JDC-BROOKDALE INSTITUTE
OF GERONTOLOGY AND
HUMAN DEVELOPMENT

WHO Collaborating Center
for Research on
Health of the Elderly

ג'וינט-מכון ברוקדייל
לגרונטולוגיה והתפתחות
אדם וחברה

ארגון הבריאות העולמי:
מרכז לשיתוף פעולה
בחקר בריאות הקשישים

Aging in Developing Countries: Source Materials and Highlights from the Literature

JDC-Brookdale Institute

December 1999

Developing.doc
December 5, 1999

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I. Introduction

In this paper we have brought together some selected materials and data from materials written about developing countries. We have not attempted to assimilate or integrate and it should be viewed as a source document.

According to the classification employed by the U.N., developed countries comprise all nations in Europe and North America, plus Japan, Australia and New Zealand. All other countries are classified as developing nations (Velkoff and Lawson, 1998). As of 1997, the number of elderly over age 65 in developing countries stood at 220 million, representing 57% of the world's total elderly population (WHO, 1998).

II. Commonalities among Developing Countries

A. Dramatic declines in fertility

Asia and Latin America have experienced rapid declines in fertility since the early 1970's. In Southeast Asia, many governments have promoted low-growth population control policies, such as China's one-child policy. For example, in China rates have fallen from 5.8 children in 1970 to 2.3 in 1990 (BOLD, 1999). Fertility rates remain high in Africa, as can be seen from the table.

Year	World Average	Africa	Latin America	Asia
1960-1965	5	6.7	6.0	5.8
Projected 2000-2005	3	5.3	2.9	2.7

Source: Myers,1992

B. Increasing life expectancy with concomitant increases in chronic disease/disability

While life expectancies have increased in developing countries, they remain particularly low in sub-Saharan Africa:

Region	Life Expectancy at Birth in 1997
Africa	49.7
The Americas	71.6
Eastern Mediterranean	62.0
Europe	69.5
Southeast Asia	61.9
Western Pacific	69.9

Source: World Health Organization, 1998

See Table 1 in the Appendix for life expectancies in selected developing countries.

Country-specific rates of disability

Estimates of disability in various countries have been made using different definitions:

- A study in Thailand (Thailand's Health and Welfare Survey of 1981) found rates of self-reported well-being (58%) and disability (7%) (Kinsella, 1988).
- Mexico (Bialik, 1999)
  Overall distribution of limitations due to disability:
  20% over age 80 (10.4% total limitation)
  11.5% age 70-79 (5% total limitation)
  7% age 60-69 (2.5% total limitation)
- Indonesia - Morbidity and disability rate for those over age 60 is 9.2% Wiadnyana, 1999)-Source: Household survey of 1995
- Korea - (Chung, 1999) - data from survey conducted by KIHASA in 1998 based on 9,355 households of elderly over 65)
  ADL measure included 6 activities: bathing, changing clothes, eating, sitting, walking, and toilet use
  31.9% had difficulty in one activity
  3.5% had difficulty in all 6
  IADL measure included 4 activities: buying living goods, telephone use, use of public transportation and cleaning/laundry:
  43.4% difficulty in at least one activity
  10.2% difficulties in all four
  Gender differences were larger in IADL (Twice as many women as men have difficulties)
- India - rate of physical immobility of 5.5% for those over age 60. Those having chronic illnesses were evenly distributed in rural and urban areas. (Kumar) - countrywide data on health status of older persons from National Sample Survey Organization study of physical mobility and 7 chronic illnesses.
- Brazil - As cited in the United Nations Demographic Yearbook in 1993, in 1981, 7% of those over age 60 considered themselves disabled. Information on specific types and severity of disabilities is not available in Brazil (Karsch and Karsch, 1999)
- A four-country survey in Korea, Fiji, Philippines and Maylasia (Andrews et al 1986) included approximately 800 adults in each country age 60 and over. Disability was assessed by means of 10 questions related to physical ADL and instrumental IADL. The activities included: eating, dressing and undressing, caring for personal appearance, walking, getting in and out of bed, taking a bath/shower, getting to the toilet in time, traveling beyond walking distance, shopping and handling one's own money. The percentage of those being able to accomplish all of the activities was particularly high in the Philippines and Maylasia:

Malaysia	90% were able to accomplish all ADL/IADL
Philippines	91% were able to accomplish all ADL/IADL
Fiji	82% were able to accomplish all ADL/IADL
Korea	71% were able to accomplish all ADL/IADL

Instrumental activities of daily living were problems for a greater proportion of people, but there was more variation between the countries.

Andrews has conducted a later study in the Western Pacific, but we could not relate to it as we do not have a copy of the final report (Andrews, 1993).

- Findings from a study conducted by PAHO in Costa Rica vis-a-vis the Asia and Oceania studies conducted by the WHO suggest that as developing countries attain relatively higher levels of life expectancy and socioeconoic development, gender differences in health and disability begin to emerge akin to those of developed nations (Kinsella, 1988). While the PAHO studies provide detailed tables on ADL/IADL in Guyana, Costa Rica, Trinidad/Tobago and Argentina, they do not provide totals for men and women together or for the over 65 population, therefore it is very difficult to summarize the information, however the detailed data are available by sex and age groups (PAHO, 1990).

Disability-free Life Expectancy

Disability-free life expectancy is the average number of years an individual is expected to live free of disability if current patterns of mortality and disability continue to apply. Calculations of disability-free life expectancy have been made for 37 countries using the Sullivan method, which is based on the observed age-specific prevalence of states of health in a population at a given time to calculate the years of life lived in the various health states at each age. These countries include 18 developing countries (Ethiopia, Mali, Myanmar, Bahrain, China, Egypt, Fiji, Indonesia, Jordan, Kuwait, Malaysia, Pakistan, Philippines, Rep. of Korea, Sri Lanka, Taiwan, Thailand and Tunisia). Table 2 in the appendix gives rates of disability-free life expectancies for several of these developing countries and reference values for three developed countries. Table 3 contrasts rates of healthy life expectancy in developed and developing countries. Healthy life expectancy is defined as the average number of years an individual is expected to live in a healthy state defined as the "favorable part" of the distribution of perceived health status. However, according to Robine, "direct geographic comparisons are still impossible. The main reason for this is the great diversity between countries in the way handicap or disability are measured. On the basis of available evidence from many countries, and contrary to widely held beliefs, years with severe handicap and/or disability do not appear to be increasing" (Robine, et al. 1995).

Qiao (1999) has examined disability-free life expectancy, healthy life and life expectancy free from disease in China on the basis of four surveys.

C. Socioeconomic status

- Pension coverage is low in developing countries

Amount spent on public pensions as % of GDP (World Bank, 1994):

OECD countries	9.2%
Mid-East, N. Africa	2.8
Latin America/Caribbean	2.0
Asia	1.9
Sub-Saharan Africa	.5

- In contrast to developed countries such as the U.S., the major sources of income for the elderly in developing countries are other family members, particularly children, and their own employment.

Percentage of persons over 65 receiving income from various sources

Country	**Work**	**Family**	**Pension/ welfare**	**Savings**
U.S.	9	--	97	--
Argentina	26	8	74	6
Costa Rica	21	23	46	--
Korea	24	64	6	8
Singapore	18	85	16	37
China	45	34	13	--
Philippines	63	45	13	2
Nigeria	--	95	--	--
Kenya	--	88	--	--

Source: World Bank, 1994

- Rates of labor force participation among the elderly are higher in developing countries, particularly among the rural elderly.

D. Living Arrangements of the Elderly in Developing Countries

We have put together data on living arrangements from various sources, as shown in Table 4. A table from the World Bank (Table 5) is also included. A study conducted by PAHO (PAHO, 1990) in four countries (Cost Rica, Argentina, Guyana and Trinidad/Tobago found rates for those living alone and those living with a spouse similar to the data in Table 4 for Latin American countries.

- Over 50% of the elderly in developing countries reside in rural/agricultural communities
- The majority of elderly co-reside with one of more of their children (see Tables 4 and 5).

- Males and the young-old are more likely to live with their children than females or the old-old (Kinsella, 1990)
- Urban elderly are more likely to co-reside with children (probably due to shortage and high cost of housing) (Kinsella, 1990)
- Hermalin (1998) has cautioned that definitions of households are constrained by census definitions of a dwelling, which may exclude taking account of children living in a multi-family compound of in the same neighborhood, both of which are very common in developing countries, so the extent of residing with other family members may be underestimated in some of the studies.

A study conducted by the Population Studies Center at the University of Michigan examined living arrangements among the elderly in four Asian countries: the Philippines, Singapore, Taiwan and Thailand (Olfsted, 1999). See Tables 6-8 for a summary of the non-formal and material sources of support of the elderly in these four countries).

E. Provision of Long-term Care

- Rates of institutionalization are less than 1% in most developing countries (Kinsella, 1990).

F. Provision of Health Services

- many elderly in developing countries have no health insurance coverage, e.g. in South Africa, over 90% of Blacks have no insurance (Kinsella, 1999)
- A study by Manton (1987) confirmed the better health status of urban versus rural elderly, due to problems in accessing and purchasing health care services among the rural elderly.
- The number of physicians per capita is low in most developing countries (Kinsella and Gist,1998)

Country	**Persons per physician (~1990-1995)**
Canada	450
Brazil	746
China	798
Mexico	935
India	2,460
Thailand	5,000
Indonesia	7,030
Kenya	10,130
Ethiopia	32,650

G. The situation of older women is particularly precarious.

- As in developed countries, their husbands are older and women's life expectancy is longer, so they have more years without a spouse
- In some countries, women do not inherit the property on the death of the husband or they inherit a portion together with the children and other family (e.g. Uganda, India). Although the practice has recently

been outlawed in Uganda, a widow may be chased off her land by her husband's relatives (Njuki, 1999).

- in countries with patrilineal systems in Southeast Asia, elderly women live with their son and must rely on goodwill of daughter-in-law (Gore, 1992).
- fewer years in the labor force and more employment in the informal sector means that women have fewer social benefits and are more likely to be poor.

H. Fewer resources available.

The developing countries are aging at a much faster rate than occurred in the developed world, therefore their populations will be older at a lower per capita income. (World Bank, 1994)

I. Claim: The elderly as a priority for resource allocation in the public sector.

According to the World Bank, "some argue that the drop in the child dependency rate caused by fertility declines will free resources to meet the needs of the growing older population. But careful analysis shows that it won't. The extra private subsistence cost of each old person is greater than that of each child. And as families and societies have fewer children, they are likely to invest more in each child (World Bank, p. 31). With respect to South Africa, Kinsella (1997) notes that with the health program's current emphasis strongly on maternal and child care, there is mounting concern that resources are being shifted away from needed geriatric care at a time when growth in the older population is increasing." Also in Uganda the focus of social programs is on education and health. As Njuki (1999) notes, "When families and communities assume all caregiving functions, including financial supports, there is little pressure on the government to develop social welfare programs as we know them today. The ASEAN Economic Bulletin notes that "when the elderly population emerges as larger and more significant than ever, there is likely to be little scope for any trade-off from the resources previously allocated to the needs of children. Children will still outnumber the elderly by two or three times and, in any case, given the established practices for care of the aged in those societies, diversion of resources to any major forms of institutionalized care for the aged is still unlikely to be the issue it is becoming in Japan and in the small populations of the countries further along that transition."

"In rural areas in low-income countries, informal systems may work better than formal ones. Given limited taxing and administrative capabilities, governments in Africa and Asia should be cautious about ambitious formal programs, which might fail, after crowding out family arrangements that function reasonably well." (World Bank, 1994)

J. Claim: The elderly will continue to play a reciprocal role in the family which will reinforce continued family support

Hermalin and others claim that contributions which are facilitated by co-residence such as child care and housekeeping will become more important as women increase their participation in the labor force. Hermalin's research in East and Southeast Asia has indicated that the elderly and their families are adapting to new pressures and roles. "Older women instead of being deferentially waited upon by their children and children-in-law in accord with traditional practices, are often involved in childcare and in cooking. But in return, the older person or couple is often invited out to restaurants with the family and may receive more income and gifts and better living quarters than would otherwise be the case" (Hermalin, 1998). Hermalin also notes that future cohorts of elderly will be quite different from those of today's elderly in that they will be better educated and more able to group together to advocate for improved services and policies. "The characteristics of today's elderly and their needs and preferences, while certainly meriting attention from policymakers and program managers, may be a poor guide to optimum arrangements for the future as successive cohorts with very different characteristics come along" (Hermalin, 1998).

II. Variation among developing regions

The World Bank (1994) has reviewed the situation in a number of regions and we summarize its highlights.

A. Asia

- Asia will have the most dramatic increases in the elderly population over the next 30 years. By 2025 the elderly will reach 18% of the population.
- There is a deeply embedded sense of filial loyalty which promote a high level of co-residence (70%-80% of elderly co-reside with children) and financial assistance on the part of children.
- The East Asian countries have the highest rates of growth and urbanization but these systems are demonstrating resilience due to high income levels, including more saving by the old and more monetary transfers which substitute for co-residence.
- In countries in Southeast Asia with a patrilineal family structure (China, Japan, Korea, Bangladesh, Northern India, Nepal, Pakistan), the responsibility for aged parents rests with the son.
- Parental control over property and inheritance reinforces willingness to care for aged parents.
- There is a great deal of outmigration from rural areas and poor communication between urban and rural areas

- In the cities, the older are forced out of the labor force earlier and the size of the extended family is shrinking.

B. Africa:

- Families typically reside in large extended household with several generations; elderly often receive informal support from their siblings
- Some community support systems have developed which stress self-help and income-generating activities
- 75% of the population lives in rural areas. There is also a great deal of circular migration - city dwellers often return to their birthplace when they retire
- Informal support systems are under less stress than in Asia and Latin America
- A pattern common in Africa is that of the skip-generation, where elderly live with their grandchildren, due either to the move of the middle generation to urban areas or to death from AIDS. Over 35% of households in rural Zimbabwe were skip generation households (Velkoff and Lawson, 1998).

C. Latin America

- There is broad variation among countries, but Latin American is further ahead than Southeast Asia in terms of life expectancy, urbanization and industrialization
- A somewhat lower rate (50%-60%) of elderly co-reside with their children.
- There are large inequalities in those countries with a poor indigenous population and a wealthy immigrant population.
- Formal support systems are more developed than in Southeast Asia and Africa, however some are nearing collapse due to demographic pressures and design weaknesses. (World Bank, 1994)

D. Sources of Support

Based on Andrews (1986) study of four countries in the Western Pacific (Fiji, Korea, the Philippines and Maylasia), we obtain the following picture:

- 12% reported that they did not have a confidante
- In most cases support was provided by either the spouse or a family member and very rarely by someone outside the family
- Assistance with disabilities is provided primarily by family members
- Among those with a disability, between 5 and 15% had no sources of support. Help outside the family was very small
- The major source of income is the family. In all four countries, the family's contribution is greatest; work plays a role with a significant minority. Pensions and welfare play a relatively small role.

E. Comparison between data from the Western Pacific study and European countries (Andrews et al, 1986):

- comparatively high rate who are married
- little difference in employment rates
- higher rate of smoking but less consumption of alcohol
- percentage with accident, injury or chronic condition affecting daily living tended to be lower
- much higher percentage live in households with 4 or more people
- the % reporting that they often feel lonely were quite similar

III. Examples of approaches which have been developed to caring for the elderly (World Bank, 1994; Gibson, 1992; Kinsella, 1990)

Housing programs:

- Maylasia - ground-floor public housing allocated to families with aged or disabled members
- Singapore - families willing to live next door to elderly relatives receive priority in housing assignments
- Cyprus - those living with older relative get priority in housing and can apply for financial assistance to add an extra room
- Hong Kong - priority allocation of public housing to families with elderly members, units for single elderly; shared housing for unrelated elderly (Kinsella 1990)

Supportive services:

- Day care and counseling are provided throughout East Asia and Southeast Asia
- Thailand: multipurpose day center provide health care, day care, family assistance and counseling
- Hong Kong and Singapore provide home help and nursing care at home as well as day care centers
- In Angola churches, clubs and local collectives are used for day care and other supportive services.
- Argentina: *clubs de ancianos* provide social, health and recreational services

Financial assistance:

- Malaysia: Adult children who live with parents receive a tax rebate and tax deductions are available for medical expenses and equipment for disabled parents (these arrangements are being considered in Korea, the Philippines and several African countries)
- Singapore grants tax deductions to people who provide support for their parents or other old people in the community.
- Argentina - economic support is given to "substitute" families who agree to care for a non-related elderly (Kinsella, 1990)

Health care:

- China has developed an efficient system of rural health clinics which have helped raised life expectancy above that in other countries with a similar income (World Bank, 1994. But some countries which had developed social welfare programs for the elderly are undergoing a period of retrenchment. For example, in China - where 20% of the world's elderly live -- they are transferring responsibility for the elderly from the social welfare system to the individual or the private sector.
- China and Vietnam - more organization of services for the elderly as a legacy of Communism, though this is breaking down

Institutionalization:

- Old age homes have become common in countries where aging has emerged as a concern, particularly in the more economically developed countries in Southeast Asia - Taiwan (5%), Singapore (2.5%) and Hong Kong (1.8%) (Kinsella, 1990)
- In China the State has undertaken the responsibility to provide institutional care for childless elderly and there are now 700 homes for the elderly.
- Many nations have an official policy to avoid institutionalized responses. The Malaysian government has stopped building welfare institutions for the elderly and Costa Rica has also advocated this.
  In some developing countries (Barbados, Taiwan, Philippines, Mexico) the private sector is taking the lead in long-term care facilities, and this raises issue of social equity as most elderly cannot afford private care. (Kinsella, 1990).

Legislation:

- China has passed legislation which requires the family to care for the elderly.

IV. Main Problems Facing the Elderly in Developing Countries

(These problems are not unique to the developing countries, but are more pervasive in light of rapid population aging and low level of economic development in most of the developing countries)

A. Move of young adults to urban centers
Many authors have cited the migration of younger persons to urban areas as a factor reducing the provision of family care and support to rural elderly who are left behind. (Andrews, 1999; Kinsella, 1990)

B. Decline in number of children available to care of parents. In the future, there will be fewer children to care for the elderly due to migration to urban centers, lower fertility, and increasing numbers of women joining the labor force. Modeling of kin availability has shown that in many developed and some developing countries, kin support networks for older people will shrink (Velkoff and Lawson, 1998). Knodel (Knodel, Dhayovan and Siriboon, 1992) examined the potential impact of declining levels of fertility in Thailand on family support for the elderly. He found that the chance of living with an adult child is only modestly jeopardized if family size is limited to two children. Having only one child presents more serious implications. Substantial reductions in the average number of children who will contribute money or provide food and clothing to their parents can be expected as a result of diminishing family size. However, the elderly with few children may accumulate more assets during their working life and provide their children with more educational opportunities

C. Poor access to basic health services, particularly in rural areas

D. Limited financial resources

* Inability to afford basic health services and and disability aides such as walking aids, eyeglasses and hearing aids

* Poor nutrtion, primarily caused by poverty.

"Modernization and rising incomes may threaten family care of the elderly, but they are less likely to threaten family [financial] support; indeed, experience in the West suggests that the economic status of the elderly is likely to rise as per capita income rises. Thus what may prove to be a more serious problem in the poorest countries.. is not their modernization, but rather their continued poverty." (Mason,1992)

E. Public services are poorly developed and often not targeted to those most in need (Lechner, 1999)

F. Lack of awareness of existing services and entitlements, particularly in rural areas.

A survey conducted in Korea (Chung, 1999) found low awareness among the elderly of many benefits and entitlements, including old age allowances (which were expanded to include lower-middle income elderly in 1998) and elderly job placement centers. Only 20.6% knew about geriatric hospitals; only 18.5% knew about home help; and only 2% knew about short-term care (which is a relatively new service).

VI. Strategies to improve the status of the elderly

A. Strategies to keep the informal system of care for the elderly from breaking down (World Bank, 1994)

- Avoid policy biases against agricultural sector, where traditional system of informal supports works best
- Improve rural/urban communication links

- Consider special programs for widows
- Try to have formal systems complement informal systems - provide goods and services that supplement rather than substitute for family care, e.g., community clinics, outpatient health facilities and day care and social facilities.
- Target social assistance programs on people without adequate income or without family transfers in order not to crowd out private transfers.

B. Gibson (1992) has suggested the following steps to improve the health status of the elderly:

- develop geriatric components within community clinics and acute care hospitals
- establish special health screening clinics
- improve access to health services for rural elderly, e.g., via mobile health units
- train family members and other lay providers in care of the elderly, e.g., simple nursing skills and self-care

C. Andrews (1999) has formulated strategies to meet the specific unmet needs of the rural elderly:

- Improved emphasis on preventive and health promoting activities
- Improvement of access by older persons to basic health care including provision of outreach primary health services and some services focused specifically on the needs of the elderly
- Improved provision of health aids for vision and hearing and basic rehabilitative devices
- Provision of continuing education (including health education) and training opportunities for older persons
- Recognizing the rural elderly as a resource and exploring ways for the to contribute and be productive

D. The Western Pacific Region of the World Health Organization has outlined a strategy for a comprehensive health care program for older persons (WHO, 1998), which includes the following elements:

- Health education, health promotion and disease prevention
- Primary health care
- Home and community-base care
- Rehabilitation
- Specialist meical services
- Mental health services
- Sheltered residential care
- Human resources development
- Roles for NGO's
- Research, information and development

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Table 1 Life Expectancy by Region

Asia	
Cambodia	48.24
China	69.92
Fiji	66.59
Hong Kong	78.91
India	63.40
Indonesia	62.92
Malaysia	70.67
Nepal	58.42
Pakistan	69.38
Philippines	66.58
Singapore	78.84
South Korea	74.30
Taiwan	77.49
Thailand	69.21
Vietnam	68.10
Latin America	
Argentina	74.76
Bolivia	61.43
Brazil	64.06
Chile	75.46
Colombia	70.48
Costa Rica	76.04
Ecuador	72.16
Honduras	64.68
Mexico	72.00
Panama	74.66
Peru	70.38
Uruguay	75.83
Venezuela	72.95
Africa	
Egypt	62.39
Ghana	57.14
Kenya	47.02
Morocco	68.87
Nigeria	53.30
Rwanda	41.31
Senegal	57.83
Somalia	46.23
South Africa	54.76
Zimbabwe	38.86

Source: U.S. Bureau of the Census, International Data Base, 1999

Table 2. Disability-free Life Expectancy
(The Average number of years an individual is expected to live free of disability if current patterns of morta lity and disability continue to apply.)

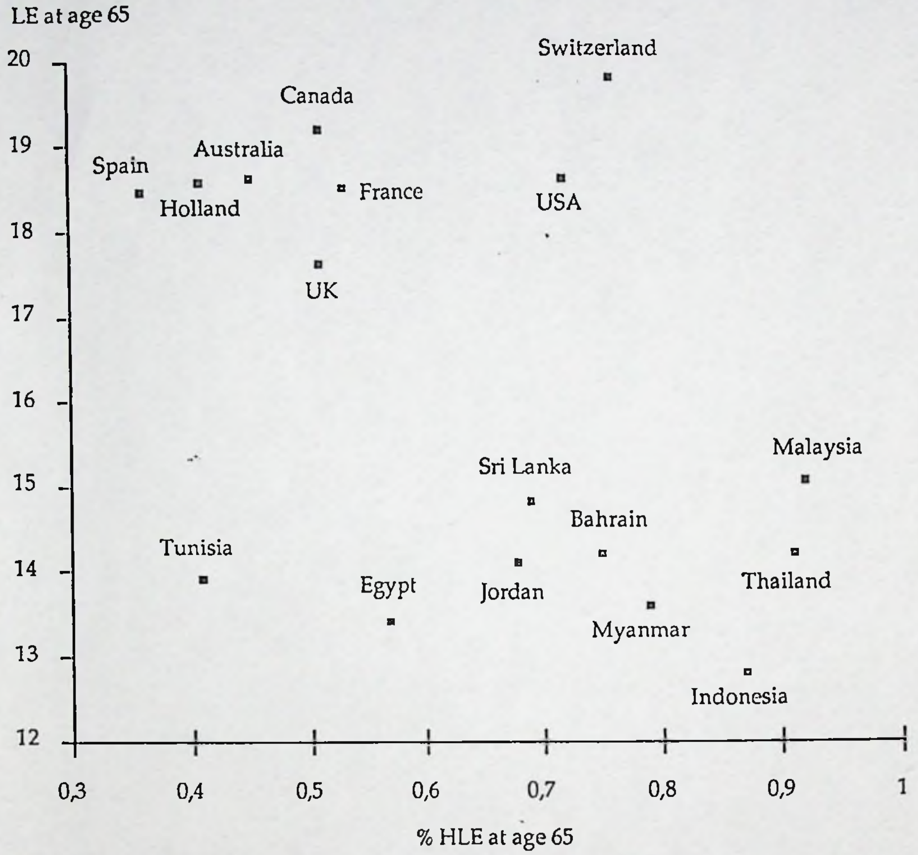
	AT BIRTH				AT AGE 65			
	Male		Female		Male		Female	
	LE	DFLE	LE	DFLE	LE	DFLE	LE	DFLE
Developed market-economy countries								
Canada, 1986 [6]	-	-	-	-	14.9	8.1	19.2	9.4
Finland, 1986 [7]	-	-	-	-	13.4	2.5	17.4	2.4
United Kingdom, 1991 [8]*	-	-	-	-	14.3	13.6	18.1	16.9
Least developed countries								
Myanmar, 1989 [9]	-	-	-	-	12.0	11.1	13.5	12.8
Other developing countries								
China					13.0	11.9	15.6	13.7
Bahrain, 1989 [9]	-	-	-	-	12.9	12.3	14.2	13.6
Egypt, 1989 [9]	-	-	-	-	12.1	10.8	13.3	10.1
Fiji, 1984 [9]	-	-	-	-	13.1	10.5	14.6	10.4
Indonesia, 1989 [9]	-	-	-	-	11.5	11.4	12.8	12.4
Jordan, 1989 [9]	-	-	-	-	12.7	11.6	14.1	12.5
Malaysia, 1984 [9]	-	-	-	-	13.4	11.9	15.0	12.7
Philippines, 1984 [9]	-	-	-	-	12.3	11.4	13.8	12.2
Republic of Korea, 1984 [9]	-	-	-	-	12.9	9.0	15.0	9.4
Sri lanka, 1989 [9]	-	-	-	-	13.2	12.3	14.7	13.4
Taïwan, 1991 [10]	-	-	-	-	15.5	11.7	17.5	12.9
Thailand, 1989 [9]	-	-	-	-	12.6	12.4	14.2	13.6
Tunisia, 1989 [9]	-	-	-	-	12.7	11.3	13.8	11.4

* In this table, life expectancy values for the United Kingdom slightly differ from the values in table 6-1. The latter are based on the complete data set of the General Household Survey, while for the calculations of the values in this table - for reason of international comparability - some respondents were excluded.
Sources in annex, some values are available at other ages and/or at a smaller geographic level for Belgium, Japan, United States of America and China. (See annex).

Source: Robine et al., 1995.

Healthy life expectancy is the average number of years an individual is expected to live in a healthy state defined as the "favorable part" of the distribution of perceived health status.

Table 3: **Total life expectancy and percentage "healthy life expectancy**



Source in annex, estimates not classified according to the WHR95 classification system; without any explicit reference to the ICIDH .

Source: Robine et al., 1995.

Table 4 Living Arrangements for the Elderly in Developing Countries

Country	Lives Alone	Spouse Only	Children	Extended family[1]	Other[8]
Thailand (rural)[3]	4	7	60		29
Zimbabwe (rural)[3]	8	2	30		60[2]
India (rural)[3]	6	1	83		10
Korea (urban)[3]	11	12	72		5
Egypt (urban)[3]	15	13	66		6
Singapore (urban)[3]	3	3	88		6
Brazil (urban)[3]	29	19	33		20
Colombia[4]	5	9		85	1
Costa Rica[4]	6	9		84	1
Dom. Republic[4]	9	7		84	1
Mexico[4]	7	16		76	1
Panama[4]	11	14		74	1
Peru[4]	8	10		82	1
Fuji[5]	2	10		84	4
Korea[5]	2	14		79	5
Malaysia[5]	6	12		80	2
Philippines[5]	2	7		86	5
Brazil[6]	11	28		61	--
Korea[7]	20	22		53	5

1 children and or grandchildren, other relatives)

2 High rate of "other" refers primarily to elderly living with grandchildren in skip-generation households

3 Hashimoto, 1988

4 Kinsella 1990 (data from 1975-1977)

5 Esterman and Andrews, 1992

6 Ramos, 1992

7 Chung, 1999

8 Other = other relatives and non-relatives

Table 5

World Bank 1994

Table 2.4 Living Arrangements of Older Persons, 1980s

Percentage of persons over 65 living

	With children or family	*Alone*	*Other*[a]
High-income countries			
Australia	7	30	62
Canada (Quebec)	16	21	63
Japan	69	8	23
Netherlands	12	33	56
New Zealand	—	39	—
Sweden	—	40	—
United States	13	30	57
Average	23	29	52

Percentage of persons over 60 living

	With children or family	*Alone*	*Other*[a]
Middle-income countries			
Argentina	25	11	64
Chile	59	10	31
Costa Rica	56	7	37
Panama	76	10	14
Trinidad and Tobago	41	13	46
Uruguay	53	16	31
Average	52	11	37
Low-income countries			
China	83	3	14
Urban	74	5	22
Rural	89	1	10
Côte d'Ivoire	96	2	2
Guyana	61	2	38
Honduras	90	5	5
Indonesia	76	8	17
Malaysia	82	6	12
Philippines	92	3	5
Thailand	92	5	4
Average	84	4	12

— Not available.

Note: Averages are unweighted.

a. Includes persons living with spouse.

Source: Japanese Organization for International Cooperation in Family Planning (1989); Pan-American Health Organization (1989b, c, d; 1990a, b); Ju and Jones (1989); Keller (1994); Kendig, Hashimoto, and Coppard (1992).

Table 2.

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Table 6 Percent of older respondents receiving various types of non-formal support from adult children, conditioned on availability

Type of support	Philippines	Singapore			Taiwan	Thailand
		Chinese	Malay	Indian		
% with no living (adult) children	4.5	4.1	3.2	7.2	5.0	4.5
% with no non-coresident child	8.4	15.9	17.0	22.4	11.0	9.1
Among respondents with 1+ (adult) child:						
Coresidence with 1+ (adult) child	70.6	89.3	91.6	78.2	71.7	72.5
Support from non-coresident children, among respondents with 1+ non-coresident child:						
Quasi-coresidence	53.2	n.a.	n.a.	n.a.	28.3	64.7
Monetary support						
- any amount	86.6	n.a.	n.a.	n.a.	n.a.	88.1
- substantial amount	46.4	n.a.	n.a.	n.a.	n.a.	69.1
Material support	88.7	n.a.	n.a.	n.a.	n.a.	89.2
Social contact*						
- weekly or more	57.8	65.0	65.1	50.5	65.6	75.6
- monthly or more	72.3	92.9	89.7	79.6	84.0	88.3
Unweighted N (total sample)	1311	3334	458	209	3626	4486

* For Philippines, Taiwan and Thailand social contact refers to visits in either direction; for Singapore, contact includes visits, phone calls or letters.
n.a. = not available

Table 7 Percent of non-coresident children providing material support by marital status, location, and sex

	Any money		Substantial money		Food/clothes	
	Philippines	Thailand	Philippines	Thailand	Philippines	Thailand
Marital status						
Single	65.9	63.4	34.3	49.7	59.5	61.5
Ever married	56.7	60.9	15.3	31.3	63.1	73.5
Location						
Adjacent Dwelling	55.0	60.0	9.9	23.9	71.6	81.0
Same Community	55.7	53.7	10.9	20.1	67.1	75.9
Same region/ Province	55.5	61.3	14.2	31.6	60.8	72.6
Elsewhere	60.9	65.9	26.1	45.9	57.1	66.3
Sex (observed values)						
Son	57.3	58.5	17.4	31.9	61.8	67.9
Daughter	58.4	63.7	18.5	34.4	62.9	76.5
Sex (adjusted values)						
Son	57.5	58.4	17.7	31.5	61.5	68.3
Daughter	58.4	63.9	18.1	35.0	63.6	76.3

Table 8. Percent of non-coresident children providing social support (visitation) by marital status, location, and sex

	See parent at least monthly			See parent at least weekly		
	Philippines	Taiwan	Thailand	Philippines	Taiwan	Thailand
Marital status						
Single	31.0	56.3	38.6	15.0	31.1	16.2
Ever married	53.0	67.6	62.8	36.2	43.5	45.7
Location						
Adjacent dwelling	n.a.	97.3	96.9	n.a.	92.8	94.6
Same community	89.3	97.8	92.6	75.5	88.9	83.3
Same region/ province	61.4	90.1	67.9	28.0	68.2	34.9
Elsewhere	18.0	50.5	21.0	6.0	22.5	4.8
Sex (observed values)						
Son	52.3	69.6	58.0	35.9	47.2	39.6
Daughter	46.7	64.7	62.7	30.0	39.5	45.7
Sex (adjusted values)						
Son	55.1	68.9	59.5	39.3	45.6	41.9
Daughter	53.7	65.4	61.6	36.8	40.7	43.8

n.a. = not available.

Home Care Initiatives in the WHO South-East Asia Region

By
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WHO/SEARO

1

Profile of the WHO South-East Asia Region

- 10 countries of the Region
  Bangladesh, Bhutan, DPR Korea, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka & Thailand
- 3 countries with >100 mil. populations
- 5 are least developed countries
- One-quarter of the world's population
- 40 % of the world's poor
- Gaps between "haves" & "haves not"

2

Global Burden of Diseases Carried by the Region

- 40% of world's maternal deaths
- 41% of world's deaths due to infectious diseases (7 million)
- 40% of world's TB cases (3.5 mil.)
- 25% of world's HIV cases (8-10 mil.)
- 68% of world's poliomyelitis cases
- 72% of world's leprosy cases (1 mil.)
- 30% of world's blindness cases (11.7 mil.)

3

Demographic Transition

- Increase in life expectancy at birth
- "Mature societies" to "ageing societies" with an ageing population > 7% by the turn of the century
- More people will be at higher risk of developing chronic & debilitating diseases associated with old age

4

Epidemiological Transition

- Persistent, emerging & re-emerging of communicable diseases
- Increase in chronic noncommunicable conditions
- Double burden of diseases

5

The Need for Community- and Home-based Care

- Shortened hospital stays
- Cost-effective care
- Home is the setting of choice for receiving care
- Ensuring accessibility of care to the poor, vulnerable & disadvantaged
- Ensuring a continuum of care

6

Elderly Population

- At risk from ageing related diseases and disabilities & changing life styles
- Arthritis, high BP, heart diseases & stomach ulcer along with visual & hearing impairments are common illnesses
- 50-80% of blindness cases in SEAR (11.7 m.) are caused by cataract
- Functional and economical dependent
- Some elderly live alone & no one to care them

8

…The Need for Community- and Home-based Care

- Elderly population
- People with disabilities
- Individuals with chronic diseases
- Other individuals

7

People with Disabilities

- Prevalence of disabilities ranges from 3-10% of the total population
- 11.7 million blind (30% of world's total) with a cataract backlog of 8.2 million cases
- 1 million leprosy cases (72% of world's leprosy cases)
- Estimated 5-10 severe mental disorders per 1,000 populations in various countries

10

…Elderly Population

- Specialized services for the elderly are inadequate
- Health personnel in community and PHC levels are not adequately prepared
- Low percentage of elderly seeking professional health care

9

Individuals with Chronic Diseases: HIV/AIDS

- > 5.5 million HIV infected persons (18% of world's total)
- AIDS cases less than 5% world's total
- Persons with high risk behaviors & general population
- AIDS cases will continue to increase
- Up to 2 million cumulative cases of AIDS by the year 2000

12

…People with Disabilities

- Accidents & injuries on the rise
  - 9-10% of total mortality in India
  - Injuries rank 5th in Myanmar and 4th in Indonesia as causes of morbidity
- Many injuries lead to permanent disabilities as trauma care is not well developed in most countries

11

Individuals with Chronic Diseases: Tuberculosis

- 39% of world's 3.8million reported TB cases in 1996
- 1/3 of global deaths each year - 1 million
- DOTS coverage was low – 12% of the total TB population
- TB is the most life-threatening opportunistic infection associated with HIV in the Region
  - 56-80% of AIDS cases in Thailand, India, Nepal & Myanmar
  - 40% of AIDS deaths in Asia

13

Individuals with Other Chronic Diseases

- CVD, CA & DM are leading causes of morbidity & mortality in several countries
- CVD, CA & DM will continue to increase
- Estimated 30 million DM cases at present, 80 million by 2005 – the highest among all WHO Regions

14

Other Individuals

- Recently discharged patients
- Pregnant women
- Mothers & babies during the postpartum
- Children under 5
- Population at large

15

Issues in Home Care: Changing family structure

- Urbanization
- Shift from extended to nuclear family
- Inadequate family support system

  Young & productive family members migrated to cities leaving behind elderly & children
- Paid professional & supportive workers for home care

16

Issues in Home Care: Roles of women

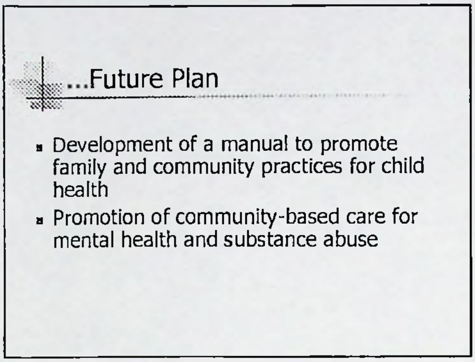
- Women in the Region are main providers of health care within the family
- Women as health volunteers
- Increased women's participation in the work force
  - Exposure to occupational hazards and injuries
  - Double burden of responsibilities
  - Insufficient support system

17

Issues in Home Care: Community participation in health

- Political commitment in all countries
- Health volunteer scheme in all countries
- Health Volunteers
  - to galvanize community for action
  - promote individual and family self-care
- Only female health volunteers are acceptable in some societies

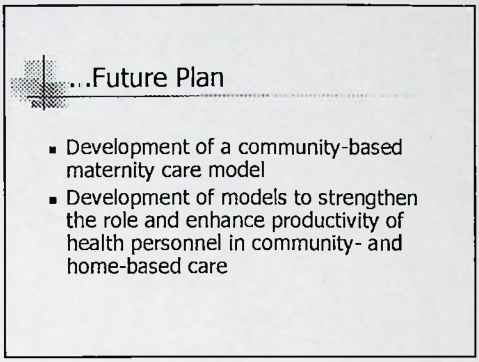
18



...Future Plan

- Development of a manual to promote family and community practices for child health
- Promotion of community-based care for mental health and substance abuse

26



...Future Plan

- Development of a community-based maternity care model
- Development of models to strengthen the role and enhance productivity of health personnel in community- and home-based care

25

…Initiatives Undertaken: Care of the Elderly

- Existing community-based care for the elderly
  - Family care
  - Primary health care for the elderly
  - Homes for care of the aged
  - Other community-based elderly support activities

20

Initiatives Undertaken: Care of the Elderly

- Creating awareness among policy makers and general public
- Collecting and disseminating information on socioeconomic and health status of the elderly
- Supporting formulation of national policies, strategies & programmes
- Improving health worker's knowledge & skills

19

Initiatives Undertaken: Community-based AIDS care

- Creating awareness
- Supporting formulation of policies, strategies & programmes with comprehensive AIDS care an integral part of the PHC system
- supporting the provision of comprehensive care
- Adapting WHO Home-care manual
- supporting the training of health personnel and community members

22

Initiatives Undertaken: Community-based rehabilitation

- Strengthening public awareness
- Collecting and disseminating information on disability situations
- Supporting formulation of national policies, strategies & programmes (with CBR as integral part of PHC)
- Strengthening infrastructure and referral facilities
- Supporting the training of health workers

21

Future Plan

- Development of a model for community-based elderly care
- Development of a model for prevention and control of major NCDs
- Development of health promoting workplaces

24

Other Initiatives Undertaken

- Promotion of self-care
- Strengthening of community health nursing
- Promotion of community- and home-based midwifery care

23

International Social Security Association

ISSA Conference
Demographic trends and globalization: Challenges for social security

Bratislava, Slovak Republic, 14-15 October 1999

Health: New requirements for long-term care

Xenia Scheil-Adlung
Programme Manager
International Social Security Association

ISSA/CONF/BRAT/99

Health: New requirements for long-term care

Xenia Scheil-Adlung
Programme Manager
International Social Security Association

There is increasing concern in many countries that social security in the area of long-term care faces great new challenges: costs are rising uncontrollably, there are not enough beds in residential care homes, and opportunities for care at home are non-existent or quite inadequate. Moreover, it is likely that given the global ageing of the population, the demand for care of the elderly will increase further in the future.

