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Response of Formal Support Systems to Social Changes and Patterns of Caring for the Elderly

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ABSTRACT

While it has been repeatedly recognized that family care and responsibility is the mainstay of community-based long-term care, formal support strategy has generally been based on a general policy of providing services when family care is absent or inadequate. A tacit presumption of such policy is that, in spite of the increasing burden of care, the family is considered a free resource.

Against the background of rapidly increasing needs of disabled elderly it is necessary to formulate policy in planning formal support based on an understanding and anticipation of changing social conditions prevalent in each society. These changes must be viewed against the background of recent trends towards reduced institutionalization, emphasis on home and community care and increased concern with quality of care and quality of life in long-term care.

It is proposed that response of formal services should be based on long-term goals of encouraging and assisting the family to continue executing its role of primary caregiver. It is suggested that we move in the direction of shared responsibility/shared costs within a flexible universal program which would include a cash benefit as one option. An appropriate administrative framework is required to implement this program as well as to develop a network of support services in the community.

One of the most acute and visible problems facing the health and social service sectors today is that of meeting the rapidly increasing needs of the disabled dependent elderly, especially those requiring long-term care. At the same time that western industrialized nations are under great pressure to reduce expenditures on welfare programs, the proportion of aged in the population, especially of the very old (75+), has been growing and is predicted to further increase over the next several decades (Rice, 1984). Demographic trends in the size and proportion of the elderly are compounded by epidemiological studies showing increasing rates of debilitating chronic disease and disability, particularly among the very old (Brody, 1982, Davies, 1984). Especially problematic is the growth of high-risk, hard-to-manage groups of elderly who suffer some form of mental disability and who require high-cost services.

Most relevant to long-term care planning are estimates of dependency in terms of activities of daily living. These estimates vary according to the definition utilized. Although the majority of elderly are not seriously dependent even at advanced ages, at least 5% are institutionalized at any one point in time. Studies in Israel have shown that of the elderly living at home, approximately 7% require the assistance of others in performing daily activities (ADL) and 28% require household assistance (IADL) (Morginstin, 1984; Silberstein, 1981). Figures in U.S. studies range from 10%-18% for ADL dependency at home to about 40% for those requiring help with household chores (Factor el at., 1982). These dependency rates increase with age (Table 1). Thus, the cost of health - primary, hospital and institutional - as well as of home and community personal care and support services spent on the elderly is beyond their proportion in the population. As

a result there has been an overriding preoccupation in western countries with the growing, often unsupportable, cost of long-term care.

Table 1

Proportion of Elderly Requring Assistance with ADL and IADL *

According to Age Group, Bene Berag - 1979

		····			
		65-69	70–74	75–79	80+
absolute number	6,694	2,652	1,810	1,210	1,022
% requiring assistance with ADL			6.4	6.8	24.3
% requiring assistance with IADL			27.3	40.5	46.9

Source: Morginstin (1984), based on data collected by Silberstein (1981).

* ADL: includes moobility in home, washing, feeding, dressing, incontinence, attendance.

IADL: daily household chores.

It is clear that meeting the long-term care needs of the elderly at home, in the community and in institutions will continue to require extensive funding. Although it may not be possible to reduce current expenditures significantly, many countries are searching for policy options for the provision of services in a more organized and

efficient manner in order that funds be used to meet most acute needs. The questions for policy and planning are: What will be the order of priority in the use of funds? How should current funds be allocated, or new funds infused into the system in an effective, efficient and equitable manner which will meet needs while preventing imbalance in service provision and use? In other words, what kind of system are we aiming at that will provide an appropriate formal response to long-term care requirements?

It is important to recognize that while the design of a long-term care system should reflect the current magnitude of long-term care requirements, these cannot be defined only in term of population data and dependency rates. Planning formal services requires a different approach in each society, based on its political structure, tradition of service provision, division of responsibility, program needs, desired short and long-range program goals and program constraints (Morginstin and Shamai, 1985). There are several factors, however, which are common to most societies and which ought to be carefully considered in planning a long-term care program:

- a) informal care patterns;
- b) current patterns of service use (institutional and non-institutional);
- c) changing social conditions.

These interrelated factors are described schematically in Figure 1.

It is suggested that the very way in which a formal long-term care program is designed, funded and implemented should be related to

these factors and will in turn affect the patterns of informal care and service use, and in particular the ability of the family to provide and manage informal care.

Informal Care Patterns

Research as well as experience continue to affirm that the family is the major provider of care for the elderly (Shanas, 1979; Shuval, 1982; Silberstein, 1981). Studies in Israel and abroad have shown that approximately 80% of the elderly, dependent in functional activities of daily living, are receiving care from family members. In Israel this figure reaches about 86% in some areas where research has been conducted. Formal services, provided by government and public agencies, cover a much lower proportion of the aged. In Israel, for example, about 14% of the non-institutionalized dependent elderly receive services for personal care and about 7% for home help. The degree of overlap is very small - most persons receive help from family only, while only a small proportion receive both informal and formal services (Table 2).

