development of the formal service system. Informal support is provided in a range of areas, such as activities of daily living (ADL, e.g., washing and dressing); household management (IADL; e.g., preparing meals and shopping); and emotional and social support. Moreover, family members now often provide support in areas that were, until recently, the domain of professional caregivers. For example, due to the shortening of hospital stays, families now care for the elderly during their convalescence from an acute illness, sometimes even when the elderly still require acute treatment. Furthermore, as life expectancy increases, care providers are increasingly called upon to confront end-of-life care at home. The care provided by informal caregivers has thus become more complex, requiring them to have understanding, knowledge and skills in a broad range of areas.
- ◆ Recent demographic, epidemiological and social changes also challenge the informal care system. For example, the aging of the population, changes in family structure, and the entry of increasing numbers of women into the labor market all affect the ability of a family to cope with the aging of a relative. In addition, for the first time in history, due to rising life expectancy and dropping birth rates, the average married couple may have more parents than children. While family care of sick and disabled relatives is by no means a new phenomenon, and has indeed typified most societies throughout history, it is now being provided for longer periods. Furthermore, it is increasingly likely that most individuals will at some time play the role of caregiver; thus, caring for disabled and sick elderly relatives is relevant to all.
- ◆ There is consensus that extensive informal help enables many elderly to remain in the community, thereby postponing or averting institutionalization. Not only do most elderly prefer to remain at home, and most professionals believe that this is important to maintaining

their quality of life, but also provision of care at home saves public resources. For these reasons, policymakers, service planners and professionals view informal care of the elderly as extremely important, and wish to preserve it as a social resource.

- ◆ Professional caregivers are increasingly aware of the advantage of training family to provide care (which they are providing in any case), so as to improve its effectiveness and quality.
- ◆ Research findings have raised the awareness of professionals to the fact that burnout and the heavy burden on the families may lead to aggressive behaviors toward the elderly and even to physical and mental abuse. To prevent these phenomena, it is necessary to support family caregivers.
- ◆ Evidence is increasing of the negative implications of the burden resulting from caregiving on the family. Professionals are becoming more aware that caring for an elderly relative can significantly undermine the quality of life, as well as the physical and mental health, of the caregiver.

## **2. Characteristics of Informal Supporters**

As noted, the system of informal support for the elderly is composed primarily of relatives. Even when the family is a large one, one member usually takes on more responsibility than the others. Most of the literature focuses on this person, known as the "primary caregiver". An examination of primary caregivers in Israel shows diversity in their characteristics and needs.

- ◆ In most cases, the primary caregiver is either the spouse or a child of the elderly person. Studies conducted in Israel have revealed that the primary informal caregiver of chronically disabled elderly (for example, among those receiving home-care services under the Community Long-term Care Insurance (CLTCI) Law) is most often a child (two-thirds) and relatively less often a spouse (between one-quarter and one-fifth). However, the primary informal caregiver of elderly who require care during the acute stages of a disease (such as patients in home hospital units) is more often the spouse (about half), and relatively less often a child (about one-third). These differences can be explained in part by the elderly person's age, the presence of a spouse, and the spouse's ability to function as caregiver.
- ◆ Most primary caregivers live with, or in proximity to, their elderly relative.
- ◆ Most (two-thirds) primary caregivers are women.
- ◆ Although the average age of primary caregivers is 55, their range of ages is broad: Between one-third and half are ages 45-59, one-third are age 60 or over, and between one-fifth and one-third are age 44 or under.
- ◆ Caregivers' health affects the level of support they can provide and their ability to cope with burden and stress. It should be noted that caregiving itself may adversely affect health. Studies have shown that about half of caregivers define their health status as poor. In addition, one-third of them report suffering from functional disabilities (this is especially true of spouses, who are themselves at advanced ages).