These and other reasons have led to reforms of social insurance in respect of dependency in many OECD countries in recent years. The starting point for new approaches to care policies in most countries is controlling costs in the health systems, which seek to exclude care provision from intensive medical care. At the same time, conceptual and administrative issues have been raised, which require old-age provision to be coordinated with other areas of social security.

Which concepts and strategies are regarded as able to control the growing care needs through the health system, other social security systems or private provision? What should be the goals of the new care policies? How can they be achieved through new forms of organization, financing methods and services? What are the core political issues that need to be clarified through the introduction of new rules on care?

The following report addresses these issues. First the causes of the worldwide increase in demand for care will be investigated, with emphasis on the demographic and socio-economic context. Next, new political ideas and strategies to overcome the problems of care provision will be explored and illustrated taking the example of Germany's care provision.

1. Causes of the rising demand for care

A comparison between the population indicators for 1950 and 1998 in most countries shows a shift from high mortality and birth rates to lower mortality and birth rates.[1] This shift, frequently described as the ageing of the population, is faster in the industrialized countries than in developing countries and is the most discussed demographic trend of the 21st century.

Greater life expectancy and falling birth rates mean not only that the absolute number of old people is rising, but also that the over-65 age group, especially people who survive past 80, is growing faster than other age groups. Thus, if past trends continue, the majority of old people will be women, as women's life expectancy worldwide is higher than men's.

A comparison of the life expectancy of men and women in 1950 and 1998 in selected regions of the world can be found in Table 1.

Table 1. *Life expectancy at birth in selected countries, 1950 and 1998*

Region/Country	**Men**		**Women**	
	1950	**1998**	**1950**	**1998**
Africa				
Egypt	41.2	60.1	43.6	64.1
Ghana	40.4	54.8	43.6	58.9
South Africa	44.0	53.6	46.0	57.8
America				
USA	66.0	72.9	71.7	79.6
Argentina	60.4	70.9	65.1	78.3
Costa Rica	56.0	73.5	58.6	78.5
Mexico	49.2	68.6	52.4	74.8
Asia				
Australia	66.7	77.0	71.8	83.0
Japan	59.6	76.9	63.1	83.3
China	39.3	68.3	42.3	71.1
Europe				
Germany	64.6	73.8	68.5	80.3
Denmark	68.9	73.6	71.5	79.1
France	63.7	74.6	69.4	82.6
Greece	63.4	75.8	66.7	81.0
Austria	62.0	74.1	67.0	80.7
Sweden	69.9	76.5	72.6	82.0
Hungary	59.3	66.5	63.4	75.4

Source: US Census Bureau, International Brief: Gender and Aging, Washington, October 1998.

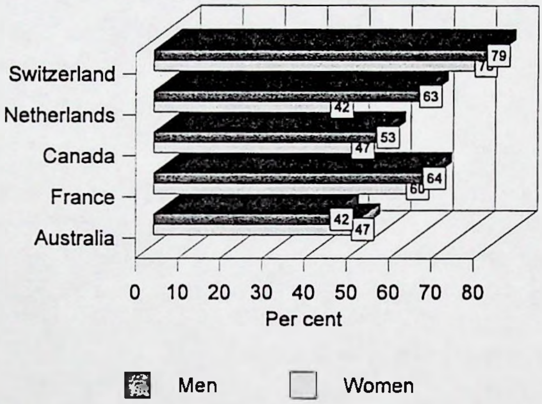
The above table shows clearly that life expectancy in the observation period of 48 years in all the developing and industrialized countries examined has risen, sometimes dramatically, as in China by 28.8 years (women), sometimes less markedly, as in the USA by only 6.9 years (men).

It is also clear that the highly industrialized countries of Asia and Europe have the oldest population, while the youngest population is in Africa. The pace of ageing appears most pronounced in developing countries, especially Asia.

Equally significant for the future development of health systems and care provision is, however, not only demographic ageing as such, but also the extent to which increasing age is linked to impaired health and the extent to which traditional carers (daughters, wives) remain available.

New research[2] shows that the extra years of life gained by old people are largely *without an increase in impairment of health*. Thus, 65-year-old men in Switzerland can expect to live 79 per cent of their remaining years without any disability. For women, the percentage is some 76 per cent.

Disability-free years of life after age 65 as a percentage, 1991



Source: J. Robine; I. Romieu, op. cit., 1993.

Only in Australia can women expect to live a greater part of their remaining life without disability than men.

In the other countries, women must expect to need care earlier than men.

Alongside *great age, its rapid rise* and the *feminization* of the elderly population, a characteristic of the group of (potential) dependants in developing and industrialized countries is the *increasing decline in the care capacity of family members*. This trend is due to:

- fewer children;
- male mortality; and
- more women working.

Correspondingly, an *individualization*[3], i.e. living in single-person households rather than multi-generation families, can be seen.

The trends described above mean not only that needs for care will rise further in the future, but also that there is a necessity of developing new approaches. Thus, the decline in the care capacity of families should result in the need to seek new formal and informal forms of care. The simultaneous pressure on social security budgets, and especially the health system, thus calls for special expert and political imagination.

2. New political approaches and strategies to long-term care of the elderly

In the past, the predominant feature of care policies in many countries was a proliferation of regulations and arrangements, frequently marked by a lack of coherent national care policies. Despite many individual laws, only in a few countries was there an integrated solution to problems that can be found in other areas of social security such as old age, illness, unemployment.

This may be due to the fact that dependency must be regarded as a relatively new risk and, from the social security standpoint, falls in the gap between the traditional risks of old age, illness, accident and disability. Depending on the social security system, it may also involve social services, welfare and private support services. This led to a plethora of regulations and jurisdictions at various administrative levels which has made a comprehensive solution to the problem, such as existed in the past in only a few countries, e.g. Israel and the Netherlands, much more difficult.

Only as a result of the constantly rising costs of health provision and national social welfare regulations did there come a political will to tackle the health-care problem in a systematic way and to undertake a businesslike and political reassessment of the risks related to care needs.

An international comparison of expenditure on care services as a percentage of health expenditure in 1994 shows that it ranged from 18 per cent in Denmark to 10.4 per cent in Belgium[4].

The changes in the period 1980 to 1994 range from an increase of 6.6 per cent in Belgium and a slight fall in expenditure in Denmark, Canada and the Netherlands, as can be seen from Table 2 below.

Table 2. *Care services as a percentage of health expenditure in selected countries*

Country	1994	Change 1980-1994
Australia	14.0	0.9
Belgium	10.4	6.6
Canada	11.9	-0.6
Denmark	18.0	-0.1
Netherlands	13.9	-0.5
United Kingdom	17.2	1.4
USA	11.5	1.4

Source: M. Schneider, op. cit., p. 158.

Cost analysis shows that mistakes have been made in the development of care provision, such as occupation of beds in medical hospitals with long-term care patients, as special care facilities are either inadequate or non-existent. This means that services are provided by highly paid nurses and doctors, when the same services could be performed by less-qualified staff, or volunteers, such as help with every day bodily care.

To avoid this trend becoming more acute, in recent years several OECD countries have brought in reforms which have partly led to comprehensive and coordinated care solutions. Fundamental health system reforms were carried out in **Europe** (Germany, Austria and Luxembourg).[5] Other countries, such as the United Kingdom, have introduced or extended targeted help for those in need of care or have considered doing so, e.g. France.

Even some highly industrialized countries in Asia have introduced new regulations on care provision or, are considering doing so. Thus, reforms have been carried out in recent years in Australia and New Zealand. In Japan[6], it is intended to bring in a new comprehensive reform in the year 2000.

An interesting aspect of the Japanese reform model is that it is a social insurance solution. As social insurance is not often encountered in Asia, the following is a brief outline of the new system:

The insurance institutions in Japan are the local authorities. The financing comes partly from the beneficiary's own contributions and partly from the Government, i.e. the State, prefectures and local authorities. Benefits start from age 65 and include home and residential care. The services can thus be delivered by both private and commercial providers.

Table 3 sets out the basic new regulations and some well-established ones, in selected European countries.

Table 3. *New and existing regulations for long-term care in selected European countries*

Country	Care provision	Financing	Private alternatives
Austria	Since 1993, cash benefits under various social welfare headings, which can be exchanged for services in kind	Taxation and contributions	Can be paid for using cash benefits
France	For some years, experiments with services in kind and cash benefits	National Budget, social welfare	Limited availability
Germany	Since 1995, social care provision covers home care and institutional care, services in kind and cash benefits	1.7 per cent of income of employees and pensioners	Care provision component
Japan	From 2000, dependency insurance to cover outpatient and residential care through benefits in kind	Contributions, personal contributions, government budget	Care provision component
Luxembourg	Since 1998, care provision covered by institutional, formal and informal care, mainly through services in kind, that can be exchanged for cash benefits	45 per cent of expenditure from the National Budget, special contribution by the electricity industry, 1 per cent of total income of insured	
Netherlands	For a long time, covered under the Exceptional Medical Expenses Scheme	Contributions by employers and self-employed	
Norway	Medical and long-term care covered by the existing system	Taxation	Development of private ventures
United Kingdom	Under the National Health Service	Taxation	

Source: Jozef Pacolet, Ria Bouten, Hilde Lanoye, Katia Versieck. *Social Protection for Dependency in Old Age in the 15 EU Member States and Norway*, Leuven, 1998, and own research.

Targets of reform

At the forefront of these solutions there are general targets which also affect other health reforms, especially cost control through the involvement of market elements.[7] In addition, proposed goals specific to care provision can also be found in the reform proposals.

Frequently found reform targets[8] for care provision in OECD countries are shown in the following table.

Table 4. *Leading care reform targets of OECD countries*

Benefits and services
- Enhanced quality of benefits and services provision - Increased efficiency in benefits and service delivery - Priority to out-patient services over in-patient
Expenditure
- Cost control - Contribution/tax ceilings - Reduced financial burden on health care and insurance and social welfare
Individuals
- Prevention of excessive demands on benefits and services - Prevention of dependence on social welfare - Prevention of excessive costs to individuals - Prevention of poverty
Institutions
- Relief of acute medical services - Expansion of long-term care infrastructure

Thus reforms will be decided both in services and expenditure as well as on the individual and institutional level.

The overriding desire of many politicians to relieve the burden on health and social welfare systems is reflected in the following goals: *cost control, reduction in the financial burden on health care and insurance and social welfare, prevention of "excessive demands" on services, prevention of dependence on social welfare and relief of acute medical services.*

Often several goals are sought simultaneously. Thus the *priority given to out-patient rather than in-patient services* is linked to the prospect of being able to offer better services, make savings, prevent poverty and reduce the need for residential homes. This can, among other things, be achieved through the provision of informal care by family members, who are often not only the best, but also the cheapest, form of care.

Performance targets such as *enhanced quality and efficiency* can be attained, for example, by the introduction of quality standards and regular evaluation in the framework of the extension and establishment of formal and informal welfare provision.

The cost burden on individuals can be controlled by caps on *contributions and taxes, avoidance of excessive charges to individuals and prevention of poverty.*

Forms of care organization

How can the stated goals be translated into organizational forms of care provision?

Here we have two alternative possibilities:

- *Revision and extension of existing regulations* for old age, illness, accident and social welfare, as in Australia, Ireland, New Zealand or Austria.

  In this solution, health and welfare provision is frequently integrated. It is thus also possible for several social welfare departments to be responsible for care provision. Cash benefits can therefore be delivered by other social welfare providers and departments than services.

- *Establishment of a new insurance system* to cover dependency risks within the existing social security scheme, as, for example, in Germany.

  This solution, unlike the first, allows the *introduction of separate budgets* for care and thus better control of costs and use of resources than would be possible under a general administrative framework, e.g. health insurance.

  With the introduction of a separate insurance method, it will also be possible to introduce new structural elements into social insurance not available in existing branches, which could be useful in long-term care provision. These include:

  - A *new basis of compulsory or voluntary insured groups of persons*, which do not have to coincide with the groups under other branches of social insurance. Thus, for example, for those aged 40 and over, the individual's compulsory insurance contribution can be reduced.

  - The *introduction of new forms* of insurance in the area of long-term care provision, without changing existing branches of social security, such as the involvement of profit-oriented private insurance into the social security scheme. It is conceivable that compulsory long-term care insurance could be introduced partly or fully through private profit-oriented insurance.

Financing of social security for care needs

Essentially, "traditional" *methods of financing* social security were retained in the countries that introduced reforms:

- *pay-as-you-go* in the framework of social insurance;
- *tax-based financing* through state programmes, such as income-related social welfare;
- in the case of profit-oriented private insurance, the *funding approach* is used.

The introduction of the above goals in the area of financing creates serious problems for many countries. As the starting point for most reforms in long-term care provision is cost reduction in health care, there is a danger that existing State resources cannot, in the long term, be adequate. In particular, because of the grey area between their application to medical treatment and long-term care, it is to be feared that resources will be pushed towards expensive medical treatment.

A particular problem is the relationship between the target of *reducing the cost burden to the State* and *preventing greater cost burdens on individuals*. These conflicting goals have in most of the reforming countries led to solutions which only partly cover the cost of care through the public purse and build on the increased provision of private resources. As will be explained below, Germany found a new form of financing long-term care, beyond the usual models, by cutting a public holiday.

A comprehensive insurance of care risk, exclusively from public or private resources, is not to be found in the reforming countries. In the context of the reform process, the existing *mixed financing* by public and private resources has been retained or extended.

The reformists saw "financial room for manoeuvre" in the income and capital situation of old people. In addition, it is assumed that economic activity at increasing age does not have to be restricted, but can be allowed to continue, unless precluded by early retirement, early-retirement pension rules, etc.

The income and capital situation of old people is not only relevant to the provision of age-related services, which are income-related - such as care provided by the social welfare system.[9] The increasing groups of contributors and taxpayers who finance long-term care provision and provide co-payments, are also an aspect of the new care provision arrangements.

Thus, the German and Japanese reform legislation provides for financing of long-term care through contributions by the insured, co-payments as well as through public subsidies.

Benefit design

When it comes to benefit design in long-term care provision, similar solutions can be found in the various reform processes. This includes the introduction of the following core innovations in the performance aspect of most reforms:

- *attendance allowances*;
- *new in-kind benefits;*
- *social security coverage.*

Attendance allowances are the most significant innovation concerning long-term care benefits. They are paid to cover the cost of home care and not to replace the beneficiary's income, as is the case with other cash social security benefits.

In most countries, attendance allowances are paid either direct to the persons in need of care or to the carer(s). In the case of direct payments to the persons needing care, this allows the possibility of employing one or more people and making a choice.

They generally consist of flat-rate payments, which individuals must use to cover the services they use. In countries with social insurance schemes, the predominant model is direct payments to those in need without any income-related means testing.

Less frequently, income-related payments are made direct to the carers. This is particularly the case in the Scandinavian countries, where informal carers, such as family members or neighbours, receive lower incomes in the context of communal households.[10]

Basically, there are graded levels of attendance allowances, depending on the degree of care needed. The distinction is often based on the following criteria, which may be further subdivided in various countries:

- dependant persons;
- seriously dependant persons;
- totally dependant persons.

Classification in the various categories is often by official doctors or medical services, who in some cases collaborate with the authorities that pay the attendance allowances.

The amount of the home attendance allowance is not only always less than the cost of in-patient care, but also less than the allowances paid for residential care.

Newly developed *in-kind benefits* are mainly related to the introduction and extension of facilities for home care, based on a combination of professional and informal services.[11] The (partial) assumption of the costs of this service is paid either as an alternative or as a top-up for the attendance allowance. A special concern is thus to achieve a better linkage between out-patient services and residential or semi-residential services.

Prominent here is another new function: support for informal carers who alone or with professional services provide *day and night home services* such as invalid care, housework, help with dressing, etc.

In order to prepare informal carers for their work and provide them with support, *advice to and training of* family carers, neighbours and voluntary helpers is increasingly offered as a new service.

A further innovation with regard to benefits can be seen in *social protection for carers*. Carers are not only often able to take leave from their job, but also during the period of care to acquire and increase their social protection. Social protection for carers is, however, limited to pension and accident insurance.

In some countries, the provision of *holiday replacements* during the care period is also included in the list of benefits.

In addition to the extension of *residential care* in special care centres, in many countries there is increased expansion of semi-residential care for those in need. These take various forms of day care centres specially equipped for old people.

3. Core issues in the introduction of new regulations for care provision

Regardless of which solution to insuring against dependency risk is chosen, there arise the same problem areas and core issues in care reform. These issues relate to the financial and administrative aspects of dependency and lie frequently at the heart of political discussions of reform. They include four problem areas, which will be briefly discussed below:

- *the distinction to be made between the need for long-term care and health care, i.e. between long-term care and acute medical treatment;*
- *centralization or decentralization of organization and service provision;*
- *dependency insurance through the public or private sector;*
- *development of a care infrastructure.*

Distinction between long-term care and health care

It is often observed that a sharper distinction should be made between sickness, disability and age, in order to allow better management of costs and services in specific programmes or branches of social security, e.g. dependency insurance, social assistance, sickness insurance or pensions insurance. Such an arrangement facilitates cost calculations and the establishment of budgets for long-term care provision.

The definition of dependency is confined in many countries to a state requiring support through regular, repeated activities in daily life, such as bodily care, feeding and mobility. However, an overlap with sickness, especially in the case of chronic or multiple disease, cannot be excluded.

In many countries, therefore, the degree of dependency is checked by special assessment procedures in each case, in order to restrict access to services to the most dependent.

Centralization or decentralization of organization and service provision?

The fundamental decision is whether long-term care provision should be organized centrally by the State, or decentralized.

The *advantages* of central provision are certainly equal access by all dependants to services and the avoidance of "service differences" in individual districts. In addition, central or national programmes generally involve lower administrative costs than locally-managed programmes.

The *disadvantages* of centralization[12] are often seen that the service structures in local care are highly developed and the planning and provision of services must take local conditions into account. The greater flexibility and less bureaucracy of decentralization allow more account to be taken of local values (e.g. religious values).

Long-term care provision through the public or private sector?

The question of to what extent insurance and long-term care provision should be provided through the public or private sector is related to rising costs, service quality and the solidarity element (redistribution aspect). Among other things, a distinction can be drawn between the following areas:[13]

- *Public or private compulsory or voluntary insurance* or provision through a *national programme financed from taxation* (like national health services). This decision will usually establish the coverage of the scheme as well as the basis of its financing (contribution/taxation or private resources).

  The Nordic countries decided to include long-term care provision in their national programmes, whereas social insurance schemes choose compulsory insurance like in Germany, which can, however, also be private.

- *Services can be provided* through national or regional administrations, state enterprises, autonomous government bodies, private cooperative bodies, voluntary or private profit-making entities.

  In view of the priority to out-patient care in all the countries concerned, the focus of care for old people is in home care, often through local, semi-private or private local services. This form of organization has also taken over for residential old-age and care homes in many OECD countries.

There could be a problem in this respect due to a lack of a coordinating network of the various service providers. That could lead to under- or over-supply, administrative mistakes and frictional inefficiencies.

- *The introduction of competition* between public and/or private enterprises plays a central role in the health schemes of OECD countries and is also relevant to long-term care provision. Questions to be answered here are, for example: What is the financial effect of "competition" between informal and formal services, between out-patient and residential care?

Development of a care infrastructure

In many industrialized countries, neither *home care* nor *residential care* is sufficiently developed to meet the growing demand.

There is an enormous lack of day centres for old people, services such as "meals-on-wheels", personal care and home visits, old-age homes and residential care. In order to allow the development of a care infrastructure, massive investment is often needed.

4. Case study: Social dependency insurance in Germany

It is frequently sought to provide dependency insurance in the framework of a national social and political philosophy. So too in Germany, as well as in other countries with social insurance schemes, it was sought to provide dependency insurance in the context of social insurance. By way of example, the new regulations on dependency insurance introduced in *Germany* in 1995 are described below.

Organizational arrangements

In Germany the social dependency insurance was established as a separate insurance scheme to supplement the statutory insurance system for old age, sickness, accident and unemployment.

Care services are provided to the insured person and family members. These services should serve to maintain or restore dependants' activity. Out-patient medical rehabilitation services can also be brought in. The quality of the services should meet generally accepted standards of medical care.

Dependency insurance providers are administered by the statutory health insurance. These are independent public corporations.

The coverage of dependency insurance equals the coverage of the statutory health insurance. This is some 90 per cent of the population. The remainder of the population must insure themselves privately, through private health insurance.

Financing

Expenditure on dependency insurance is currently around DM31 billion. It is financed through contributions by the insured. The amount is currently 1.7 per cent of monthly salary. The amount is paid half by the employer and half by the employee.

In Germany, further innovative ways of providing resources have been explored to find new sources of financing. In addition to the normal contribution-based financing by employers and employees, State supplements were introduced, e.g. to invest in residential care, and a statutory holiday was abolished. That partly compensates the employer for the burden of the dependency insurance contribution.

A further innovation in the financing of German dependency insurance is that deficits previously covered by the State would no longer be so. Thus, excess expenditure by the dependency insurance must, in the long term, be covered by contribution income.

This decision meant that the dependency insurance, otherwise financed by transfer from the normal fluctuation reserve, also retains financial surpluses to cover demographic risks. The surplus on statutory dependency insurance at the end of 1998 was DM9.5 billion.[14]

With the introduction of dependency insurance, the burden on social assistance, especially for "care support" services, fell by some DM8 billion between 1995 and 1996.[15]

Provision of service and benefit

At present, some 1.5 million people are in receipt of dependency insurance services in Germany. The costs of these services are not, however, always fully covered and must be supplemented by resources from other social security schemes, such as social assistance, or from the insured's own resources.

When long-term care services are requested, the dependency insurance arranges for the health insurance medical service to check whether the conditions for dependency are met and what level of care is needed. The health insurance medical service consists of some 2,000 doctors and 700 care specialists nationwide who are responsible for the assessments.

The degree of care determines the benefits and service provided. Category I comprises people who need help with bodily care, feeding or mobility at least once a day (one and a half hours) and help with housework several times a week.

Seriously dependent people come into category II. The care requirement is at least three times a day (three hours) and several times a week for help with housework.

Category III is where care is required day and night (at least five hours a day) and help with housework several times a week.

In particular, the following types of service for old people must be distinguished.[16]

In the area of **home care**, a distinction should be made between services in kind, cash benefits, combined in-kind and cash benefits, home care in the absence of regular carers, equipment and technical aids, social security coverage for the carer and long-term care training.

- Care services in kind

  The right to home care by professional carers covers all household services and basic personal services such as washing, help with dressing, etc. These benefits can be claimed up to DM750 for category I, up to DM1,800 for category II, up to DM2,800 for category III and hardship cases up to DM3,750. Costs in excess of this must be paid privately.

- Cash benefits

  If the care is provided by an alternative means, e.g. spouse, neighbour, etc., the amount of cash benefit for category I is DM400, for category II DM800 and for category III DM1,300.

- Combined cash and in-kind benefits

  Cash and in-kind benefits can be combined; e.g. if the service is only partly claimed, then the insured receives a partial cash benefit in addition.

- Home care in the absence of regular carers

  Dependants who received cash benefits to pay for home care are also entitled to payment for a substitute home help for up to four weeks a year. A maximum of DM2,800 is allowed for this. The substitute help is for the period of the carer's holiday or illness, for example.

- Equipment and technical aids

  Dependency insurance also covers aids such as wheelchairs, or financial subsidies are available for adapting the home, provided that this is needed on the grounds of dependency and not sickness. The total amount is DM60 per month for consumption of equipment and up to DM5,000 for home modifications. Technical aids should normally be loaned.

- Social security for the carer

  Dependency insurance covers the informal carer's pension contributions. If the carer returns to work, the carer can claim a so-called remuneration grant from the unemployment insurance. Accidents related to care are covered by the accident insurance.

- Care training for family members and voluntary carers

  In order to lighten the mental and physical burden of care for informal carers, free training and courses are available.

Semi-residential care services include day and night care and short-term care.

- Day and night care

  Semi-residential care offers special day and night care in special centres as well as return transport. Services in centres are provided up to the value of DM750 for category I, up to DM1,500 for category II and up to DM2,100 per month for category III.

- Short-term care

  Where home care cannot be provided temporarily, short-term care can be claimed in residential centres. This is possible for up to four weeks a year, with an entitlement up to DM2,800.

Services in **fully residential care** centres are paid up to DM2,800 per month and in hardship cases up to DM3,300. However, this amount may not exceed 75 per cent of the centre's charges. In total, the average annual cost of dependants under the dependency insurance should not exceed DM30,000.

5. Conclusions

The problem of dependency arises in almost all countries, albeit in different guises. Yet only a few social security schemes are equipped to deal with it.

Since the early 1990s, significant reforms have been carried out, especially in countries with social insurance systems. Thus, comprehensive new regulations were introduced in *Austria* in

1993, *Germany* in 1994, *France* in 1995 and *Luxembourg* in 1998. *Japan* likewise envisages a far-reaching reorganization of long-term care provision in the form of social insurance.

In the context of these reforms, the following *new socio-political developments* stand out:

- Dependency services are seen as a new risk and are either:
    - incorporated into the social system as a separate branch of insurance; or
    - built on to the existing sickness, pensions, accident and social welfare system.
- New forms of financing long-term care services include, *inter alia*:
    - the abolition of statutory holidays;
    - greater co-payment and partial coverage of the cost of the service claimed;
    - introduction of informally provided services without or with lower cost structures.
- Lump-sum home care services include:
    - cash benefits covering part of the formal and informal help;
    - new opportunities for short-term semi-residential care;
    - introduction of social security coverage and training for family carers.
- Integrated cooperation in service delivery between:
    - health care, old age and accident, social assistance and social services;
    - public and private sector.

The former strategy of providing care for the elderly through family members appears in the longer term not sustainable in many countries. Not only because of demographic trends, but also because of the pressure of ever-rising costs of sickness insurance and social assistance systems, it can be expected that the number of countries providing dependency insurance as part of the social security system will increase further in the future.

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LTH/HSC/SG/99/10

REVIEW OF REGIONAL EXPERIENCES AND MAJOR CONCERNS ON HOME-BASED AND LONG-TERM CARE

STUDY GROUP ON HOME-BASED AND LONG TERM CARE
ISRAEL, 5-10 DECEMBER 1999

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SUMMARY.

1. Introduction

Home-based and long-term care has become increasingly important in the Africa. The reasons for this are many, but the shear magnitude of health problems, coupled with poor socio-economic conditions and inadequate infrastructure has resulted in the need to for home-based and long term care in most countries of the region.

Malaria is the leading health problem in Africa, south of the Sahara. A total of between 300-500 million clinical cases are reported every year. Deaths due to malaria are estimated to be between 1.5 and 2.7 million per year; about 5% of children under 5 years die of malaria-related illness.

Sub-Saharan Africa remains the worst affected region with regard to HIV/AIDS. An estimated 21 million adults and children are infected with the HIV virus. 83% of the total AIDS deaths are from the region. 80% of the HIV +ve women and 90 % of the infected children are from the region. This condition has lead to the worsening of TB control, with 2 million new cases and 600,000 deaths per year.

This trend, coupled with the occurrence of epidemics and outbreaks, has resulted in an overwhelming burden to the health infrastructure, which in most countries is far from adequate. It has also stretched the meagre financial and human resources beyond the limit.

Given this scenario, home-based and long-term care has become a reality for many households in Africa.

2. Political, economic and cultural context

After two decades of significant socioeconomic growth and development in most independent African countries, the 1980s ushered in a period of worldwide economic recession that negatively impacted on the economies of most countries of Sub-Saharan Africa. The health care delivery systems of many countries became so weakened that they were incapable of coping with the increasing health challenges, as well as meeting the needs of a growing population which had become better informed about their right to quality of health care.

The problems facing the health sector in most countries include:

- Absence of well articulated health policies and / or plans;
- Weak and fragmented health systems;
- Inadequate resources, financial, human and material;
- Overdependence of key programmes on donors;
- Poor management of health expenditure;

- Inefficiency and wastage in procurement, storage, prescription and use of drugs;
- Poor support services, including supervision, logistics and information management;
- Ineffective referral systems;
- Poor coordination among service providers (public and private);
- Inadequate and inefficient regulatory mechanisms;
- Inadequate community participation.

In most countries of the Region, there has been rural to urban migration such that many families have at least two abodes, one in the working area and another in the rural area. Sexual activity begins early, e.g. in Botswana, 23% of first-time antenatal care attendees annually are teenagers, of whom 6% are below the age of 15 (Botswana annual health statistics 1995). This level of teenage pregnancy indicates a high level of unprotected sexual activity in this age group.

The use of limited health care resources can be made more effective and efficient by involving all caregivers, i.e. health organizations, professionals, community members and family members, through home-based care thus reducing the workload of professional health providers in the hospitals. Home-care is seen as a key strategy for sharing care tasks between hospitals, district health services, communities and families.

Home-care and long term care experiences

Home-based care is given to individuals in their own natural environment-their home. In most countries of the Region, home-based and long-term care has been rendered in a piecemeal fashion by different health care providers, without an emphasis on linking services within the health care system. A number of countries have developed operational guidelines for home-based care (Uganda, Botswana). In addition, there are other key issues that have to be considered, e.g. social support and drug kits.

The specific objectives for home-based care are:
- To assess the health and health-related needs of patients/clients and their families.
- To develop a plan of action for the identified needs.
- To provide continued support and care to the client/patient and family.
- To identify community support groups.
- To provide training and education for health care providers, patient/client, caretakers and community groups on managing clients at home.
- To establish a comprehensive referral system in order to ensure continuity of care.
- To monitor and evaluate home-based care.

Social welfare providers, including caregivers at home level must be trained in home-care. In addition, they should be provided with basic supplies such as gloves, incontinence pads, reusable bedpans, plastic aprons, mackintoshes, disinfectant iodine, etc. It is important to have support from the community, particularly from religious groups interested and experienced in home visits and home-based care. Strengthening the referral system will ensure continuity of care. Counselling must be provided to patients and families before, during and after care.

WORLD HEALTH ORGANIZATION

STUDY GROUP
HOME-BASED AND LONG-TERM CARE
Ma'ale Hahamisha, Israel § 5-10 December 1999

"HOME CARE ISSUES-- AMRO-PAHO"

World Health Organization
Regional Office for the Americas
Pan American Sanitary Bureau

LTH/HSC/SG/99/9

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(A)

Background:
It has been demonstrated that adequate coordination between hospital services and good home care programs reduces hospital occupancy rates, increases discharges, and shortens hospital stays, with significant savings in the direct cost of health services (32,10,8,13,24).

The advantages of home care include: greater efficiency in the use of existing hospital beds, a lower rate of hospital admissions and readmissions, shorter hospital stays, lower health care costs, greater user and caregiver satisfaction, home health care delivery to an ever-larger elderly population, and improvement of the quality of life for patients and their families (10, 39, 19, 4, 22). An illustrative example in this regard is the home care provided to mothers and newborns as a consequence of early hospital discharge (24).

(B)
PAHO has initiated work on home care in the last year in an interprogrammatic activity between HSO and HCN on Palliative Care for patients with Cancer. As we progress further with this avenue it becomes clear that the need for home care for individuals and their families is not being met. We have taken the initiative to explore Home Care in the Region of the Americas and to focus initially on feasibility to develop home care services. Anecdotal information suggests that organized systems of home care are not generally operating in developing countries. The exception is programs developed to care for patients with a particular diagnosis (usually cancer or AIDS) and which use volunteers rather than paid staff or those associated with prepaid or managed care insurance schemes. A number of experiments in developing home care schemes have failed due to financing problems.

To date a review of Spanish language databases and inquiries to key informants in Latin American countries has provided additional information about programs in the countries. This includes a roster of Latin American country experiences for services in the area of home care and palliative care. A registry of information that includes the organization of the home care system, financial issues, and coordination of the different levels of care, when this information is available. A directory of organizations with experience in home care was also compiled. In addition, a draft paper in Spanish on issues in the development of home care has been prepared and is currently under review in HSO and HSN. This paper is based on the literature reviews, information from key informants, and the database of programs. It addresses some of the problems surrounding definitions such as home care, home visits, and home procedures. It also provides a conceptual model that recognizes that home care should be at the center of a network of services at all level of care--primary, secondary, and even tertiary.

All home care programs must undergo their own unique development in response to community needs. The diversity of home care programs is both a strength and a weakness in development in this sector (18). While individual programs allow for specific and local responses to address needs, the lack of common terminology, standards for service delivery, and information gathering has kept individual programs from benefiting from the development of collective initiatives, including research activitities, analysis of the cost-effectiveness of interventions, and information systems to support improved management and policy-making (18).

The potential collective benefits of home care programs would be further research activity to support improved management and policy-making. There is considerable variation among home care programs and much can be learned from their experiences, especially now that countries are experiencing a relative period of growth and reform in this area compared to other sectors of the health system. Systems need to be developed and used to support the collection and dissemination of information to support evidence-based decision-making at the subnational, national, and international level.

This background paper and the steps included will address home care issues such as; developing and establishing common terminology and discussing key issues with respect to organization and management, proposed models of care, and resource issues, which can then be used as a tool to help establish general guidelines that can assist individual countries in developing standards for home care service delivery that are suited to the needs and demands of each specific population.

Introduction:

Home care for patients with a variety of pathologies has been widely described as an alternative to institutionalized health care. Although its development has not followed a path parallel to that of institutional care, extensive experience has nevertheless been amassed with regard to the various forms of home care and their disadvantages and advantages(25).

Addressing this issue means dealing with a "new modality of health care," which in turn, implies the development of a new profile of public and private health services. The bases for considering home care as a preferred care alternative are mainly epidemiological, technological, economic, and social in nature.

The latest trends in morbidity, mortality, and demographics in the developing countries point to an aging population, accompanied by a concomitant increase in chronic diseases and the typical complications associated with the end of life. In 1990 the population over 65 years of age in Latin America numbered more than 21,434 thousand and is expected to rise to more than 39,396 thousand by the year 2015(14). With regard to mortality, it is predicted that cases of infectious disease, which have thus far been the highest cause of mortality, will be equaled in number by cases of neoplastic disease by the year 2000. By 2015 neoplastic diseases will account for double the number of infectious diseases as a cause of death in Latin America and the Caribbean(14).

(C)
These figures indicate that national policymakers in many developing countries must begin to develop programs designed to support significantly higher numbers of the elderly in the coming decades. In light of the declining family support available to the elderly population in many urban settings it is essential to develop health policies to explore how formal and informal services are provided by home care programs.

The current advances in technology make it possible to ensure an adequate level of quality in home care. The transfer of hospital technology, however, is an issue that requires special consideration of the costs and benefits of such procedures as parenteral feeding, peritoneal dialysis, and oral rehydration(5,1,34).

From an economic standpoint the need to control the ever-rising cost of health care, coupled with current cutbacks in health budgets, points to the need for serious consideration of home care in health care delivery. Early discharge has been institutionalized as a way of controlling hospital expenditures, resulting in a greater workload for health workers--who must now provide the same amount of care in a shorter time--and growing health problems due to complications after discharge, which in certain cases incurs further expenditures. With regard to reducing the cost of care for mothers and newborns through home care programs following early discharge, Malnory's findings (1997) are encouraging . This cost-cutting was achieved mainly by curtailing visits to emergency services, reducing hospital readmissions due to subsequent complications in mothers and their infants, and reducing the frequency of outpatient consultations(24). Comparative studies of institutional and home care conducted by Shepperd, et al. (1998) did not show any decline in health care costs in any of the patient groups studied(44). It should be noted, however, that these groups generally required highly complex care and that the goal of the home care programs in these cases was to transfer "all" the services provided in the hospital to the home.