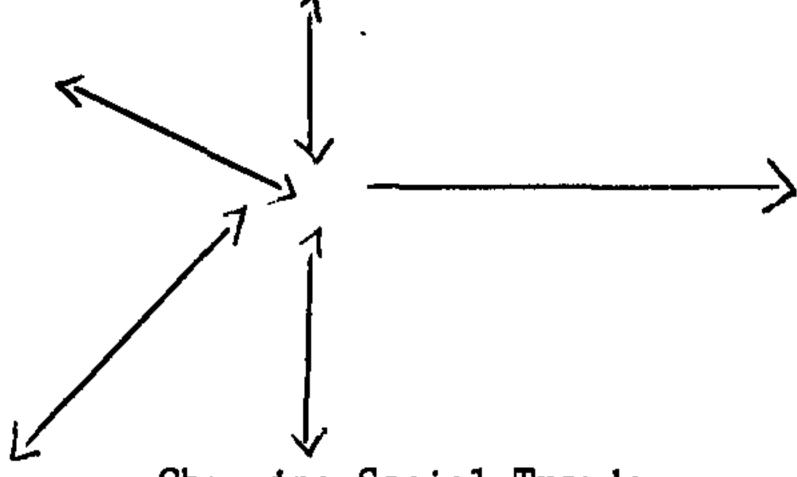
FIGURE 1: Some Factors Affecting Long-Term Care Planning

Informal Care Patterns

- preferences for services and benefits
- use of public and private services
- readiness to provide or manage care
- costs incurred in provision of care
- informal resources

Current Pattern of Service Coverage

- rates of institutionalization
- home care provision
- community care provision



Population Data

- size and proportion of elderly
- morbidity rates
- dependency rates

Changing Social Trends

- family size
- marital status,
 divorce rates
- living arrangements
- women's labour market participation rates
- individual characteristics of elderly, including economic circumstances

Formal Service Response

- cost containment measures
- concern with quality
- increased emphasis
 on home & community
 services
- options for funding,
 provision,
 administration

Thus, there is a significant need for additional services from the formal sector - mostly to complement family care or to reduce overburden on the family.

Table 2

Need for and Provision of Personal Assistance
and Home Help Services among Dependent Aged

Bene Berag, 1979

	/ rece	iving servi	ces	/ with needs			
type of assistance	from family only	from community only	from family & community	% with unmet needs	with need for alleviating family burden		
personal assistance	76.6	3.6	9.7	26.0	12.1		
home help	58.5	4.2	2.8	43.6	10.7		

Source: Morginstin (1984), Silberstein (1981).

Given the recognition of the increasing burden on the family, it may be expected that there be a shift in emphasis on target population from the elderly themselves to the older person and his family. The concern with family support services is one indication of the increasingly accepted approach that the family is indeed becoming a target in long-term care planning (Montgomery, 1984). This broadened view of the target population should be accompanied by a flexible approach in designing the kinds of benefits and services which will be

included in a long-term care program. If we are to respond adequately to family needs and expectations, concern with the family should become an integral aspect of planning beyond the creation of the occasional seminar or self-help group.

In this context, however, it is important to expose a duality in professional thinking about family caregiving which is probably a result of the historical development of social welfare services for the elderly (Parker, 1980). These services have generally been provided on a selective rather than a universal basis. On the one hand, the existence of kin as potential and actual providers of care has repeatedly been documented as an invaluable resource, often the principal factor affecting the probability of institutionalization. In fact family care has been and is viewed as the primary component of community care. On the other hand, while the growing burden of care is recognized by professionals, there is a tendency to consider family caregiving as a <u>free resource</u>. In fact, the family caregiver has in the past been neglected by the formal service system.

In planning programs for the elderly and their families at home, it is necessary to define carefully our concept of social policy in a way that closely reflects actual patterns of care, expectations and preferences of the family and expected family behaviour in the future as influenced by changing social trends. It is suggested in this paper that these changes, while they will not undermine or diminish the basic family willingness to continue fulfilling its responsibility, they will inevitably affect informal care patterns and the expectation on the part of the elderly and his family for government support. It is further proposed that response by the formal sector should be in

the form of a flexible universal program of long-term care which will provide a variety of in-kind services and cash benefits in order to enable and encourage the family to continue fulfilling its role as the principal manager and provider of care.

Changing Social Trends

Several changing demographic and social conditions that may affect patterns of care, family expectations and service usage have been documented in recent literature which has examined determinants of the magnitude of long-term care (Brody, 1981; Luce and Liu, 1984; Rice, 1984; Sang, 1983; Shanas, 1979; Vogel and Palmer, 1982). In general, the magnitude of need for long-term care has been discussed in terms of expected demographic changes in age/sex population structure and rates of chronic disease and disablility.

Other demographic and social factors might not affect the basic level of need but have been identified as affecting the patterns of service response which have evolved in various societies, especially the balance of formal and informal care. These factors include: differential fertility rates among age cohorts, divorce rates (affecting the availability of children to provide informal care), marital status of the elderly (availability of spouse caregiver) and female labour force participation (availability of women to provide informal care at home) (Davis, 1985). To this we would add patterns in living arrangement and household composition trends, as well as economic status and level of education, all of which would affect not

only patterns of care, but also expectations as to the kinds of formal programs which might be made available.

Some of these conditions should be carefully examined in each society when describing current and emerging patterns of formal care. For example, although researchers have predicted an expected increase in the absolute number and proportion of old people in most societies (Rice, 1984), in Israel predictions indicate that we may expect a a levelling off of growth at the turn of the century (Kop, 1981). This is one factor which should be considered in planning a program which might not respond to continued growing needs, but would be flexible enough to be modified periodically in terms of changes in kinds of services required and the differential allocation of funds according to such changes.