### **3. The Nature of the Support Provided by Primary Caregivers**

#### **3.1 Types of Support**

In Israel, there is no strict division of roles between the formal and informal support systems. In fact, the prevailing model is that formal care does not replace informal care, but rather supplements it as the following descriptions indicate:

- ◆ Personal care. This includes assistance with washing, dressing, eating, mobility in the home, going to the bathroom, and all other ADLs. Interestingly, studies have shown that even when a formal caregiver is employed – including for 24 hours a day – relatives still help with personal care. It thus appears that care of the disabled elderly – especially those who are severely disabled – requires the support of more than one person.
- ◆ Household management. This includes cleaning, cooking, laundry and all other household chores. Most caregivers provide extensive assistance in these areas. When the caregivers live with the elderly person, they often manage the household for all of its residents. Sometimes, however, the elderly person's condition necessitates performing additional tasks, such as preparing special meals or doing more laundry (if the elderly person is incontinent).
- ◆ Errands outside the home. This includes going to the bank and post office, purchasing medications, and accompanying the elderly to medical treatments. Studies revealed that most caregivers provide such assistance.
- ◆ Help with medical care. Studies have shown that caregivers usually help the elderly person take his or her medications. Many also provide more complex medical care, such as changing bandages, catheters or stomas, and giving injections.
- ◆ Mediating between the elderly and other community services. This is another important role assumed by caregivers, particularly when the elderly person has difficulty with daily functioning.
- ◆ Financial support. Nearly all caregivers provide some financial support and participate in the expense of caring for their elderly relative.

#### **3.2 The Extent of Support**

The number of weekly hours of support provided by caregivers is also significant. Several studies that attempted to measure the extent of support found that caregivers had difficulty in reporting the exact number of hours they spent providing care. This may in part be because activities such as household management are carried out for all members of the household (even if additional effort is required to meet the elderly person's special needs). More important, however, is that support is provided whenever the need arises (such as when the elderly person has to go to the bathroom). Moreover, the support required is often that the caregiver be at home because the elderly person cannot be left alone. Consequently, many studies have found that caregivers report helping their relative "all the time". One study, which evaluated the number of monthly hours of assistance to an elderly relative with dementia (including coping with behavioral and psychological symptoms, providing personal care, managing the household, and monitoring the patient) found that primary caregivers invested 210 hours a month in care, and that secondary caregivers invested 55 hours a month.

## **4. The Effect of Caregiving on the Family and on Unmet Needs**

### **4.1 The Effect of Caregiving**

Although the burden on informal caregivers has been studied since the early 1980s, investigation has intensified in recent years, and includes a broader examination of the whole range of aspects involved in caregiving and of its effects on the employment, personal, family and social life, and health of primary caregivers.

A significant part of the literature is based on sociological and psychological models of stress. Many studies have thus examined the negative aspects of care provision, to identify caregivers who are at risk and develop models linking the causes of stress to the characteristics that engender them. Recently, however, attention has also begun to be paid to the positive aspects of providing support, including the caregivers' feelings that they are of help to their relative, that they are needed, and that caregiving adds a new facet to their life.

As noted, there is much literature on the effects of caregiving; findings from major studies conducted in Israel and elsewhere are presented in this report. The following are selected findings from studies recently conducted in Israel.

- ◆ A significant percentage (between half and two-thirds, depending on the population) of primary caregivers report feeling burdened. According to various studies, more than two-thirds of caregivers report having physical difficulties (caregiving requires too great a physical effort and adversely affects their health); more than two-thirds report that their social and leisure activities have suffered (caregiving leaves the caregivers little time for themselves or their family); over 90% of caregivers report emotional stress (caregiving increases tension in the caregiver's own home, or the relative's condition worries and upsets the caregiver).
- ◆ The following have been found to affect a caregiver's sense of burden: the elderly person's characteristics and level of disability or illness; the characteristics of the caregiver himself (age, gender, relation to the elderly person, marital status and employment); the existence of a support network (e.g., whether there are other caregivers); and the existence of a formal support system.
- ◆ Several studies found that a sense of burden was related to the elderly person's level of disability or illness: The greater the disability, the greater the sense of burden of the primary caregiver.
- ◆ The burden on spouses who serve as caregivers is greater than that on children. Not only are spouses themselves older, and in some cases suffer from poor health or physical difficulties that make it hard for them to provide care, but also their sense of commitment seems to be deeper; and their physical proximity to the elderly person means they are more exposed to his need for assistance. Some studies have also found that when the primary caregiver is the spouse, other family members are less involved in caregiving.
- ◆ Shared living affects primary caregivers even if they are not the spouse: Caregivers who live with a disabled relative tend to report a greater sense of burden. One reason for this may be