Finally, in many cases--provided that adequate instruction is provided--the sociological, sociocultural, and spiritual aspects of care given in a family setting are major advantages for the recovery and/or maintenance of health or a dignified death(29,12). Various studies have demonstrated that in all cases home care significantly increases the satisfaction of patients, families, and health providers(28,,41,,43,44,14).
The purpose of this document is to present concepts, objectives, systems of organization, and a description of the key participants in home care. The concepts presented here are the result of a literature review and interviews with experts, in addition to observations in the field. Suggestions have been included that may be expanded or modified in keeping with contractual needs

Definition of Terms:

There are a number of ways to bring health professionals together with users in the home, which leads to varying concepts. Although these concepts appear to be similar in form, they are substantially different in their essence, characteristics, and methods.

(D)

Due to the diversity, range, and orientation of services among programs, when referring to home care programs, differences exist within and among countries. Home care programs may include different services and clients, or home care programs with an acute care orientation are defined differently from those incorporating a broader range of services into one program. The scope and definition of home care must be broadened to recognize that home care needs to be built on innovative approaches. It appears essential to standardize the definition of terms in the interest of developing structures capable of providing home care as a component of a health care model. A clear-cut presentation of such terms would provide a common language and lead to easier management in practice.
The following table presents a summary of the terms most frequently employed in the literature, in addition to a brief definition of concepts and objectives, providing examples in each case.

	CONCEPT	OBJECTIVE (s)	EXAMPLES
HOME CARE	Coordinated delivery of health services in the home. Includes use of support networks (public, private, and community institutions). Care is delivered in a comprehensive and systematic fashion.	- Precision - Management of problem - Comprehensive care - Reduction of hospital stays - Expanded coverage - Greater user satisfaction	Palliative care program. Programs for kidney patients.
HOME VISITS	Access to patients' homes with a specific purpose. Provided by one or more members of the health team without community participation. Is not part of a home care plan.	- Investigation of cases at risk. - Evaluation of personal, family, or environmental situation.	- Follow-up and outreach to women who missed Pap smears. - Follow-up and outreach to women who missed well child care. - Socioeconomic evaluation of the family group.
HOME PROCEDURES	Home care for patients with a specific intervention purpose, usually provided by a member of the health team.	- Organization of an activity or specific health technique in the home.	- Catheter changes - Collection of specimens for testing

Home Care:

Home care is defined as the coordinated provision of health care in the home that delivers a certain number of services of limited duration and complexity and that enable the beneficiary to remain in the family environment under the best possible conditions(28). Another definition identifies home care as a formal support network. These services include both health professionals and other community support networks (public, private, and volunteer.) Home care implies holistic delivery of care, which includes physical care, the training of health care providers (family or neighbors), social and psychological support of the patient and family, orientation with regard to social and financial benefits, and referral to services and professionals, as needed(28).

OBJECTIVES OF HOME CARE

- *Prevention of health problems, whenever possible*
- *Management of existing problems*

Comprehensive care directed toward the family unit and promotion of self-care(51(b))

Home Visits:
Home visits are defined as visits to the patient's home by one or more members of the health team. They usually form part of the program priorities of the health services at the primary care level and are also a component of the socioeconomic and demographic care/assessment of a family or household; they do not, however, form part of a holistic home health care program.

Their main objectives are:
1. Assessment of patients, their families, and their environment, with a view to establishing a diagnosis of their health or socioeconomic status
2. Follow-up of at-risk cases and/or those who have missed check-ups, treatments, or examinations

Home Care:
Home care is the result of the specific diagnosis of a health problem. Health interventions conducted within the framework of home care focus on the solution of these specific problems through specific health activities, usually carried out by a member of the health team. Home care is usually described as "sporadic" care provided in the home. If this care is part of a home care program or plan that is coordinated with other home interventions and employs a holistic approach, then home care and home procedures can be defined as equal and, hence, interchangeable terms.

These three concepts have been selected as those mentioned most frequently in the literature. Consequently, this sample does not seek to diminish the value of other definitions or terms in use nor to limit the emergence of new concepts and definitions that may result in further development of this kind of care.

Organization of Home Care:

Before organizing a home care program it is important to define the needs it must address and the best means for meeting them. It is also very important to consider the sociocultural context of the environment in which a given program will be implemented(28) . At the same time cooperation and communication between the various sectors of the community and the health professionals are the cornerstone for the organization and operation of a home care program. The following case exemplifies the concepts of home care, home visit, and the sociocultural characteristics to be taken into account in their organization. (Contribution of Mrs. Guadalupe Palos, Nurse, Research Group in Pain and Palliative Care, M. D. Anderson Cancer Center, University of Texas):

> ***Case 1:***
> *A Hispanic immigrant, male, 70 years of age, with a diagnosis of terminal cancer is referred for home care. A home evaluation visit is conducted by professionals from the institution that will provide home care, with the object of discussing any doubts, problems, or conflicts, and finding possible solutions. On this occasion the professionals of the health team encounter an extended family that includes at least three generations, in addition to several other significant people (some 25 people in all at the meeting), all of whom wish to assist in providing care for the patient. The coordinator of the professional team requests the patient to fill out the forms for evaluating his pain (all in a language that the patient does not fully understand); however, one of his daughters takes the form before it is put into the hands of the patient. His vital signs are taken, and the health personnel note that family members appear to be concerned about the patient, who is speaking to them very slowly and in a somewhat agitated manner in his native language. Nevertheless, when the patient turns to the health workers, he merely smiles and nods his head in a sign of assent. When the patient is asked about the written information, one of his daughters interrupts and answers for her father, appearing not to take the patient or his wife into account. The team takes note of this situation, in which the patient does not appear to be given the opportunity to voice his own perception of his pain or the relief or satisfaction he is receiving from his current treatment.*

A thorough evaluation of the sociocultural, environmental, physical, and spiritual aspects was considered in planning the home care, with a view to meeting the different needs of the patient and his family.

The organization of a home care program should basically consider four factors (Karpati, 1994):

a. The place occupied by home care in the health system
b. The financing of home care
c. Definition of care standards
d. Human resources development(1)

(E)

Existing home care services are often fragmented among acute and community care organizations and between health and social agencies. Therefore, responsibility for services to clients is spread over many agencies, and no one is really accountable (3,618) Governments have been encouraged to fund and facilitate home health care. Therefore, it is important to establish who is accountable to the health authorities for funding allocation and service delivery.

The transition from institutional care to home care must be planned, managed, and part of a comprehensive system of health care. Moreover, since home care is multifaceted, the planning must be tailored to the particular circumstances. It is therefore important to decide who will administer the home care programs and who will refer clients to receive home care services (18).

Principles and guidelines are required to ensure equity. The Canadian National conference on Home Care and concluded that national standards on portability, comprehensiveness, accessibility, universality, funding, skills and training for caregivers, and public administration were desirable. They also suggested that all levels of government should meet to discuss and define acceptable options for standards. All nations should confirm who sets overall policy guidelines and standards for service delivery, reporting requirements, and monitoring outcomes. A movement to promote the development and use of a standardized home care assessment mechanism should also be established. Eventually, legislation on guidelines or policies governing the delivery of home care services should be considered (18). Finally the quality, cost, and effectiveness of services should be monitored and evaluated in order to determine future strategies for ongoing improvement of the overall system (9,51).

The basic eligibility requirements for home care services must be considered. Vulnerable groups such as the elderly, patients dependent on technology, the disabled, minority and indigenous groups, certain high-risk infants and children with complex medical problems, and those with out anyone to care for them should receive home care services. Such requirements may include; proof of residence; needs assessment conducted prior to any service provided; care as a response to unmet needs; a safe home that is suitable for service delivery; and the consent of the patient or his legal representative.(18) Yet, not everyone in these groups may need full services or services over the same length of time at the same level of service or from the same type of provider. Therefore, the length of the service should vary with the specific needs of the patient or group of patients. In nonindustrialized countries such as those of Latin America and the Caribbean, home care and home help services are not recognized as a right and, hence, are not included in the basic package of services. (23) Social insurance is available only for those employed by the government or major employers .(33) It is also important to consider whether or not there is a lack of equity between facility-based and home care programs. For example, will drugs, supplies, and equipment needs be covered in an institutional setting but not if the client is receiving care at home? (43,44)

Reforming the organization and management of the home care health services designed to improve equity, efficiency, and quality can be an obstacle. It includes measures to improve home care services at the peripheral levels of the health system, to strengthen referral, and to reform existing health financing mechanisms to generate proper signals to users and ensure that the indigent are not excluded from care. (18)

Principles for the development of home care services(1):

- *Adequate division of labor*
- *Continuity of the care*
- *Delivery of a broad spectrum of care*
- *Care for all who require it without discrimination*

The organizational forms of home care programs may be classified by the origin or institution that delivers the service or the kind of services provided, as follows:

- *Community-based multisectoral programs.* The interrelated organizations in this case include a broad spectrum that ranges from governmental and private health institutions to insurers, including the informal or traditional sector—all of them centrally or locally coordinated. The inclusion of alternative health resources represents both a need and a challenge for the delivery of home care(28).
- *Programs associated with a hospital or public health institution*: These programs are a response to a need perceived by both the community and the professionals of a service within the larger institution. They are limited to specific and specialized care, provided in a specific geographic area. They are usually not-for-profit initiatives, and their services are available to all who require them within the constraints of the program(10).
- *Private programs:* These are for-profit institutions that deliver home health care services, usually restricted to the upper-income sectors. They may be associated administratively with a major health institution (hospital), also private, or operate independently. They usually cover a broader spectrum of care than those described above.

Relationship between the administrative structures of the various types of home care programs and organizational forms

Type of Health Program	Place in the System	Financing	Coverage
Public	Part of the government health services system. May be associated with a hospital or specific unit or operate independently.	Social insurance or social security system	Limited to beneficiaries of the public health system.
Community-based multisectoral	Independent of the public health administration	Mixed social security systems and/or private health insurance	Universal
Private	Independent of the public health administration	Through direct payment agreements with institutions. Health insurance coverage.	Dependent on the social insurance system

(F)
Models of Home Care:

Home care should be *an integral part of the health care delivery system.* The restructuring and downsizing has placed an unsustainable burden of care on individuals and families due to shorter hospital stays, the increasing number of unskilled caregivers and cost. Home care programs may be one way to rebuild and modernize the health care system. Home care programs may be coordinated systems for home and community health-related services that enable people to live in their home environment and to achieve their optimal functional capacity. Improving communication and service coordination in the health care system needs to be strengthened. A smooth transition from hospital to community and home care and vice versa must also take place. An integrated delivery system would allow this to happen. (3,6,18,36,48)

The goal of home health care is to promote self-care capabilities in the client's home. An appropriate model for home health care should include concepts of health service delivery, standards of care on which to focus practice, and guide the development of caregiver interventions that are cost efficient and effective (18,36,48,53). The model should also include the ability to measure the quality of services in the home. What is needed are comparisons of patient outcomes with these services and information on which level of provider results in improved outcomes, what mix of services is necessary for which vulnerable group, and which services are most cost effective. Moreover, because of differences in cultural and economic environments it is impossible to rely on a single approach in home care services; rather, it is important to identify a range of effective models rather than focus on a single program model. (36,52)

Location of Home Care in the Various Care Programs and Levels:

Achieving universal access to home care is presently subject to the recognition and development of firm support strategies for this type of care by government health care systems. Similarly, the recognized benefits of a home care system, such as a general reduction in health costs, greater user and professional satisfaction, and greater effectiveness in the care provided, can only be achieved through appropriate integration of home care into the health systems, which in all cases implies coordination and collaboration between the various health care modalities in the health services and the home care systems.

The model sketched below is a graphic representation of the various systems and relations underlying home care. This model is based on the following assumptions and concepts:

1. The three levels of care that make up the health services systems are related to one another through referral and back-referral systems. These levels differ not only in their degree of specialization and coverage, but also in the various forms in which they relate to the community and in the strength of these relationships.

2. The coordination, collaboration, and interaction of the various levels of health care with one another and with a home care organization is essential for achieving the objectives and desired outcomes in a home care program. These kinds of relationships should be expressed to ensure at least that:

- Patient referral to available home care systems is adequate and timely
- Timely and adequate education of patients and their families is a priority of the institution or professional who refers a patient to a home care system, ideally with coordination between the two entities
- Immediate care is available within the institutional system and the home care system if a patient needs to move quickly from one system to the other.

3. A home care program should be effective in terms of functions and costs. The system of coverage should make it possible for patients and their families to receive home care without incurring higher costs for the family.

4. The community is the environment in which home care programs are developed, and consequently its support and active participation in the provision of these services is essential for meeting the health objectives. The community consists of the family (as the principal group closest to the patient), other important persons, and organized volunteer groups and support services for general needs, such as hygiene, nutrition, and transportation.

   Application of the principles of primary care will permit effective utilization of all the available and necessary community resources in each case, thereby optimizing the care delivered directly by the health team and imbuing it with a holistic approach.

Comparative Table: Characteristics of Institutional Care and Home Care

Place where the care is delivered	Clinic, hospital, general polyclinic, general physician's or specialist's office exclusively	Home (in special circumstances patients should recur to a health care center
Persons who provide the care	Mainly health workers	Patients (self-care), mainly family members Health personnel Volunteer health workers, support services
Influence on decision-making	Providers (health team)	Family members/patients (mainly)
Professional care center	Patients and their specific health problems	Patients/family members Specific health problem Holistic care

Criteria and Characteristics for Consideration Prior to Developing a Home Care Program or to Transferring a Patient to Home Care

Necessary Basic Questions	**Responses and Results** **YES**	**NO**
Does collaboration, communication, interaction, and coordination exist between the various health providers and home care programs?	Delivery of appropriate, highly valuable care to users.	Disorientation of patients, families, and professionals
Is the education of patients and their families timely, relevant, and adequate?	Adequate and effective decision-making and participation of patients, families, and the community.	Reduces participation of the family in direct care and decision-making, which negatively influences health outcomes
Have the patients' and families' sociocultural and psychological situation been taken into account, in addition to their environmental conditions, when proposing home care as a viable alternative?	Realistic objectives established jointly with patients and their families. Greater cooperation and commitment to health outcomes are obtained and self-care is promoted.	Feeling of failure and frustration expressed by patients and family members. Complications in the health of patients may arise or increase.
Is there adequate technological, professional, and financial support for the kinds of patients who will be referred to home care?	It is possible to make appropriate decisions with regard to those who should and should not be referred to home care. Minimum outcomes in health and user satisfaction are ensured.	Patients and families reluctant to participate in the home care program as they feel a lack of support.
Analysis of the decision-making process within the family. Analysis of the capacity of the health professionals with regard to the transfer of	Adequate distribution of responsibilities and priorities in decision-making and promotion of consistency between decisions and functions.	Conflict of power and decision-making within the family and with health professionals.

Basic Model: Systems and Relations Underlying the Structure and Operation of a Home Care Program

HEALTH SERVICES

Third Level

Second Level

First Level

HOME CARE PROGRAM

COMMUNITY

△ Representation of the health services and their various levels of care by specialization and coverage.

△ Representation of a home care program

⇩ Links between home care and the community

⟷ Integration, coordination, and collaboration links.

(Alternatives to this scheme at the end of the document)

(G)
Advisory versus Comprehensive Home Care Service Models

Home care services can be lumped into two main categories: Comprehensive or Advisory. Comprehensive services offer patients 24-hour access to a doctor, nurse, either visiting several times a day or remaining with the patient at all times) and all equipment likely to be needed. This expensive model is being used in both developing and developed countries. The services provided can range from primary health care to tertiary care. Advisory models are the most common models worldwide (21). Advisory services may be staffed exclusively by trained nurses or by teams of nurses and doctors. In both cases there is usually access to social workers, occupational therapists, and physiotherapists from which the home care team operates.

Comprehensive services can and should be designed to meet local needs and conditions. Primary and other local health care services should collaborate in planning the model. This model allows terminally ill patients to die at home, but costs are high. (21)

Advisory services have been designed to complement existing services and are designed only for primary care services. The objectives can be defined as:

-offering expert advice on symptom palliation in the homes;
-offering expert advice on psychosocial problems;
-liaising with other specialized services on behalf of the patient and;
-providing support to colleagues in primary health care. (21)

This type of service allows people to remain at home longer but usually does not allow terminally ill patients to die in the hospital.

1. Few things are more important than defining, beyond the shadow of a doubt, how patients are referred to advisory services, who is in clinical charge, and who is legally responsible for the services provided.

2. Any home service can either empower and encourage relatives and friends to care for their loved one or inadvertently make them feel unskilled for the task.

3. These services can easily threaten other primary care workers, particularly general practitioners/family physicians. They may not resent nurse specialists, but often resent other doctors coming into what they view as their domain. It is vital that all primary care providers be involved in planning from the outset and that regular consultations with them occur frequently.

4. Though "nurse only" teams have a place and, in some countries may be the only model possible, they give the impression that hospice/palliative care involves nursing only and do not have the same educational impact on doctors that a "team service" does. Extensive experience shows that few doctors listen to, and want to learn from, expert nurses talking about pain management. Doctors worldwide prefer to learn best from fellow doctors.

5. Any home care service is difficult to manage, evaluate, and audit. It is important that managers be particularly aware of this. How do you assess or try to measure the effectiveness of an hour spent listening to a terminally ill patient at home, or evaluate the advice given to help the family to cope? How is it possible to know whether a home visit was needed?

6. It is easy to forget that most families and friends can provide excellent care in the home if they are encouraged and helped to do so. Every good team will set time aside to demonstrate things such as lifting, feeding, toileting, and even how to sit quietly by a bedside.

7. Advisory services do not prescribe, carry drugs or equipment, or order studies. They advise on these matters. Comprehensive services do the opposite. Therefore, the authorities must grant them special permission, including meeting the strict requirements related to controlled substances.

8. Adequate clinical records must still be kept, although the services may be simple and aim to serve as many patients as possible at the lowest cost.

9. In many countries, it is important to decide at the planning stage whether members of the teams will be invited to work within residential care and nursing homes when people there need such help.

Source: http://www.hospicecare.come/FactSheets/FSHomeCare.htm (21)

Caregiver Issues

As society and the health care system change, so too does the context for nursing practice. As the context for practice changes, the boundaries between old roles and new roles blur. These changes produce serious challenges for both formal and informal caregivers in the home. Providers of home care vary as much as programs and services. Caregivers range from individuals with little preparation in health care to trained nurses with specialties in different areas, and the services of other medical professionals. With an increasing shortage of skilled health care providers, it is clear that strategies are needed to ensure that the right home care provider is available and accessible to consumers. (48a,49) In relation to this, the needs of family caregivers must be addressed.

The shift to a community focus with earlier discharge, more outpatient treatment and more services being provided in the community rather than in facilities requires the support of family and volunteer caregivers, and of the clients themselves. In turn, to support these individuals who enable home care to occur, the significant role of home support services in the home care service mix should be recognized. Qualified health professionals should be caring for patients; however, this care should be part of a continuum that is well-coordinated at the community level, using multidisciplinary teams (36,41,47,48a,b)

Informal Caregivers:
The shift of care from inpatient settings to home care has resulted in movement of personnel, predominantly nurses, into home care. Many of these nurses have minimal home care experience. Researchers have documented the tremendous burden on family caregivers in home care of patients. Issues for *informal caregivers* have been documented as the lack of recognition, inadequate training, insufficient support, and the expectation that women will serve as informal caregivers. (16,33,41,47)

In developing countries the family is the most important source of support for health care and the economic and social well-being of the elderly. However, rapid urbanization and the growing number of young people entering the workforce are undermining this support system. Also, urban housing is ill-suited to the traditional extended family. (14,26,41) Women have traditionally been the family caregivers, but because they are increasingly joining the labor force, they are less available to care for older family members. In light of the declining family support available to the elderly population in many urban settings, it is essential to develop health policies to explore how formal and informal services are provided by home care programs and for governments to develop policies such as allowances or tax concessions to encourage intergenerational living arrangements and strengthen individual families that are caring for aged parents. (33,41,47)

Higher costs and less effective health interventions for all populations occur with financial cutbacks in the health sector, but especially for vulnerable groups such as women and children, minority and indigenous populations, the elderly, rural dwellers, and the poor. Many of the obstacles arise from decisions made at the home level and are not readily amenable to short-term policy. Measures to improve women's lives in developing countries aimed at changing cultural norms directly are likely to fail. (33,48,50) Measures that are likely to be more cost-effective in practice will be those that explicitly consider the barriers to women's access to care and their role as caregivers and attempt to minimize their consequences. In the medium to long term, catalyzing social changes in attitudes toward women will require information, education, and communication (IEC), together with a social and political commitment to change. (33,47)

Family caregivers have their own personal needs, which includes time to themselves and time away from the home. Studies have shown that they also do not get enough rest or sleep (47). Family caregivers require information about the patients' conditions and potential symptoms or side effects. In order to provide guidance and support to family caregivers, formal caregivers such as nurses should assess the needs of caregivers and tailor interventions to meet those needs. There is also a need to develop a social, volunteer, and professional support network (47).

Formal Caregivers:
Issues for *formal caregivers*: concern was expressed about working conditions, inconsistent salary and benefits, inadequate training, a perceived increase in the number of unlicensed formal caregivers, a blurring of roles and responsibilities among various categories of formal caregivers, and safety issues. (48) An article by Florence M. Moore (1990) documents the lack of standards for recruitment, hiring, and training of formal caregivers--in this case home health aides.(29) Moreover, standards for assigning aides and for supervision are not always clear, and even when specific criteria are set for the training of home health aides, the standards vary with regard to the curriculum and the length of the training.(11) The recruitment, hiring, and retention of home health aides are major problems for many agencies that offer low pay and limited benefits. These agencies do not attract the most reliable employees and experience a very high turnover rate. When many incentives are offered, including good pay, benefits, and accountability, the quality of care and satisfaction of formal caregivers increases (11,29).

Staffing Considerations:

In several countries where the following points with regard to staffing considerations have been ignored, considerable tension and friction with other doctors and nurses has developed.

1. All clinical staff must have the necessary clinical experience and training in modem palliative care. They are going to advise, and must therefore be both expert and knowledgeable.
2. Working in such a community team, in peoples' homes, is not the same as working in a general hospital. Staff must have experience and training in community care.
3. There is much to be gained from home care staff spending some time each year in an in-patient hospice/palliative care facility, if possible.
4. Educational opportunities must be offered to staff, both to maintain their competence and confidence, and to reduce the sense of professional isolation that is a feature of home care services.

Source: http://www.hospicecare.com/FactSheet/FSHomeCare.htm (21)

Training Formal and Informal Caregivers
The modem worldwide emphasis on public heath and home care services requires a change in the perspective and orientation of nursing organizations and nursing practice. Nurses are mostly accustomed to hospitals and health facilities, and little training is normally devoted to home care nursing. Also, educating the patient and the family is one of the most critical aspects of home care services. The home care nurse can provide training to the patients' family in various necessary areas subjects explicitly and repeatedly (47). When phones are available, a hotline number can be an important resource for informal caregivers and may give the formal caregiver time to care for other patients. Also, in the future, middle class and more affluent families may be able to receive support on the web and through support groups. In the future, the entire world will be more dependent on technology. This transition will eventually take place, either in the homes of clients and/or for the communication and education of formal caregivers (53) It is entirely a local team decision whether to use mobile telephones, car radios, the web, or e-mail, and it depends greatly on the infrastructure, resources, and the culture. What applies in one environment may not apply in another.

Cultural Barriers:
An attempt to provide a culturally specific response to existing barriers is a challenge. These include measures to support and integrate "traditional" practitioners who provide home care health services to clients and to increase the supply of health care providers in the formal system. The effectiveness of these options can be improved by government investment to inform communities about health needs, problems, and services.(2) Improving client access and the cost-effectiveness of service utilization may require an expansion of primary health care outreach programs to bring services closer to communities. Home-based care is an option in settings where clients have limited mobility (33)

Also, the rising number of elderly and the present difficulties in assuming their care requires a paradigm shift if a system is to meet their needs and be cost effective. A shift would involve viewing community-based continuing care needs as part of a complex system of health and social services. (45) Population needs-based funding models used to allocate community health funds to help improve the delivery of home care services can contribute to a smoother transition. Location of residence is also a determinant of health and health care. Older populations tend to live in rural areas, but Latin America is an exception., because it is the most urbanized of all the developing regions of the world. Here, at least 60% of the population aged 60 and up lives in urban areas. (33) The increase in urbanization brings special problems for the elderly, particularly for women, since they tend to live longer than men do, especially since they often take on the role of family caregiver.(19,33)

Home care issues concerning the provision of health services to indigenous populations by authorities must be addressed. Indigenous populations may suffer from insufficient resources and a lack of program flexibility to address their unique yet diverse needs. (26,36) Reducing transportation and time costs by bringing services closer to communities, possibly through home-based outreach, may be a solution. Funding must also be adequate and flexible to meet the diverse needs of these communities. (26)

Financing of Home Care:
Home care is a viable strategic alternative for controlling health costs in many countries in the Region. Some studies have demonstrated that home care is cost-effective, provided it is accompanied by a reduction in hospital occupancy rates(19), which implies restructuring the health services.(43)

Shepperd (1998) did not detect significant differences in the health costs incurred by certain patient groups cared for at home compared with hospitalized patients; this study even showed a significant cost increase ($p=0.009$) for patients with specific pathologies(41). These studies, however, referred to patients of average to high complexity, which necessitated the organization of complex home health care systems--systems that required not only constant supervision by the professional team, but also the extensive use of technology in the home in terms of equipment and supplies. **(H)**Another study conducted by the Hospital Clínico San Carlos in Madrid and presented at the Meeting for Provincial Nursing Schools in Tenerife in October 1998, found that the cost of home care was one-third that of traditional hospitalization. The study found that the medical equipment needed in the hospital for chronic illnesses cost an average of 31,000 pesestas per day, but if the patient resided at home the cost was reduced to 12,000 pesetas per day.(30)

Although certain studies have shown a reduction in health costs, it is not immediate, since costs may hold steady or even increase during the initial stages of home care plans. This is attributable to the expenditure involved in launching a home care program without any significant reduction in hospital occupancy rates or in the number of bed/days used by potential home care patients.

Financing Alternatives:
The diversity of economic realities and financing modalities in health systems makes dealing with the range of reimbursement alternatives a complex undertaking that requires specific analysis of every area in the Americas. Essentially, consideration of payment for home care services entails defining the organization and systematization of reimbursement. Alternatives that include payment based on professional visits, episode, or exacerbation of disease, or on procedures are some of the alternatives currently in place and now being studied. One financing alternative to be considered for this kind of care is prospective payment based on episodes or visits. Prospective payment for home care, although highly complex, is a financing alternative that being tested in several communities in the United States(26)

(I)
Financial home care concerns for Canada are (18):

- The direct cost of services can be calculated, but indirect costs such as the prevention of rehospitalization, acute care visits, decreased employment, and burden on family caregivers are more difficult to determine. These data are important when examining the overall cost, benefits, or cost-effectiveness of such home care services.
- Determining the role of the different levels of government, programs, and public vs. private funding, sustainability, provider accountability, and integration with other parts of the health system were identified as basi components of funding issues.
- Home care issues centering on the delivery of health services to Indigenous populations by the authorities must also be addressed. Indigenous populations may suffer from inadequate resources and the lack of program flexibility to address their unique yet diverse needs. Funding must be adequate and flexible to meet the diverse needs of these communities.
- Determining who maintains control over home care budgets and funding levels is a fundamental question that needs to be addressed if home care programs are to be implemented. (18)

Quality versus Cost:
Two major transitions in home care delivery have taken place place. With the advent of managed care and the shift from inpatient to community-based services, home care service delivery systems have experienced tremendous growth. Second, the principles and practices of total quality management and continuous quality improvement have permeated the organization, administration, and practice of home health care.(48d) Also, the cost of informal caregivers provided by family and friends has become increasingly important to health services research. Accounting for these costs is important for both "cost-of-illness" and cost-effectiveness analyses (16). One study conducted by the National Institute of Nursing Research in the United States of America showed that 80% of the care provided to disabled elderly patients came from informal caregivers. In this study, the cost of caregiving is estimated using the market value approach, which uses a wage rate for paid employees providing similar services. The cost of caregivers who participate in the labor force is estimated by valuing the caregivers' time in their next best alternative, such as the hourly rate for their specific type of employment. (29)

Home care providers everywhere are grappling with financial issues and are concerned about maintaining high-quality care in changing environments. Striking a balance between maintaining the quality of services and holding down costs is a global problem. A global survey asked home care colleagues around the world to discuss cost vs. quality issues (9) The following questions were posed: "Do you believe that in your country the pressure to reduce the cost of heath care (of which home care is a part) will result either in reduced access to home care services by needy persons or to a deterioration in the quality of home care services? If so, what do you believe should be done to prevent this cutback in the availability of home care services and erosion of the quality of health care services?"

The response from the Nurses Association of Jamaica was that if less money is available from the government, the quality of home care services will definitely suffer. There will not be enough trained personnel to care for those in need of assistance. People need to be educated more on the preservation of life, improving the quality that should be lived. More funds should be provided for more educational opportunities. P.A.L.S. in Bermuda noted that(9) in Bermuda, there is no government or other pressure to reduce the cost of health care or access to home care services for needy persons. The budget for 1997-1998 has actually increased. With reference to P.A.L.S. and home care for cancer patients, al though costs continue to rise, there is no plan to reduce services, and funds will be found through heightened public awareness, direct requests, and hopefully, an increase in the annual government subsidy. Finally, the Columbia Homecare Group and Quality Care Home Health Services in the United States responded by saying that the increase in quality and efficiency should make services more cost-effective. Government programs are shifting to a managed care model, which would allow services to stretch farther. However, if the funding is cut too drastically, many people who cannot afford services will lack care (9)

Some suggestions to create or preserve quality home care services were:

- Consolidate standardized services and programs
- Create clinical and administrative policies/procedures for practice standards.
- Create integrated, disease-specific clinical pathways
- Accredit practitioners and programs using consistent standards
- Educate consumers and legislators who receive and pay for these services
- Encourage consumers and legislators who receive and pay for these services.
- Encourage a National Association to take a leadership position on quality. (9))

More and more individuals, governments and insurance companies will turn to home and community care because it is less costly and preferred over institutional care by both consumers and institutions. When addressing the issue of quality versus cost, there appear to be two major trends: an accelerated demand for home- and community-based care and pressure to reduce the cost and payments for health care in many countries (9)

Accreditation of Home Health Care Services:

Accreditation of the organizations and professionals providing home care is a vital mechanism for ensuring a minimum quality of the services being delivered. Initial accreditation and systematic evaluations should be an integral part of any home care system or program.

The accreditation of home care services or programs in certain countries is conducted by the institutions that pay for the services, including government financing systems, social services, and insurance companies. In other localities the accrediting agencies are either government health systems or independent entities.

Some of the criteria in use for the accreditation of home care institutions are:

- The number of families per professionals hired
- Review of the financial background of the institution delivering the service
- Administrative resources
- Type of services provided
- Hired personnel(17).

These criteria may be expanded or modified according to the specific situations in each locality.

Frequent Problems:

Although it is true that the implementation of a home care program offers innumerable benefits for the health services, patients, and their families, it is nonetheless also true that implementation of programs of this nature can also present major difficulties and risks.

Some of these problems are listed below.

1. The high variability of referral standards stemming from communication and cooperation difficulties among the working teams within an institution or among the different care levels is a critical factor in the operation of a home care program. It is thus essential to design systems that ensure adequate coordination among the different institutional and professional levels.
2. The resources necessary for launching a home care program may pose a serious risk to implementing these kinds of programs, unless it is borne in mind that programs of this nature will not produce immediate, but only medium- or long-term savings for the health systems.
3. Geographical isolation, which is a hindrance to referral and monitoring
4. The availability of drugs may be compromised
5. Family expenditures are frequently increased
6. The workload and responsibility of the families of patients receiving home care is increased, with much of it borne by women.
7. There is a need for additional training for health workers who provide home care, specifically for nurses who will be challenged by greater autonomy and responsibility in decision-making.

Awareness of these potential problems will make it possible to act proactively and thus give these initiatives a better chance of success.

(J)
The Way Forward: Possibilities for Future Work by PAHO and the Countries.

Countries need to establish health information networks to facilitate the collection and transmission of timely, accurate information for home care and other health sectors. There is also a need to develop an accountability framework for the health system that includes home care and attempts to apply accountability mechanisms to this sector through the development of performance measurs and outcomeassessments. Eventually, standards and guidelines for the services provided under home care programs and for new classification of workers who are charged with delivering these services should be developed.

In order to fill these gaps countries will need:

- Detailed descriptions of the different home care programs.
- To compare the different home care programs.
- To determine the similarities and differences in their approaches and development in home care.
- To develop standards for terminology and home care delivery services.
- To bridge the gap between existing services and new standards.

One of the Pan American Health Organization's goals is to offer guidance through technical cooperation on the organization and management of home care systems and services in Latin America and the Caribbean, while promoting the integration of home care as part of the health care delivery system.
For PAHO/WHO to be at the forefront in reforming health care delivery systems we must help countries to review issues with respect to home care delivery systems and note the challenges that caregivers, consumers, the health sector, and policy-makers must face in an environment of reform.

PAHO's future objectives for providing technical co-operation for the organization and management of home care as an integral part of the health care system are to:

- provide an international focus for an exchange of views among health authorities, care givers, and users on ways and means of dealing with key issues around home care.
- incorporate home care information into a framework of factors that can be used for a descriptive comparison.
- facilitate wider participation in the support of present and future activities by PAHO and the national counterparts related to home care systems and services. (Clearinghouse)
- eventually, to develop standard guidelines with the countries in order to improve and develop home care delivery service.

This initiative will undertake the following activities:

OBJECTIVE	*ACTIVITIES*	*TIME*
STAGE I		
To provide an international focus for an exchange of views among health authorities, caregivers and users on ways and means of dealing with key issues surrounding home care.	Background Paper (see proposed outline)	September 1999
	English draft paper will be translated into Spanish.	
	A working group will be brought together in Washington to discuss and exchange home care experiences in the Caribbean and Latin America, review the document, and propose lines for future technical cooperation by PAHO.	October 1999
	Comments and suggestions from the working groups will be incorporated into the document to improve its quality.	November 1999
To incorporate home care information into a framework of factors that can be used for a descriptive comparison.	Country representative from the working groups will be responsible for putting together a report on experiences in home care to be incorporated into the final document.	
	Final English paper will be translated into Spanish, and written accounts will be translated from Spanish to English or vice versa.	December 1999
	Dissemination of the final paper will commence.	

OBJECTIVE	*ACTIVITIES*	*TIME*
Proposal for Future Stages:		
STAGE II		
• To facilitate wider participation in the support of present and future activities by PAHO and national counterparts related to home care systems and services.	• Clearinghouse	
STAGE III		
• To develop standard guidelines with the countries in order to improve and develop home care delivery service.	• Launch 3 pilot studies to develop national guidelines for homecare as an integral part of the health care system.	

Conclusions
Home care is a viable alternative that has yielded encouraging results in terms of improving the quality of life for patients, increasing user satisfaction, and producing better or equal health outcomes for home patients compared with hospitalized patients(15,44)

The cost-effectiveness of home care programs nevertheless depends on the proper selection of patients and the time for their inclusion in programs of this nature. The structuring of home care programs, as much as the coordination of these programs with the different levels of health care and the community, is a key element for the success of these initiatives, in terms of health outcomes and cost-effectiveness.

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Appendix I:

Professionals who Participate in Home Care - Functions and Responsibilities.

1. Health Team:
   - Physician: mainly exercises clinical and administrative functions. Depending on the complexity of each case, the physician may be a specialist or general practitioner
     - Administrative role: The director of an institution that provides home care is usually a physician, which in many cases is a prerequisite for the accreditation of an institution. Generally speaking, the director is a professional who makes the decision about admitting patients to a home care unit, prescribing the specific care to be given to patients at home and making whatever referrals are appropriate(7). The care given to patients should be authorized by the physician, as this is a prerequisite for subsequent reimbursement.
     - Clinical role: The direct care the physician provides is highly variable, depending on the complexity and specific situation of each patient and family.
   - Nurse: mainly carries out administrative, clinical, and educational functions.
     - Administrative functions: Nurses generally perform the administrative functions related to the daily work of a home care institution. Their responsibilities include financial management, registries, and coordination of the care provided by professionals, technicians, and volunteers, as well as coordination of the required teams and supplies.
     - Clinical activities depend on the type of patient and the complexity of each case. Clinical functions may encompass a broad range of activities from the management of patients and high complexity teams, (for which specialized nurses are required) up to basic nursing care (usually delegated to technical auxiliaries or the family, depending on each case). Among the general activities carried out by the nurse are: assessment of the conditions of the patient, family, and environment; delivery of care, counseling, education, and emotional support; treatment of complications; and referral to other professionals(5). Nurses also monitor compliance with indications and may collect specimens for examination if the situation warrants it(7).
   - Kinesiologist: usually has only clinical responsibilities. In the event that physical therapy is required, the kinesiologist assists patients with physical disorders or disabilities, developing an exercise program focused on achieving a maximum level of independence. Some of the activities conducted are retraining in walking, teaching the family maneuvers for the mobilization of patients, and training in the use of accessories, such as wheelchairs.
   - Occupational therapist: usually engages only in clinical and educational activities, with the aim of recovering the skills to perform daily living activities and providing training for potentially productive activities.
   - Nutritionist: provides evaluation and education related to special diets and monitors proper compliance with dietary indications, in addition to conducting food surveys, especially in patients with celiac disease, chronic diarrhea, diabetes, and malnutrition(7).
   - Speech pathologist: assists in helping patients who as a result of disease or accident have difficulties in speaking or understanding, including training in speaking, listening, and writing; training in swallowing; and exercises to improve memory, reading, and comprehension.
   - Social worker: provides counseling with regard to community resources, financial assistance, and services available to meet the needs of patients and their families.
   - Psychologist: provides psycho-social support for patients and their families, helping them to adapt to new conditions of health and life productively and effectively, making use of personal and family resources based on the situation of each family group.
   - Nursing auxiliary (paramedic): carries out clinical and educational activities under the supervision of a professional nurse. Functions may include helping to monitor vital signs, provide assistance in personal care and comfort (bathing, hair brushing, etc.), and in mobilization(5).

Other professionals who may participate in home care, depending on the particular situation in each case are family counselors, speech pathologists, and special education teachers.

Country Profiles on Home Care:

ANTIGUA AND BARBUDA

Organization

Health care in Antigua and Barbuda is a function of the national government. Public Health Nurses administer formal home care, a component of the Community Health Programs.