In Israel the fact that informal care is in fact available in most cases is evidenced not only in survey findings, but also in data regarding living arrangements. Israel is distinguished from European countries in its much lower proportion of persons living alone and a higher proportion of couples. As pointed out by Achdut and Tamir (1985), single females, who are the most economically vulnerable group, comprise approximately 50% of all families in the 75+ age group in the U.S., Canada, the United Kingdom, Sweden, Norway and West Germany. In Israel only 23% of all families in this age group are non-married females while the percentage of couples is 47% - double that of other countries. The percentage of single males is lowest in Israel and West Germany - 11%, as compared to 17%-18% in Sweden and Norway. This data, coupled with income trends, is significant for long-term care planning in Israel. Any program should be based on the

assumption that in those cases in which family care is available, this care might be facilitated by a benefit to cover part of the expenses incurred in providing care. Other countries, however, having higher proportions of elderly living alone, might put greater emphasis on in-kind services rather than on cash benefits.

caregivers, will inevitably have an effect on caring patterns, expectations regarding kinds of services required and on the response of formal services to these patterns. In general, even when there are several siblings, there is a tendency for one person to assume caring responsibilities. In most cases this single caregiver is a daughter or a female spouse. An increasing proportion of women who have traditionally been the caregivers in our society are working outside of the home and are thus unable to fill the role of caregiver on a full-time basis. This trend, together with the smaller number of siblings to share the burden of caring, aggravates the already heavy burden of care.

Labour force participation rates are particularly interesting when we look at figures for age groups which are particularly vulnerable as potential caregivers. Experience shows that the problem of providing care to older parents or to a spouse is especially characteristic of upper middle age. Examining changes in labour force participation for persons aged 55+ according to sex, one finds that while, other sex/age groups have experienced a <u>reduction</u> in labour force participation, in most countries the proportion of working women aged 55-64 increased significantly (Table 3).

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However, Brody (1983) has pointed out that women's increased participation in the labour force will have an unknown impact on the caring situation in the family. The question is whether there will be a redistribution of responsibility among family members or an additional burden and strain on the working woman, thus aggravating the "woman in the middle" syndrome. The burden of care, if it is not relinquished, will be compounded. However, it should be emphasized that increased labor force participation rates for women may have a dual effect: while the time available for caring may be reduced, the improved economic situation of women, accrued pension rights, savings, etc., may enhance their position as consumers of services. There seems to be evidence that families in which the wife works are more likely to purchase care (Luce, 1984). In other words, the tendency to acquire services from the formal sector will increase.

In view of studies that, despite predictions to the contrary, families are not relinquishing their responsibility as caregivers, the implication of this trend is twofold": a greater proportion of women will expect to be able to exercise greater independence in the way in which they manage care and in their choice of acquiring services: and as their earning power increases, women, who are traditionally the managers of care, will be able to purchase more services.

Thus, trends in labour force participation for women might be expected to affect the <u>expectation</u> of caregivers that the kinds of formal assistance available in long-term care programs permit them to make more <u>independent choices</u> in service acquisition while, at the same time, some groups of caregivers may enjoy somewhat improved

economic circumstances which will enable them to cover at least some part of the cost of caring.

It would seem then that an important determinant of long-term care requirements and, by implication, patterns of care and service use, is the economic resources available to older people in the future. In the United States, for example, the average income of the elderly is expected to continue to increase, even in real terms, although at a lower rate than in the past. Moreover, traditionally large differences in income between men and women living alone are expected to narrow as more women enter the labor force and as men continue to leave the labor force earlier (Luce et al, 1984).

Certainly, cross-national comparisons of long-term care programs and attempts to learn or extrapolate from one society to the next should be based not only on a good understanding of demographic and cultural differences and of differences in tradition of service provision, but also on reliable comparative data which describe the economic circumstances of the aged in relation to demographic factors. Long-term care policy and planning should take into consideration the changing economic circumstances of the elderly population, especially in terms of retirement and earning patterns, capital income, public transfers and occupational pensions. One would expect, for example, that the relative proportion of public and private expenditure on long-term care, the emphasis on public or private service development, be related to the income available to groups of elderly. That the economic circumstances of the elderly may have an effect on long-term care needs and the concommitant response of formal services to these needs is evidenced by the example of Switzerland. Gilliand (1983) has

Table 3

Labour force Participation Rates in Several Countries*

Country	early 1960's	1980 men 65+	%change	early 1960's	1980 men 55-64	%change
U.S.	33.1	19.0	-14.1	86.8	72.1	-14.7
Canada	30.0	14.7	-15.3	86.7	76.2	-10.5
Japan	56.5	40.8	-15.7	85.6	85.2	- 0.4
France	24.0	9.0	-15.0	76.2	69.9	- 6.3
Germany	24.9	7.5	-17.4	81.8	67.8	-14.0
G. Britain	23.4	8.9	-14.5	94.4	83.0	-11.4
Italy	25.2	8.4	-16.6	73.5	57.7	-15.8
Sweden	34.8	11.6	-23.2	91.1	79.2	-11.9
Israel	35.4	27.9	- 7.5	84.6	82.4	- 2.2

		women 65	<u>+</u>		women 55-6	<u>54</u>		
U.S.	10.80	8.1	- 2.1	37.2	41.3	4.1		
Canada	5.6	4.3	- 1.3	22.0	33.7	11.7		
Japan	24.4	14.9	- 9.5	44.4	43.6	- 0.8		
France	9.0	4.3	- 4.7	36.9	38.3	1.4		
Germany	7.7	3.0	- 4.7	27.2	28.8	1.3		
G. Britain	5.7	2.9	- 2.8	29.3	39.0	9.7		
Italy	7.0	1.8	- 5.2	20.2	14.0	- 6.2		
Sweden	8.6	2.5	- 6.1	40.5	55.6	15.1		
Israel	6.1	6.6	0.5	17.9	26.0	8.1		

Source: Rojas-Pakes, et al., 1985.

Based on Monthly Labor Review, U.S. Department of Labor, Bureau of Statistics, February, 1983.

^{*} Proportions for Japan, Germany and Great Britain include institutionalized population. Data for France are for 1979.

reported that in Switzerland a significant increase in old age pensions in 1966 significantly reduced the number of admissions to old people's homes which were primarily funded by the government.