that assistance is not time-bound, such that the caregiver may have particular difficulty finding time for other roles.

- ◆ When other informal caregivers are involved, the primary caregiver tends to report a lesser sense of burden. This is particularly true when another relative can replace the primary caregiver during a vacation or illness.
- ◆ Studies have found a connection between self-reported health status and sense of burden: Caregivers who assess their own health as being fair to poor also report a greater sense of burden than do caregivers who assess their health as being good. A relationship was also found between sense of burden and the caregiver's characteristics and mental state. For example, caregivers who are at risk of depression report a greater sense of burden. This relationship can be explained in two directions: Caregivers whose health and mental state are poor may also feel more burdened and, conversely, their greater sense of burden may adversely affect their health and mental state.
- ◆ Studies in Israel have shown that caregiving also has implications for the caregiver's participation in the labor force, and for the working life of those who are employed. Between one-third and a half of all caregivers are employed; the percentage increases to 75% among caregivers who have not yet reached retirement age. A considerable proportion (14%-25%) of caregivers who are not employed report having left their job because of the need to care for their relative. The number of work hours of those who are employed is also affected. For example, a significant percentage (some 40%) of caregivers report working fewer hours than they would like, and 40%-50% report actually missing work days or hours. Moreover, caregivers report that they are often preoccupied with errands or concern for their relative during work hours, and this affects the quality of their work.

## 4.2 Unmet Needs

Studies have also addressed the unmet needs of caregivers, and the additional services they require. It is difficult to separate the elderly person's unmet needs from those of the caregiver, since any improvement in the care received by the former affects the quality of life of the latter. For example, provision of more formal hours of care would alleviate the burden on the informal caregiver. Caregivers cited unmet needs in the following areas:

- ◆ Home care. Caregivers report a need for more hours of formal care by a home caregiver. Sometimes what is required is a change in the mode of providing assistance, rather than in its extent. Some caregivers report wanting more freedom to select the services their relative will receive, while others report preferring a monetary benefit that would enable them to purchase the services their relative needs.
- ◆ Day-care center. Several studies have found that caregivers of elderly people who do not attend a day-care center or other social framework would like their relative to do so. These studies indicated a problem with caregivers' knowledge and awareness of the community services and choices available to them.

- ◆ Information, counseling, instruction and training. A relatively small percentage of caregivers have received counseling and instruction about caring for their relative. Caregivers expressed a need for information about their relative's medical condition and about the service system. Many also asked for information and instruction on coping with their relative's condition.
- ◆ Emotional support. Caregivers have expressed interest in receiving psychosocial support, which will enable them to continue functioning as caregivers. Studies have found unmet needs for emotional support.
- ◆ Respite care. Caregivers report a need for "time-out" from caregiving. A need to find solutions to this problem was discovered by several studies.
- ◆ Volunteers. Studies have revealed that only a small percentage of elderly are visited by a volunteer. A significant number of caregivers have expressed a wish for help from volunteers.

## **5. Strategies and Types of Support for Family Caregivers**

In general, there are two ways to alleviate the burden on family caregivers:

- ◆ Provide direct formal services for the elderly (e.g., a home caregiver, a day-care center).
- ◆ Provide direct services to caregivers (e.g., financial assistance or emotional support).