Participants

Home care services are provided mainly by informal caregivers, including members of the family, community and religious organizations. Traditionally, professional services, including medical, home help, social service and physical therapy visits, have been carried out and overseen by district doctors and nurses and welfare and community aides.

Finance

Primarily the government finances health care with additional donations from outside sources. Their clients pay private agencies.

Coordination

A referral system had resulted in Collaboration between the informal and the professional caregiver. however, there seems to be a growing need to develop appropriate policies so as to coordinate home care services. This seems to be of particular importance as there has been significant growth in the number of both independent professional caregivers and private for-profit agencies.

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ARGENTINA:

<u>Rosario, Santa Fe</u>

Area de Servicios:
Cuidados Paliativos
Sistema de Internación Domiciliaria (SID).

Organización:

El Sistema de Internación Domiciliaria es un organismo mediador entre los proveedores de cuidados, (en este caso grupo de médicos especialistas en oncología) y los pagadores de la atención (aseguradoras u obras sociales). El SID administra contratos entre pagadores y proveedores y funciona como sistema de referencia de pacientes. No tiene injerencia en honorarios, gastos por atenciones especificas, manejo de personal o en decisiones clínicas.

Participantes en atención directa:

- El equipo base lo conforman Medico y Enfermero(a). Colaboran en la atención según necesidad psicólogo, nutricionista y terapeuta ocupacional. Medico y enfermero asumen rol educativo dirigido a un miembro de la familia quien se compromete a ser la persona responsable de la atención.
- Médicos evalúan al paciente y familia, decidiendo la frecuencia de visitas y medicación necesaria, así como otras necesidades (cama ortopédica, oxigenoterapia, otros). Así se acuerda entre SID y obra social el módulo en que se incluirá al paciente. Existen diferentes módulos según complejidad de la situación.

Organización de la Atención:

- En el domicilio del paciente queda un maletín con todos los medicamentos necesarios, material desechable y ficha clínica. Este maletín es de uso exclusivo de profesionales, no hace uso de el la familia.
- Miembros del equipo de salud, personal administrativo (SID) y familia están en contacto telefónico (celulares) las 24 horas para solucionar emergencias. Las emergencias son escasas debido al enfoque de atención proactivo del personal de salud.
- Se coordina atención con servicios de emergencia en caso que estos sean requeridos, educando adecuadamente a los familiares sobre estas situaciones. En caso que ocurra una emergencia, el familiar

llama a un servicio de urgencia desde donde acude un médico al domicilio, es este médico el que tiene la responsabilidad de contactar a algún medico del equipo de cuidados paliativos en el domicilio.

- Si se requiere servicio de rayos o exámenes de laboratorio estos también se realizan en el hogar.
- Semanalmente se reúnen equipos de profesionales que atienden a un paciente determinado y quincenalmente todos los miembros del equipo de cuidados paliativos en el domicilio se reúnen para tratar temas científicos de interés general.

Financiamiento:

- 70% de la cobertura de salud es a través de " Obras Sociales", (seguros). El SID es un intermediario que hace convenio con las diferentes Obras Sociales y los prestadores de la atención y tramita aceptación del modulo frente a la obra social.
- SID paga mensualmente por paciente atendido, si un paciente es atendido menos de un mes, se paga por días de atención.
- Los pacientes son incorporados a diferentes "módulos" o programas de atención según la complejidad de cada caso. El costo de los módulos oscila entre US$15 y US$45 por día según complejidad del caso.

Remuneraciones:

- Medico recibe remuneración mensual de US$600. Este valor cubre 30 visitas domiciliarias, si las visitas sobrepasan esta cantidad, recibe $20 por visitas extras.
- El enfermero recibe US$500 mensualmente por las atenciones prestadas visitas extras son cobradas aparte.
- Otros profesionales cobran entre US$10 a US$15 por consulta.

Buenos Aires
"PALLIUM, Hospital Bonorino Udaondo"

Area de Servicios:
Cuidados Paliativos
PALLIUM es un programa sin fines de lucro que reúne a profesionales y centros de cuidados paliativos con implementación y prestigio en Buenos Aires y La Plata, que reúnen experiencia en aspectos clínicos, docentes, de investigación y organización en medicina y cuidados paliativos. Pallium pretende responder con un alto nivel de calidad a las demandas de formación, investigación, documentación y asesoramiento en cuidados paliativos.
Pallium esta comenzando una experiencia piloto en cuidados en el domicilio a través del hospital Bonorino Udaondo. Se cuenta con medico, enfermera y auxiliar de enfermería. En este momento esta enfocado a la capacitación de profesionales y técnicos en cuidados en el domicilio.

I. Internación Domiciliaria "En Casa"
II. Hospital Privado de Comunidad

BERMUDA

Service Delivery
Hospital social workers arrange for discharge using services such as Home Help and Meals-on-Wheels.

Organization
The demand for home care services in Bermuda is increasing due in part to shortened hospital stays.
Home health care agencies, as the term is used in the United States, do not exist in Bermuda. The Health Department provides registered community nurses and, in addition, there is a Private Duty Nurses Register, which is in the for-profit sector.

Participants
Other caregivers that provide home health care services include physicians, home resource aides, social workers and therapists of various types. Home care providers must be licensed of have attended specific courses, thereby assuring a certain standard of quality. The role of nurses has expanded substantially so that procedures formerly restricted to the hospital setting are performed in the home.

Financial
Home health care is funded predominantly by the local government with some assistance form various charitable organizations. Patients Assistance league and Service, for example, is a registered charity that cares for cancer patients in their homes. Some private insurance companies needs will pay for certain home health.

Ann Smith Gordon Chairman

Patients Assistance League and Services (PALS)
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BOLIVIA

Dirección General de Salud, Ministerio de Salud y Previsión Social.
Atención domiciliaria que se maneja en el país comprende: Atención de parto en domicilio (Personal tradicional, auxiliares de enfermería y familiares), atención de programas para la mujer y el niño de nivel domiciliar por responsables populares de salud supervisados por personal de enfermería, control y seguimiento de embarazos, control y seguimiento de niños desnutridos, hidratación oral domiciliaria.
Para todas estas actividades, en el ámbito institucional y comunitario, se cuenta con manuales y normas establecidas por el Ministerio de Salud y Previsión Socia, su manejo es sistemático por parte del personal comunitario e institucional.

BRASIL

Río de Janeiro
Instituto Nacional Del Cáncer INCA

Area de Servicios:
Asistencia domiciliaria a enfermos oncológicos

Organización:
Participantes en la atención:
Los miembros del equipo de salud que brindan cuidados en el domicilio en forma directa son: médicos, enfermeras y auxiliar de enfermería. Participan también en el equipo asistentes sociales, choferes y administrativos.
Se esta en proceso de entrenamiento de personal voluntario para asistencia de pacientes en el domicilio.

Organización de la atención:
Previo al ingreso de un paciente al programa de cuidados en el domicilio se realiza entrenamiento de 5 días a familiar o persona que tomará la responsabilidad de atención en el domicilio. Este entrenamiento se realiza estando el paciente hospitalizado 5 días antes del alta. Si el paciente no esta hospitalizado se interna con este objetivo.
Se realiza evaluación del dolor a través de escala analógica (1-10). En general existe un bajo consumo de morfina. No se realiza evaluación de calidad de vida.

Financiamiento:

- Inca vende servicios al estado, no así a privados.
- 100% de los costos de salud lo cubre el estado

CANADA

Service Delivery:
British Columbia:

- Home support services provide assistance with the activities of daily living.
- Home support respite service provides relief for family caregivers.
- Adult day center services provide personal assistance, supervision and organized programs of health, social nd recreational activities.
- Meals program is a voluntary community service that provides meals to those who are unable to cook for themselves.
- Community home care nursing provides around the clock nursing care .
- Community rehabilitation provides consultation, occupational and physiotherapy treatment.
- Assessment and case management's to ensure that clients receive appropriate continuing care services.

Alberta:

- Alberta Assessment and placement Instrument (AAPI) standardizes documentation of assessment information.

- Case coordination is mandatory to endure that all clients have their needs assessed, are involved in serve planning, receive appropriate serves and to have needs reassessed.
- Treatment services include various types of therapy, social work and nutritional services.
- Support services include personal care and homemaking.
- Self-management care is an administrative option for service delivery and those considered must meet the criteria for home care.
- Palliative care for clients and respite services for family caregivers.

Saskatchewan:

- Acute care which eliminate the need for hospital care.
- Palliative care for client who are dying and wish to spend as much time at home;
- Supportive care which assists the client to remain in the community and also provides respite to client supporters.
- Each of these types of homecare provides: assessment and care coordination, nursing, homemaking, meals and home maintenance services for clients

Manitoba.

The following services are considered to be core serves of homecare:

- Assessment of eligibility for home care services
- Care planning
- Case management
- Coordination of services
- Nursing service
- Therapy assessment
- Health teaching
- Personal care
- Meal preparation
- Respite/family relief
- Access to adult day care
- Cleaning and laundry
- Assessment for and facilitation of personal care home placement
- Medical equipment and suppliers required supporting the care plan.

Especially programs include:

- Self-managed care program/family-,managed care program
- Home oxygen therapy program
- Clustered care
- Terminal /palliative care
- Support housing/alternative housing.

Ontario:

Professional services include nursing, occupational therapy, physiotherapy, social work, speech-language, pathology, nutrition counseling and homemaking.
Specific support services include drug cards, medical supplies, health care equipment, and transportation to and from medical appointments and in-house laboratory services.
Specialized services include HIV and IV therapy, home chemotherapy and palliative care.

Quebec

The range of services include:

- Intake, assessment and orientation
- Development of the treatment, plan or a service plan if a number of organizations are involved
- Medical care (physician and nurses)
- Rehabilitation (occupational therapy and physiotherapy)
- Psychosocial services
- Support services (personal care, domestic support, household management task)
- Caregiver support (sitting services, respite)

Community organizations services (support, development of community resources, information, education)

- Loan of equipment and technical support /aids

- Health information (telephone response by nurses)
- Group activities to provide support to clients and caregivers
- Access to public nursing homes for people living at home
- Reference to complementary resources

New Brunswick

The types of home care that are provided are:

- acute care
- continuing care
- preventive care
- palliative care.
- Assessment, treatment, education and consultation are part of each type of care.

Nova Scotia

Home care services include:

- care coordination
- referral, home support
- personal care
- nursing and oxygen services.

Newfoundland

Core homecare services include:

- Assessment and case management
- Professional services
- Home management(personal care, respite services and home maintenance)

Major categories of professional and home management services within the continuing care/home support programs are:

- Home nursing
- Physiotherapy
- Occupational therapy
- Home support services
- Meals-on-wheels
- Respite care
- Day programs
- Personal care homes

Prince Edward Island

Core support services include:

- Assessment to identify needs of clients
- Care coordination (including care planning and reassessment)
- Support services (personal care, household tasks, respite and environmental support)
- Adult protection (investigation and assessment of reports of neglect, abuse)
- Community support to identify, build and maintain services
- Professional and consultative services (nursing, occupational therapy, physiotherapy, speech and language pathology, pharmacy services, social work and dietetics).

Northwest Territories

Home care programs may include:

- Assessment and case coordination
- Home nursing
- Personal care
- Accreditation for activities of daily living
- Homemaker service
- Respite and palliative care
- Meals program
- Life skills training
- Linkages with other consultation services (rehabilitation, nutrition and physicians)

Yukon

Home care programs include:

- Acute care services
- Long-term services

- Palliatives care

Within each service each program may include:
- Assistance with personal care, home management and meals
- Assessments regarding adaptations to the clients home
- Help with dressing changes, wound care, medical treatment
- Assistance with reparatory care and pain management
- Help with basic exercises, braces, splints, orthotics
- Counseling, advocacy, placement and referral services
- Respite care

Organization
The objective of having medical and support services provided in the home setting are to meet the needs of individual and informal caregivers.

The purpose of home care programs in Canada is to provide:
- A substitution function for services provided by hospitals and long-term care facilities
- A maintenance function that allows clients to remain in their current environment
- A preventative function which invests in client service and monitoring costs.

Care Participants
Professional services such as nurses and therapist provide homecare and typically provided free of charge. Support services such as homemaking, personal care, housecleaning and transportation may require user fees.

Organization of Care
- Provincial and territorial health/social services departments or local community/regional health boards administer home care programs. In provinces social services departments may provide where the departments are separate from health department's services such as homemaking and personal care for clients.
- Home care services can be delivered in two ways: directly by home care program staff and/or by external agencies (voluntary, proprietary, not-for-profit). Home support is contracted out and professional services are also moving in this direction, although currently staff delivers them.
- There is a growth in privately purchased services since they are offering provide services to people who are not eligible for publicly funded home care.
- Client, professional and family/volunteer caregivers should be considered as part of the "system's mix of services" to enable homecare.
- Home care services vary across the country and depend on the home care policies of each province or territory.

Financing
- Publicly funded home care programs exist in every province and territory.
- Home care is not included in the Canada Health Act therefore services are not insured in the same way as hospital and physician services.
- Provinces and territories are responsible for funding and providing services .
- Professional services are provided free of charge.
- Support services may require a user fee.
- User fees depend on a sliding scale based on income.
- Supplies, equipment and medical fees may or may not apply.
- Eligibility criteria vary from program to program across the country.

Coordination
Home care in Canada has been defined as "an array of services enabling Canadians, incapacitated in whole or in part, to live at home, often with the effect of preventing, delaying or sustaining long-term care or acute care alternatives (ref: Health Canada 1990). This is well illustrated in the Service Delivery section for each province and territory of Canada.

Health Canada
National Conference on Home Care
March 8-9, 1998

CHILE

Concepción:
Servicio de Salud de Concepción

Sub-Dirección Médica, DIPRED
Sub-Programa de Cáncer
Ministerio de Salud

Area de Servicios:
Atención a Domicilio y Cuidados Paliativos
Se considera la atención en el hogar cuando el paciente esta imposibilitado de deambular (por dolor o falta de compañía).

Organización:
Existen dos modalidades para la organización de las visitas domiciliarias:

- Sectorización según residencia del paciente y del prestador de servicios,
- Atención es entregada por el equipo central independiente del lugar de residencia del paciente.

Participantes en la atención:
Principalmente profesionales del equipo de salud y comunidad organizada a través de grupos voluntarios.

- Los profesionales que realizan atención en domicilio son principalmente la enfermera y asistente social, médico acude a domicilio solo si se necesita una evaluación para cambios de medicamentos. Las visitas son libre demanda, según las necesidades de cada paciente.
- Los voluntarios realizan visitas semanales de una hora. Las funciones son principalmente de acompañamiento y asegurar adecuada disposición e ingesta de medicamentos. Infoman resultado de cada visita a enfermera del programa.

Financiamiento

- Empieza financiamiento formal de las atenciones en domicilio en diciembre de 1997 (hasta ese entonces eran voluntarias). La atención domiciliaria se considera dentro de la programación general del servicio, con un pago mensual por paciente de $44(dólares), con una cobertura máxima de 4 meses.
- Los voluntarios financian sus actividades a través de proyectos municipales y actividades de beneficencia.

Coordinación con los diferentes niveles de atención:

- En general es expedita, debido a que los profesionales que conforman el equipo de atención domiciliaria prestan a su vez servicios en los demás niveles de atención.

Santiago
Ministerio de Salud,
Servicio de Salud Metropolitano Oriente
Instituto Nacional del Cáncer

Area de Servicios:
Atención a Domicilio en Cuidados Paliativos
La atención domiciliaria en cuidados paliativos procura dar al paciente y su familia el soporte necesario para que el enfermo permanezca en el hogar durante la etapa final de la enfermedad y hasta el deceso, siendo atendido por un equipo profesional interdisciplinario que realiza una asistencia coordinada con los cuidadores, con el objetivo de prevenir y solucionar los eventos relacionados con el fin de la vida desde una perspectiva integral.

1. Organización:
Participantes en la atención:

- Enfermera con destinación exclusiva a trabajo en domicilio, 33 horas semanales
- Chofer con capacitación específica para colaborar en la asistencia del paciente en domicilio, 44 horas semanales.

- Psicólogo con destinación de 4 horas semanales, colabora en situaciones especiales o críticas.
- Médico con destinación de 4 horas semanales

Organización de la atención:

El Programa Domiciliario se desarrolla a través de visitas domiciliarias interdisciplinarias y se describe de la siguiente forma:

- Visita de Diagnóstico (tipo I): Se evalúa realidad social y familiar de los pacientes que ingresan al programa con el objetivo de estimar las condiciones de cuidado a futuro y fortalecer la red de apoyo.
- Visita de Seguimiento (tipo II): se realiza control de enfermería regular definiendo frecuencia según situación clínica. Se realizan tratamientos, procedimientos, educación y apoyo psicosocial, apoyándose en coordinación interdisciplinaria.
- Visita de asistencia al paciente agónico (tipo III) se lleva a cabo control de enfermería con apoyo educativo y psicosocial enfocado a la proximidad de la muerte.
- Visita de atención de necesidades no médicas (tipo IV): Destinadas a aquellos pacientes que no cuentan con una red de apoyo familiar y en su reemplazo son asistidos por un voluntariado específico, debidamente capacitado.

Financiamiento

- El programa pertenece al sistema público de salud y tiene un financiamiento mixto (gubernamental-privado).
- El vehículo se obtuvo a través de la donación de privados
- Los gastos de gasolina y otros insumos, así como el financiamiento de sueldos de profesionales y funcionarios esta a cargo del Instituto Nacional del Cáncer que depende del Ministerio de Salud.
- Otras instituciones privadas, como el Hogar de Cristo, aportan una ayuda económica consistente en alimentos para ser entregadas a las familias más pobres.

COLOMBIA

Cali

Centro Médico Imbanaco

Area de Servicios:

Cuidados Paliativos en enfermos terminales de cáncer principalmente. Se brinda asimismo cuidados a pacientes crónicos no terminales, como por ejemplo: pacientes con falla renal crónica, SIDA, enfermedad de Alzheimer, falla cardiaca congestiva refractaria a manejo médico, otros. También se utiliza manejo domiciliario en pacientes post-quirúrgicos con el fin de acortar periodo de hospitalización. Se contrata con entidad de Home Care para compra de algunos servicios.

Organización:

Participantes en la atención: (rol de cada uno bien definido)

- Médicos internistas (oncólogo con entrenamiento en cuidados paliativos)
- Médicos generales
- Enfermeras
- Psicólogo
- Trabajador Social
- Nutricionista
- Terapeuta respiratoria (según demanda)
- Auxiliar de enfermería
- Chofer
- Se cuenta con grupo de apoyo que se junta cada 15 días
-

Organización de la atención:

- Médico coordinador del programa hace visita inicial y evalúa necesidades. Sobre la base de esta evaluación se programa un determinado número minimo de visitas por profesional (por definir).
- Cada profesional completa historia clínica, la cual se ingresa en sistema computacional (Epiinfo), con el objetivo de realizar seguimiento, investigaciones y estadística.
- Se cuenta con sistema de beeper para trabajo en red.
- Cada 15 días se realiza consulta externa de dolor y síntomas para pacientes ambulatorios
- Se considera a la familia como pilar básico de la atención, esta se entrena según necesidades individuales de cada paciente. El propósito es disminuir tiempo de atención directa de enfermería.

Financiamiento:

- Se contrata con entidad de medicina prepagada (actualmente solo una Coomeva) a quienes se vende "paquete de servicios".
- Aparentemente sin financiamiento de seguro estatal.

Coordinación:

- Se realiza difusión tanto en la comunidad en general como en la comunidad médica, con el fin de que sepan que se cuenta con este tipo de servicios.
- A medida que se entregan los servicios se mantiene informado de la evolución de los pacientes a los médicos tratantes o que refirieron al paciente en una primera instancia.

GUYANA

Service Delivery

Nursing care in the home, including post-surgical follow-up, a well as counseling services for patients and their families.
In addition to basic nursing visits to provide assessment and care, the service provides pre and post-natal care, and assistance with bathing, personal hygiene, diet planning, and companionship. A nurse may also accompany a patient to the hospital or assist those who need to leave Guyana in order to receive medical attention in another country.

Organization

The Home Based Nursing Service in Guyana provides comprehensive nursing services in the home. This privately run service was started in 1994. The service targets any patient in need of home care, including recovering patients, the chronically ill and the handicapped.

Participants

All nurses on the Home Based Nursing Service must be registered with the General Nursing Council of Guyana and must be certified and experienced.

D. Roberts
Principal Nursing Officer
Ministry of health
Brickdam, Georgetown,
Guyana

HONDURAS

Tegucigalpa

Area de Servicios:

Cuidados Paliativos, Centro de Cáncer "Emma Romero de Callejas"

Organización:

No existe estructura especial para cuidados paliativos y cuidados en el domicilio, sin embargo existe grupo profesional que realiza visitas domiciliarias a pacientes que ya no pueden asistir a consultas, que han sido pacientes en el hospital y que han estado en contacto con el personal en todo momento. El grupo de profesionales, que realiza las visitas domiciliarias según necesidades de los pacientes, lo integran médicos residentes, hematooncólogo, enfermera, trabajador social, y auxiliar de enfermería.

JAMAICA

Services:

- Home visits

Organization

Traditionally, Jamaican families provide home care, with assistance from other members of the community when it is needed. However, as women join the workforce and younger family members move to urban areas in search of economic opportunities, the elderly are increasingly being left without the traditional sources of support, resulting in the growing need for formal home care services.

Currently, personal and support care is available for vulnerable groups, for example, infants, children, the physically and mentally disabled, and the chronically and terminally ill. The provision of care is based on age, physical and mental abilities, and healthstatus.

Participants of Care

A Visiting Nurse Service and a Community Health Aide Service assist clients in their homes. Caregivers are employees of Jamaica's public primary health care system. These providers include nurses and midwives, enrolled nurses (LPNs) and nurse's aides, as well as physicians and physical therapists.

Financing

At present, out-of-pocket payments by clients of their families finance home care services. However, some health insurance companies are beginning to include home care in their coverage.

The Permanent Secretary
Ministry of Health
10 Caledonia Avenue
Kinston 5
Jamaica

MEXICO

Guadalajara

O.P.D. Hospital Civil de Guadalajara "Dr.Juan I. Menchaca"

Area de Servicios:

Cuidados Paliativos

Organización:

Los objetivos de los cuidados paliativos domiciliarios son el fomento de la autonomía del enfermero y la familia y el respeto a su dignidad.

Participantes en la atención:

El equipo es multidisciplinario y cuenta con médico, enfermera, trabajador social, psicólogo y voluntarios de la fundación mexicana de medicina paliativa y alivio del dolor en cáncer (FMMPAC).

Organización de la atención:

- Se realiza una revisión de casos y se seleccionan a aquellos pacientes que por sus características deben ser visitados y atendidos en sus domicilios.
- En otros casos la asistente social recibe la llamada telefónica con la petición por parte del paciente y/o familia requiriendo cuidados en el domicilio. En este caso se realiza breve interrogatorio y se determina la prioridad para realizar la visita por parte del equipo de salud
- La asistente social solicita al área de transporte el traslado del equipo de la unidad de cuidados paliativos al hogar del paciente.
- En el domicilio, el médico determina el manejo a seguir, teniendo en cuenta las necesidades del paciente y su familia. En este momento se determina si el paciente puede seguir recibiendo los cuidados en el domicilio o si es necesario el traslado al hospital (previo consentimiento del paciente).
- La enfermera es la encargada de explicar y adiestrar al cuidador y a la familia sobre el manejo y cuidado del paciente de acuerdo a las características particulares de la enfermedad y a la idiosincrasia del grupo familiar. Se pone gran énfasis al mantenimiento de la intimidad, pudor y dignidad de los pacientes ante su grupo familiar y el entorno social.
- Alguno de los procedimientos realizados durante la provisión de cuidados en el domicilio son: toracocentesis, colocación de sondas, paracentesis, enemas evacuantes, entre otros.
- El horario para la entrega de servicios es de 8:00 a 15:00 horas. Por servicio de radio localizador, los pacientes pueden solicitar servicios de urgencia a personal del hospital sin costo para ellos y durante las 24 horas.
- A raíz de los bajos salarios, los profesionales se contratan a tiempo parcial.

Financiamiento

- El Hospital Civil de Guadalajara "Dr. Juan Menchaca" es la entidad encargada de cubrir salarios de quienes laboran en la unidad de cuidados en el domicilio. Es esta entidad así mismo la que suministrar los medicamentos opiáceos, camas de hospital, transporte u otros insumos necesarios.
- El O.P.D. es un organismo público descentralizado que recibe financiamiento de la federación (nivel nacional) y del gobierno del estado.
- La atención es abierta ya que es un hospital de beneficencia. Se atiende a personas sin seguridad social o seguro médico.
- Los voluntarios, agrupados a través de la Fundación Mexicana de Medicina Paliativa y Alivio del Dolor en el Cáncer A.C. (FMMPAC) financian sus actividades a través de una colecta realizada una vez al año. Los fondos son destinados a ayudas económicas y en especie tales como: despensas, traslados, exámenes de laboratorio, otros.
- Los fondos recolectados a través de estas colectas anuales alcanzan un promedio de entre US$2,500 a US$3,000; esta cantidad se distribuye según números de pacientes por año y necesidades específica.
- No se cobra por visita a los pacientes, ni por procedimientos realizados. Una estimación del costo de visita por paciente fluctuaría entre US$15 a US$30 dependiendo del procedimiento realizado

Coordinación con los diferentes niveles de atención:

- Se difunde la labor que realiza la unidad de cuidados en el domicilio, dentro y fuera del hospital. Al interior de la institución en los servicios de oncología y clínicas del dolor. Fuera de la institución la difusión se realiza a través de medios masivos de comunicación (radio y televisión).
- Existe un servicio de referencia y contrareferencia. Al recibir a un paciente para cuidados en el domicilio se obtiene un resumen clínico del médico tratante, así como la información acerca de como se entero del programa de cuidados en el domicilio.
- Durante la provisión de cuidados en el domicilio se mantiene comunicación con el médico tratante. Después de la muerte del paciente se envía resumen de contrareferencia donde se informa sobre deceso del paciente y las condiciones en que este ocurrió.

Principales áreas de problemas: Coordinación y colaboración por parte de paciente y familia, tramites burocráticos en el sistema de salud y dificultad de acceso a transporte, lo que dificulta la realización de visitas con la frecuencia requerida.

NICARAGUA

Nicaragua has no formal system of home health care perhaps in part because it has a young population. In 1990, 47.9% of the population was under the age of 15. Health care, including mental health care, is providing by the Ministry of Health. Six "day hospitals" in the city of Managua provide counseling and occupational therapy. Social services, which in Nicaragua include homes for the aged, are provided by an institutional called Inssbi. In the entire country, there are 21 elder homes or nursing homes. Most of these homes are dependent upon the national government for funding, with supplemental funding coming from local governments and volunteer organizations. A few are privately financed.

Dr. Carlos Jarquin Gonzales, Director General of health Promotion and Protection
Dr. Guillermo Gosebrunch Icaza, Director of Infectious Diseases
Complejo de salud "Dr. Conception Palacio"" Managua

PANAMÁ

Provincia de Los Santos

Ministerio de Salud

Cuidados en el Domicilio es una necesidad consciente por parte de los profesionales, sin embargo se ve limitada por falta de transporte y personal profesional.
Las visitas domiciliarias realizadas tienen un enfoque preventivo y de diagnostico precoz principalmente. Se realizan visitas a los inasistentes a vacunas, controles citológicos, puerperas, embarazadas, diabéticos e hipertensos. En algunos casos a pacientes encamados, con problemas mentales, desnutridos o a aquellos que rechazan ser hospitalizados.

Cuidad de Panamá

Asociación Hospes Pro Cuidado Paliativo

Área de Servicios:
Asociación sin fines de lucro, data de 1994, cuya finalidad es la compañía del moribundo y su familia en el proceso de muerte y duelo. Desde el alivio físico, emocional, psicológico y espiritual. Se atienden enfermos terminales de cáncer y SIDA.

Organización:
Participantes en la atención:

- Participan profesionales de las ciencias de la salud (médicos enfermeras, psicólogos) y laicos que pertenecen a la pastoral de enfermos de la Iglesia Católica

Organización de la atención:

- Existe consejo directivo integrado por miembros fundadores, directivos y asesores.
- Se realizan reuniones semanales de 2 horas de duración.
- Anualmente se atienden entre 10 y 12 casos.

Financiamiento: a través de donaciones.
Home care services in Panama are provided by private nursing groups and for-profit agencies. As the Ministry of Health endeavors to provide coverage for that portion of the population not covered by social security or by private insurance

Coordinación:
Los pacientes ingresan a través de referencias de los miembros del grupo que pertenecen al tercer nivel de atención.

Dr. Nilda Chong, MPH
Departmento de Salud de Adultos
Ministerio de Salud
Apdo. 2048
Panama

PERU

Traditionally, the elderly in Peru live at home and are cared for by relatives, or they are placed in private institutions. Wealthy families may hire aids to assist with the care of the elderly person, but this is rare.

Some small private institutions, or "academies," exist which employ home care and health aides, but these employees primarily care for infants rather than the elderly.

Carlos Santa-Maria, M.D.
Consultant to the Vice-Minister's Office
Ministerio de Salud
Av. Slavery s/n
Lima, Peru

SAINT KITTS

Organization

In Saint Christopher (Saint Kitts) and Nevis, the majority of home health care is provided by private organizations, churches and voluntary organizations. District public health nurses visit homes on a regular basis to provide assistance to persons who are unable to attend regular clinics. The public nurses fall under the jurisdiction of the Ministry of Health.

Patricia A. Hobson
Permanent Secretary
Ministry of Health and Women's Affairs
P.O. Box 186
Church Street Basseterre
St. Kitts, W.I.

ST. LUCIA

Organization

The government has realized the need to increase services for the elderly as people are living longer and more of the population is migrating to the cities. Non-governmental organizations have been encouraged to establish residential homes and day care centers. However, families are also encouraged to care for their elderly at home.

Participants

Currently, five agencies employing 50 professional staff, including physicians, nurses, home health aides and other therapists, provide home care in St. Lucia.

Gilrey Joseph
Ministry of Social Affairs
New Government Buildings
Waterfront, Castries
St. Lucia, West Indies

TRINIDAD AND TOBAGO

Trinidad and Tobago does not have a formal home care delivery system. In general, the elderly are cared for in the home by relatives or paid help, most likely aides or nursing assistants. Affluent families may elect to hire a trained private nurse. Two or three private agencies keep a list of nurses, assistants and aides who desire this type of work.

The number of nursing homes for the elderly has increased, but these homes are not accredited or administered by the government.

Dr. P. Ramal
PMO (CS)
Ministry of Health
Rondabout Plaza
Barataia

SURINAME

Services:
Cost-effective maternity services. Both Pre and postnatal services are provided. A basic package offers prenatal information, advice and guidance, whereas, post natal services offer mother and childcare and monitoring. Physicians and midwifes provide information about the use of health care centers and vaccination programs.

Organization:
The delivery of Primary heath care is the responsibility of the government; however, civilian and non-government organizations provide substantial care. Suriname recognized its need to develop primary care at the village, local and national level, which will allow individuals and families to help themselves. The Suriname Home Care Foundation developed a service delivery models which for Paramaribo (the capital) which is being used for the entire country, including the Amerindian and Maroon indigenous groups.

Care participants:

- Nurses
- Midwifes
- Physicians
-

Pilot Project
Foundation for the Support of Home care in Suriname (SOTS)
Suriname Home Care Foundation (STS) Established in 1994.
STS's purpose is to develop a viable and sustainable system for professional home care, especially in the Amerindian and Maroon communities. They developed a three-year pilot study (1995-1997) with the following objectives in mind:

- Provide different types of packages of services
- Become cost effective in the long run
- Demonstrate to the government that professional home care can contribute to lowering health care costs and that home care provides a more client-Fridley treatment,
- Acquire government and insurance funding for professional home care services and
- Convince other smaller private home care initiates in Suriname of the need to cooperate and dorm an association.

Financial:

- The pilot study was supported by SOTS and the Suriname Medical Mission organizations.
- STS is building relations with the business sector both inside and outside of Suriname to address concerns about the sales of home care equipment and supplies. Their objectives include:

- To guarantee that STS continues to subsidize the professional home care of those in the fringes of life long to reach government aid
- To contribute to create the financial means necessary to make STS a cost-effective system in the long run.
- To convince the government of the contribution that a well-organized professional home care system can make by finding ways and means to finance the costs of health care.

Coordination:
Homecare is viewed as an inextricable part of primary care delivery-a means to individualize primary care services and health information in the community. The first national Congress on Home Care was held in Suriname in March 1988.

Ernst Stanley E. (1997) Home Care in the Republic of Suriname. Caring.(16) 26-7.

TRINIDAD AND TOBAGO

Organization:
Trinidad and Tobago does not have a formal home care delivery system. In general, the elderly are cared for in the home by relatives or paid help, mostly likely aides or nursing assistants. Affluent families may elect to hire a trained private nurse. Two or three private agencies keep a list of nurses, assistants and aides who desire this type of work.

Dr. P. Ramal
PMO (CS)
Ministry of Health
Rondabout plaza
Barataia

UNITED STATES OF AMERICA

Services:
Many home care organizations also provide a wide variety of other services,
Including:

- physical therapy
- occupational therapy
- speech therapy
- medical social services
- nutritional services
- Day care
- Respite care
- Meals on wheels
- Transportation

Organization:
Home care is appropriate whenever a person needs assistance that cannot be easily or effectively proved only by a family member or friend on an ongoing basis for a short or long period of time.

Personnel
Home care agencies employ a variety of professional and paraprofessional to deliver home care services:

- Nurses
- Home care aides

- Social workers
- Therapists
- Physicians
- Pharmacists
- dietitians

Organization of Care
Home care services are provided by home care agencies. Home care agencies are public organizations or private nonprofit or for profit organizations, that have developed over the past century around a core of professional nursing services and home care aide services. Home care agencies can be categorized into three main groups: home health agencies, home care aide organizations and hospices:

Home Health Agencies are the most common. Home health agencies are concerned with the treatment or rehabilitation of patients who need skilled nursing care or therapy. Their patients are predominantly under the care of a physician and the care they receive through the home health agency in accordance with a physician's order. These agencies offer a multidisciplinary program of care-usually; nursing and home care aide services at a minimum. The Medicare-certified agency is the prototype home health agency.

Home care aide organizations or paraprofessional organizations are primarily or exclusively concerned with the delivery of care to functionally impaired persons who need help with personal care, such as bathing, and with homemaking services.

Hospices provide palliative care for patients in the final stages of a terminal illness through a team composed of physicians, nurses, social workers and counselors who are concerned with the physical, psychological, social, and spiritual welfare of the patient.

Financial
Home care is paid for by a variety of sources. Often it is paid for by the individual or the family, but both private and public insurance programs cover some home care costs. Benefits and requirements vary greatly, however. For those whose insurance does not cover home care, some agencies offer a sliding-scale fee schedule so that a family need pay only what it can afford.

Major payment sources that cover home care include Medicare, Medicaid, Social Services Block Grant, Older Americans Act, private health insurance, Veterans Administration, workers' compensation, health maintenance organizations (HMO), CHAMPUS, social services organizations and patient/private pay.

Medicare:
It is for those 65 and over. The federal health program pays for home health services, some home making and agency-provided medical supplies and equipment.

Medicaid:
This is for low-income people. Each state has its own set of eligibility requirements. Home health services must include part-time nursing, home health aide and medical equipment and supplies.

Social Services Block Grant:

States receive allotments of funds on the basis of the state's population. In-home services may include home care aide chores and personal care.

Older Americans Act:
It is for those 65 and over. IN-home services include home-delivery meals, home care aides, personal care, chore, escort and shopping services.

Private Health Insurance:
Policy coverage varies. Many policies only cover services that already are covered by Medicare.

Veterans Administration:
Veterans with a 50% or more service –connected disability are eligible for home health care coverage. A physician must authorize services.

Workers Compensation:
Any person needing home care services as a result of injury on the job is eligible.

Health Maintenance Organization
Organizations with Medicare contracts must provide Medicare-covered services, included home care.

Champus:
For dependents of active military personnel and retirees. On a cost –shared basis home care is provided.

Social Service Organizations:
Organizations that operate with private charitable funds may offer supportive health care services. Services may require payment, donation or are provide free of charge.

Patient/Private Pay:
Home care services can be personally paid for. Most home care services are paid out of pocket. Scope of services and price varies.

Medical equipment is supplied by a separate and distinct industry. Although a relatively few home care organizations sell and rent medical equipment as a sideline to the services they provide, the great bulk of the medical equipment is marketed by other organizations, which are generally referred to as "home medical equipment dealers." Some 6,000 to 7,000 companies sell and rent home medical equipment. Find/SVP, a New York-based market research organization, estimated the home care products market at $1.6 billion in 1992, and predicted it would grow at an annual rate of 9.6 percent to reach $2.4 billion by 1996.

Coordination
Home care agencies bring these services into the home, singly or in combination, in order to achieve and sustain an optimum state of health, activity, and independence for individuals of all ages who require such services because of acute illness, exacerbation of chronic illness, or long term or permanent limitations due to chronic illness and disability.

National Association for Home Care

228 7th Street , SE
Washington, DC 20003

URUGUAY

Montevideo

Departamento de Oncología del CASMU, asistencia a enfermos terminales.

Area de Servicios:

Asistencia domiciliaria a enfermos oncológicos terminales u otros que no reúnan las características de terminal pero que por diversas razones (dificultad para traslado u otras) sean referidos por oncólogos.

Organización:

Participantes en la atención:

- Los profesionales que en la atención en el domicilio son: médicos enfermeras, fisioterapeuta y nutricionista principalmente. Psicólogo actúa como voluntario.
- Se cuenta con apoyo de auxiliar de enfermería.

Organización de la atención:

- En un lapso menor 48 horas hábiles desde la referencia, médico de cuidados paliativos realiza visita, planifica tratamiento y abre historia clínica domiciliaria.
- Atenciones sucesivas en el domicilio se realizan según necesidades específicas.
- Se realizan visitas de duelo.
- Existe base de datos para almacenar la información específica de los pacientes asistidos.
- Las maniobras realizadas son escasas, incluyen punción evacuadora de ascitis, extracción de fecaloma, entre otras.
- Los procedimientos realizados en el domicilio incluyen: toma muestras de exámenes de laboratorio, oxigenoterapia y exámenes radiológicos principalmente
- Existe evaluación y seguimiento continuo de resultados con el objetivo de corregir prontamente los problemas
- Aproximadamente un 86% de pacientes que reciben cuidados en el domicilio fallecen el domicilio.