The analysis and comparison of long-term care development requires reliable comparative data over time. A good beginning has been made in generating and analyzing this kind of data in the Luxemburg Income Study (LIS) which has collated data from seven countries: Canada, Israel, Norway, Sweden, West Germany, the United States and the United Kingdom. From preliminary findings presented at the first LIS conference (July 1985) one finds some interesting differences in the economic well-being of the elderly at the beginning of the present decade (Table 4).

Thus, for example, comparison of the extent of poverty in different age groups shows that the risk of poverty is generally higher amongst those aged 75+ than those aged 65-74. Significant differences are found between countries, with Sweden having virtually no poverty for these groups. The authors (Hedstrom and Ringen, 1985) point out that this is due to reform in public pension benefit levels. Between 1952 and 1976 the average Swedish pension increased by over 300% in real terms as compared to a 97% rise in average income among full-time industrial workers.

Table 4

Poverty Rates in Several Countries

for Persons Aged 65+ and Total Population

Aged 65-74	Aged 75+	Total Population
11.2	12.1	12.1
12.7	15.2	7.2
22.6	27.1	14.5
2.7	7.3	4.8
0.0	0.0	5.0
16.2	22.0	8.8
17.8	25.5	16.9
11.9	15.6	9.9
	11.2 12.7 22.6 2.7 0.0 16.2 17.8	65-74 75+ 11.2 12.1 12.7 15.2 22.6 27.1 2.7 7.3 0.0 0.0 16.2 22.0 17.8 25.5

Source: Hedstrom and Ringen (1985).

Longitudinal data of this type for future cohorts, coupled with projected labor participation rates, income from universal flat rates and occupational related pensions, should be considered when estimating the kinds of resources which will be available for long-term care. The elderly are still characterized by low incomes and a relatively high incidence of poverty. This seems to be especially true of Israel where almost half the retired population receives income supplements. Long-term care strategy should reflect this data just as

Defined as persons belonging to families with an adjustable disposable income below half the median for all families in the specific country.

does income maintenance policy. Although individual differences will remain, some groups of elderly, such as working women, may be expected in coming years to enjoy better economic conditions with a greater sense of independence. This economic independence might, for example, be reflected in greater ability to purchase day care in the community or to participate in sheltered housing arrangements where long-term care services would be available if necessary. The proportion of public funding for these and other long-term care services, in the home, community or in institutions should reflect trends in income level. Thus planning for services and public allocation of funds should be based not only on forecasts of magnitude of needs but also on a projection of the various groups who will be the consumers of services in the future, their preferences and their ability to acquire services from the formal sector.

It is not suggested that improved economic circumstances means a reduced need for publicly-funded benefits and services. However, some groups of elderly will be able to pay for a part of their service requirements. On the other hand, for low-income groups a cash benefit would constitute an important compensation for expenses incurred in direct service provision by the family. A benefit calculated to cover part of the costs, in order to share the cost of caring with the older person and his family, might therefore meet needs in those cases where informal care is already available.

The point is that increased awareness of changing social conditions and of demographic and income trends is crucial not only for estimating the scope of services required, but also for designing the kinds of benefits - cash and in-kind - which would be made

available, the procedures whereby these formal services could be acquired by the individual and his family and the <u>flexibility</u> of a long-term care program to adapt to individual differences and expectations and to growing expectations for making <u>independent choices</u> in care management. Trends in labor force participation of women, data regarding living arrangements and the availability of informal care, improved economic circumstances for some groups as well as expected higher education level among the elderly would seem to indicate that caregivers will expect to be able to make more independent choices in service acquisition within a program of formal services based on the concept of shared responsibility/shared cost between the caregiver and the formal service sector.

Current Patterns of Formal Service Provision: Institutional and Non-Institutional Care

A basic policy goal in long-term care then is the need to develop a broadly diversified system of benefits and services to meet a continuum of changing needs, from need in the home to the need for institutions. On the one hand, the long-term objective is to assist the family and to develop services so as to enable the disabled, dependent individual to remain at home and in the community for as long as feasible and to confine the use of nursing home beds to the most seriously disabled and to those living alone. On the other hand, an acute and most visible need in most countries is the current demand and waiting lists for nursing home beds. The issue behind these two seemingly conflicting goals becomes a practical question of priorities

in allocation of limited funds in a model where cost containment is in itself a basic issue.

We find a great degree of variation among societies in the form and extent of institutional response to long-term care needs. However, the differential rates of institutionalization which have evolved in various countries cannot be attributed to demographic factors alone. A recent ISSA report (Davis, 1985) which sought to estimate the effect of demographic variables such as population age/sex structure on cross-national institutionalization rates found great variation when actual use rates were compared to protected use rates, using U.S. age/sex specific institutionalization rates as the comparative standard. It was found that whereas population characteristics alone would suggest similar use rates in the U.S., Sweden and Netherlands, both latter countries use institutional services at almost twice the rate of the U.S. In the Netherlands, however, rate of use of medical institutions is one-third less than the U.S. rate while the use of non-medical institutions is almost seven times greater (Table 5).

In the same study, reported institutional rates vary from a low 3.6-4.5% in the Federal Republic of Germany to 8.7-10.5% in Sweden. A striking finding is the difference in medical and non-medical institutionalization rates. There is a much higher use of non-medical residential care in Western Europe than in Canada and in the U.S. The Swedish use of medical institutionalization is similar to that of the U.S. but its use of non-medical facilities is almost five times greater (Table 5).