These two ways affect one another and contribute to meeting the needs of both the elderly and their caregivers. Direct help for the elderly not only meets their needs, but also alleviates the burden on their family. Similarly, direct support for the caregivers improves the efficiency and quality of the care they provide.

This report did not address services for the elderly, but rather focused on direct services for primary caregivers. It is interesting to note that, in the past, the formal subsidized help provided by public agencies in most service systems in the world focused on elderly people who had no family or a dysfunctional family; it was only in these cases that society felt responsible for the welfare of the elderly. The coverage provided by service systems today is much broader, recognizing that the family alone cannot carry the entire burden of care, and that too much of a burden has ramifications for society. In fact, assistance to the family is now official policy, affecting the development of formal services for the elderly. However, until recently, informal caregivers were viewed with a great deal of ambivalence, and the needs of the elderly were the focus of service systems.

The current tendency is to pay more attention to caregivers as a target population of the service system. Increasingly, efforts are being made to identify their needs, out of concern for their physical and mental health. This tendency has been accompanied by changes in how professionals perceive primary caregivers: Whereas they once focused on the caregivers' sense of burden, they are now paying greater attention to the positive effect of caregiving on caregivers and much more emphasis is placed by professionals on giving caregivers a sense of security and support, developing their skills, and enhancing their ability to cope.

## **Types of Intervention**

In general, support programs for family caregivers can be classified according to their principal goals:

- ◆ Financial support
- ◆ Information and referral
- ◆ Case management
- ◆ Development of skills, training and instruction
- ◆ Counseling and emotional support
- ◆ Respite care (enabling a time-out from caring)
- ◆ Arrangements to do with employment and work.

Below we present the types of support available to caregivers in Israel, and examples of intervention programs used in other countries.

### **5.1 The Status of Informal Caregivers in Israel: Laws, Programs and Policy**

This report includes a section on current Israeli policy regarding family caregivers, including their obligations and rights. The following are highlights:

- ◆ The service system sees the family as primary agent of the elderly person's well-being and welfare, and formal services as supplementary. Moreover, in Israel, family members are legally obligated toward their elderly relatives: Israel is one of the few countries in which the obligation of children toward their elderly parents is anchored in law. Not only are elderly persons entitled to demand subsistence payments from their relatives, but in principle government offices may also require families to care for an elderly relative before they agree to supply formal services. As long as the elderly remain in the community, the government rarely exercises its right to require their family to care for them. However, they do demand that families fulfill their legal obligation to finance the residence of an elderly relative in a long-term care institution.
- ◆ The situation regarding medical care is more complex. New technologies make it possible to supply complicated treatments (e.g., an intravenous drip, a respirator) in the home. This is also compatible with the prevailing view that it is best for a patient to be at home. Accordingly, Israel's Ministry of Health has published instructions for family members on performing relatively complex medical procedures – such as a tracheotomy and tubal feeding – at home.
- ◆ One of the family's main tasks is to represent the elderly person to service providers. In some cases, such as when a legal guardian has been appointed or power of attorney has been granted, this is defined by law. In other cases, the caregiver's role as mediator grows out of the dynamic among the elderly person, the family, and the service system.
- ◆ The legal rights of family caregivers center on finances and employment. Four laws govern caregiving by a relative:

- An individual is entitled to miss up to 6 annual work days because of the illness of a parent or spouse; these are considered "sick days" (Sick Day Payment Law 1993, 1995).
- An individual is entitled to compensation from his employer if he resigns because of a relative's poor health (Section 6 of the Compensations Law 1963).
- A tax exemption is granted to individuals who help finance a parent's placement in an institution (Section 44 of the Income Tax Law 1980).
- An individual is entitled to an income supplement without undergoing an employment test if he cares for a sick relative (Section 2,7 of the Income Tax Law 1980).