Financiamiento:

no existe información al respecto

Coordinación:

- Médicos oncólogos refieren a pacientes a sistema de cuidados en el domicilio.
- Los pacientes son referidos desde servicios de oncologia (ambulatorio y hospitalizados), servicios de urgencia, por médicos particulares, otros.

De los pacientes referidos 89% son ingresados al sistema de cuidados en el domicilio

North and South America: ***(3rd International Home Care Nursing Conference 1998 Seoul)***

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WORLD HEALTH ORGANIZATION

STUDY GROUP
HOME-BASED AND LONG-TERM CARE
Ma'ale Hahamisha, Israel § 5-10 December 1999

"WESTERN PACIFIC REGION OVERVIEW OF WORK IN PROGRESS AND MAJOR CONCERNS ON HOME-BASED AND LONG-TERM CARE"

Ms Kathleen Fritsch
WHO Nurse Educator Fiji
World Health Organization
Regional Office for Western Pacific Region

LTH/HSC/SG/99/8

STUDY GROUP ON
HOME-BASED AND LONG-TERM CARE,
5-10 DECEMBER 1999

Western Pacific Region Overview of Work in Progress and Major Concerns on Home-Based and Long-Term Care

Kathleen Fritsch, WHO Nurse Educator

Political, economic and cultural context

The Western Pacific Region presents an interesting array of political, economic and cultural contexts and an equally various set of demographic and epidemiological profiles. Data contained in the WHO publications, *Health of Older Persons in the Western Pacific Region*, permit comprehensive demographic and policy analysis of older persons in populations throughout the Region. Consisting of some 36 autonomous, quasi-autonomous and dependent states extending over a vast geographical area, the Western Pacific Region encompasses nearly half of Asia and all of Oceania. The majority, all but eight, in fact, are island states, most quite small both in land mass and in population, although also included are Australia, Japan, New Zealand, Papua New Guinea, the Philippines and Singapore, all with populations numbering in the millions. The bulk of the Region's population, however, resides on the Asian mainland, mostly in China, along with Korea, Malaysia, Mongolia, Viet Nam, Cambodia and Laos.

Political systems range from the monarchical, as in the Kingdoms of Brunei and of Tonga, to the state socialisms of China and Viet Nam, although most are constitutional republics, practicing modified variants of the Westminster parliamentary system. Some of the market economies in the Region are among the most dynamic in the world, and the Region is not without resources, although those richest in resources, Papua New Guinea and the Solomon Islands, for instance, have remained, by and large, along with Cambodia and Laos, the least developed. The majority of the countries in the Region, however, lie in Oceania, small often quite isolated island states or territories, some consisting entirely of atolls, that are identified culturally as Polynesian, Melanesian or Micronesian. Many of these countries have small Asian or European communities as well, which have been instrumental in the limited development that has occurred.

Awareness efforts and initiatives concerning ageing in the region were begun in some countries as early as 1983, particularly in Australia, New Zealand and Japan, which were the first developed and industrialized nations within the Region. Increased life expectancy at birth, reduced child mortality and decreased birth rates were clear indicators that their populations would soon experience rapid ageing. More than half of the countries in the Region have at least some programmes and services for older persons already in place. During the past decade, most of the countries in the Region have taken steps towards establishing policies and plans for the health of older persons.

Demographics and epidemiological developments

The Western Pacific Region contains China, whose population at 1.3 billion people is more than twice as large as the sum of all of the other countries in the Region combined. It also contains tiny Tuvalu, whose population at 15 000 is still larger than that of five other states within the Region. It contains Japan, where the median age has already reached 40 and life expectancy at birth is nearly 80. It also contains Nauru, Papua New Guinea, Laos and Cambodia, all countries where life expectancy at birth is only slightly more than 50 years and the median age is 20 years or less.

Most of the Western Pacific countries have experienced significant population growth due to increased life expectancy and lowered infant and child mortality, and in some cases, despite high rates of immigration. It has been estimated that by the year 2050, more than 20% of the population in the Western Pacific Region will have reached 60 years of age, compared to only 16% in all other parts of the world. Although 47% of countries in the Region have not formulated national policies with respect to ageing, several countries have established national legislation devoted to older persons, including Australia, Japan, New Zealand, Singapore, Mongolia and the Philippines.

Many of the countries in the Region, in fact, have quite youthful populations and the immediate concern for government is a matter of finding employment or other productive activity for growing numbers of school leavers. Korea, Singapore and China are anticipated to be the next countries in line for whom the needs of a relentlessly ageing population will soon be, if they are not already, a pressing issue. Change, however, particularly in the form of development and industrialization, is occurring throughout the Region and as the world continues to shrink there can be little doubt that all of these countries will experience problems associated with a rapidly ageing population during the first half of the 21st century.

Most Pacific Island countries are undergoing epidemiological transitions in which birth rates, and infant and child mortality rates are declining, and as the older population grows, the morbidity and mortality rates of noncommunicable disease are rising. Some countries are continuing to face the double burden of communicable diseases common to developing countries as well as the noncommunicable diseases common to developed countries, along with a trend towards more sedentary lifestyles. The noncommunicable diseases, in particular, cancer, heart disease, hypertension, cerebrovascular accidents and diabetes, in combination with lifestyle changes, lead to increased rates of premature death and disability. Chronic diseases, and increasing environmental and economic stress, increase the risk of older persons developing impaired psychological, physiological and cognitive functioning.

Older persons experience altered homeostatic mechanisms, and often, one or more chronic diseases, which put them at increased risk for diminished function and disability. These complex health changes of older persons, along with increased prevalence of disability, can contribute to high costs of health care, due to increased hospitalizations, longer hospital stays, increased use of health care technology, increased use of medications and increased demand for social services and supportive home care and day-care programmes. Other factors contributing to the increased health care costs include inflation and health care provider practices and demands.

The care-takers of aged family members are themselves at significant risk for rising incidences of disease and disabilities and possible decreased life spans, due to the high prevalence of noncommunicable diseases in most countries. Urgent attention must therefore be paid to promoting health and preventing disease in children and young persons, as well as middle-aged and older persons. If children in their youth fail to receive adequate education and are at risk for disabling noncommunicable diseases, less human and economic support is available to provide for the needs of society's older persons. Maintenance of good health of potential care-takers is essential if home and community-based care of older persons is to be successful.

Urbanization is increasing throughout the Region, though often without adequate improvements in housing and living conditions (safe water and sanitation) for the urban poor. Many older persons may be left alone in rural communities as younger members of the family search for work in cities. Economic recessions, slow economic growth, declining revenues, growing unemployment, increased competition for limited resources, inadequate fiscal and human resource management systems and shortages of in-country trained health professionals are all factors contributing to the difficulty of effective planning for old age.

Changing family structures

Attempts to maintain traditional culture and family values can be difficult to sustain in the face of increased rates of violence, decreased size of extended families due to migration, urbanization, and the pressures of modern consumerism. Family size is decreasing in some countries due to decreased fertility rates, HIV and AIDS, civil conflict in some countries and losses of family members due to outward migration for better job and life opportunities. Younger family members are moving in greater numbers to urban areas, leaving increased numbers of older persons alone in more isolated settings. Contributing stresses to families also include the loss of essential caretakers of young children when grandparents are chronically ill or disabled.

The model of the family for the developing world is the extended family; the model for the developed world is the nuclear family. The transition from one to the other might be termed 'nuclearization.' In some countries the process may be gradual and planned to the extent that the creation of one does not necessarily entail the destruction of the other. Other countries may not be so fortunate. Countries the size of China, Korea, Malaysia, Viet Nam and the Philippines are large enough so that the best efforts of the best people are required over a period of time, perhaps three or four decades or more, to bring about the many benefits of modernization. In tiny countries such as Palau, Niue, Tokelau, Nauru, Cook Islands or Wallis and Futuna, where whole countries are smaller than a small town and every citizen belongs, by blood or marriage, to essentially one large extended family, the effects of nuclearization can be devastating.

In many of the Pacific Island countries, although urbanization is increasing, at least 50% or more of the populations live in rural areas. Maintenance of older persons in villages is the norm in most of the developing countries of the Region. Though families provide support to the elderly, in many developing countries there continues to be a lack of community-based services for older persons. Nongovernmental organizations providing supportive services and respite care are limited in number. A lack of formal hospital discharge planning programmes in many developing countries contributes to increases in hospital re-admission rates of older persons.

Roles of women

Women's roles are becoming more complex and multifunctional as women are usually the primary care-givers, holding both household and out-of-household jobs. The care of older persons is, in many cases, the responsibility of women, who may be caring for their young children and for their ageing, disabled parents at the same time. The labour of women in the home is often not recognized in terms of its economic contribution to societies. Women are facing increased risk of domestic violence and neglect as economic decline impacts family functioning. Women in later life are much more likely to be suffering from disabilities. In some countries, women may experience discrimination on the basis of gender, class, or religion. Increasing poverty and stressful lifestyles contribute to higher rates of illness and disability for women.

Nurses represent the front-line in the ongoing struggle to meet the growing needs of the elderly. For instance, in Samoa, an Integrated Community Health Nursing Scheme has been implemented which began as a means to provide maternal child health services through a network of women's committee clinics. The service has expanded in recent years to provide service to schools and now includes home care visits, as well. Here is an excerpt from a WHO mission report filed earlier this year.

"By noon the nurses had visited a stroke patient and taught the family how to do range of motion exercises; had visited a patient with probable Alzheimer's disease and given support to her family; had cared for an elderly man with hypertension, checking his blood pressure and monitoring his medication; and had checked a 93 year-old woman with an enlarged heart and slight ankle oedema."

A subsequent excerpt from the same report details activities of the home-care team later that same day.

"We accompanied the home-care team to visit three cases needing palliative care. All three had terminal cancer and were given narcotic pain medication. Unfortunately, morphine had been out of stock for the past month, so the nurses were administering pethidine injections around the clock. One patient was in the late stages of cancer of the pancreas. His home-care team provided support for his wife, a nurse, who could do much of his care. The second patient had cancer of the femur and needed six-hourly dressing changes for a large external tumour. The third patient was a young man who had undergone surgery overseas for cancer of the oesophagus. He had a tracheotomy and a gastric feeding tube. The home health team had helped him and his family set up a self-care situation, which was truly amazing. When we visited, we found the young man lying on a mat, comfortably propped up with pillows, his family nearby. Within his reach was a set-up for suctioning his tracheotomy tube. The equipment for his gastric feeding was neatly arranged on a low-lying table, also within his reach. The young man was more comfortable giving his own care, so the nurses had taught him to suction his own tracheotomy tube and to feed himself through his gastric tube. The nurses visited him twice a day to monitor his care and to give him his injections. Under almost any other circumstances, this patient would have been hospitalized. But with the help of the home-care team, hospital costs have been saved and the quality of the man's life has been improved immeasurably."

The Integrated Community Health Nursing Service in Samoa was not designed with the primary intention of providing home care services for the elderly. It is merely one of many functions that the service performs. Elderly care, in fact, may be of lower priority in Samoa than in most other countries in the Region, as its older person dependency ratio of 3.5 is substantially less than its young dependency ratio of 88.8. Samoa, in an attempt to meet the health care needs of its children, has demonstrated, simultaneously, a capacity to fulfil a major component of the home care needs of its elderly citizens.

Fiji, a country with a population four times greater than that of Samoa, and with an older person dependency ratio of 6.5, is culturally quite similar to Samoa, particularly with regard to the respect accorded to their aged citizens. Most persons continue to be cared for in the home, with only 0.4% of older persons residing in Homes for the Aged. A major nurse training initiative in Fiji, the institution of nurse practitioner training, can be expected to contribute to quality health care of the elderly there, as the nurse practitioner graduates will come equipped to assess and manage common health problems, including problems of older persons. The services provided by nurse practitioners should help to alleviate gaps in the care of older persons due to shortages of medical personnel.

Concerns/Needs Arising

Perhaps it would be useful at this point to consider a few of those elements that are necessary if quality health care for the elderly is to become a reality in the coming decades. Improvements in the quality of life of populations in the Region requires that emphasis be placed on the preventive health care of children and youth, and the establishment of health and social programmes focused on healthy ageing. Such healthy ageing programmes would emphasize maintenance of good nutrition, regular exercise, stress reduction, and avoidance of smoking.

Attention needs to be given to the analysis of alternative methods of health care financing to ensure that national budgets, taxes and savings plans and pension funds will provide sufficient economic support for home and community-based services, permitting elderly persons to live independently as long as possible.

National councils on ageing and appropriate policies, if not already in place, should be established. Policy development should take into account gender issues. Women are intimately involved in multi-focal work and care-taking roles; and though they live longer than men, women experience greater morbidity and disability than men.

Human resource development needs to include the training of health care workers in quality care of older persons, along with delineation of methods of monitoring the quality of health care received by older persons. The development of standardized functional assessment guidelines for health workers is needed, in order to facilitate assessment of older persons' functional status, medications, social interactions and support, and to identify early signs of disease or altered functioning. The quality of care of older persons can be improved through the use of guidelines, which delineate monitoring parameters for persons with chronic diseases such as diabetes, hypertension and cardio-cerebrovascular disease.

Strengthening of community-based support and services for care of older persons in the community requires:

- Support and education for caregivers;
- In-home adaptive devices and equipment to support continued functioning of older persons in the home; along with
- Respite, foster and day-care.

The success of community-based support to older persons will also require that the services of nongovernmental organizations providing support to the elderly (meals, respite home care, assistive care in the home, etc.) be strengthened.

Highly developed, high income countries in the Region, with demographically older populations, such as Australia, Japan and New Zealand, have already developed systems of care for older persons that are well established. In Japan, for example, a wide variety of non-profit organizations provide support and in-home services for older persons in the community.

Rapidly developing, upper middle income countries, and those with demographically middle-aged populations are devoting increased attention to the development of health services for older persons. They often have a variety of community-based services for older persons. Guam has a relatively full range, including adult day care services, case management services, in-home assistance programmes, and respite care and transportation services to support older persons and family members providing care for older persons. Older persons in the Commonwealth of the Northern Mariana Islands, although they have Medicare health insurance, and, for some, U.S. social service retirement benefits, may not be able to afford home nursing assistance.

In Palau, the family is the primary caregiver for the elderly. The Ministry of Health subsidizes 80% of medical and dental care of elderly persons. Private clinics, when providing care to the elderly, are also subsidized by the Government. Periodic home visits, when necessary, are provided by public health nurses.

In selected lower income and low-income developing countries, including Fiji, Samoa, the Philippines and Viet Nam, health services for older persons are being initiated. Fiji has attempted to train most of its public health and primary health care nurses in care of the elderly, using strategies and content outlined in the WHO publication entitled, *Quality Health Care for the Elderly*. A number of physicians and nurses have undertaken fellowships and training courses in rehabilitative and geriatric medicine, geriatric nursing and community-based rehabilitation. Many health-training curricula still require changes to place increased emphasis on the needs of older persons.

Much has already been done to improve the well-being and independence of older persons in the Western Pacific Region, in large measure because of prospective, socio-political and intersectoral commitment to national plans and policies. We are all challenged to continue these developments by taking an active leadership role in promoting the health of older persons, particularly in regard to the health and social-sector development of community-level programmes designed for the care of older persons and their caregivers.

for CHC meeting participants

WORLD HEALTH ORGANIZATION

STUDY GROUP
HOME-BASED AND LONG-TERM CARE
Ma'ale Hahamisha, Israel § 5-10 December 1999

"HOME CARE INITIATIVES IN THE WHO SOUTH-EAST ASIA REGION"

Dr Duangvadee Sungkhobol
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LTHHSC/SG/99/7

HOME CARE INITIATIVES
IN THE WHO SOUTH-EAST ASIA REGION

Presented at

Study Group on Home-Based and Long-Term Care
Ma'ale Hachamisha, Israel
5-10 December 1999

By

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CONTENTS

1. INTRODUCTION

The South-East Asia Region of WHO comprises ten Member States - Bangladesh, Bhutan, Democratic People's Republic of Korea, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka and Thailand. These countries are characterized by many complexities with considerable social, cultural, political and economic diversity. Three of the ten countries, Bangladesh, India and Indonesia have populations more than 100 million people. Five of them, Bangladesh, Bhutan, Maldives, Myanmar and Nepal are least developed countries. The region is home to one-fourth of the world's population and about 40 per cent of the its poor.

There have been dramatic changes in the socioeconomic situation in most countries of the Region over the last few years. While economic and political reforms have resulted in improvements in the overall economic condition, wide disparities still exist, both among as well as within countries. The gap between the "haves" and the "have nots" appears to be widening in many countries. The recent economic crisis, which has struck many parts of Asia, has further aggravated the situation in some countries of the Region.

Infectious diseases are still the leading cause of morbidity and mortality, and the Region is still the major contributor to the global burden of many communicable diseases. While tremendous progress has been made towards the eradication of diseases such as poliomyelitis, guineaworm and yaws, and towards the elimination of leprosy and neonatal tetanus, diseases such as tuberculosis and malaria continue to take a heavy toll of lives and to economically cripple many families. New, emerging and re-emerging diseases, such as dengue fever, Japanese encephalitis, viral hepatitis and HIV/AIDS, pose increasing threat to the health and well-being the people of the Region.

Declines in crude birth and death rates and increases in life expectancy have resulted in a progressive ageing of the population. These demographic changes, as well as the emergence of an increasing affluent middle class, have brought with them the attendant problems of cardiovascular diseases, cancers, neurological and metabolic disorders, and other chronic conditions as well as trauma and injuries. Many countries of the Region are therefore facing not only the burden of communicable diseases, but also an increasing burden of noncommunicable diseases. They can no longer address these problems sequentially, but must face them simultaneously. This double burden of diseases imposes a tremendous strain on national health budgets.

The health sector alone is not able to cope with such problems. Hence, there is an urgent need for close interaction with other social sectors such as education, industry, housing and environment for health development. In addition, there is a need for a shift towards more holistic health care, with adequate attention given not only to curative care but also to health promotion and protection and rehabilitation. With the increasing cost of health care, countries are also striving for new and better ways to provide good quality cost-effective health care. Hence, in addition to strengthening institutional health services, countries of the Region are taking steps to develop and strengthen community- and home-based care, including empowering individuals, families and communities for self-care. Several initiatives have been undertaken by the WHO South-East Asia Region towards this end.

2. DEMOGRAPHIC TRANSITION

During the 1980s and 1990s there was a stead increase in life expectancy at birth in most of countries of the Region. In 1983, only three of the ten Member States reported life expectancy at birth at 60 years or more. By 1997, seven out of the ten countries reported life expectancy above 60 years.

The tremendous achievements in the economy, industry, modern technology, and medical science will continue to contribute to even greater increases in life expectancy in all the countries. Yet this means a growing number of older people, and that more and more people will therefore be at higher risk of developing the chronic and debilitating diseases associated with old age.

The increasing in the total number of elderly people of 60 years and above will be further accelerated during the years to come. The proportion of elderly people is expected to increase from 5.3 per cent in 1980 to 12.4 per cent in 2025 for the whole Region. As compared to the changes in the global population between 1995 and 2025, more dramatic changes can be seen in countries of the Region, during the same period (Figures 1 and 2).

Figure 1: World Population structure by age and sex, Year 1995 & 2025

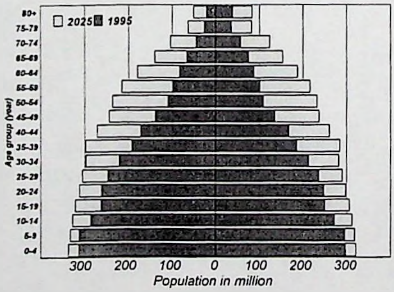
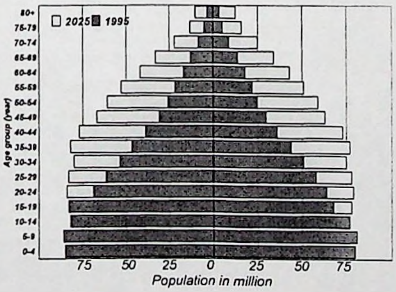


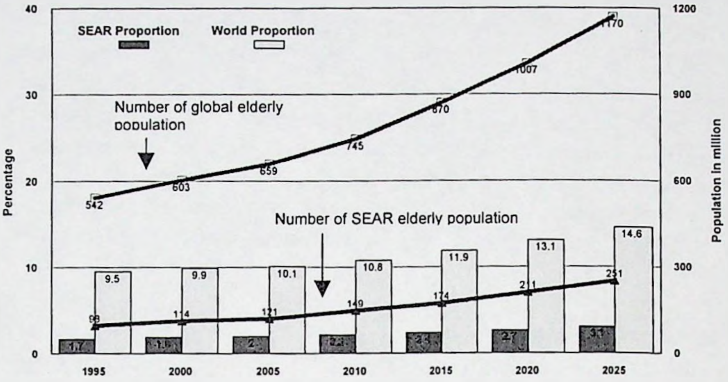
Figure 2: SEAR country population structure by age and sex, Year 2995 7 2025



Source: United Nations medium variant predictions, as cited in WHO (1999) *Regional Situational Analysis on Demographic and Epidemiological Transitions and Strategies on Active and Healthy Ageing* (WHO/NCD/Meet 2/5, 25 September 1999, Unpublished manuscript). WHO, New Delhi.

This demographic transition effectively transforms most countries of the Region from "mature societies" to "ageing societies", with an ageing population of more than seven per cent by the turn of the century. The proportion of Regional elderly population will increase from 18.1 per cent in 1995 to 21.4 per cent of the world's elderly population in 2025. As this trend continues, the number of the world's and the Region's elderly population will more than double from 1995 (Figure 3).

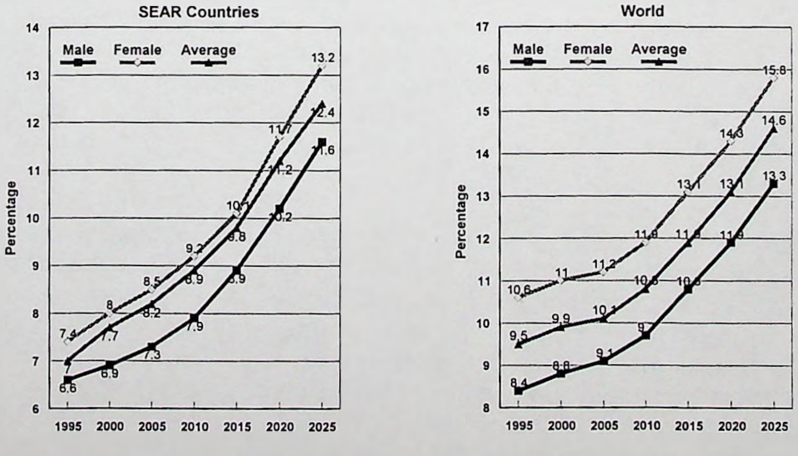
Figure 3 : Number and proportion of elderly population in the world and in SEAR countries, 1995 - 2025



Source: United Nations medium variant predictions, as cited in WHO (1999) *Regional Situational Analysis on Demographic and Epidemiological Transitions and Strategies on Active and Healthy Ageing* (WHO/NCD/Meet 2/5, 25 September 1999, Unpublished manuscript). WHO, New Delhi.

Universally, women have a longer life expectancy than men. They therefore constitute both a larger accumulated number as well as a large proportion of the elderly population. A similar pattern is seen in the global and in Regional populations. While the proportion of elderly women in the Region is expected to increase to 13.2 per cent by 2025, the proportion of elderly men will be 11.6 per cent (Figure 4).

Figure 4: Population of elderly population by sex in SEAR countries and in the world, 1995 - 2025



Source: United Nations medium variant predictions, as cited in WHO (1999) *Regional Situational Analysis on Demographic and Epidemiological Transitions and Strategies on Active and Healthy Ageing* (WHO/NCD/Meet 2/5, 25 September 1999, Unpublished manuscript). WHO, New Delhi.

3 . EPIDEMIOLOGICAL TRANSITION

All countries of the Region are proceeding along the path of epidemiological transition, with differences in where they lie on the path and at the rates at which they are changing. However, the proportion of the global burden of disease carried by countries of the Region is enormous. These ten countries account for 40 per cent of the world's maternal deaths, 41 per cent of the global deathsl due to infectious diseases – almost 7 million each year and 40 per cent of the global burden of tuberculosis, estimated at 3.5 million cases. By the year 2000, 8 to 10 million people in the Region are expected to be infected with HIV, which would be over 25 per cent of the global cumulative infection. The Region also accounts for 68 per cent of the poliomyelitis cases, 72 per cent of the leprosy cases and 30 per cent of blindness cases, in the world.

As noted earlier, along with declining death rates and gradually increasing life expectancy, the process of epidemiological transition – the pattern of mortality and morbidity changes in association with demographic changes – is under way in most of the countries. The main change in the morbidity and mortality patterns of the countries of the Region during the past two decades has resulted from a decline in cases of polio, neonatal tetanus and other vaccine preventable diseases. The Region has demonstrated a dramatic acceleration of polio eradication activities, particularly with the implementation of national immunization days.

The other positive epidemiological trend is the decline in the incidence and prevalence of leprosy in the Region. Multi-drug therapy has proved so successful that it is expected that leprosy will be eliminated by the year 2000. At the same time, the treatment of deformities and rehabilitation will require increased attention.

Despite overall improvements in the socioeconomic status of the people and increased life expectancy, communicable diseases are still well-entrenched in the Region. Old diseases like cholera and tuberculosis still dominate the scene, while malaria, plaque and kala-azar, which were once on the verge of eradication, have reappeared. Acute respiratory infections and diarrhoeal diseases continue to be the leading causes of mortality in children under five years of age.

As the transition proceeds, the infectious component of the disease burden is gradually being replaced by non-infectious conditions such as cardiovascular diseases, cancers, accidents, diabetes and congenital anomalies. At present the risk of death from noncommunicable diseases during adulthood (15-60 years) is considerably higher in the developing world, including South-East Asia, than in the developed world. Cardiovascular and cerebrovascular diseases, cancer and diabetes have emerged as major contributors to morbidity and mortality in many countries of the Region (Tables 1 and 2). Mental health problems, particularly during political and economic turmoil, as well as problems related to substance abuse, continue to be of serious public health concern.

Table 1: *Trends in leading causes of morbidity*

Country	**Rank**	**Leading Causes of Morbidity**			
		1983-1985	**1988-1990**	**1991-1993**	**1994-1997**
Bangladesh	1	Diarrhoeal diseases	Diarrhoeal diseases	Diarrhoeal diseases	Fever/pyrexia of unknown origin
	2	Respiratory diseases	Infectious/parasitic diseases	Skin diseases	Diarrhoea/dysentery
	3	Nutritional disorders	Measles	Infectious/parasitic diseases	Dyspepsia/gastritis/ peptic ulcer
	4	Skin diseases	Malaria	Respiratory diseases	Common cold/upper respiratory infection
	5	Eye diseases/night blindness	Nutritional disorders	Nutritional disorders	Malaria
Bhutan	1	Diarrhoeal diseases	Diarrhoeal diseases	Respiratory diseases	Acute respiratory infections
	2	Respiratory diseases	Respiratory diseases	Skin diseases	Intestinal infection/ diarrhoea/dysentery
	3	Infectious/parasitic diseases	Infectious/parasitic diseases	Diarrhoeal diseases	Skin diseases
	4	Skin diseases	Skin diseases	Infectious/parasitic diseases	Peptic ulcer syndrome
	5	Malaria	Malaria	Eye diseases/night blindness	Musculoskeletal disease
DPR Korea	1	Not available	Whooping cough	Diarrhoeal diseases	Cardiovascular diseases
	2		Diarrhoeal diseases	Whooping cough	Cancer
	3		Fevers	Fevers	Diabetes
	4		Infectious/parasitic diseases		
India	1	Not available	Diarrhoeal diseases	Respiratory diseases	Not available
	2		Influenza	Diarrhoeal diseases	
	3		Malaria	Malaria	
	4		Tuberculosis	Whooping cough/measles	
	5		Whooping cough	Neonatal tetanus	
Indonesia	1	Not available	Respiratory diseases	Diarrhoeal diseases	Intestinal infections
	2		Skin diseases	Pregnancy related diseases	Complications of obstetrics/abortion
	3		Diarrhoeal diseases	Injury/poisoning	Injury and poisoning
	4		Bronchitis/asthma	Respiratory diseases	Respiratory infections
	5		Malaria	Aches and pain	Cardiovascular diseases

Table 1: *continued*

Country	Rank	Leading Causes of Morbidity			
		1983-1985	**1988-1990**	**1991-1993**	**1994-1997**
Maldives	1	Aches and pain	Asthma/bronchitis	Respiratory diseases	Not available
	2	Respiratory diseases/influenza	Fever	Diarrhoeal diseases	
	3	Eye diseases/night blindness	Aches and pain	Decayed/missing/filled teeth	
	4	Skin diseases	Pregnancy related disorders	Hypertension	
	5	Traumas	Skin diseases	Anaemia	
Myanmar	1	Malaria	Malaria	Not available	Malaria
	2	Diarrhoeal diseases	Diarrhoeal diseases		Tuberculosis
	3	Pregnancy related disorders	Pregnancy related disorders		AIDS
	4	Respiratory diseases	Tuberculosis		Diarrhoeal diseases
	5				Protein energy malnutrition
Nepal	1	Pregnancy related disorders	Skin diseases	Diarrhoeal diseases	Not available
	2	Infectious/parasitic diseases	Infectious/parasitic diseases	Respiratory diseases	
	3	Injury/poisoning	Respiratory diseases and nutritional disorders	Malaria	
	4	Diarrhoeal diseases	Diarrhoeal diseases	Nutritional disorders	
	5	Respiratory diseases	Fevers	Infectious/parasitic diseases	
Sri Lanka	1	Pregnancy related disorders	Infectious/parasitic diseases	Traumas	Injuries/poisoning/ external causes
	2	Injury/poisoning	Pregnancy related disorders	Diarrhoeal diseases	Infectious/parasitic diseases
	3	Diarrhoeal diseases	Respiratory diseases	Malaria	Respiratory diseases
	4	Heart diseases	Injury/poisoning	Respiratory diseases	Genitourinary diseases
	5	Circulatory system diseases	Circulatory and nervous system diseases	Sexually transmitted diseases	Circulatory system diseases
Thailand	1	Pregnancy related disorders	Diarrhoeal diseases	Diarrhoeal diseases	Infectious/parasitic diseases
	2	Diarrhoeal diseases	Motor vehicle accidents	Respiratory diseases	Respiratory diseases
	3	Accidents	Accidents	Malaria	Injury/poisoning/ accidents
	4	Motor vehicle accidents	Fevers	Fevers	Circulatory system diseases
	5	Fevers	Bronchitis/asthma	STDs	Mental disorders

Source: WHO (1999) *Health Situation in the South-East Asia Region, 1994-1997.* WHO, New Delhi.

Table 2: *Trends in leading causes of mortality*

Country	Rank	Leading Causes of Mortality			
		1983-1985	1988-1990	1991-1993	1994-1997
Bangladesh	1	Diarrhoeal diseases	Tetanus	Diarrhoeal diseases	Not available
	2	Respiratory diseases	Pneumonia	Tuberculosis	
	3	Old age complications	Diarrhoeal diseases	Tetanus	
	4	Fevers	Injury/poisoning	Respiratory diseases	
	5	Asthma	Hypertensive diseases	Measles	
Bhutan	1	Not available	Not available	Respiratory diseases	Not available
	2			Skin diseases	
	3			Diarrhoeal diseases	
	4			Worms	
	5			Malaria	
DPR Korea	1	Circulatory system diseases	Not available	Cardiovascular diseases	Cardiovascular diseases
	2	Neoplasms		Hypertensive diseases	Cancer
	3	Respiratory diseases		Neoplasms	Diabetes
	4	Injury/poisoning		Respiratory diseases	Traffic accidents
	5	Diarrhoeal diseases		Injury/poisoning	
India	1	Senility	Infectious/parasitic diseases	Diarrhoeal diseases	Cardiovascular diseases
	2	Respiratory diseases	Circulatory system diseases	Respiratory diseases	Infectious/parasitic diseases
	3	Diseases of infancy	Respiratory diseases	Diseases of infancy	Injury and poisoning
	4	Circulatory system diseases	Injury/poisoning	Pneumonia	Conditions of perinatal period
	5	Fevers	Diarrhoeal diseases	Infectious/parasitic diseases	Respiratory diseases
Indonesia	1	Respiratory diseases	Diarrhoeal diseases	Cardiovascular diseases	Cardiovascular diseases
	2	Diarrhoeal diseases	Cardiovascular diseases	Tuberculosis	Respiratory diseases
	3	Cardiovascular diseases	Tuberculosis	Respiratory diseases	Tuberculosis
	4	Tuberculosis	Measles	Diarrhoeal diseases	Infectious/parasitic diseases
	5	Tetanus	Respiratory diseases	Injury/poisoning	Diarrhoea

Table 2 *continued*

Country	Rank	Leading Causes of Mortality			
		1983-1985	1988-1990	1991-1993	1994-1997
Maldives	1	Not available	Fevers	Senility	Cardiovascular diseases
	2		Diarrhoeal diseases	Cardiovascular diseases	Respiratory diseases
	3		Abdominal pain	Fevers	Diabetes
	4		Tuberculosis	Stroke	Cancer
	5		Pneumonia	Asthma	Tuberculosis
Myanmar	1	Senility	Malaria	Not available	Not available
	2	Cardiovascular diseases	Tuberculosis		
	3	Pneumonia	Pneumonia		
	4	Diarrhoeal diseases	Diarrhoeal diseases		
	5	Tuberculosis	Cardiovascular diseases		
Nepal	1	Infectious/parasitic diseases	Not available	Not available	Not available
	2	Respiratory diseases			
	3	Nervous system diseases			
	4	Circulatory diseases			
	5	Injury/poisoning/ accidents			
Sri Lanka	1	Injury/poisoning	Cardiovascular diseases	Cardiovascular diseases	Cardiovascular diseases
	2	Cardiovascular/hypertensive diseases	Cerebrovascular diseases	Cerebrovascular diseases	Injury/poisoning/other external causes
	3	Diarrhoeal diseases	Diarrhoeal diseases	Injury/poisoning	Respiratory diseases
	4	Neoplasms	Circulatory system diseases	Diarrhoeal diseases	Infectious/parasitic diseases
	5			Tuberculosis	Diseases of digestive system
Thailand	1	Cardiovascular/ circulatory diseases	Cardiovascular/ circulatory diseases	Respiratory diseases	Circulatory system diseases
	2	Diarrhoeal diseases	Accidents	STDs/AIDS/ARC	Accidents and poisoning
	3	Accidents	Neoplasms	Diarrhoeal diseases	Malignant neoplasm
	4	Injury/poisoning/ homicide	Diarrhoeal diseases	Tuberculosis	Diseases of liver and pancreas
	5	Neoplasms	Respiratory diseases	Malaria	Pneumonia and other respiratory diseases

Source: WHO (1999) *Health Situation in the South-East Asia Region, 1994-1997.* WHO, New Delhi.

A public health approach is therefore of vital importance, not only for the effective prevention and control of communicable diseases, but also for noncommunicable diseases.

4. THE NEED FOR COMMUNITY- AND HOME-BASED CARE

With the increase in health care costs, accessibility to health services will become an important issue that countries must address. There is a continuing trends that hospital stays will be shortened. For cost-effective care, several health interventions/services can be effectively carried out within the community or at home. Such care can be provided by less trained health personnel or family members, given proper guidance and supervision from qualified health personnel. For almost all people, home is the setting of choice for receiving care. Given the escalating cost of health services, the poor, the vulnerable and the disadvantaged groups who normally have only limited access to health care will be even more deprived. There is an urgent need therefore for countries of the Region to extend the health services beyond hospital walls. This will ensure the accessibility of care as well as a continuum of care between the hospital and home

There are several groups of clients who have the greatest need for community- and home-based care. For example, elderly and disabled people would be able to have healthier living environment with proper community- and home-based care. Individuals with chronic diseases - both communicable diseases (such as HIV/AIDS) and noncommunicable diseases (such as diabetes or cancers or cerebrovascular diseases) - and terminally ill patients requiring long-term care would also benefit greatly from home-based care. Home care may prevent, delay or be a substitute for institutional care. Thus, such patients would be required to be in the hospital only when there are real needs for it.

4.1. Elderly Population

With a longer life span, individuals are at a higher risk from a number of ageing-related diseases and disabilities as well as changing life styles. A five country study on elderly care showed that arthritis, high blood pressure, foot problems, heart diseases and stomach ulcers were the most common illnesses among the elderly, along with visual and hearing impairments. Countries of the Region continue to be major contributors to the global burden of blindness. It is estimated that the number of blind people in the Region in 1998 was about 11.7 million. Around 50-80 per cent of this blindness is caused by cataract, which is most common in those aged 60 years and over.

The age-related diseases along with visual and hearing impairements greatly affect the elderly. They are often unable to carry out daily activities, self-care functions and more importantly, employment. Thus they become functionally dependency and sometimes economically dependent, and so require support for daily living.

In most countries of the Region, a relatively high proportion of elderly people work. However, only 34 per cent of the rural elderly and 29 per cent of the urban elderly are reported to be economically independent in India. A study in Thailand revealed that six per cent of the elderly live alone, while two per cent reported they did not have any one to help them in times of sickness and disability.

National health services in the Region, however, still focus primarily on communicable diseases and maternal and child health. Health services for the elderly are inadequate. Health personnel working in the community at the primary health care have neither the knowledge nor the skills necessary to tackle the health needs of the elderly. In addition, the proportion of elderly people able to obtain professional health care is substantially lower in the Region than in developed countries (Table 3).

Table 3: ***Percentage of the elderly who consulted a health professional***

Males	**60-74 years**	**75 + years**	**Total males**
Australian Study			
Doctor	71.9	74.1	72.5
Nurse	3.3	0.0	0.1
Pharmacist	30.3	42.1	33.9
South-East Asia Region			
Doctor	29.3	28.7	29.2
Nurse	3.9	5.6	4.2
Pharmacist	2.3	2.3	2.2
Females	**60-74 years**	**75 + years**	**Total females**
Australian Study			
Doctor	71.3	80.8	74.2
Nurse	8.7	7.1	8.2
Pharmacist	30.6	21.7	28.0
South-East Asia Region			
Doctor	32.1	33.7	32.4
Nurse	3.8	5.4	4.3
Pharmacist	2.1	2.8	2.3

Source: Australia, Centre for Ageing Studies, *Ageing in South East Asia – A five country study as cited in* WHO (1999) *Health Situation in the South-East Asia Region, 1994-1997.* WHO, New Delhi.