In other words, it would seem that factors other than need defined in terms of population characteristics are responsible for

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Comparison of Projected Versus Actual Institutional Use Rates

1980

	Projected rate*			Actual rate			
Country	Medical facilities	Non-medical facilities	Total	Medical facilities	Non-medical facilities	Total	
United States	4.5	1.2	5.7	4.5	1.2	5.7	
Australia,1981	4.2	1.1	5.3	4.9	1.5	6.4	
Belgium, '81-83	4.5	1.2	5.7	2.6	3.7	6.3	
Canada	4.2	1.1	5.3	7.1	1.6	8.7	
Costa Rica,198	3.7	1.0	4.7	N/A	1.5-2.0	1.5-2.0	
Denmark	4.5	1.2	5.7	N/A	N/A	.7.0	
France,1982	4.8	1.3	6.1	5.3	1.0	6.3	
Federal Rep. of Germany, 1980	4.3	1.2	5.5	1.2-3.6	0.9-2.4	3.6-4.5	
Greece, 1982	4.2	1.1	5.4	N/A	0.5	0.5	
Israel, 1981	3.5	0.9	4.4	1.4	2.6	4.0	
Japan, 1981	3.9	1.0	4.9	3.1	0.8	3.9	
Netherlands 1982-1983	4.6	1.2	5.8	2.9	8.0	10.9	
Spain, 1982	4.2	1.1	5.3	N/A	2.0	2.0	
Sweden, 1980	4.5	1.2	5.7	4.6	4.1-5.9	8.7-10.5	
Switzerland '8	2 0.5	1.2	5.7	2.8	5.0-7.2	7.8-9.0	

N/A = Not available

Source: Davis, C.K. Long-Term Care Provided Within the Framework of Health Care Schemes, ISSA/MSC/XXI/2, Provisional Report, 1985.

Based on a U.S. age/sex specific institutional use rate (measured by the 1977 National Nursing Home Survey).

institutionalization rates. Given the fact that current data regarding need for beds based on waiting lists and rates institutionalization reflect exigencies of the existing system, defining future need for nursing home care on the basis of extrapolated data alone would seem to be misplaced in view of long-term goals. This has been the experience in the Netherlands, where during the last few years one finds a contradiction between forecasts of the increasing need for institutionalization based on current practices and national policy norms which call for a reduction in the proportion of aged in nursing homes and other institutional settings (Morgenstin and Werner, 1982). In fact the aforementioned ISSA report notes that on the basis of responses to its questionnaire, most advanced industrial countries perceive their rate of institutionalization as higher than necessary or desirable. "Most of these countries are currently pursuing deliberate policies to expand home and community-based long-term care services in part as means of reducing the need for institutionalization" (Davis, 1985). At the same time, however, some of these countries report experiencing considerable pressure to expand bed capacity to meet current unmet needs. In a broad sense, the need for institutionalization is not only a reflection of current requirements, but also becomes a question of long-term goals versus short-term pressures.

The costs of existing long-term care services point out the importance to Israel and to other countries of formulating clear-cut policy regarding the optimal balance between community and institutional long-term care, and the role of whatever program is developed in promoting such policy. Experience in other countries (Doron, 1978; Morginstin and Werner, 1982) as well as findings for

Israel (Factor et al., 1982) indicate that although community and institutional services are theoretically part of a single continuum of care which should reflect differential population needs, there is, in fact, a trade-off between community and institutional services which may be the result of emphasis placed on one aspect of care at the expense of, or to compensate for, a shortage of the other.

The issue of allocating resources between institutional and non-institutional sectors of long-term care has raised much discussion among professionals and policymakers. On the one hand, institutional care should be available for that group of chronically ill who, for various reasons, will inevitable be unable to remain living at home. On the other hand, recent developments in social policy increasingly emphasize the importance of assisting the family and of developing services in order to enable the disabled individual to remain in his community for as long as possible. In some cases, inevitable institutionalization may at least be deferred for a period of time.

Examining long-term care schemes in other countries indicates some imbalance between the two sectors. In England, for example, where there is some overlap between acute and long-term care, chronically ill disabled aged are hospitalized due to the lack of sufficient long-term care services in the community. Since nursing homes are, in effect, hospitals, residential homes which were originally meant for the independent aged are slowly becoming transformed into nursing homes which are not always suited to the needs of residents from the point of view of physical condition, manpower, budget, etc. In Japan as well, much medically oriented long-term care is provided in acute care facilities. In the Netherlands, one of the results of the ABWZ

Law, which had originally provided reimbursement primarily for institutional long-term care, is that there have been insufficient resources allocated to the community care sector. Indeed, the question that should be raised is whether the increase in institutionalization has been a result only of the increase in the number of chronically ill, or whether it is also a result of policy which makes it easier and more efficient for the family, and especially for professionals, to institutionalize an individual in a government-funded nursing home rather than provide services in the community.

' Experience has shown that state policy and especially funding practices give rise to increased demand and use of services which are publicly financed. Countries which did not sufficiently consider the desired balance between community and institutional long-term care have overemphasized the institutional end of the continuum of care, in terms of both policy and funding. In practice, such policy has constituted an incentive to the continued growth of costly institutional services at the expense of services provided by the community and the family. Much criticism has been voiced in recent years regarding the reduced role of the family and community as compared with the expanded role of institutions. Today the U.S and several European countries are increasingly supporting the financing and growth of the community sector while attempting to reduce the role of institutions. For example, the Netherlands has pursued a policy of reducing institutionalization over the past few years by expanding benefits under ABWZ to include reimbursement for services provided at home and in the community. In Norway too, policy in the past decade has encouraged a growth in community long-term care by making available reimbursements for such services.