No data are available on the extent to which family caregivers of the elderly take advantage of these benefits. Moreover, it is not clear whether the public in general, employers, and family caregivers are aware that these benefits exist. Furthermore, the definition of eligibility for these benefits is narrow and is not uniformly applied. Under most of these laws, the elderly person's spouse and children are eligible for benefits but other relatives are not, even if they take part in caregiving. Also, the definition of "disability" that entitles a caregiver to miss work is strict: An employee is entitled to sick days only if his relative is disabled in all six ADLs. In other words, only if an elderly relative is completely dependent in ADL may his family caregivers miss work without having their pay docked and this only for a few days.

- ◆ Direct support of other kinds for family caregivers is limited. Some local programs exist for caregivers, but the national government has not devised comprehensive programs to directly support family caregivers. For example, no clear guidelines exist in the Ministry of Social Affairs guidelines for social workers and therefore local government is not obligated to offer programs, and these remain dependent on the good will and the availability of a budget. Nevertheless, important initiatives have been introduced, such as the counseling and information services provided by Reut-ESHEL.

## **5.2 Direct Support for Family Caregivers in Other Countries**

Two sections of this report are devoted to the situation in other countries, as a means of outlining the major trends. One section presents the general policy, financial support and rights of informal caregivers in several countries and the other describes specific programs in several countries, which directly support family caregivers.

### ***5.2.1 Policy and Rights – Financial Support***

Countries differ greatly in the policy governing types of support for informal caregivers. This is reflected in laws, work arrangements, and types of monetary benefit (such as pensions and tax exemptions). The following summary outlines general practices and trends:

- ◆ Monetary benefits
  - ***Direct monetary support.*** Several countries give family caregivers of elderly and disabled relatives direct monetary support. In England, for example, caregivers have been entitled, since the 1970s, to monetary support under a program currently known as

the Carers Allowance. In Australia, caregiving spouses have received monetary support since 1983 under the Spouse Carers Pension; this law was expanded in 1985 to include other caregivers (Carer Payment). In Sweden, a primary caregiver can receive payment equal to that received by formal caregivers, including all social benefits (the Carer Allowance). Germany does not offer a direct monetary support to caregivers, but under the Social Dependency Insurance Law enacted in 1995, disabled persons are entitled to monetary benefits; in fact, family caregivers can receive payment for the assistance they provide. Interestingly, this law also entitles a person who has provided care to a relative for one year to receive an alternative service: respite care. This includes an alternative caregiver for up to four weeks, or temporary, short-term placement of the disabled relative in an institution.

- ***Tax exemptions and discounts.*** One of the most common forms of support for family caregivers is tax exemptions and reductions. These may take the form of a reduction in property taxes (in England) or in income tax (the US, Australia, Canada, and The Netherlands).
- ***Old age allowances.*** In some countries, being a caregiver entitles a person to an old age allowance or to a reduction in the number of years required for saving up for a pension (England, Germany, Sweden).
- ◆ Work arrangements or holidays for family caregivers. All of the countries we examined enable caregivers to take time off from work to care for an elderly or disabled relative. However, the types of arrangement differ greatly. We would note that, in some countries, a work culture is developing that gives greater consideration to the needs of the caregiver.
- ◆ Laws and other arrangements. During the past decade, a number of interesting initiatives have developed in the following countries:
  - ***England.*** According to the 1995 Caregivers Law, caregivers are entitled to a needs assessment by the social services, in which their needs – as well as those of their disabled relative – are identified. This assessment is the basis for the formulation of a care plan.
  - In 1999, England introduced a national strategy concerning caregivers, whose main points are a survey of existing sources of support for them, and of their needs for information, support and treatment (National Strategy for Carers, 1999).
  - In 2000, the Carers and Disabled Children Act was passed. This law includes a section on monetary benefits, which allows local councils to supply some services directly to caregivers.
  - ***The US.*** In 2000, the federal National Family Caregivers Support Program (NFCSP) was initiated. This recognizes the needs of caregivers in the community. The program, implemented under an amendment to the Older Americans Act (OAA), requires all states that offer support services for caregivers to supply information, support, counseling and respite services. Monies are allocated to states according to a formula set by Congress, which takes into account the relative share of residents of the state

who are over age 70. In 2001, the Administration on Aging allocated \$110.9 million; this allocation increased by 25% in 2003, amounting to \$138 million dollars.