4.2. People with Disabilities

Data on disabilities in countries of the Region are scanty. Overall, however, the magnitude of disabilities and their patterns vary from country to country. Results obtained from small surveys indicate that the prevalence of disabilities ranges from three to ten per cent of the total population. While disabilities due to poverty-related diseases remain the major concern, emerging problems such as those due to traffic accidents, occupational injuries and chronic and degenerative diseases as well as old age-related disabilities pose new challenges in the Region.

It is estimated that there will be approximately 45 million people in the world who are blind by the year 2000. Of these, countries of the South-East Asia Region account for 15 million, with a cataract backlog of 10 million cases. It is also estimated that the Region accounts for more than one-quarter of the moderate to severe hearing impairment cases in the world. The Region has an estimated one million leprosy cases, representing 72 per cent of the world's total.

Accidents and injuries are on the increase in countries of the Region. They constitute nine to ten per cent of the total mortality in India. As causes of morbidity, injuries rank fifth in Myanmar and fourth in Indonesia. Trauma and injuries are the leading causes of hospitalization in Sri Lanka. Since trauma care is not well developed in most of these countries, many injuries lead to permanent disability.

The prevalence of severe mental disorders (psychoses) has been estimated to be 5-10 per 1000 population in various countries of the Region. About seven million people in India alone are affected by severe mental disorders at any given time.

These disabled people are in need for treatment of deformities and rehabilitation of which the majority of care can be effectively provided in the community and at home.

4.3. Individuals with Chronic Diseases

4.3.1. HIV/AIDS

The human immunodeficiency virus (HIV), which caused the acquired immunodeficiency syndrome (AIDS), came much later to the South-East Asia Region than to other parts of the world. However, HIV has emerged as a serious public health and development concern in the Region. It is estimated that currently there are more than 5.5 million HIV-infected people in the Region, representing nearly 18 per cent of the world total, while the proportion of reported AIDS cases represents less than 5 per cent. Besides in persons with high-risk behaviour, HIV infection rates have now begun to increase in the general population as well. Given the mean progression time for initial HIV infection to develop into AIDS, it can be concluded that AIDS cases in the Region will continue to increase into the next century, and up to two million cumulative cases of AIDS may occur by the year 2000. *These AIDS patients will require substantial family and social support to live meaningful lives in the community.*

4.3.2. Tuberculosis

Tuberculosis (TB) is an ancient disease, which continues to pose a major public health challenge in developing countries. Though it is now possible to cure and control tuberculosis, particularly with "directly observed treatment, short course" (DOTS), it still affects and kills millions of people each year. It is estimated that eight million people worldwide develop TB. Of the 3.8 million cases reported to WHO in 1996, 39 per cent were reported from the South-East Asia Region. One million deaths – one-third of the global deaths each year – occur in this Region. Access to the DOTS strategy in the Region is still relatively low, and currently reaches only about 12 per cent of the total population.

To add to the problem, tuberculosis is the most important life-threatening opportunistic infection associated with HIV in the Region. HIV and TB each speed up the progression of the other. Of the 4.5 million who were HIV positive in 1997, about one-third were also infected with tuberculosis. Between 56 and 80 per cent of the AIDS cases in Thailand, India, Nepal and Myanmar have had TB. Tuberculosis accounts for at least one-third of the AIDS death worldwide, and 40 per cent of the AIDS deaths in Asia. Thus, there is urgent need to intensify the implementation of DOTS in countries of the Region.

In Thailand, DOTS was recommended as the most effective method to contain the emerging TB/HIV co-epidemic. The Ministry of Public Health, in 1997, issued new policy guidelines for TB control based on the DOTS strategy. It is also endorsed a plan to cover the entire country by 2001.

The accessibility to the DOTS strategy in countries of the Region can be further improved by active involvement of family and community members in providing necessary care in the community or at home. From successful experiences in some countries of the Region such as Myanmar and Thailand, trained community volunteers and family members can effectively carried out the short course of directly observed treatment for tuberculosis.

4.3.3. Other Chronic Diseases

Increased longevity together with changes in life styles and diets, sedentary habits, and the increased use of tobacco and alcohol have contributed to the sharp rise in the incidence of cardiovascular and cerebrovascular diseases, malignancies, metabolic and degenerative disorders, and mental illnesses. As seen in Tables 1 and 2, cardiovascular diseases, cancers and diabetes are among the leading causes of morbidity and mortality in several countries of the Region.

The increase in cardiovascular disease prevalence and mortality rates is expected to continue in the coming years in the majority of the countries. Cancer incidence will also increase substantially in many countries as well. The increase in the prevalence of diabetes mellitus will be marked in the Region, with an estimated 30 million persons affected at present. It is estimated that by the year 2025 there will be nearly 80 million diabetics in the

Region – the highest among all WHO Regions. *Contrary to what is found in developed countries, where the majority of persons with diabetes are 65 years of age and over, most diabetics in the Region belong to the younger, more economically productive age group.*

Patients with these chronic diseases often require long-term care, a large portion of which can be effectively given at home.

4.3.4. Other Individuals

In addition to those mentioned earlier, other individuals who will also benefit from home care include those who are discharged from the hospital but still require continuity of care, pregnant women, mothers and babies during the postpartum period, and children under five to name just a few. Moreover, the population at large will also benefit from home health care, particularly for health promotion and protection for healthier life styles.

5. ISSUES IN HOME CARE

5.1. Changing Family Structure

In the past, the majority of the Region's population resided in the rural areas. With rapid urbanization and industrialization, the percentage of the population residing in urban areas has increased dramatically in all countries. For example, the urban population in Bangladesh increased from 4.2 per cent in 1950 to 18.3 per cent in 1995, and is expected to reach 40.6 per cent by the year 2030. The average annual growth rate of urban populations, however, varies widely among countries of the Region.

With urbanization, there is often a shift from an extended to a nuclear family environment. Thus, contacts that normally frequently occur in extended families between parents, children and their spouses as well as their offspring, and other relatives are somewhat limited. Many countries of the Region have witnessed increased migration from rural areas to cities in search of better economic opportunities. The young, productive members of the family migrate to large urban centres in search of jobs, leaving behind the elderly and children in the rural communities. This has broken down the traditional family support system, where the younger generation takes care of their elders. As noted earlier, a study in Thailand showed that six per cent of the elderly lived alone and two per cent did not have any one to help in time of sickness and disability. Well-to-do families can hire professional help or support workers to provide the necessary help to their elderly parents, but poor families cannot.

Changing family structures, therefore, pose a major challenge for the provision of home health care for individuals who are ill and/or functionally dependent. Mechanisms need to be in place to ensure that those family members and others who provide such services have adequate knowledge *and skills as well as a positive attitude towards care of the elderly and disabled.*

5.2. Roles of Women

A study of health-seeking behaviour in 16 developing countries found that women most often make decisions about health care use, including self-care. At least 75 per cent of health-related decisions take place within the family.

The role of women in the family as health care providers is known to be of great importance. Normally, women of the Region are the main providers of health care within their own families. Their role begins at home, where illness usually begins. Caring is their intuitive response to the sick and disabled. Outside the home, their role as doctors, nurses, midwives, other categories of health workers, and volunteers is well recognized.

Some countries of the Region have made special attempt to select mostly females as health volunteers and to provide them with training. This enhances their confidence, skill and status in the community. It thus contributes to the improvement of their own health as well as that of their families and the communities in which they live.

In some societies within the Region, male health workers or volunteers are not acceptable as care providers to women. In this case, only female health workers or volunteers can provide cultural-sensitive and women-friendly care, meeting the needs of the women and their societies. Hence, recruitment of female health volunteers will also increase the accessibility of services to needy women.

However, there is an increase in women's participation in the work force in many countries of the Region. They work primarily in the agriculture sector. Female labourers comprised 90 per cent of the total persons employed in agriculture in Nepal in 1991 and 62 per cent in Bhutan in 1997. In Thailand, however, female labour participation is predominantly in the manufacturing, service and tourism sectors. With the growing garment industry and the establishment of free trade zones in some countries, large numbers of women are entering this labour market. This has also exposed more women to occupational hazards and injuries. This may have an adverse effect on their own health, which may prevent them from fulfilling the caring functions at home.

Many workingwomen have to cope with a double burden of responsibilities, both at home and at work. This entails being constantly concerned about their families', particularly their children's, well-being, while fulfilling their job expectations. Support systems to help women with their family responsibilities while at work have not yet been developed to any significant extent in the Region. Recently, there has been an attempt to intensify men's participation in the health care of their own family, particularly that of their wives in some countries of the Region.

Thus, there is the greatest potential if men can also be mobilized to provide home care for their own families and the community. At the same time, women need some support for their traditional caring role in the family. Support systems need to be established to assist workingwomen to carry out home care without overburdening them.

5.3. Community Participation in Health

There is political commitment in all countries of the Region to facilitate community involvement in health and development activities. Community participation is perceived as a dynamic partnership process. It enables people to become agents of their own health development. Thus, there are health volunteer schemes operating in all countries of the Region. Volunteers in community health activities not only bring health services to the community, they also act as agents for health development. They benefit both the recipients and the health care providers.

Volunteers play an important role in galvanizing communities for action. They provide information that enhances individual and family self-care and responsibility as integral components of every day life. Since health care starts at home, family members and various groups within the community should be empowered to assume the responsibility for their own health and that of their community.

In Indonesia, for example, the Family Welfare Movement is a community-based volunteer women's movement. This has been recognized by the Government of Indonesia for its dedicated and innovative work to mobilize women at all levels of society in support of primary health care. It emphasizes self-reliance and mutual help for self-improvement, including elimination of poverty. One component is the integrated health post, which provides maternal and child health care including health education at the village level. It also provides a helping role in the areas of food, clothing, housing, home economics, education, handicrafts, protection of the environment and promotion of cooperation.

There are examples of effective community involvement in drug abuse control in India, Myanmar and Sri Lanka. People in a locality are mobilized to take care of their "community" drug problems, such as identifying drug users; spreading optimism about rehabilitation; organizing users' group; parents, teaching relatives and significant others how to handle drug problems; mobilizing assistance and planning for detoxification camps, and various skill training sessions; motivating drug users together for detoxification. Detoxification camps are then set up and, ideally, with all drug dependent persons being detoxified together. Such efforts have transformed communities into self-help groups to keep their localities drug free.

Special efforts need to be made to strengthen community action for health and enhance the role of health volunteers, and to develop their capacity for providing effective support for home health care in their own communities.

6. INITIATIVES UNDERTAKEN

6.1. Care of the Elderly

Over the years, WHO Regional Office for South-East Asia has made substantial efforts to improve health care of the elderly. The principal focus of WHO's activities has been on community participation and family care. The "promotion of traditional family ties" has therefore been put ahead of "institutional care". Making optimal use of the available primary health care services is the cornerstone for supporting traditional family care.

In collaboration with Member States, the Regional Office has been concentrating its efforts in several areas of elderly care. These include:

- Creating awareness among policy makers and the general population
- Collecting and disseminating information on the socioeconomic and health status of elderly people through intercountry and country studies
- Supporting formulation of appropriate national policies, strategies and programmes
- Improving health workers' knowledge and skills on health care for the elderly.

WHO supports the training of health personnel as a top priority. Various studies of the determinants of healthy ageing have been supported by the Regional Office. Several countries of the Region recently initiated WHO-supported programmes on Ageing and Health. In addition, a workshop on active and healthy ageing for mega countries was recently convened to develop strategic directions for intercountry cooperation.

At present, the community-based care of the elderly in countries of the Region can be categorized into four groups, i.e. family care, primary health care for the elderly, homes for the elderly, and other community-based elderly support activities.

Family Care

The existence of extended family networks in which parents, children, uncles and aunts are in regular and frequent contact with one another is a fundamental part of the traditional welfare system in the Region. In most developing countries, the family remains the only source of support and long-term care for the elderly. Being in the house with other family members also creates a moral support for the elderly.

Family involvement in health care is the most constant and reliable source of support for the elderly. The family can be a valuable help in identifying chronic diseases, assisting with visits to health care facilities as well as other physical support. The elderly living in joint families enjoy respect from family members and are well looked after during illness.

In well-off families in big cities in several countries of the Region, families hire professional caregivers, properly trained to provide live-in care for the elderly at home. Although costly, it is popular as it provides the opportunity to have their elderly parents cared for by professionals without investing much of the children's time on their parents. However, many elderly are not this fortunate. Due to financial constraints, their offspring leave home in search of better economic opportunity, and so many live alone in their old age.

Primary Health Care for the Elderly

Health care services to provide specialized geriatric care are grossly inadequate in most countries of the Region. Nevertheless, some countries have established a system for taking care of their elderly populations. In Indonesia, for example, the elderly can obtain free health services at health centres provided that they have a health card. However, they are often treated as general patients, since specialized geriatric health services are not available usually general. The health workers at field level, including doctors and health personnel at the primary and secondary levels of health care have very little or no knowledge of the health problems of the elderly and healthy ageing.

In Thailand, primary health care for the aged is provided at the village health centre, which is staff by a public health technical officer and a nurse-midwife. Health care services provided are basic. For complex health problems, the elderly will be referred to a district hospital. Medical consultation is given at the village health centre during routine supervision visits of a medical doctor from the district hospital. The provincial and regional hospitals provide sophisticated medical care for referred patients.

Specialized geriatric services, where they exist, are mostly located in tertiary care hospitals which serve only a small proportion of the population. Moreover, in almost all countries of the Region, only a small number of qualified geriatric specialists are available. It is common that the practice of these specialists is mostly confined to clinical aspects of diseases.

Homes for Care of the Aged

There are a number of old-age homes in most large cities of many countries of the Region. These are for the elderly who do not have adequate family support. The majority is run by non-profit organizations. Nevertheless, some homes established by private organizations do request payment. Services provided include provision of accommodation, food, general health care, recreation, day care, assistance for families, counseling services, and home visits to the elderly living in the surrounding area. These homes receive little support from the governments, and are primarily dependent on charitable donations.

Community in several countries have organized day care centres for elderly in the form of coffee and tea clubs. Hence, the elderly can gather together and communicate with each other. This can keep them from social isolation and improve their mental alertness.

A few nursing schools in Thailand have organized day care centers for the elderly as a service to the community as well as a field practice area for student learning. These provide an opportunity for nursing students to acquire requisite knowledge and skills as well as a positive attitude towards geriatric care.

Other Community-based Elderly Support Activities

The health care of the elderly has to go beyond disease orientation. It must take into account the interdependence of physical, mental, social, emotional, spiritual, rehabilitative and environmental factors. Care of the elderly is a "composite" of these aspects.

In most countries of the Region, there are several non government organizations (NGOs) and private voluntary organizations which have come forward to provide support for the elderly. Being close to the communities, NGOs have often succeeded in areas where the government machinery has found outreach difficult.

HelpAge is a prominent NGO for elderly support that operates in many countries of the Region. It is believed best to keep the elderly working as long as possible so that they will be economically independent, thus, supporting old age social security. HelpAge has undertaken various security projects through traditional occupations to help the elderly.

An extensive network of Buddhist temples is available in Thailand, which the elderly frequently visit. The monks are highly respected by society and are a potential source for disseminating information to promote healthy ageing.

6.2. Community-based Rehabilitation

During the past few decades, the Regional Office has promoted the use of available rehabilitation technologies so that the disabled can access essential rehabilitative care, enabling them to lead meaningful lives in their communities. Emphasis is placed on the prevention of disabilities, integration of rehabilitative services within the general health care infrastructure, and intersectoral approaches.

WHO, in collaboration with its Member States, has concentrated its efforts in several areas of community-based rehabilitation (CBR). These include:

- Strengthening public awareness
- Reviewing disability situations at regional and country levels and disseminating information
- Supporting the formulation of appropriate national policies, strategies and programmes with CBR as integral component of the primary health care system
- Strengthening infrastructure and referral facilities
- Building national capacity for local production of assistive devices and aids
- Supporting the training of health personnel for CBR
- Translating the WHO CBR manual into local languages.

As in care of the elderly, special consideration has been given to support the training of health workers. A regional consultation was recently convened to identify strategies to further strengthen training programmes for health workers, particularly at the primary health care level, in rehabilitation and CBR.

As a result of these initiatives, most countries of the Region have established national rehabilitation programmes or activities. In a few countries, CBR coverage has been expanded. National capabilities in management and referral support have been substantially improved, and several countries have adopted or enacted legislation and disability acts for the promotion and protection of the rights and responsibilities of persons with disabilities.

Community-based rehabilitation is a multifaceted programme that involved many sectors, including education, social welfare, employment and health. At present, charitable institutions and NGOs carry out many of the programme activities.

6.3. Community-based AIDS Care

WHO Regional Office for South-East Asia has made substantial efforts to develop and strengthen comprehensive care for HIV/AIDS patients in which community-based AIDS care is an integral part of the system. The principal focus of WHO's activities has been on integration of HIV/AIDS care as integral part of primary health care. Efforts are also given for making optimal use of the available local resources within the community including NGOs for AIDS care programmes.

In collaboration with Member States, the Regional Office has been concentrating its efforts in several areas of AIDS care. These include:

- Creating awareness among policy makers and the general population

- Supporting the formulation of appropriate national policies, strategies and programmes with comprehensive care (a continuum of HIV/AIDS care at various levels, i.e. hospital, community and home) an integral part of the primary health care system
- Supporting the provision of comprehensive care (including counseling) to people infected with HIV or those with AIDS, as well as health promotion and education
- Adapting the WHO Home-care Handbook for use in the Region. The handbook was field tested in Thailand, India, Myanmar and Indonesia before being promoted for use in countries of the Region. It has enabled health workers to help individuals, families and communities to manage AIDS-related problems and to build their own capacity to provide safe and compassionate HIV/AIDS care at home.
- Developing and disseminating a numbers of technical documents on HIV/AIDS, e.g. "HIV/AIDS counselling: A module for trainers", "Understanding and living with AIDS", "HIV testing policies and strategies" and "Planning and Implementing HIV/AIDS Care Programmes: A step-by-step approach"
- Supporting the training of health personnel as well as community workers.

With comprehensive care – the continuum of care between hospital and home – the majority of people living with AIDS can be managed at home. They require hospital care only for specific needs. Home-based AIDS care includes the provision of comprehensive care by family members, community members including those living with AIDS themselves, community-based organizations, NGOs, as well as visiting health workers or volunteers. Home and community-based care have been instrumental in building the capacity of the community to be responsible for taking care of their own members living with HIV/AIDS, not merely in HIV/AIDS care, referral and prevention, but also in skill development and income generation.

The Regional Office therefore provides special support to countries for developing and strengthening AIDS care, including community-based AIDS care. The first community-based prevention and care programme for HIV/AIDS in the Region was started in 1992 at Ban Dong Luang, Lampang, Thailand. It was the first community to form an anti-AIDS association in the northern part of Thailand, where HIV/AIDS is a major problem. Later on, several NGOs joined in developing community- and home-based care programmes for persons living with AIDS. Buddhist monks at several temples in Thailand also actively provide community- and home-based care and other support including income-generating activities in order to enable AIDS patients to lead meaningful lives.

6.4. Other Initiatives for Community- and Home-based Care

6.4.1. Promotion of Self-care

The WHO Regional Office for South-East Asia accords high priority to the promotion of self-care as a means to support primary health care. Several initiatives have been undertaken towards empowering individuals, families, communities, and various groups within the community, e.g. youth groups, and women group for self-care for self-reliance.

For example, WHO has provided support for the development of self-care manuals in Myanmar. Through collaboration of township community health nurses, midwives and local NGOs, women have been trained on self-care and are empowered to take care of their own health needs, as well as those of their families and communities.

A manual for women's action for health has been developed by the Regional Office to further facilitate self-care development in the Region. This manual provides guidance on how women can take care of themselves, their families and communities in various illnesses.

With the implementation of the Integrated Management of Childhood Illness (IMCI), the Regional Office has made concerted efforts to promote family and community action for health at home, including self-care of major childhood illnesses, i.e. pneumonia, diarrhoea, malaria, measles and malnutrition. Parents are taught to provide healthier living to support the healthy development of their children. They also are taught what to do if their children fall ill, what the danger signs are, when and where to go for appropriate help, how to look after the sick child at home, and the importance of following treatment advice.

6.4.2. Strengthening of Community Health Nursing

Community health nursing services in most countries of the Region are not well developed. The majority of nursing personnel are employed in the hospitals at which there are acute nursing shortages. Consequently, nurses have not been optimally utilized for primary health care. They could be used not only as direct caregivers, but also as back-up support for community health workers in the field.

With the increase in the elderly population and the double burden of diseases, it is essential that community health services be strengthened, particularly for prevention and control of diseases. Nursing services, particularly community health nursing, need to be responsive to these changing health needs. They need to be geared for health promotion. Special efforts, therefore, have been undertaken to assist Member Countries in establishing and strengthening community health nursing services. This initiative also aims to strengthen the home visit component of community health nursing in order to provide a continuum of care between a hospital and home. Concerted efforts are being made in several countries of the Region to develop "best practice" models for community health nursing and home health care. In these models public/community health nurses will assume the role of managers or coordinators of care that will be given by various health professionals and family members in the community and home.

The Regional Office supports the training of nurses, to update their skills and knowledge in community health nursing. A regional training programme on community health nursing, based on the assessed training needs of countries of the Region, has been developed.

6.4.3. Promotion of Community- and Home-based Midwifery Care

As noted earlier, maternal mortality is unacceptably high in many countries of the Region. The majority of deliveries in the Region occur at home and are assisted by unskilled attendants. Many maternal deaths also occur at home, in the community, or on the way to a hospital.

It has long been recognized that provision of community-based maternity care will help reduce maternal deaths. It is critical that all pregnant women have access to skilled attendants at birth, and to essential obstetric care when encountering obstetric complications and emergencies and medical assistance is not available.

The Regional Office has developed *Standards of Midwifery Practice for Safe Motherhood* to assist Member States ensure and enhance quality of their midwifery care. In implementing these standards, community- and home-based midwifery care is strengthened. The midwifery-trained personnel must be proactive and reach out to the community that they serve. In addition, they need to be equipped so that they can provide selected life-saving interventions in order to save women's lives.

7. FUTURE PLAN

The Regional Office will continue its efforts to work with Member States and other development partners – both national and international - to strengthen community- and home-based care in order to promote healthy living for people of the Region. The activities highlighted below are planned to be carried out during the 2000-2001 biennium.

- Development of a model for community-based elderly care with an emphasis on collaboration and partnerships with NGOs
- Development of a model for community-based prevention of major noncommunicable diseases, directed at disease surveillance and health promotion and education for healthier life style

- Strengthen community-based rehabilitation strategies and approaches in selected areas in Member States to increase accessibility of the rehabilitation services
- Development of health promoting workplaces (or healthy workplaces) to facilitate occupational health as well as health of the general public
- Development of a community-based maternity care model which emphasizes the provision of good quality, integrated care with the active involvement of the community and man
- Development of models to strengthen the role and enhance the productivity of nurses, midwives, doctors - general practitioners and other health personnel in community- and home-based care
- Development of a manual to promote family and community practices for child health
- Promotion of community-based care for mental health and substance abuse.

Various concerned technical units within the Regional Office are responsible to carry out these initiatives. To optimize the use of resources, special attention is being given to greater collaboration among units and programmes. This will help to ensure and foster coordinated development in countries of the Region.

8. CONCLUSIONS

The WHO South-East Asia Region is in demographic and epidemiological transition. Countries are confronting a double burden of diseases. There is a shift towards holistic health care, with an emphasis on health promotion and protection and rehabilitation in addition to the curative aspects of care. There is increased attention being given to the provision of community- and home-based care particularly for the elderly, the disabled, those with chronic diseases, and the vulnerable and the marginalized groups. Several initiatives have already been undertaken to support countries for these developments. WHO and its Member States will continue their collaboration to further strengthen community- and home-based care for healthier population in the Region.

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for CHC meeting participants

WORLD HEALTH ORGANIZATION

STUDY GROUP
HOME-BASED AND LONG-TERM CARE
Ma'ale Hahamisha, Israel § 5-10 December 1999

"HOME-BASED LONG-TERM CARE"

Paper To Cabinet
Social Change And Mental Health
World Health Organization
25 May 1999

LTHHSC/SG/99/5

Paper to Cabinet

25 May 1999

To: Cabinet
From: Dr Y. Suzuki EXD/HSC
Date: 25 May 1999
Topic: Home-Based Long-Term Care

Background

1. The next two decades will see dramatic changes in the health needs of the world's populations with noncommunicable diseases as the leading causes of disability. Increases in the older population by up to 300% are expected in many developing countries. In addition, HIV/AIDS, TB and malaria continue to be a major cause of disability (and death). Everywhere there is a steep increase in the need for long-term care.

2. These changes require a very different approach to health sector policy and health care services since a disease-specific approach, alone, is no longer appropriate. The one common denominator resulting from these demographic and epidemiologic changes is **functional dependency and the growing need for care to manage everyday living**. Rising health care use and spiraling costs have everywhere led to a trend and the necessity to treat patients in the home[1]. The burden of caregiving is primarily on women, who have very little access or control of the resources needed to assume this responsibility. Well managed and supported home care, however, can improve the quality of life of patients of all ages and caregivers alike.

3. In all countries, the family has always been and still is the major provider of long-term care. This is true for care of older persons as well as for care of patients with chronic conditions, including HIV/AIDS, TB and malaria. However, the heavy burden of care cannot be shouldered by families alone. Due to a wide range of social, economic, demographic and epidemiological factors, family resources are dwindling (e.g. migration, changing rural and urban social environments, poverty, family members themselves being old or impaired, etc.). In addition, family care givers need guidance, support and skills to manage often complex care.

4. In the very poor countries, most common ailments are treated in the home and most people die in the home. Health centres are at the same time overwhelmed and underutilized (staff not paid for months, drugs and equipment not available, client expectations for quality of service not met, etc). At the same time as there is a growing need for home care, there is a very real danger of, more than ever, families--who do not have the means or the knowledge--being left to their own devices to carry the caregiving responsibility and work. Again, **the price is most often paid by women**.

5. In all WHO regions there is strong interest in home care. But while the need for it is growing rapidly everywhere, so is the danger that the label of home care will be used to forego public and government responsibility with dire consequences for the quality of care, for families, and in particular for the health and lives of women who are the main care givers not only for their own families and communities, but also in the formal health sector. An optimal balance between family and public responsibility must be sought.

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[1] Home care is defined as the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximal level of comfort, function and health including care toward a dignified death. Home care services can be classified into preventive-promotive, therapeutic, rehabilitative, long-term maintenance and palliative care categories. This paper primarily addresses long-term and palliative home care.

6. Home and family care giving has implications for many sectors (e.g., education, labour, transport, etc.) and is an integral part of the health and social care systems pertinent to all age groups. It must be integrated with other public health, clinical and social care. Concerns of equity, quality, and sustainability and a life-course approach must guide its development. All aspects of home care (policy, financing, legislation/regulation, its human and physical resources, continuity and support of care, etc.) need to be addressed.

Recommendation

For Cabinet to agree to launching an inter-cluster project which will result in:

1. An evidence base from research and experiences in developing and industrialised countries. (see Annex 1).
2. Collaboration with Member States to develop country policies and home-care programmes which will make a difference to the quality of life of their people. (Annex 2). Work at country level might have different points of entry. One country might choose to begin with strengthening district level capacity; a second country might first develop support to family care givers; and a third country, involved in health sector reform, might choose to begin with national capacity strengthening and policy development. It is also possible that a country might choose multiple-entry points simultaneously.
3. A partnership to develop home and long-term care strategies with Regions, other UN agencies, NGOs, donors, academia and the private sector.
4. Establish an Oversight Group which will co-ordinate WHO work related to home-based care and develop a WHO policy and strategies.

Phases: The project will progress in stages. After initial consultation, the implementation will depend upon the human and financial resources and the readiness of the partners (in particular, the speed at which countries and regions wish to go ahead). (see Initial Components of Work Plan, Annex 3)

Consultation

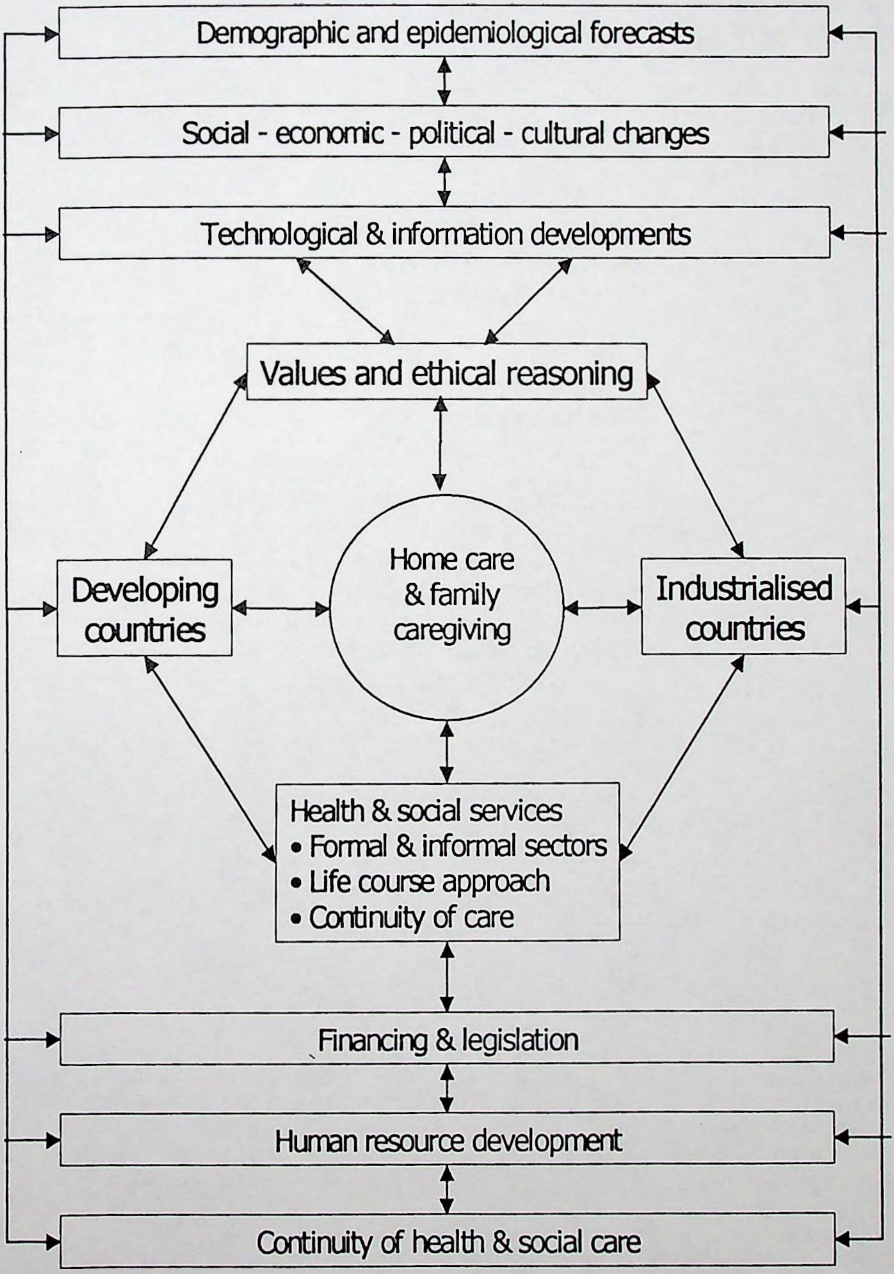
A draft of this paper has been discussed with colleagues within the

- HSC Cluster, CDS, NCD, CHS, SDE, HTP, and EIP clusters and their comments have been included in this version.
- RDs or DPMs from the six regions gave the green light to send the draft work plan to their region. Feedback received from AFRO, AMRO, EURO, SEARO and WPRO (included in present version) and interest expressed by WRs.
- UN, ILO, (in future: World Bank, Regional Banks, OECD, UNICEF, UNDP and UNESCO).
- Bi-lateral donors (to date: Japan, Germany, U.S., Israel).
- Selected NGOs.
- Selected academic institutions.

Conclusion

Given the staggering and growing need, the technical complexity and the political importance to industrialised and developing countries alike, the project needs to move forward. A detailed plan of work for accessing extrabudgetary resources is being prepared. Collaborative work with EIP has been initiated.

Home and Long-Term Care
Developing Evidence-based Standards & Norms



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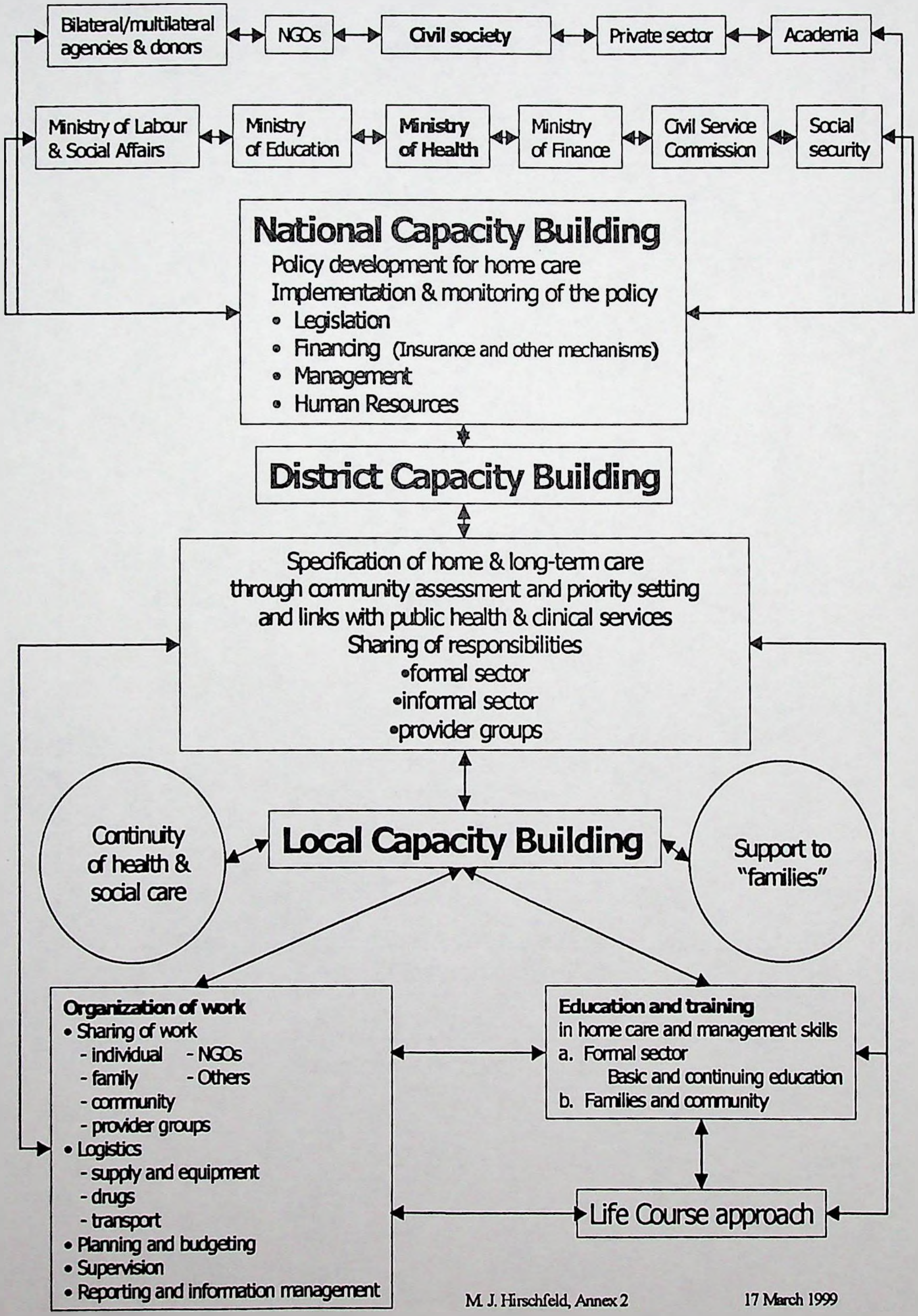
Home and Long-Term Care

Country Intervention



Bilateral/multilateral agencies & donors

NGOs

Civil society

Private sector

Academia

Ministry of Labour & Social Affairs

Ministry of Education

Ministry of Health

Ministry of Finance

Civil Service Commission

Social security

National Capacity Building

Policy development for home care

Implementation & monitoring of the policy

- Legislation
- Financing (Insurance and other mechanisms)
- Management
- Human Resources

District Capacity Building

Specification of home & long-term care through community assessment and priority setting and links with public health & clinical services

Sharing of responsibilities

- formal sector
- informal sector
- provider groups

Local Capacity Building

Continuity of health & social care

Support to "families"

Organization of work

- Sharing of work
  - individual
  - family
  - community
  - provider groups
  - NGOs
  - Others
- Logistics
  - supply and equipment
  - drugs
  - transport
- Planning and budgeting
- Supervision
- Reporting and information management

Education and training

in home care and management skills

a. Formal sector

Basic and continuing education

b. Families and community

Life Course approach

M. J. Hirschfeld, Annex 2 17 March 1999

Initial Components of Work Plan

Developing Evidence-based Standards & Norms

- To develop an analytical framework for the review of evidence to direct future work.
- To analyse the existing knowledge and experiences.
- To initiate discussion circles on the values and ethical reasoning underlying home care, considering the changing social, economic, political and cultural realities.
- To analyse the evidence on the effectiveness of education and training for home care for the formal and informal sector as well as for different provider groups.
- To analyse the effects of different financing approaches and legislation on the availability and quality of home care.
- To develop a range of approaches for ensuring equitable, affordable, culturally appropriate, quality home care.

Country Intervention

- To strengthen the national capacity of selected countries to develop, implement and monitor policies for home care which are an integral part of human and economic development, as well as health and social policies.
- To strengthen the district capacity in selected countries to develop home care as an integral part of civil society, public health and clinical services.
- To develop a life-course approach to the planning, management and delivery of home care.