Formal Service Response Towards a Flexible Program of In-kind Services and Cash Benefits

Current trends emphasizing the growing importance of home and community long-term care have developed primarily as a result of pressures for cost-containment, although there is no clear evidence community services are less that home and expensive institutionalization when one imputes economic costs to informal care and includes opportunity costs. One could argue, however, against this type of conceptual approach to cost analysis of care provided in different settings which gives the same weight to economic cost of formal service provision often funded by the public sector and to the cost of informal care. It is unclear, for example, whether institutional care is less expensive if one looks only at public costs - the cost to the state of providing total care in an institution as compared to supplementing the informal care provided at home.

It is important to point out that increasingly, the trend toward community care reflects not only cost considerations but also growing sensitivity to the preferences and needs of the dependent older person and his family and the desire to improve the quality of life and well-being of the chronically ill individual and to create more alternatives for care prior to institutionalization. Moreover, sufficient non-institutional services would make it possible to view nursing home care as only one option within a range of community services, an option which is not necessarily final and which can be utilized for short periods of time. For this reason, it is essential to emphasize the importance of coordinating between the two sectors in order to maintain a contimuum of care. Such coordination would view

the process of professional and family decision-making regarding a suitable long-term care plan as a single process in case management which includes <u>all</u> options of institutional and non-institutional care. Today, the lack of coordination between professionals and organizations involved in care planning has resulted in separate and often duplicate procedures of need assessment and decision making for the two sectors. The literature today, especially that originating in the U.S., abounds with discussion of policy options for long-term care planning and funding (Callahan and Wallack, 1981; Gottesman and Cohen, 1985; Grana, 1983; Kane, 1985; Rossiter, 1984; Vogel and Palmer, 1982).

Whatever program is chosen, the basic question for each society is, given its specific population data, changing social conditions, cost considerations and existing modes of service provision, what is the <u>desired</u> pattern of care aimed for? What balance, what mix of benefits and services, against the background of current practices and expectations, will sustain the continued provision of family care, which seems to be the preferred vehicle in all societies? What program will facilitate the important link between formal and informal care, between public and private expenditures, and will build on the resource of family care while reserving formal services for hard-core need and for complementing family care?

It is important to recognize the fact that the kind of program developed, and especially its funding structure, will inevitably affect the pattern of care. As Gottesman (1985) has pointed out, by creating a service we make a decision on how the service will be used. By building a nursing home bed we make the decision that it will be

occupied. Proposals for various kinds of programs vary from reimbursement, to fees for service programs, to block grants to universal insurance programs providing benefits and services. Most programs are based on government funding with some role left for the private sector. In general, the trend is for more and better services.

As already stated, common to most approaches is the tendency to consider family care as a free resource and to plan for services in-kind when family resources are inadequate or unavailable. This approach has not sufficiently considered the effect of family preferences on current patterns of care. We are not referring to the danger of families relinquishing responsibility for care. However, the incentive to substitute formal for informal care is strong if this is the only alternative being offered, just as institutionalization has been the preferred alternative if it is the only service being funded by government. Thus, social goals calling for more and better services, while important in themselves, cannot but constitute an incentive to overutilize these services, if a cash benefit is not included as an alternative within a range of services being offered to the families.

It seems that while some recent literature has seriously weighed the pros and cons of cash versus in-kind transfers, or insurance-based versus other selective programs (Callahan and Wallack, 1981; Grana, 1983), none has addressed itself to the possibilities of incorporating a statutory cash benefit within a broad spectrum of long-term care. Unfortunately, in fact, the two possibilities have generally been regarded as mutually exclusive, perhaps based on the assumption that

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the two types of benefits cannot be effectively organized under a single program. This remains a challenge to professional planners.

Proposals for Long-Term Care Insurance in Israel (Morginstin and Shamai, 1984) are based on the hypothesis that, in order to design a more flexible response to need, one that will most effectively utilize existing informal resources, including some private expenditures for services, Long-Term Care Insurance measures should include as one benefit option some form of a cash benefit to the older person and his family which has made the decision to provide care on its own or to purchase some of the services on the open market. This type of benefit would be one option within a range of services provided to older persons and their families who are capable of making decisions about care and who provide adequate care. Experience and research (Gottesman, 1985) has shown that a good proportion of those families requiring long-term care are capable of managing this care, or in other words, of being their own case management.

Some of the trends described earlier would seem to support this approach. It is believed that in the long run a program which would include a cash benefit as one option will on the one hand be more flexible to changing conditions which on the other hand indicate that the family cannot indefinitely be considered a free resource of care, and on the other hand take into consideration that caregivers may prefer to exercise independence in choosing services. The emphasis is on partial compensation for informal services in contrast to more expensive formal service provision under government funded programs, if we consider the enormous administrative costs involved

in a program that would provide services.

It is hoped that cash benefits provided to some families will also constitute an impetus to the development of private or non-profit services which can be purchased by the older person. Needless to say, those receiving inadequate care, or the more isolated elderly, would be eligible for in-kind services.

A universal, insurance-based program which provides cash and in-kind benefits would take into account not only the needs of chronically ill dependent individuals, but also the needs of their families who are the primary providers of care. It is important to point out that this approach recognizes the principle of personal entitlement within an insurance program and does not exclude from eligibility individuals who are receiving adequate care from informal sources. Under Long-Term Care Insurance in Israel eligibility to benefits will be based on the principle of personal entitlement according to the degree of functional disability, irrespective of whether the family is providing care. The existence of family might affect whether there is a need for in-kind services and of what type. For example, persons living alone might be eligible for a higher benefit which would reflect the higher cost of services they must obtain; persons receiving no, or inadequate, family care might be eligible for in-kind services; those receiving help from family would indeed still be eligible for a benefit which would in fact be a form of partial compensation for services being provided or being bought on the open market generally at a significant cost to the family.