- **Australia.** In 1966, the federal government initiated a national plan to supply temporary alternative solutions to families, in response to the need of primary caregivers for a respite from caregiving (The National Respite for Carers Program). This program is implemented through Carer Resource Centers, which supply information, referral, counseling and assistance to caregivers. Similar centers are part of a national organization of caregivers in Australia (Carers Australia) which has branches in each state and region, and which is funded by the government of Australia.
- ◆ Caregivers' organizations. Several countries have caregivers' organizations that are well-organized and have political clout. Usually, one national caregivers' organization or umbrella organization exists alongside a large number of local organizations. These organizations advance the interests of caregivers, promote laws and work arrangements, disseminate information to the public, and provide information and counseling to families. Interestingly, in England, the most important umbrella organization – Carers UK – receives considerable funding (about 60% of its budget) from the government.

### **5.2.2 Special Programs and Services**

This report includes a description of eleven programs implemented around the world that provide other types of assistance apart from financial support to caregivers. To demonstrate possible avenues of action, we included a variety of types of program, which provide information, training and skills, case management, social and emotional support, empowerment, and respite care. We chose to present programs which, on one hand, appeared to be innovative, and, on the other, had been accompanied by evaluation studies and were found to be valuable to caregivers.

Some of these programs developed aids, such as instruction manuals and evaluation tools. Most of them are implemented by non-profit organizations, although some operate in partnership with national and local government agencies and involve both professionals from a variety of disciplines and volunteers. Their sources of funding are diverse and sometimes integrate government funds, donations, and payment from participants. Several programs use technologies to create support networks via the computer.

## **6. Selected Issues**

Following are issues that should be considered when developing policies and programs for families caring for an elderly relative:

1. There seems to be a need to develop appropriate tools to assess the situation of informal caregivers, including their sense of burden, as a basis for formulating programs for professional intervention. These tools may also facilitate identifying at-risk groups and monitoring the situation of caregivers over time.
2. Support for informal caregivers entails developing a variety of intervention programs, which reflect caregivers' needs for information, counseling, skills, case management, social and

emotional support, respite, and financial support. Setting priorities for the development of intervention programs could be based in part on identifying the greatest gaps. At present, emphasis seems to be more on counseling and information, and less on training and practical instruction or social and emotional support.

3. Dying and end-of-life care are not currently receiving sufficient attention. In addition, although most support is geared towards the caregivers of elderly people living in the community, a need exists for counseling, instruction, and other assistance for families who are placing or have placed their relative in an institution; and later to assess the needs of family members who support a relative residing in an institution. It is also important to examine the needs of informal caregivers after the death of a relative for whom they have cared, particularly widowed spouses.
4. When developing interventions, it is important to address the differential needs of the individual receiving the care arising from their characteristics (physical disability, dementia, behavior problems, acute illnesses) and from the characteristics of the caregiver (relation to the patient, living arrangement, age, gender, marital status, employment). It is also important to consider the cultural diversity of population groups in Israel.
5. In-depth examination is recommended of how to use the current service system infrastructure to enhance interventions to support and assist family caregivers (e.g., home visits by nurses and social workers).
6. It is important to identify potential desirable avenues for developing policy, which may be reflected in law as subsidies, tax exemptions, or work arrangements. It is also important to examine how to increase the awareness of the public, service providers, and others (such as employers), so that caregivers may realize their rights (e.g., their entitlement to sick leave).

This report serves as a basis for the development of a variety of programs by ESHEL and other public organizations.

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