WORLD HEALTH ORGANIZATION

STUDY GROUP
HOME-BASED AND LONG-TERM CARE
Ma'ale Hahamisha, Israel § 5-10 December 1999

"ISSUES IN HOME CARE SERVICES"

"ISSUES IN INFORMAL CARE"

Chapters 4 and 5
Social Policy Studies, No. 19
Caring For Frail Elderly People, Policies in evolution
Published by the Organisation for Economic Co-operation and Development
OECD 1996

LTH/HSC/SG/99/4

Chapter 4

ISSUES IN HOME CARE SERVICES

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There is widespread agreement that older people should be able to live as long as possible (or as long as they wish) in their own homes, or at least closely integrated into the community. This idea has been part of the policy discourse at national as well as international levels for decades, but the debate has intensified in the last decade. A recent manifestation is a declaration by the European Union Council of Ministers for Social Affairs on policy objectives for older people, which calls upon member states to "promote a range of qualified services (...) so that dependence and institutionalization can be avoided as far as possible" (Council of the European Union, 1993).

The concept of "ageing in place" is both useful and pertinent – useful because it embraces a principle to which we can all adhere, pertinent because it does not make any assumptions about levels or patterns of care to be provided, or about the role of the state and of families. This is just as well, because beyond the consensus about this general principle are a number of conflicting objectives and expectations, as well as widely varying practices. The following issues should be borne in mind in any international debate about "ageing in place".

The issues

Countries have experienced and are experiencing quite different rates of ageing, and therefore the challenges it presents are varied. Many of the northern European countries of the OECD have been ageing for several decades and are not facing any significant shifts in the next 10 or 15 years. Southern European, North American, and Pacific members of the OECD are currently experiencing relatively rapid ageing of their populations. Thus it matters a great deal which countries one is talking about, as well as what time scale one uses. For many countries, the new challenges will not present themselves until several decades into the next century. This makes the potential problems of less concern to politicians, and it makes predictions even less certain.

It is well known that predictions regarding the challenges for the future are based on a range of assumptions about trends in mortality, morbidity, fertility, levels of productivity, unemployment, and women's labour market participation. Very pessimistic scenarios suggest that the problem is of such magnitude that it cannot be solved within the existing structures of health and social care provision. Critics of this position point to the significant rates of ageing which many societies have already experienced and coped with, and the uncertainties of the demographic and economic predictions (van den Heuvel *et al.*,1992). This debate will of course continue; new evidence will appear and old predictions will be reassessed. Whatever the trends, however, there is no doubt that the assumptions underlying the predictions, and certainly the policy implications which are drawn, are often based on political, ideological, and ethical considerations, even if couched in terms of "economic necessity". This is highlighted particularly well in international analyses of policies and practices.

There are significant variations between countries as regards existing patterns and levels of care provision. These variations affect the policy agenda, which, other things being equal, is very different in a country like Denmark, where provision of institutional and home care is high, from the agenda in a country like Greece, where publicly funded long-term care of any kind is almost non-existent.

The challenges facing countries are determined not only by existing levels of provision but by the nature of their health and social welfare systems. I use the term "systems" to refer to a number of different aspects, reflecting different perspectives and levels of analysis:

- First, there are particular structural features, like organisational and professional fragmentation, particularly the separation of health and social services, which is so common in most countries. Much has been written about the need for better coordination between the different parts of the systems. I will argue that, although there is undoubtedly scope for much improvement in this area, the impediments to change are not primarily structural.
- A second aspect of systems is the historically inherited arrangements for health and welfare. Countries with insurance-based health care systems face very different problems from those with national health service systems. Similarly, the ''welfare regime'' of a country (Esping-Andersen, 1990), that is, the basis on which its citizens receive social benefits and services and the role of the state, sets certain parameters within which policy options are considered. It is important to consider the criteria of eligibility for health and for social services, this will be illustrated by examples from four countries: Denmark, Germany, the United Kingdom and the United States.
- These examples also illustrate a third aspect of systems, namely the particular political priorities which affect policies within the constraints of the other features of the systems. More will be said about this below in discussing recent ideas about the need to consider voluntary and private solutions. Such thinking, I will argue, is very much politically grounded.

The four country examples given later illustrate that policies concerned with ageing in place have very different aims. The aim could be to improve the quality of life of older people and to relieve families. This is very different from aims which stress cost savings. This raises the very complex issue of substitution. If home care is expected to be a less costly substitute for other forms of care, at least two questions need to be addressed: first, for what other forms of care is it expected to substitute? Second, is there any evidence that home care is cheaper than other forms of care? The answers to these questions are by no means obvious and require prior answers to other questions about the relation between services such as hospitals, nursing homes, residential homes, and home care.

In addition to substitution, the notion of ageing in place should be seen as part of a process of ''normalisation'', that is, as a way of improving the quality of life of older people, of enabling them to participate in normal social life as far as possible. This will be addressed in the last section, which will also consider the implications of such normalisation for the debate about the future of long-term care.

Trends in institutional and home care

It is notoriously difficult to get reliable and comparable figures in this area, owing partly to differences in statistical calculations and sources, partly to variations in the nature of services compared – for example, an ''institutional place'' can be anything from a bed in a crowded dormitory to a self-contained flat in a small unit. Such differences can be crucial when one considers future forms of care and the role of institutions. Nevertheless, for the purpose of comparing broad trends, we may have to accept that it is better to be broadly correct than precisely wrong.

The figures indicating the broad trends are analysed in Chapter 3 and other literature (Jamieson, 1991; and Thorslund and Parker, 1992). They reveal enormous variations between countries as regards provision of care, whether institutional or home-based care.

The proportion of people aged 65 and over being cared for in institutional settings ranges from less than 0.5 per cent to around 10 per cent. Low rates of institutionalisation (less than 3 per cent) are found in Greece, Italy, Portugal, Spain, and Turkey. A medium provision group (4-5 per cent) consists of Austria, Belgium, Denmark, France, Germany, Ireland, Sweden, the United Kingdom, and the United States. Slightly higher rates (6-8 per cent) exist in Australia, Canada, Finland, Japan, Luxembourg, New Zealand and Norway. The Netherlands is in a category of its own, with about 9 per cent of older people living in institutions. Looking at the trends over time, there are more similarities than differences. Thus, in all countries, the proportion of older people living in institutions grew in the 1960s and most of the 1970s, and since about 1980 a downward trend is visible in a number of countries including Australia, Denmark, the Netherlands and Sweden.

Regarding trends in the provision of home care, there are even larger problems in obtaining reliable and comparable data. ''Home care'' covers a range of formal services available in the community or delivered to people in their own homes, of which the quality as well as the duration varies a great deal. ''Home help'', that is, help with personal care and homemaking, is a key service for an ''ageing in place'' policy and, as with institutional care, the international variation in provision is considerable. The OECD estimates that provision of home help (see Table 3.6) is almost non-existent or at best negligible (1 per cent or less receiving home help) in Greece, Italy, New Zealand, Portugal, and Spain. Four of these countries (the Mediterranean ones) are also in the low-provision category as regards institutional care. Countries with very modest levels of home help (2-3 per cent) are Austria, Canada, Germany, Ireland and Japan. Many areas of the United States would also fall into this category, but it is difficult to generalise about the United States, where coverage ranges between states from 0 per cent to 8 per cent. The countries with a significant level of provision (6-9 per cent) include Australia, Belgium, France, the Netherlands and the United Kingdom. The countries with a high level of provision of home help (over 10 per cent) are the Scandinavian countries. Of these, Denmark and Finland stand out as extremely well covered.

Substitution of services

There is no clear pattern of substitution between institutional and home care. In some respects it is rather the opposite. Most of the countries with the lowest provision of home care are also lowest in respect of institutional care. None of the countries with high levels of provision of home care have particularly low levels of institutional care. There is no country where the balance of service provision could be said to be clearly in favour of one or the other, although Canada, Ireland, and Germany come closest to this in having a significant balance towards institutional care. Also, if one considers the (relatively small) differences among the countries which have high levels of provision of home care, there is a slightly discernible trend in the direction of substitution.*

If one considers the trends in the development of home care services, and the patterns of use by factors such as age and functional ability, the picture becomes more complex. Although there is a clear tendency for the use of home care services to increase with age, the trend is not the same everywhere. Services are more heavily concentrated on the oldest elderly people in the United Kingdom than in Denmark and France. Denmark is so well provided that all age groups seem able to share in the services, and it is particularly remarkable that, compared with the United Kingdom, three times as many young elderly people receive home care in Denmark as in the United Kingdom. In France the service is rather thinly spread over all age groups and, because of the overall low levels of provision, this means that very old people receive relatively little home help.

This is a reminder that figures for coverage, that is, the proportion of the population receiving home help at any one time, are not the same as overall provision and amount of care received. For the purpose of identifying broad trends between countries, differences in coverage are generally a reasonable indication of differences in overall provision. However, for examining trends in regard to particular age groups or other subcategories, the distinction is important, and increasingly so, as there are signs in many countries that recent changes entail some redistribution of existing services. Thus, although in most cases the balance of overall provision does not point to "ageing in place" policies, such policies may be more evident if one is able to consider the distribution of existing services more closely. Home care strategies could entail the targeting of services to those perceived to be most at risk of institutionalisation. This is considered later.

Lack of well-planned policies

The picture which emerges from a comparison of patterns of provision and use of services reflects a lack of well-planned policies in the area of long-term care for older people. Thus, until the 1980s the notion of home care as a cheaper substitution for institutional care had had little effect on policy statements or practice. Yet, at the same time the notion of "remaining at home as long as possible" had been part of the policy discourse in many countries since the 1960s. Home help services developed in many countries as a gradual adaptation to demographic changes, more in parallel with than as a substitute for institutions. In many places, in Europe and elsewhere, the home help service was first established as a family service, providing "substitute housewives" (Gambeson, 1991; Howe *et al.*, 1990). As the pattern of demand changed, the home help providers, encouraged by generous government subsidies, gradually switched the service towards older people, and the economic and political climate of welfare expansion made it possible to expand home help provision in countries such as Denmark and the rest of Scandinavia, Australia, the Netherlands and the United Kingdom. Thus, among the countries which are now most highly provided with home help services, the most significant growth actually took place before policy measures related to the care of older people began to intensify. One could say that there was a period of growth without policies, which has now been followed by a period of policies without growth.

This is perhaps not surprising, as the increasing interest in home care is driven by financial considerations in a climate of cost containment and limited growth. Thus the slight reduction in the proportion living in institutions which has been seen in a few countries has not been matched by a corresponding increase in provision of home care, but more by some redistribution of existing services.

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* Comparing Denmark, Finland, the Netherlands, Norway and Sweden, one finds that the ranking for institutional care is the reverse of that for home care.

Factors affecting policies: four country examples

By the 1980s a large number of countries began to produce plans related to care of older people. However, the extent to which they have been followed up by concrete policy measures varies, and, even more important, the solutions considered reflect the particular concerns and circumstances in different countries. Four country examples illustrate some of the differences and point to some of the questions which must be addressed in any more general debate about future policy directions.

The examples which follow are from two countries with a tax-funded national health service, Denmark and the United Kingdom, and two countries with insurance-based health care, Germany and the United States. The nature of the funding of health care is one important factor affecting home care policies. The nature of the welfare regime (Esping-Andersen, 1990) is also a significant factor; indeed, any attempt to understand policy developments must consider the particular combination of the health and social welfare arrangements. The examples illustrate this, but they also illustrate that these two "systems" factors alone are not sufficient to explain current trends.

Two "national health service" countries: Denmark and the United Kingdom

Denmark and the United Kingdom have similar structures of health and social services. The health care system is funded and administered separately from the social services system, in Denmark by elected county councils and in the United Kingdom by centrally controlled, locally administered health authorities. Social services are organised and funded by locally elected authorities at municipal level, and both residential and home care come under the auspices of these authorities. In Denmark community nurses are part of the social services system, whereas in the United Kingdom they are part of the health service. The health and social budgets are separate and to a large degree funded by separate sources: social services by local taxes (plus central government grants), and health services from central government tax revenue.

Providers in Denmark are almost entirely within the public sector. In the United Kingdom there is a mix of public, private, and some voluntary provision in the institutional sector, whereas public services still dominate the home care sector. In both countries people have free access to general practitioners, who are paid on a list basis. Access to both health and social services is based on professionally defined needs. Health-related services are free. Home care services (other than nursing) often entail co-payment, although in the United Kingdom the extent to which this is the case varies considerably among local authorities. In Denmark home help was for a brief period free for all, but recently some co-payment has been reintroduced.

Both countries have recently introduced significant changes through legislation, aimed at encouraging a shift towards non-institutional care.

Recent reforms in Denmark

In Denmark the distinction between institutional and home care has simply been "legislated away". New institutions can be built only in special exceptional cases. The new concept is "elderly-friendly housing", coupled with services delivered to people according to needs, irrespective of where they live. The idea is that services should follow people, not the other way around, and that the status of people should be the same irrespective of the nature of their residence. Local authorities differ in the extent to which they have introduced changes, but many have now set up new service structures, with emphasis on "elderly housing", combined with decentralised, multidisciplinary teams of service providers, including 24-hour availability of care and respite care (see Chapter 8).

Cases where successful shifts in care provision are reported (Wagner, 1987; Holstein, 1993) point to some interesting lessons:

- The highly decentralised structure of provision, combined with an integrated and uniform set of providers (all local authority employees), enables local authorities to implement changes consistently and to integrate and coordinate social and nursing care services.
- Training of personnel in new approaches and in teamwork is another important ingredient in these success stories. Such training – much of which entails teaching nursing home personnel new skills – carries costs.
- An important aspect of success is that resources have been made available, as the changes do not, as yet, appear to have entailed overall cuts in costs.

In the Danish setting favourable conditions for change exist, partly through historically inherited unified structures and attitudes to welfare, partly through recent central government legislation. Among these is the existing high level of public spending on social services – not least on services for older people – reflecting one of the most comprehensive roles of the state in providing welfare.

Paradoxically, this may also be the source of the emerging resistance to current changes. One of the reasons for the popularity among policy-makers and social service practitioners of the shift towards home-based care is that spending on institutions previously has been very high, and this makes alternative forms of provision, even for quite needy people, appear cost-effective. But the high level of spending on institutions is reflected in the very high quality of accommodation and care provided. This means that for many people "going into a nursing home" has been an attractive prospect. Herein lies the source of what seems to be growing disquiet in the population about the idea of abolishing nursing homes in favour of elderly-friendly housing. The current government's response to this is interesting: the Minister for Social Affairs recently declared that local authorities are allowed again to use the term "nursing home" (*Politiken Weekly,* 12 January 1994).

Two important aspects of the development of Danish home care policies should be noted:

- Although the proportion of people in more traditional institutions has declined slightly, there has been a corresponding increase in the provision of elderly-friendly housing, that is, housing which is specially adapted to older people, whether designated flats in general housing or specially constructed buildings for older people. Many of these come very close to institutions in terms of physical facilities offered and intensity of services available if needed. Thus, the home care policy does not merely entail the notion of older people remaining in their original homes.
- There is already a very high level of provision of home help. The overall level has increased slightly but the main change has been a shift in allocation towards those over 80. Plans for the period until the year 2000 are for the provision of home help to keep up with the increase in the number of very old people, and for the number of places in home care to remain static, thus reducing the proportion of older people living in them. For the same period, the proportion of older people living in elderly-friendly housing is planned to increase (Socialministeriet, 1993).

Thus, while developments in Denmark have in part been driven by cost considerations, these are severely curbed by the continuing strength and popularity of the welfare state, a popularity which so far has excluded from the centre of the policy agenda any serious consideration of more private, voluntary, or individual/family-based solutions. In this respect Denmark differs from Sweden, which is increasingly held up as the example of the possible demise of the "Scandinavian welfare regime".

Recent reforms in the United Kingdom

In the United Kingdom the Community Care Act of 1990 reflected different concerns, partly arising from particular financial structures, partly from political priorities. It has been implemented from 1 April 1993 (see Chapter 13).

Very briefly, the Act was originally prompted by a concern with the dramatic rise in the number of private residential and nursing homes in the 1980s. Local authorities were responsible for the care of older people outside hospitals. Faced with an increasing demand combined with cash limits, they encouraged many older people to enter private nursing homes, for which older people would either pay themselves or, if they were poor, have the cost met from the central government social security system. In other words, the financial burden could be shifted from local to central government. The new Act has closed this option, transferring all responsibility to local authorities. Those on low incomes cannot now obtain central government funding for residential care through the social security system. Local authorities have a financial incentive to keep down referrals to institutions, since all the costs are to be met within an overall budget covering both institutional and home care.

Another important aspect of the Community Care Act is the stress on provider pluralism. The impetus for this is the government's commitment to free enterprise and to minimising the role of the public sector, especially the role of local authorities. These local authorities are no longer allowed to be the sole providers of care, but are obliged to contract out a significant proportion of both institutional and home care services to private and voluntary agencies. The government's intention is to create a market of competing providers, with the intention of improving cost-effectiveness and consumer choice. Local authorities are to act as "enablers", purchasing services and, through case management, packing them to suit the needs of individual clients, or "customers". This trend is not, of course, unique to the United Kingdom. It has been argued that service allocation has too often been provider-led rather than needs-led in part, it is alleged, because it has been a public monopoly which is not responsive to consumer preferences nor able to regulate itself for quality. Thus "provider pluralism", "(internal) markets", "needs assessment", and "case management" are now well-known terms in the discourse about care in the United Kingdom and many other countries, if not in Denmark.

"Case management" is seen as a way of achieving needs-led provision and of overcoming the structural barriers between different providers (see Davies, 1994). The need for case management clearly increases as the number of providers multiplies. But even before the introduction of provider pluralism the problem of organisational fragmentation, especially the separation of health and social services, had been widely seen as one of the main impediments to continuity and flexibility of care. As this chapter will argue, the nature of this problem differs between countries, as do the attempts to overcome it. In the United Kingdom the organisational and financial separation of health and social services, including the separation of community nurses from other forms of home care, continues. But the two sectors are required to cooperate more closely at the strategic as well as the operational level, and case management is part of the response to the problem.

At this early stage, assessment of the implications of the new arrangements must be largely speculative. Responses to the changes from planners, providers, and older people themselves have ranged from excitement and optimism to cynicism, confusion, and anxiety. One possible effect is that the stress on "proper needs assessment" will lead to the uncovering of new needs, resulting in increased demands. Thus, on the consumer side the issue has been raised of whether the explicit recognition of people's needs automatically carries with it a right to receive services. No one has yet tested this in court, and it is doubtful whether such a claim would be upheld. Certainly, there is an important general issue here about the implications of improved needs assessment: the better we get at identifying and making explicit the needs of the population, the more visible these needs become. This in turn may give rise to increasing expectations and demands, which will serve to expose the possible deficiencies and inabilities of the system to meet all these needs. Since the stress on needs assessment arises from a desire to "filter out" those who do not need services, the possibility that it would uncover more unmet needs is not likely to be terribly popular with politicians. In the United Kingdom the intention was not to increase the resources allocated to care of older people, but to shift the balance from the residential or nursing home care towards home-based care.

The changes in the financing structure seem likely to have the intended effect of stemming the growth in institutional care, but whether this will be replaced by adequate provision of home care is debatable. Although resources have been transferred from central government to local authorities – from the money which would otherwise have been spent on institutional care – it is possible that the sum may be inadequate and that, in practice, authorities may be faced with an increased burden. It is possible, but by no means certain, that the emergence of new competing providers will lead to increased efficiency. Much depends on whether there will actually be enough new providers in the system. Better needs assessment and case management could improve "targeting efficiency" by directing services to those who need them most. A possible effect of this is that many of those considered less needy will be deprived of help, their quality of life will deteriorate, and the burden on informal carers increase. In short, the changes may lead to overall savings for the public sector and to a shift from institutional to community-based care, but they may do so at the expense of older people and their families.

Another possible effect relates to the role of the voluntary sector. Their core mission of help and advocacy on behalf of older people may be eroded by pressures to compete with other providers for resources.

Developments in the United Kingdom reflect many of the issues facing policy-makers elsewhere, including the general disillusionment in East and West with socialism and state welfare. On the face of it, the changes in the United Kingdom suggest that a shift is in process towards a more liberal and residual type of welfare regime (Esping-Andersen, 1990). But to what extent the political rhetoric has actually resulted in a reduction of the role of the state is debatable. As funder and regulator of services and benefits, it is still very much at the centre. As provider of services its role may diminish, but this does not necessarily change the nature of the welfare regime.

Two "health insurance" countries: Germany and the United States

In contrast to Denmark and Britain, Germany and the United States are examples of welfare systems characterised by insurance-based health care combined with a residual social welfare system. This combination is one of the major barriers to any significant development of long-term home-based care.

Care of elderly people in Germany

The majority of the German population is covered by insurance for acute health care. Access to doctors and hospitals is easy, and treatment is an insurance-based and legally enforceable right. Within the insurance framework there is a strict hierarchy of service entitlement, ranging from medical treatment, specialised nursing, and basic nursing to home help as a supplement to nursing. The system of provision is a pluralist one, a mix of the different welfare organisations and private providers. For those who have completed their medical treatment, that is, who are not labelled as "ill" but "merely" as disabled and in need of help, health insurance has not until recently provided any coverage; and even recent changes do not provide adequate coverage for long-term care.

People in need of long-term care have had to rely on the social welfare system, which is a highly selective, means-tested system operating on the basis of the principle of ''subsidiarity'', whereby the state plays a residual role (Dieck and Garms-Homolova, 1991; Grunow, 1990). It is the combination of these two systems, with their very different criteria of eligibility, which poses a problem for policies concerning long-term care.

The pressures to find solutions are as strong as the barriers which stand in the way. Thus the system encourages medicalisation, and health care expenditure has been increasing. Yet an extension of the insurance system to include care, as opposed to cure, has been resisted for fear of breaking with the implications of ''subsidiarity'', namely that care in the first instance is a family responsibility. For short-term care following medical treatment, home care policies have been fairly successful in enabling early discharge. Changes which were introduced with the 1988 Health Insurance Reform Act introduced some coverage for long-term care at home, but both the amount and the period of time covered were severely limited. A more radical solution has been sought with a law in 1994 introducing a compulsory insurance scheme for long-term care. In view of the residual role of the federal government, the main issue has been whether employers and unions would accept financial responsibility (for details see Chapter 18).

Care of elderly people in the United States

The United States is similar to Germany in that the insurance principle dominates health care funding and that home care is generally covered only if short-term and prescribed by a physician. A major difference is that a large proportion of the population is not adequately covered for health care. The United States also differs from Germany in having separate health insurance for older people (Medicare), which depends on financial support from the federal government and involves a significant burden of co-payment by recipients. In principle, Medicare provides home care in the same way as the German health insurance scheme, that is, care has to be medically prescribed. Older people in need of long-term care have increasingly come to rely on Medicaid, although it was not originally set up for this purpose. Medicaid is linked to the welfare system and operates along lines similar to those of the German welfare system, being means-tested and financed jointly by the federal government and the states (see Chapter 14). The problem of medicalisation also features in the American system, and for largely the same reason as in Germany. Because coverage for home care is conditional upon a doctor's prescription, there has been a tendency for agencies providing care under these schemes to medicalise the services they provide, for example, to shift provision from personal care and homemaking to ventilators or blood transfusion (Binney *et al.*, 1990).

Some of the major policy measures of the 1960s can be seen as an adaptation to changing needs associated with the ageing of the population. Medicare, introduced in 1965, was specifically aimed at older people, but coverage was largely restricted to acute care. The Medicaid programme, on the other hand, was not introduced specifically with older people in mind, but came to be used by them to fund long-term residential care. Paralleling policy changes in Denmark and the United Kingdom was section 2176 of the 1981 Omnibus Reconciliation Act, which was prompted by an increase in the use of nursing homes. It allowed states to provide some home care within the Medicaid scheme. Similarly, the Medicare programme has been modified to include more cases of home care.

The measures taken in the 1960s have been described by some as representing a significant shift in American policy towards the acceptance of old age and disability as a basis for certain entitlements to care (Fox, 1989). However, they have far from solved the problems for this client group. Cost-containment measures have put severe restrictions on the extent to which services reach those in need, and older people are competing with younger generations for Medicaid resources (Tannenbaum, 1989). As far as home care is concerned, it is in the area of high-tech health care that the major successes have occurred (Goldberg, 1990). At best it can be said that the system has allowed a great deal of experimentation; practices in the different states and within them therefore vary considerably. Certainly there is widespread interest, judging from the number of experiments and studies evaluating the cost-effectiveness of home care. However, the bulk of long-term care is done by families or individuals themselves.

As with Germany, policies in the United States have to be understood in the context of political priorities, which are to find ways of controlling health care costs and to maintain the residual role of the state in social welfare. In the United States health care reform is clearly a priority and an urgent problem because of the unequal distribution of health care. How far any new health reform proposals will address the problems of long-term care seems uncertain (see also Chapters 14 and 19). In view of the pressing need to provide basic health care for all, it will not be surprising if issues related to long-term care are pushed further down the list of priorities.

Comparing systems

In dwelling upon four selected systems, the aim has been to illustrate some of the factors affecting policy developments. The brief country descriptions are in many respects inadequate for a thorough comparative analysis, and serve mainly to suggest what kinds of factors to bear in mind. These include the following factors.

The mode of funding for health care has important effects. In insurance-based systems, for example, there has been a stronger tendency towards medicalisation of elder care. As far as policy debates are concerned, the actors involved and the interests at stake are different in the insurance systems.

The nature of the difficulties and the solutions likely to be on the agenda are also dependent on the role of the state in social welfare provision. In systems where the state has played a residual role, the obstacles appear particularly serious. In Germany the proposals debated in recent years illustrate the constraints inherent in the system, for example, the reluctance of insurance organisations to extend coverage beyond medical treatment and the reluctance of the state to extend social welfare entitlements. In other words, the policy issues, and therefore the nature of the debate, have been very different in these systems from those in the United Kingdom or Denmark. In the latter two countries the debate has been more about new forms of provision already within the public domain, rather than with whether and how long-term care should be financed.

However, the differences highlighted within the two categories of countries should also caution against any mono-causal explanation. The nature of the systems and types of welfare regime are likely to pose constraints in certain directions, but they do not fully determine or predict outcomes. The constellations of political power at any particular time can clearly be influential in shaping the direction of the changes. For example, the recent debates and struggles between political parties in Germany differ from the American situation. The United Kingdom and Denmark are similar in that recent policies have been aimed at shifting the balance from institutional towards home-based care by means of central state legislation creating financial incentives for local authorities. But the specific factors which drove the two governments to take action differed, as do the specific directions of the solutions, partly reflecting different organisational and financial structures and partly the different political persuasions of the respective governments.

A comparison between Denmark and one of the other Scandinavian countries also illustrates how the current political climate can affect policy directions. The recent changes in Swedish politics have been interpreted by many as the beginning of the end of the Scandinavian welfare state. Irrespective of whether this is perhaps a premature judgement even for Sweden, the continued strong support for a comprehensive state role in Denmark points to significant variations within welfare regimes.

In parallel with all these factors, economic pressures clearly play their part in setting policy agendas, although, as argued above, the drive towards efficiency does not fully explain the policy debates and solutions adopted across countries. However, it is one of the interests which seem to be shared between countries, and any debate about ageing in place must inevitably address the question of the cost of this compared with other forms of care.

Home care as a substitute for other forms of care

Is home care a lower-cost substitute?

In recent years, research into the allocation of home care has intensified, as pressures for more cost-effective provision have increased. The focus of many such studies has been on the issue of substitution, that is, on whether home care is a cheaper alternative to institutional care. The answer from studies from Australia, Denmark, the Netherlands, the United Kingdom and the United States, can be summed up as "this is an extremely complex issue, it all depends, but on balance the answer is: probably not". This section will briefly summarise some of the main issues which emerge from this literature: Kemper *et al.*, 1987; Weissert *et al.*, 1988; Vertrees *et al.*, 1989; Australia, Department of Health, Housing and Community Services, 1992; Coolen, 1993; Christensen and Hansen, 1993; Holstein, 1993; Monk, 1993; Davies, 1993.

There is plenty of evidence that community care options can enable frail older people to stay in their own homes. However, whether it is cheaper and whether it reduces the use of alternatives is much more doubtful. In experimental situations where there is a coordinated effort and competent case management, some substitution effect can be found, but even in such cases the evidence is not overwhelming. They also clearly raise the question of whether it is possible to replicate such experiments: "A single demonstration in a single state cannot show us whether these conditions can be replicated and maintained in an ongoing programme" (Kemper *et al.*, 1987). Thus one of the conclusions which emerge is that if substitution is to be at all successful it requires skilful management, or what some refer to as a cultural change (Davies, 1993) in organisations, something which would itself be costly, if possible at all (as the case of Denmark illustrated).

For what is home care a substitute?

One of the crucial dimensions of "substitution", adding to the complexity of the issue, is: What is substituting for what? Most care systems consist of a number of different services, ranging very broadly from community and home-based services, various degrees of "sheltered housing", nursing homes, and other institutions to hospitals. The ways in which these different services complement or substitute for one another are by no means clear. Some evaluation studies which demonstrate savings have done so through a shift from hospital to nursing home care, for example the ACCESS project reviewed by Weissert (1988). As Kemperand colleagues put it, "community care might be a substitute for hospital care by permitting patients awaiting nursing home placement to be discharged to their homes instead. On the other hand, expanding community care might increase hospital use" (1987, p. 93). Thus nursing homes may be able to treat some conditions for which people living in their own homes would have to enter a hospital. Policies in many places have in fact been at least as concerned, if not more so, to reduce the rate of hospitalisation as to reduce use of nursing homes. The introduction of insurance coverage for short-term acute treatment at home in countries like Germany and the United States reflects this. Similarly, the expansion of facilities within institutions to include more medical care, as in the Netherlands or France (which has added *sections de cure medicales* to many institutions), is a deliberate policy of substitution.

Can better targeting reduce costs?

One of the questions which arise from many studies is whether it is actually possible to identify those at risk of entering an institution or a hospital. Being in need of services, that is, capable of benefiting from some help, is not the same as being "at risk" of institutionalisation at some time in the future (see for example Davies, 1993, 1994; Kemper *et al.*, 1987). Similarly, it is difficult, if not impossible, to predict the long-term course of events for individuals (mortality and morbidity), and many evaluation studies focus on short-term benefits, which might be cancelled out if a longer-term perspective were taken.

Whatever the effects in relation to substitution, better targeting of services could have implications for costs. As systems become better at targeting services to those with severe disabilities who require the most help, whether in the community, nursing homes, or indeed hospitals, the costs of caring for the same number of individuals clearly increase. Furthermore, the nature of the clientele changes from a "mixed caseload" to a "heavy caseload". It changes the service from the point of view of the recipients (for example, residential homes may become less attractive), and from the point of view of the providers, who will be dealing increasingly with people in need of a great deal of personal care. A certain amount of slack in the system, while giving care staff more job satisfaction and keeping the unit costs down, could perhaps also benefit the recipients.

The cost implications also depend on the financial structures. In systems with overall cash limits, it can be argued, for example, that hospital "bedblockers", that is, people waiting for a nursing home bed and requiring little attention, can actually be quite a convenient excuse for keeping out patients who would require expensive medical treatment. The problem of bedblockers is seen to stem from financial separation of hospital and community care budgets. However, in structures where these are not separated, as for example in some cases in Denmark where provision of hospital and community care is funded by the local authorities, the number of "waiting patients" in the hospitals is greater than in many other parts of the country. One explanation of this is that these local authorities simply cannot afford for their hospitals to be more efficient.

Can home care be a substitute for institutional care?

There is little evidence that the provision of home care is associated with a corresponding decrease in the use of institutions. Rather, home care may tap into a different category of consumer population, and evidence from many countries may cast "a shadow of doubt whether home care will make an indent, let alone replace institutional care" (Monk, 1993, p. 78). The review by Weissert and colleagues of 27 of what they deemed to be the most rigorous and generalisable studies from the United States concludes that home and community care "probably did reduce nursing home use in the majority of studies, but typically the level of use available to be reduced was small, the amount of reduction small, and so potential for cost reduction was relatively small" (1988, pp. 326-327). The implication is that so-called inappropriate admissions are already decreasing because of more rigorous gatekeeping by the institutions themselves. An evaluation report from Australia (Department of Health, Housing and Community Services, 1992, p. 96) goes so far as to say that "the original concern with inappropriate admission to residential care is now dated" because of improved assessment and admission procedures.

There are signs in many systems that the population of institutionalised people is getting older and more frail. It is tempting to ask whether there is an optimum level of institutionalisation, a point at which one should not expect any further reduction. However, as will be argued below, a more fruitful way forward would be to consider more closely what is meant by an institution and what kind of housing is appropriate for older people.

Another factor which affects whether or not home care may be a cheaper alternative to institutions is the role of informal carers. Many studies do not take the effect on carers into account, and often the financial and psychological burden on them can be significant. Whether this is seen as a problem is of course very much a political or ideological question. Some of the Dutch studies, for example (Coolen, 1993), are quite clear that the aim of home care services is not to replace carers, rather the opposite. Carers are increasingly part of the policy rhetoric in many countries. It is recognised that they carry the main burden of care, and that service providers should consider their needs as well – but not in order to replace them, rather to ensure that they do not relinquish their role. The situation in the Scandinavian countries is different, although in some of them things may be changing. Certainly Danish studies of the impact of shifting services from institutions to other forms of care do not consider carers. Indeed the term "(informal) carer" is not part of the Danish discourse, which uses the term "relatives". Here carers are "superseded", to use the Twigg terminology (Twigg, 1993); they are not expected to have any obligations to care, and home care services have long been there to replace them (although the presence of a spouse in the household is taken into account in service allocation; there are still implied obligations between spouses).

Does home care create new demands?

The issues related to carers – are they to be seen as a cheap source of care or as people with needs to be met? – can be extended to include older people themselves. If home care is to be viewed mainly as a cheaper alternative to other types of formal provision, the problem arises that making it more available and visible may in itself create new demands. This is shown in some Dutch studies, for example, where new clients of sheltered housing appeared. This, together with many of the uncertainties regarding the substitution function of home care, has led to a call to shift the attention towards the targeting of home care to those most in need, whether or not they may be at risk of institutionalisation. Studies of home care allocation (Jamieson, 1991) show that there is scope for improvement of allocation criteria and practices. How far improved techniques of assessment can identify those most in need is debatable. Furthermore, the question of whose needs should be given priority in service allocation is not a technical one. As Kemper and colleagues conclude, "it is primarily an issue of equity: Who deserves the limited community care that society can pay for?" (1987, p. 97). Another question could be added to this: How much community – and other – care is society willing to pay for?

Clearly societies would vary in their answers to such questions. But these possible variations are not at all clear, because the questions are rarely addressed in any coherent and consistent way. Changes in patterns of service provision are taking place, more as a result of cash limits than as a result of any debate about what levels of provision are acceptable from the point of view of older people and their relatives. Changes in Sweden, for example, whereby the reduction of institutional places has not been offset by an equivalent increase in home care, appear to be taking place without any explicit acknowledgement of the effect this may have on families. In Britain, despite the "family orientation" of the present government, guidelines and regulations for provision are vague and contradictory. For several years hospitals have been reducing the number of continuing care beds, but without ensuring that such beds be replaced by community care places. This trend has intensified with the changes in the financing of hospitals associated with the introduction of internal markets. National Health Service guidelines stipulate that patients should not be transferred to private nursing homes against their will, yet this is happening, on the grounds that, although the authorities have a duty to provide care, this has to be done "within resources available".

In short, as long as older people and their relatives are relatively powerless and as long as there is no open debate about what constitutes an equitable distribution of resources, it will be possible to reduce or to keep down the number of beds in hospitals and institutions without replacing them by any alternatives, and without therefore worrying too much about the complexities of "substitution".

Rethinking, not replacing institutions

Although the popularity of ageing in place or community care policies is partly driven by economic concerns, it also rests on a concern with the interests of older people which has roots in the de-institutionalisation movement. Thus normalisation rather than substitution is another principle underlying community care policies. Of the four countries described above, Danish policies are still very much driven by this principle. It would clearly be meaningless to present Danish policies as a model for others to follow. Yet the radical effect of those policies on the way in which care issues are conceived shows clearly what is entailed in normalisation. The cornerstone is housing, and a conviction that both ''institutions'' and ''home'' are often unsuitable, and that the whole distinction may be unnecessary. Danish policies differ from those of many other countries in their radical and consistent nature. The focus on housing, through adaptations of people's homes or the development of various forms of sheltered housing, is found in most countries, but in a more sporadic manner (see Tinker, 1994).

Interestingly, among the few cases cited by Weissert and colleagues (1988) where money was saved was ''Highland Heights'', a form of sheltered housing. Critics had dubbed it ''institutionalisation by another name'', but, as the authors point out, ''this case does point to the important role played by the housing component''. They go on to note that ''many people would consider such sheltered housing a different kind of intervention than the opportunity to remain in one's own home that is generally implied by the notion of home care'' (1988, p. 340). This indeed is one of the problems: even if, in the long run, adequate housing could be an economical way of replacing conventional institutions, in the short term it would require considerable investment to improve existing housing stock and develop new and more suitable forms of housing. In most countries, therefore, the changes would be gradual, and a total integration of all housing forms combined with integrated care packages is difficult to imagine in systems where providers and funders are fragmented.

New forms of living based on these principles are developing in isolated instances and in the private sector. In the United States and elsewhere life care communities have become popular among some of those who have enough capital and income (van Mering and Neff, 1993). Although this is a growth area, it will not in the foreseeable future be the solution for the majority of older people, who will not be able to afford it. Nor will they necessarily wish to live in such artificially created communities. However, many of the ingredients of successful ageing in place can be found there: living in a secure environment, with opportunities to be independent, to participate actively in social life, and to receive care as needed without having to move residence.

If this is accepted as the basis for ''ageing in place'' policies, the focus of the debate should be on acceptable forms of living, whether they are called ''own home'' or ''nursing home''; and the focus should be on acceptable forms of care and equitable distribution of care. This is not to say that issues of efficiency and substitution should not continue to be part of the agenda. But the agenda for policy analysts should be based on a realistic assessment, not only of the structural and technical impediments to change, but also of the degree to which there is a political will to consider long-term care a matter for public policy.