What this means is moving toward a concept of shared responsibility/shared costs in long-term care. By providing a benefit which will cover part of the cost of service provision, it will be possible to help meet family needs as well as encourage family responsibility. This type of program would enable the individual and his family to acquire services in the community, if they so desire, thus facilitating the link between formal and informal support sectors.

An argument against an insurance program which would include a cash benefit has been that this type of program will be costly since all eligible persons would be entitled to some benefit - cash or kind - whereas under a program providing only services there would be individuals who are already receiving adequate informal care and would therefore opt not to receive a service. It is argued that those who are currently being adequately cared for by the family, at none or little public cost, will become eligible for publicly funded benefits. The concern is that if large numbers of older people apply, the ultimate cost of this type of insurance-based program might be unpredictable and possibly unsupportable (Gruenberg and Pillemer, 1981).

Proponents of a cash benefit as part of a comprehensive program of long-term care visualize Long-Term Care Insurance as a social policy response to alleviate a given social condition, i.e. the increasing burden of dependency borne primarily by families, whether they receive additional services or are already providing adequate informal care. This approach makes a case for further strengthening the family's role in a long-term care program by enabling it to make

decisions regarding the utilization of public resources according to personal preferences (Sager, 1983). In the long run, in-kind services or cash benefits, both of which can meet only part of the cost of service provision, will alleviate the burden of caregiving. One might go further by suggesting that provision of flat-rate cash benefits in some cases would be less costly than the involvement of expensive service structures. Indeed, it is believed by some professionals that defining social policy response to meet needs primarily in terms of expensive public services would lead to increased demand and spiralling costs of services. Moreover, one may point out serious problems of equity: limiting benefits to persons who do not receive adequate family care means "punishing" families who are currently meeting heavy responsibilities.

By providing a benefit to the eligible person living at home, and at the same time expanding the network and variety of community services, a flexible program of this type would, it is hoped, enable the disabled person to remain in his home and community for as long as feasible. It must be emphasized that the role of the benefits is not to replace family functions and responsibilities. The family will continue to have primary responsibility for the care and welfare of the individual. Therefore, the benefit will be calculated to cover only part of the costs incurred in caring for the functionally disabled, but will be high enough to enable the acquisition of some services, according to the older person and his family's choice and order of priorities.

Community Services

As part of a long-term care program which provides a mix of cash and in-kind benefits, it would be essential to develop a network of public and private services in the community, one that would allow the family flexibility in service acquisition and would enable it to continue performing its caring role. Some of the services which are being advocated are:

1. Center for Long-Term Care

This service will provide a single address for the family in need of consultation, services or referral, especially given the multitude of services and regulations faced by the family searching for assistance.

Experience shows that families do not apply for services until they are near the exhaustion point or in the midst of a crisis, at which time the potential effect of the service might be minimal. A center for long-term care providing case management would make it easier for the already overburdened family to apply for assistance.

2. Case Management or Service Coordination

Case management, a much discussed and examined service in the U.S., should be the focus of the center for long-term care. The primary responsibility of case management should be the coordination of a continuum of care, from the home to the institution if necessary. Although case management might be made available to all families, it

has been shown to be most cost-effective for multi-service high-risk groups requiring intensive home care and professional involvement in introducing formal support services into highly personal, highly emotional caring situations. The role of the case manager, coupled with the family's feeling of "belonging" and trust, facilitates the provision and acceptance of services.

3. Day Care/Psychogeriatric Day Care

The importance of intermediate day care for the dependent elderly has been increasingly recognized over the past decade. This service seems to be insufficiently utilized for high-risk groups, however, because of the difficulties and costs involved in transporting and caring for these individuals. Given the increase in labor force participation of women, this type of service should receive higher priority in planning if we desire to enable working families to continue performing the caring role. An important group requiring day care is the growing group of elderly suffering from some form of mental deterioration and living at home.

4. Services for the Caregiver

Some services geared to family caregivers themselves which have become more available, especially in the U.S., are:

- <u>family study and support groups</u> - organized by service agencies which provide practical information instrumental to the caring task as well as the opportunity for generally isolated caregivers to meet and exchange views with others in the same situation.

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- Respite service both voluntary and paid, in the home or for short periods in an institution.
- Organization of self-help groups usually by families who have common problems in caring - such as those of Alzheimer victims.
- Services to families whose elderly relatives reside in <u>institutions</u> should not be neglected. Such services would be geared at counseling for placement and increased family involvement in the institution, including family representation on public committees responsible for monitoring quality of care in institutions.
- Volunteer services visits by volunteers which have generally been provided primarily to isolated elderly should be extended to older people with caring families.
- Congregate housing facilities should be extended to provide adequate long-term care so as to enable dependent residents to remain in their homes for as long as possible without having to move to a different facility.
- Finally, providing <u>medical services</u> at home is of the utmost importance. Often the decision to enter an institution is based on experience of the difficulties of receiving the care of a doctor at home. Unfortunately, whereas other sectors have recognized the importance of extending home services, home visits by doctors are still hard to come by. This remains one of the weak links of the home care service system and deserves more extensive examination and discussion.

Coordinating Long-Term Care - The Administrative Framework

One would be remiss to present an outline of formal service response to caring patterns without referring to guidelines for implementation. Many countries report a lack of coordination in long-term care, whether at the stage of referral and need assessment, gate-keeping functions, professional decision making regarding care plans and case management, or with procedures for service provision, reporting and monitoring. Although there have been several attempts at coordinating the administration of long-term care in the U.S. and Europe, this is being done primarily on an experimental basis, as in the U.S. Channeling or Access projects. There are useful examples of informal attempts at coordination on a local level in Europe, some of which center around a hospital geriatric unit. However, although some countries have regulations for coordinated planning or allocation of funds on the central level, there seem to be few statutory provisions which set forth regulations for use of resources and administrating case management functions on the local implementational level.

Most experiments at coordinating the administration of long-term care constitute attempts to provide a continuum of adequate care at home and in institutions in a more cost-effective program. Issues most often addressed relate to the following functions:

- short-term and long-term planning, goals and program strategy;
- efficient allocation of resources according to regional and population needs;
- overall need identification on basis of data-gathering;

- individual need assessment;
- defining and implementing criteria of eligibility for benefits;
- case management and coordinated service provision, including inter-agency coordination;
- institutionalization:
- effective utilization of manpower and other resources;
- reporting and monitoring of service provision.

At the heart of these functions is the basic and controversial issue of centralization versus decentralization of long-term care. This issue, which has implications for program design and administration, relates to the importance of decentralization in terms of service provision versus the necessity for centrally defined regulations and tools for determining eligibility, need assessment procedures, monitoring, etc.

In general, there seem to be two main trends in the reassessment of long-term care administration currently being undertaken by various countries. On the one hand, there is a trend for preferring increased decentralization at the level of service provision, primarily due to growing recognition that population needs as well as needs for service development are best understood and dealt with at the local professional level. On the other hand, however, the importance of centrally defined criteria and procedures for determining eligibility and monitoring has been emphasized in order to ensure regional and personal equity in service provision, as well as the efficient use of funds in meeting needs. In addition to the need to determine eligibility criteria, there is a need for centrally defined guidelines for resource allocation which will ensure that funds are utilized for

their designated purposes at the operational level of program implementation, thereby complying with national goals and orders of priority for service development.

In Israel the problem of allocating central and local functions has generated much debate centering on the aforementioned issues. How can these various and equally important goals be reconciled in order to assure equity and uniform implementation of an insurance program based on the principle of personal entitlement, while at the same time leaving the responsibility of professional decision-making to the local level?

The main question for policy and planning an administrative framework is, how can the various elements of a flexible program, which include cash benefits and in-kind services, be incorporated into a unified, comprehensive and effective system?

Under Long-Term Care Insurance in Israel, central functions, including determining eligibility for benefits and level of benefits, will be the responsibility of the National Insurance Institute, according to centrally defined guidelines and tools. Determining care plans, provision of services, monitoring and reporting will be the responsibility of local professional committees, coordinated by the Ministry of Labour and Social Affairs. It is hoped that in order to ensure a continuum of home, community and institutional care according to the changing needs of the chronically disabled individual and his family, these local interdisciplinary committees will be able to coordinate Long-Term Care Insurance provisions being provided by other frameworks (Morginstin and Shamai, 1985).

The main functions of the committees will be as follows:

- a. Designing a comprehensive care plan for those individuals eligible under law. The care plan will be designed after the National Insurance Institute has determined level of eligibility for benefit, on the basis of degree of functional disability.
- b. Determining whether there are available services according to law, who will provide the services and the level of provision. In those cases in which benefits are to be granted as a service in-kind, i.e. not in the form of a cash benefit provided directly to the eligible individual, the committee will determine which services will be covered by the benefit and which will be funded by other agencies. The benefit will be transferred directly to the stipulated service provider.
- c. Setting up uniform procedures for service and case monitoring as well as for need reassessment at the local level.
- d. Determining required changes in the care plan or in the form of benefit provision. For example, in those cases in which an eligible individual receiving a cash benefit is receiving inadequate care from informal sources, the committee might recommend changing the benefit to a service.
- e. Recommending nursing home care.
- f. Ensuring the individual's continued rights to benefits other than those provided under Long-Term Care Insurance.

g. Gathering data, proposals and requests for aid for local service development projects to be submitted to a Central Development Fund.

Summary and Discussion

This paper has examined several issues related to the response of the formal service sector to patterns of long-term care provision against the background of changing demographic and social conditions. A flexible approach in policy planning and implementation is advocated, in a universal Long-Term Care Insurance program which includes, as one option, a cash benefit to the older person and the family which provides direct care. Recognizing the fact that the family can no longer be regarded as a free resource and that some groups of elderly may be able to purchase some services, a cash benefit to cover part of the cost of caring would be effective in assisting some caregivers, while others would require services in-kind to complement informal care provision. This type of program recognizes the need to support the continued provision of family care while enabling the older person and his family to choose the kinds of services they require.

At the same time, it would seem that there is growing awareness of the need to develop and expand a network of support services which would enable the older person to remain at home for as long as possible. These services should be made available to older people and their families before severe crisis sets in; at which time services become least effective and institutionalization becomes imminent.

In any case, a flexible approach to program planning should be predicated on an understanding of family expectations and patterns of care. Services should be designed to facilitate and encourage independent caring as much as possible while providing supports as a complement to family care. Some questions are: How can we achieve an optimal balance, both in terms of cost-effectiveness and social goals, in the linkage between informal and formal services networks? What kind of services should be developed that are geared directly to family caregivers rather than to the elderly themselves? What is the role of a cash benefit to the family in a caring situation which is by definition non-static and often deteriorating, and which therefore requires some form of professional involvement in the form of monitoring, counselling, etc.? What long-term care services are required by the modern care-provider (e.g. case management, support groups, respite care, day centers, home helps, volunteers)? What will be the impact of these services? What are the issues of equity that arise in a program which recognizes the family's eligibility for cash benefits and services? Is it justified to provide high cost services for high-risk groups when they could be cared for more efficiently in institutions? How and when would families utilize these services? Can some services be more efficiently provided by the private sector? These questions must be addressed in policy discussion and in applied research.

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