In basing one's discussion on a realistic assessment of what is likely to be possible, at least in the short and medium term, it is tempting to conclude on a note of caution against going too far down the road of ''ageing in place''. Without a decent supply of home- and community-based services, and without opportunities for older people and their carers to participate in normal social life, ''ageing in place'' could well be associated with increasing neglect and isolation for too many people. If this is the case, life in an institution could well be a more attractive option, one which should not be dismissed too readily as long as other solutions have not been put in place.

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Chapter 5

ISSUES IN INFORMAL CARE

by

Julia Twigg
University of Kent, United Kingdom

Over the last decade informal care has emerged as an issue in public policy across the countries of the OECD. Representative national data on caring are available from some but not all OECD countries (Green, 1988; Stone *et al.*, 1987; Jani-Le Bris, 1993*a*). The data present a fairly consistent picture of continued high involvement of families in caregiving. The chapter that follows first outlines the factors commonly thought to affect the availability of informal care, and then explores the policy debates and responses raised by the issue.

The availability of informal care

Demographic change

Across the western world, declining fertility and, to a lesser degree, rising longevity have produced an increasingly ageing population. Kosberg (1992) divides countries into three categories: adult (with 8-10 per cent over age 65), such as Israel; mature (11-14 per cent), such as Australia, Greece, Japan, and the United States; and aged (more than 15 per cent), such as Austria, Britain, and Sweden. Although different countries experience the transition to a more aged population structure at different times and at different rates, and with some intervening variables particular to their circumstances such as migration, the trend is a general one across the developed world.

This trend has implications for policy in relation to pensions, to health and social care, and to family care. The potential fiscal crisis in relation to the funding of pensions has received the greatest policy attention, but care rather than pensions is the focus in this review. Much of the current concern over caring is driven by anxieties over the rising costs of the health and social care of older people. The assumption is that their needs will have to be met by a greater reliance on the family. However, the capacity of the family is itself under threat from changing demographics. Lower fertility means fewer family members potentially available to give care (Moroney, 1976, 1986).

Labour market participation of women

Women are more likely to be carers than men, and caring is often presented as an essentially female activity (Graham, 1983; Hooyman, 1990; Waerness, 1984; Ungerson, 1987). Men are involved in caring, but in restricted ways: mostly caring for their spouses or performing more distant tasks such as helping with transport or giving financial advice (Brubaker and Brubaker, 1992; Arber and Gilbert, 1989; Arber and Ginn, 1990; Atkin, 1992). Heavy-duty, intimate caring, particularly across the generations, tends to fall to women. Although this gendered pattern emerges across the OECD countries, there is variation, reflecting cultural differences in the degree to which gender roles are segregated both within marriage and between generations (Jani-Le Bris, 1993*a*; Maeda and Shimizu, 1992).

The labour market participation of women has increased across the OECD countries in the postwar period, though rates still vary. It is often assumed that involvement with the formal economy will limit the willingness and capacity of women to take on care, further compounding the shrinkage of the potential pool through

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The labour market participation of women has increased across the OECD countries in the postwar period, though rates still vary. It is often assumed that involvement with the formal economy will limit the willingness and capacity of women to take on care, further compounding the shrinkage of the potential pool through demographics. Empirical evidence on the subject is contradictory (Doty, 1986). Paid work can operate as a legitimate reason for being unavailable to provide care (Finch and Mason, 1993); however, many women combine working and caring, taking on a double burden. There is also evidence of women leaving the labour market early in order to care for family members. Although the interaction of working and caring is complex, we can perhaps assume that as paid work for women becomes increasingly normative and essential to families' economic survival (particularly with the rising numbers of women who are heads of households), it will increasingly affect decisions concerning care.

Household structure

The three-generation household has never been the norm in large parts of Europe, nor in the American and Australasian countries that inherit these cultural traditions (Wenger, 1992; Brubaker and Brubaker, 1992). In northwest Europe the historical pattern is particularly clear, with new households being formed on marriage and few elderly people living with their children (Smith, 1984). Where intergenerational shared living occurs, it usually reflects necessity rather than choice and is associated with low income (Doty, 1986). Greater affluence among the old – and the young – has resulted in fewer shared households and a trend towards living alone. That it reflects choice is borne out by attitude surveys which recurringly endorse the wishes of both older people and their children for independence and what has been termed "intimacy at a distance"(Rosenmayer and Kockeis, 1963). In one Australian survey only 8 per cent of elderly people faced with the prospect of not being able to manage chose the option of moving in with kin (McCallum and Howe, 1992).

Among OECD countries, Japan is an outlier in regard to household structure. Japanese family patterns are different from those of the West, and about 60 per cent of older people still live with their children. This proportion is declining, however, and it is estimated that by the beginning of the next century it will be only 53 per cent (Maeda and Shimizu, 1992).

Sharing a household is sometimes taken as a proxy for the availability of care, on the assumption that older people living in the household will be cared for. This is probably correct insofar as they need care, though not all older people sharing a household will be disabled and some will themselves be contributing to the care economy of the household. Considerable amounts of care are provided between households. This can be the case even where the elderly person is severely disabled, if the family lives nearby or has easy access. It is wrong to assume, therefore, that an absence of shared households means an absence of caregiving.

There are, however, some features of caring that should alert us to the significance of household structure. Caring in a shared household can be particularly stressful because it allows little relief. People looking after someone with dementia or behavioural problems endure difficulties on a 24-hour basis. Even where the problems are less acute, sharing a household can mean sharing the limitations imposed on the older person by his or her disability. This is particularly significant for those who care for their spouses. As we shall see below, services are often targeted away from shared households, with the result that some of the most highly stressed carers receive the least support.

Family obligation

Earlier analysts, following a functionalist approach that emphasised the structural affinity between the nuclear family and modern industrial capitalism, failed to see how far the family was still closely involved in the life and care of its older members. Family support is still the primary source of help to frail older people. When elderly people are not supported by family it is usually because they have none: up to 30 per cent of people over age 65 in the United Kingdom are childless; 20 per cent in the United States and Australia (Wenger, 1992). What Brody termed the "myth of abandonment" has been exploded (Doty, 1986); there is no evidence in the literature of a slackening of family commitment (Qureshi and Walker, 1989; Finch, 1989; Finch and Mason, 1993).

The significant exception to this is Japan, where analysts, although recognising the continued significance of family care, and indeed by implication its greater significance than in the West, regard it as under threat from modern values. Western individualism is seen as eroding traditional family piety, while the social and demographic changes consequent on industrialisation and urbanisation are seen as undermining the social and living arrangements that made close family care possible, indeed mandatory (Maeda and Nakatani, 1992). These changes have been relatively rapid, and it is not surprising that accounts from Japan should emphasise the impact of modernisation, at the same time as western sociologists appear to be discounting it, at least in relation to its effect on family obligation.

While recognising general trends, it is important to avoid too easy an assumption of convergence. Cultural differences in regard to the family may still be significant. These are clearest in relation to Japan, which starts from a radically different, non-western culture and one that has retained many of its features through the process of industrialisation. Northwest Europe, by contrast, developed at an early stage a family form whereby independent households were formed by each generation. Smith (1984) and Thomson (1991) both argue that this resulted in the assumption that responsibility for the support of indigent older people fell in large measure on the collectivity, and they contrast this pattern with that found historically in southeast Asian and Mediterranean societies. Commentators from Greece and to some degree Italy also refer to cultural differences, emphasising the nature of societies in which the family is the primary resource for individuals in all aspects of their lives – economic, social, cultural – and family care of older people is just part of a larger network of mutual opportunity and obligation rooted in the family (Mestheneos and Triantafillou, 1993).

Welfare state traditions

There has been much interest recently in the differences between countries in regard to welfare state traditions – differences that relate not only to stage of economic development but to political values and assumptions. Esping-Andersen, whose work has been widely influential, identifies three regimes: 1) the "liberal" welfare regime, which aims to encourage market provision and in which means-tested assistance, modest universal transfers, or modest social insurance predominate, of which the archetypal examples are Australia, Canada and the United States; 2) the conservative and "corporatist" regimes, where social insurance is tied to employment status and the family is expected to meet many welfare functions, of which Austria, France, Germany, and Italy are examples; and 3) the social democratic regime, associated mainly with Scandinavian countries, in which the emphasis has been on achievement of an "equality of the highest standards", such that high-quality benefits and services have been made available on a universal and tax-funded basis. Others have elaborated Esping-Andersen's categories or developed parallel typologies (Langan and Ostner, 1991; Lewis, 1992; Leibfried, 1993). None of this work takes family care of older people as its starting point. Most focus on income maintenance; and the models tend to be weaker on the service-based aspects of the welfare state that are particularly significant in relation to family care.

Some attempts have however been made to explore the issue comparatively, notably by Jani-Le Bris (1993*a* and *b*), Jamieson (1990, 1993) and Chamberlayne (1993), and in detailed national work (Johansson, 1991; Evers, 1993; Holstein *et al.*, 1993; Twigg and Atkin, 1994). Jamieson suggests that there are significant differences between the Danish, and by implication the Nordic tradition generally, and that of other European countries. In Denmark there is no overriding expectation that families will provide care for elderly parents – this is seen as the proper role of the state – and there are laws absolving younger generations from responsibility for their forebears. Families are still close emotionally, but (with the exception of spouses) they are not the primary source of physical care. Jani-Le Bris notes that of the countries of the European Union, it is only in Denmark that the political debate does not centre around the fear of withdrawal of family care if formal support is given. In Germany, by contrast, the family is regarded as the source of help of first recourse, and assistance is available from the welfare state only where that has failed. The responsibility of the family is, furthermore, directly encoded in statute.

The distinctiveness of the Nordic model is also reflected in its commitment to enabling women to participate in the labour market through extensive entitlements to leave and care support. Scandinavian countries are more willing to see caring as a form of work, and possibly as a form of waged work.

The policy issues

Certain tensions in how the field of informal care is conceptualised affect the way policy is structured.

"Support from the informal network" or "heavy-duty caring"?

A study of informal care might focus on either the informal network or heavy-duty carers. The first encompasses not just physical help but also emotional support, visits, social contact. It looks at what families do widely, and recognises that there is rarely a discrete point at which caring starts; rather, caring develops slowly out of an earlier relationship, though marked by phases imposed by the onset of disability. This approach extends the focus beyond the main carer and includes other members of the family more peripherally involved. It can extend to the informal sector more generally, encompassing the involvement of friends – important for the morale of many older people and often a preferred source of company – as well as neighbours. It recognises that different people in the network give different sorts of help (Litwak and Kulis, 1983; Bulmer, 1986).

The second approach is focused more narrowly. It takes as its subject the heavy end of caring and the situation of an individual who can clearly be identified as the carer. It recognises that responsibility for care usually falls on one person. Far from being embedded in a network of support, caring is often an isolating experience. Most of the literature that has explored the burdens of caring has done so within this second perspective, focusing on heavy-duty carers and the difficulties they face.

Each approach has its advantages, and its own implications for policy. The first allows for an easier disaggregation of the concept of family support. Once we recognise that families provide many different sorts of help, we can make better sense of the debate concerning family obligation and the possible decline of commitment. The Scandinavian model does not represent abandonment by the family; rather it presents a different idea of who should provide various sorts of help. Family support is not a unitary thing, either present or not. The recognition of the involvement of wider kin, including grandchildren, also allows for an acknowledgement of the ways in which older people continue to contribute to the life of the family: actively when younger, providing child care (Alber, 1993), but also in less visible ways as they become more disabled. By setting the study of the support of older people in the wider context of family relations, the approach is less prone to concentrate only on the burdensome aspects of their existence.

From the perspective of policy-makers, however, this wider view is too diffuse. It is hard to plan for or address the problems of a particular situation when it is conceived of in such a broad way. Policy needs to be more narrowly focused; intervention across the board in relation to informal care is unlikely to be successful (Gordon and Donald, 1993).

The emphasis on heavy-duty carers also reflects assumptions about costs to the state, for implicit in it is a belief that these are inputs of sufficient significance and that, were they not provided by a carer, they would have to be provided by the state in the form of an institution or otherwise heavy commitment of services. This does not apply to the inputs of the informal sector conceived more generally.

Finally, the narrower focus in its emphasis on the primary carer allows for the recognition that carers may have interests in their own right and that society or the state has obligations to them that parallel its obligations to the cared-for person. This question of moral responsibility tends to be diffused or lost when the subject is the informal sector as a whole.

"Disincentives" or "supports" for care?

Some policy-makers and analysts have voiced concern that welfare services to older people may introduce a disincentive to care. This view embodies a number of underlying assumptions:

- that the support of older people is the responsibility of their families and any erosion of this principle is wrong morally and politically;
- that the primary determinant of people's involvement with their elderly relatives is the push/pull of incentives, particularly financial incentives;
- that family care needs to be enforced by the lack of any alternatives.

Another approach presents the issue in terms of supporting rather than substituting for care. It too embodies assumptions:

- that people's involvement in care derives from their social relations;
- that social relations are long in genesis and exist prior to the influences of public policy;
- that support for older people can properly be provided from a variety of sources, formal and informal;
- that service support should both support care and enable choice.

In general the literature on caring reflects the second view both politically and empirically. Services do not appear to drive out family care; rather they complement and augment its involvement.

Costs to the state or the interests of carers and disabled people?

The third tension in how we conceptualise the subject concerns whose interests matter: those of the state or those of carers and disabled people. Much of the policy debate around family care focuses on the interests of the state and anxieties over public costs. Even where the debate does encompass the burdens and difficulties facing carers, it tends to do so on an instrumental basis, seeing support for carers only as a means to an end, that of supporting older people, thus presenting it as a cost-effective form of intervention.

This instrumental approach has been a powerful motive in the growing inclusion of carers in service planning. But is it an adequate response? Do we need to recognise the interests of carers in themselves and not simply as a means to an end?

There are two justifications for recognizing the interests of carers. First, caring has consequences for the lives of carers, imposing costs both literal and metaphorical. There is a large literature now on the subject of carer burden that outlines these costs (Parker, 1990*a*, 1992; Sinclair *et al.*, 1990; Zarit, 1989). While not wishing to see caring only in terms of burden, it is important to give weight to these negative aspects. How far are we willing as societies to recognise that certain burdens are beyond the acceptable and deserve to be alleviated of themselves and not simply for instrumental reasons?

Second, carers are bound into family relationships that mean that they cannot simply give up when the balance of interest turns against continuing. Carers often care against their own interest. To regard them as subject to a form of rational calculation of costs and benefits whereby they give up caring once the former outweigh the latter is to miss the nature of the ties that bind them. It is because of these ties, I would suggest, that public agencies have a moral as opposed to simply instrumental relationship with them. Carers present moral responsibilities to the state precisely because they cannot be assumed to pursue their interests in a straightforward way.

For these two reasons – the extreme nature of some of the burdens and the character of obligation – the needs and interests of carers need to be incorporated into the policy debate. In policy terms this means accepting that costs to the state are not the only focus; that the service system cannot be run solely on the principle of supporting only those cases where the carer is about to give up; and finally that there may be occasions when it is proper to recognise that the time has come for care to end.

The disability critique

Just as the policy debate has often neglected the interests of carers in its emphasis on costs to the state, so too has it sometimes neglected the interests of the cared-for person. The disability movement, which has its origins in the United States but is increasingly influential across the Anglo-Saxon world, presents a critique that emphasises the ways in which disability is socially constructed – the product not of impairment but of a disabling environment and oppressive social assumptions. The social creation of disability and of caring are seen as linked: without disability, there is no need for care. Out of these perceptions has developed a critique of the debate on informal care that argues that policy should not endorse dependence through an emphasis on supporting carers but should underwrite the independence of the disabled people they "care" for (Oliver, 1990; Morris, 1991). People with disabilities should be able to have personal and family relationships, but these should not be made the basis for caring. The recent emphasis on the needs of carers, in this view, diverts attention and resources from the real issue: the support of disabled people.

The disability critique was formulated largely with the interests of younger disabled people in mind, but it has implications for older people also. As we have seen, many, indeed most, older people value their independence. They may look for social support from their families but not necessarily wish to rely on them on a day-to-day basis or for intimate care and sometimes prefer the care of paid workers. If we are concerned with the expression of choice for carers, perhaps we should also be so for disabled older people.

Certain provisos should, however, be made to the acceptance of the implications of the disability critique for older people. First, not all disabled people – young or old – want to be free of reliance on their families. Some disabled people want and indeed demand that they be cared for. Spouses in particular often regard care as part of the mutual interdependence of marriage, and resist attempts to intrude upon it. In these cases caring continues to have consequences for the carer, affecting their life and opportunities. Second, there are situations where only the support of close relatives will enable the disabled older person to remain at home. This applies in particular to cases of dementia, where transcending the need for a carer is an unrealistic aspiration and one contrary to the interests of the disabled person.

The dual focus of caring

As we have seen, there are good reasons to recognise and incorporate the needs and choices of both the carer and the cared-for person. These separate needs have, however, to be placed in the context of the relationship; and the fact that caring takes place in a relationship imposes on policy an inescapable duality of focus. We cannot concentrate exclusively on one side.

To a large degree carer and cared-for have the same interests. But sometimes the carer and the cared-for person have different wishes and the interests of one may be pursued only to the detriment of the other. Respite services provide a clear example of these dilemmas: the cared-for person is often reluctant to go into respite, and the carer knows that respite may produce a deterioration, and yet the carer needs a break and may, indeed, collapse if one is not provided. Carers can also fear that the experience of relief may weaken their resolve to continue. Respite is an important service for carers, though a difficult one for these reasons (Twigg *et al.*, 1990; Twigg and Atkin, 1994).

The tensions around this dual focus have implications for policy, raising concrete issues around the question of who is properly to be considered the subject of the welfare intervention. In terms of benefit support, who is to receive the benefit: the disabled person or the carer? If we accept the disability critique, we should favour routing all monies through the hands of the disabled person. This might, however, result in the exclusion of the carer from any form of support. Whose needs should form the basis of an assessment: the disabled person's or the career's? Service-based systems may be able to incorporate both and balance them to some degree, but this is harder for insurance- or benefit-based forms of help.

Finally, should all help to the disabled person be regarded as a form of help to the carer? There is an obvious sense in which it is so: anything that improves the independence of the disabled person helps the carer, and assistance given by others does not have to be given by the carer. But this point of view rests on an assumption that carers are there to meet all shortfalls and that they represent, as it were, the bottom line of care and responsibility. This is often the case, but it may not always be the right assumption to make.

There is no simple or single answer to these questions. Different welfare systems and different parts of each system will adopt different solutions depending on how they choose to perceive carers. In earlier work I have proposed a typology of such frameworks in the form of four models or ideal types of the relationship between carers and welfare agencies: carers as resources, as co-workers, as co-clients, and superseded carers (Twigg, 1989, 1993*b*).

Policy responses

Financial measures

Some countries support caring through the tax system. In Japan, for example, taxpayers supporting someone over age 70 receive a credit, which is larger where the person is severely impaired (Maeda and Nakatani, 1992); in the United States families can obtain tax relief for expenditure incurred in caring (Doty, 1986). The use of tax credits presents some problems. Doty suggests that families rarely pay out large sums on care. Most of their costs relate to personal time or stress; and although values can be imputed to these costs, tax policies do not in general recognise them. Tax credits are usually across-the-board and rarely large; as such they do little to reflect the real or the individual costs of care. Credits favour those who pay tax, whereas many carers are too poor to do so. They also favour the rich, who may pay higher rates of tax and who can afford to pay tax advisors (Doty, 1986).

The second option is a benefit for carers, of which the Invalid Care Allowance (ICA) in the United Kingdom and the Carer's Allowance in Ireland are the main examples. ICA is available to carers of working age who give more than 35 hours of care per week and who are wholly or largely out of the labour market (McLaughlin, 1991). Overlaps with other benefits and the exclusion of those over working age mean that relatively few carers of older people receive it. The Carers Allowance in Ireland is available to carers who live with, and provide care to, a pensioner. Since it is means-tested, few married women receive it unless their husbands are unemployed or on very low wages (Glendinning and McLaughlin, 1993).

Such benefits present certain problems. If they are to be seen as compensation for being out of the labour market, they are rarely paid at a sufficient level to achieve it, and certainly never reflect the lost opportunity costs. If the benefit is to be seen in terms of a reward – a token compensation for the burdens of caring – its limited application raises questions of equity. In particular the employment emphasis excludes one of the most significant groups of carers: those of pensionable age.

Sweden and parts of the United States provide for payment to carers in recognition of their work (Glendinning and McLaughlin, 1993). Concern has been expressed that payment will affect the relationship in undesirable ways; that monitoring carer involvement creates a bureaucratic nightmare and an undesirable intrusion into private life; and that such payments are unnecessary. In practice payments are discretionary and usually either part of a package of income support or made on the understanding that the person would otherwise be on welfare.

Service-based forms of support

Service support for carers falls into four broad categories: in-home assistance, respite services, advice and support for carers, and services provided for the cared-for person. Work evaluating the effectiveness of the first three is reviewed in Twigg *et al.* (1990), Sinclair *et al.* (1990), Twigg (1992), and Leat (1992).

In-home assistance covers a range of help with housework, with personal care, and with nursing tasks. In some countries such help is provided as part of medically based care; in others it is more directly located within a social care system (for this shifting boundary in the European Union see Alber, 1993). In most cases help is provided to the older person who is regarded as the client, though with some understanding of how it may assist the carer.

Respite services can take a variety of forms. Any time away from the cared-for person – particularly where the carer shares a household – can be regarded as respite. Day respite is provided by day centres or day hospitals, though it can also be provided in more flexible forms through the use of in-home care attendants. Over-night respite is sometimes offered in hospital when there is a vacant bed, though such acute-care settings are usually less satisfactory than settings designed to provide respite. Respite is particularly valued in relation to dementia, though its use is sometimes associated with feelings of guilt, anxieties over abandonment, and concern over deterioration. For those under severe pressure it can be useful, though it may only delay and not prevent institutionalisation.

Advice and support to the carer is a diffuse area covering emotional support, advice, and training. Such help can come from a variety of sources: from individual service practitioners, often as a by-product of other contact; from advice centres or help lines; and from carer associations. Carer support groups have proved an increasingly popular and relatively low-cost response. Support groups are most successful when they allow personal sharing of experiences; a purely informational format is less effective.

Carers are rarely the focus of intervention in their own right; they are largely assisted by mainstream services provided for the cared-for person. It is difficult to separate out distinctive services for carers; responses to carers are embedded in those of the service system in general. The issue therefore is how far and in what ways the needs of carers are incorporated into the decisions of service providers. There has been little evaluative work in relation to this fourth area, though its significance is great.

Money or services?

Service support for carers is not always something separate from financial support. In many systems services are provided through payment or reimbursement. This can apply to the carer as well as to the cared-for person. In Germany, for example, respite is available in the form of a holiday care allowance which funds a substitute carer for a period of up to four weeks a year (Glendinning and McLaughlin, 1993). Differences in the balance of cash and care reflect differences in the structure of welfare systems. In some countries recipients are offered a choice of either money or services. In Germany, again, the care allowance for severely disabled people provides either a cash payment or reimbursement of service costs, with the cash payment set at a lower level than cost reimbursement (*ibid.*). Similar choices are available within the Israeli system (Habib and Windmiller, 1992).

The debates around the merits of in-kind services as opposed to payments raise larger questions than just those relating to carers. Giving money directly to disabled and older people to purchase care of their choice is in tune with current ideas of user empowerment, though it also draws on older concepts of entitlement and citizenship. Problems can arise where the older person is very frail or confused and where direct provision of services may be more appropriate. Money purchase systems tend to be associated with insurance- or benefit-based approaches in which the categories of eligibility are inevitably broader and cruder than is the case where support is negotiated through individual assessment for in-kind services. These tensions were reflected in the Israeli debates around the 1988 long-term-care reforms; it was argued that a financial entitlement approach would mean more recipients but at lower sums, whereas a system based on discretion would allow for larger amounts to be targeted on the needier recipients (Habib and Windmiller, 1992). Finally, it is easier to control and cap the budget where it is service- rather than insurance-based, as the history of the British national health service makes plain.

In relation to carers, debates about payment raise again the question of the dual focus. Payment approaches are nearly always based around the disabilities of the older person and rarely encompass directly the difficulties and burdens experienced by the carer. The needs of the carer are more likely to be acknowledged in a service-based approach where discretionary assessment can reflect the duality of interests and balance the needs of the two parties. Money provided to the disabled person may not find its way to the carer. Some disabled people are understandably reluctant to regard themselves as a burden to their family, particularly their spouses. Glendinning (1992) has drawn attention to some of the complexities entailed in the distribution of resources within caring households.

Tensions around the provision of money or services also raise perennial questions of substitution and reward. In the Israeli debates, those favouring cash benefits to older people saw them as fairer to families who did provide care. Those favouring services argued that most of the variation in support related to family capacity, not family willingness (Habib and Windmiller, 1992).

Targeting services

Most services are targeted on those who live alone and who are unsupported. In some systems this is overt. In Japan, for example, in-house support is available only to those who live alone – a minority among older people – or are bedridden (Gibson, 1992); in Germany help in the home can be provided by insurance only where there is no relative available (Glendinning and McLaughlin, 1993). In Britain the principle is less clear-cut: the home care service is potentially available on a flexible basis and in recent years, under the impact of heightened debate about carers, has included support of family carers among its aims; however, because of the scarcity of resources, most home care is still targeted on those who live alone (Bebbington and Davies, 1993). This has particularly important consequences for carers who share a household with someone with dementia, resulting in a pattern, Levin and her colleagues argue, in which those carers who face the greatest difficulties and the most unremitting stress are the least likely to receive support (Levin *et al.*, 1985, 1989).

Case management systems, with their closer targeting and emphasis on budgets, are sometimes presented as inimical to the carers (Parker, 1990*b*; Challis and Davies, 1991). However, it is possible to incorporate the interests of carers into a case management system if that is made an explicit aim (Twigg, 1993*b*), as the example of the Home and Community Care Programme (HACC) in Australia shows, where carers were specifically identified among those to be targeted (Howe *et al.*, 1990; McCallum and Howe, 1992).

Finally, should services target their resources narrowly on those carers who are on the brink of giving up or of collapse, and away from those who are merely distressed but likely to continue? The logic of the instrumental argument would support such a view, seeing it as maximising the cost-effectiveness of intervention. Research in Britain suggests that service personnel are reluctant to endorse such an approach (Twigg and Atkin, 1994).

Employment-related measures

Combining working and caring can be difficult. Though women are more likely than men to give up paid work in order to care, they may find it easier to obtain part-time work. Such work is, however, rarely well paid. Work is important for carers not just for the income it provides but for self-esteem. Paid employment provides an alternative focus in the carer's life and a form of respite. The psychological benefits of work apply as much to women as to men. Helping carers to remain in employment has also to be set in the context of the larger debate concerning the reconciliation of work and family responsibilities in advanced industrial societies (European Commission, 1993).

Measures to support employment divide into those provided by employers and those provided by the state. Examples of employer-provided schemes are flex-time to allow for the demands of caring, unpaid leave to ease carers over periods of crisis, and guaranteed re-employment after longer periods of absence, sometimes with support provided in the interim to maintain confidence and skills. Some companies have set up employee advice services or facilitated work-based carer support groups. In a small number of cases employers have either paid for support services or provided work-based facilities (Laczko and Noden, 1992; Hoskins, 1993; Naegele and Reichert, 1993). Most examples come from the United States; and they tend to be confined to certain sorts of enterprise: those with high levels of female labour and complex internal systems with high training costs. They also tend to be associated with prosperous blue-chip corporations with reputations for ethical practices. Such schemes are not found in secondary labour markets, where many women are employed. The interest of employers in such programmes is sensitive to the state of the labour market, and in the United Kingdom concern with the issue has waxed and waned in line with the economy. The global trend towards the fragmentation of labour and non-standard forms of work is likely to undermine any trend towards such provision, except in certain employment niches, unless governments and supragovernmental organisations such as the European Union make such schemes mandatory.

At the governmental level, help with employment tends to be provided through the benefit system; though the interaction of employment and benefits makes it harder rather than easier for carers to combine working and caring. In Sweden the state provides for care leave in the case of those nursing a severely ill adult, as an extension of earlier provision for sick children. Some countries, for example the United Kingdom and Germany, provide social security credits when the carer is out of the labour market. These are particularly important where pensions and other benefits are provided on a social insurance basis. Heavy reliance on private insurance which does not allow for such socially based credits can leave carers particularly vulnerable financially.

Conclusion

Carers are now recognised as the bedrock of care for older people across the countries of the OECD. As such their interests are increasingly drawn into the larger debate concerning the welfare state and the future of the long-term care of older people. How they are to be incorporated into that debate remains a matter of contention. As we have seen, carers pose a series of dilemmas for policy-makers. How they and their interests should be conceptualised remains open to debate. It is a debate that few countries can afford to ignore.

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WORLD HEALTH ORGANIZATION

STUDY GROUP
HOME-BASED AND LONG-TERM CARE
Ma'ale Hahamisha, Israel § 5-10 December 1999

"HEALTH CARE IS HOMEWARD BOUND"

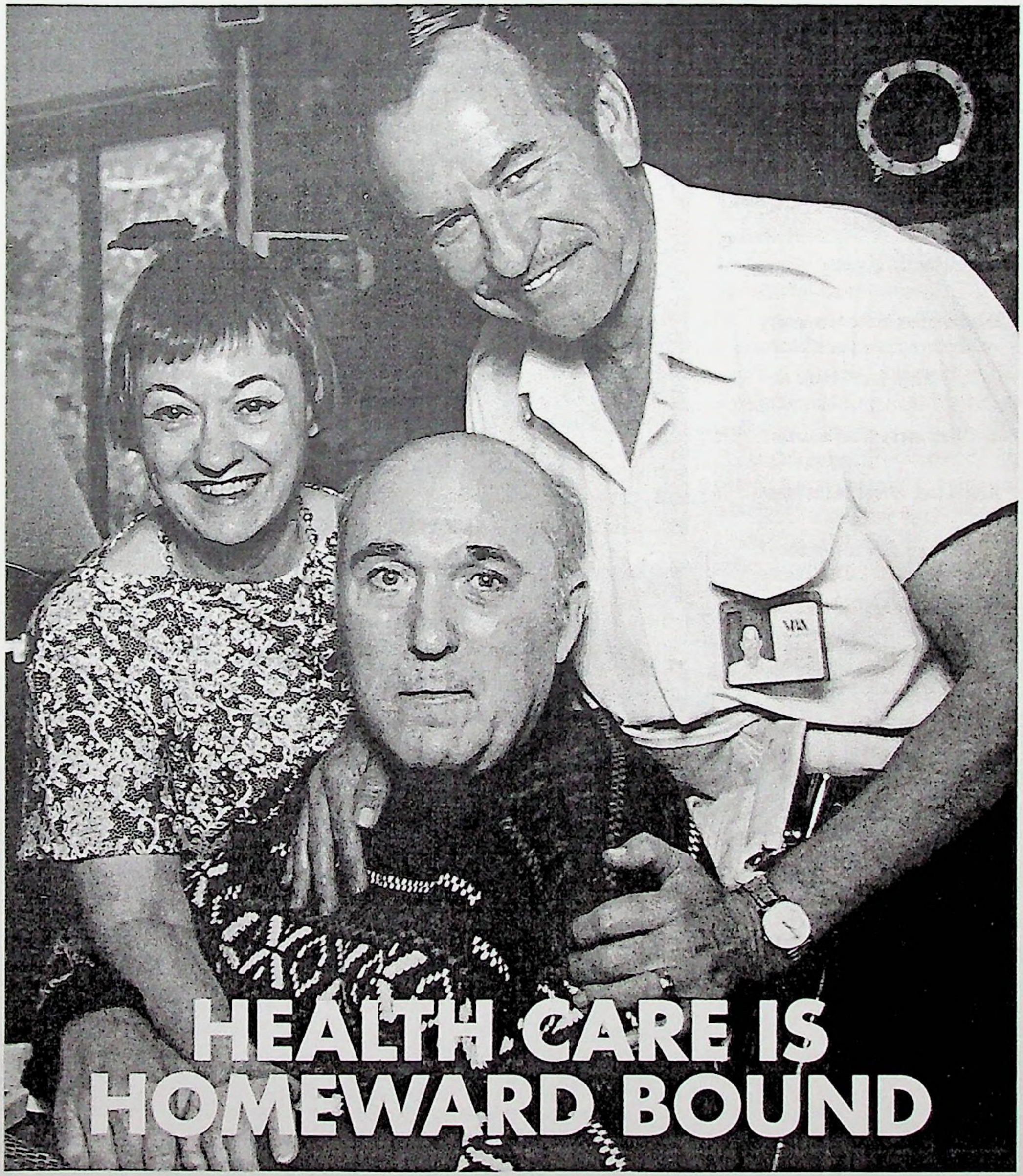
World Health
The Magazine of the World Health Organization
47th Year, No. 4, July-August 1994

LTH/HSC/SG/99/3

WORLD HEALTH

THE MAGAZINE OF THE WORLD HEALTH ORGANIZATION

47TH YEAR, NO. 4, JULY-AUGUST 1994



HEALTH CARE IS HOMEWARD BOUND

THE MAGAZINE OF THE WORLD HEALTH ORGANIZATION

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WHO in action

Cover: WHO/Marilu Halamandaris

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The National Association for Home Care for the United States (Mr Val Halamandaris, President) has kindly contributed the resources to provide colour pages in this issue.

World Health ■ 47th Year, No. 4,
July-August 1994
IX ISSN 0043-8502

Correspondence should be addressed to the Editor, World Health Magazine, World Health Organization, CH-1211 Geneva 27, Switzerland, or directly to authors, whose addresses are given at the end of each article.
For subscriptions see order form on page 31.

World Health is the official illustrated magazine of the World Health Organization. It appears six times a year in English, French, Russian and Spanish, and four times a year in Arabic and Farsi. The Arabic edition is available from WHO's Regional Office for the Eastern Mediterranean, P.O. Box 1517, Alexandria 21511, Egypt. The Farsi edition is obtainable from the Public Health Committee, Iran University Press, 85 Park Avenue, Teheran 15875-4748, Iran. The Russian edition can be obtained from "Meditsina" Publishing House, Petroverigski per., 6/8, 101000 Moscow, Russian Federation.

Home care in an aging world

Dr Knight Steel, Director-General of the World Organization for Care in the Home and Hospice.

Dr Hussein Gezairy, Director of the World Health Organization's Regional Office for the Eastern Mediterranean.

ne of the formidable challenges in the approaching century is to provide health care to the rapidly increasing numbers of elderly throughout the world. While the developed countries are beginning to take a series of measures to respond to the economic, social and health care issues of this transition, the developing countries have yet to assess the magnitude of the impact of these changes. A decade or so into the future, 10-12% of the total population will be 60 years old and over. In only six years time there will be 600 million elderly individuals, of which two out of three will reside in the developing world. What worries planners most is that a majority of the elderly will be economically non-productive, and many will be socially isolated and at risk of unnecessary and even permanent disability.

Today there are many developing countries where the primary health care system is far from being able to achieve the goal of health for all, in spite of very substantial efforts having been made during the last two decades. Economic pressure has forced many governments to make adjustments in national planning among which unfortunately the social sectors, health and education, are so often the victims. Primary health care is the only available means to serve the majority of the elderly population in the developing world, but there is often no operational component targeted to the needs of the elderly. Most developing countries should therefore begin by including health care of the elderly within their health protection and promotion programmes for the general population.

The prevailing cultural norm in most countries in all regions of the world is that parents and sometimes grandparents are looked after at home by their grown children. Most families, in both the developed and developing world, are more than willing to care for their elderly members to the limits of their abilities, but they too need support. However, the extended family system is breaking down in several countries with the result that many elders are finding it difficult to obtain home care. Day care centres for the elderly and community care through informal carers clearly have potential. Efforts in many developed countries to maintain healthy elderly persons in the workplace will go a long way to providing economic independence, as will old-age pensions and similar subsidies. In addition, families must have support from the national health care system, in collaboration with nongovernmental organizations wherever they are active, and social support from the community to enable the elderly to remain socially active as long as possible. Although specialized hospital care will be required at times, the strategy should always be to bring health care to the individual homes.

This issue of *World Health* focuses on compassionate home care which is loving as well as technologically sophisticated. It highlights the policy implications of home care as governments consider costs and efficiencies of service. There will be a need for curricular changes for all types of professionals who will provide services in the home and education and support for families, as well as more and better research in the home setting. These efforts need to be directed to ways of providing better services, and the most effective way to prevent diseases that preclude us from achieving the highest quality of life for the longest possible duration. ■

Knight Steel

Knight Steel

Hussein Gezairy

The "greying" of the nations

Ghada Hafez

Developing countries in general have not yet felt the impact of the rapidly increasing proportion of elderly people in their populations. Where will all these elderly live and who will care for them?

The proportion of elderly in the populations of developing countries is rising sharply, posing new challenges for health services.

he global demographic transition commonly known as the "greying" of nations is causing considerable concern – both nationally and internationally. It is a daunting prospect for any country to have to maintain aged individuals constituting 15-25% of its total population, many of whom will be economically non-productive and physically frail with multiple disabilities and handicaps, due to a number of chronic clinical disorders.

The countries of Western Europe and North America have felt the impact of this transition for decades and have adopted many measures to meet the major challenges ahead, especially economic and health-related ones. The developing countries in general have not yet truly felt this impact, and many are unprepared and even unaware of this demographic phenomenon. The WHO Regional Offices for Africa, the Americas, the Eastern Mediterranean, South-East Asia and the Western Pacific have been alerting countries to this "writing on the wall". They have developed a strategy covering the period 1992 to 2001 to assist countries to respond to the challenges.

It is ironic that when the aspirations of every country to ensure a long life-expectancy for every individual are going to be achieved, there is now global concern about how to maintain the quality of life for this ever-increasing elderly population. In the last century, one could have counted the number of centenarians in a given country on the fingers of one hand. Today, Japan – with the highest life expectancy – has more than 3000 centenarians.

The gloomy prospect of one economically productive person maintaining three or four non-economically productive individuals is a matter of considerable concern. Where will the elderly live and who will care for them?

Break-up of families

In most if not all developing countries the prevailing practice, based on long-standing cultural traditions, is to maintain aged parents at home. But in recent years, the large-scale migration of young adults to urban areas and even to richer countries, and the gradual breaking up of extended families, have to a large extent been responsible for the elderly population being left uncared for. Homes for the aged and similar institutions in some big cities may cater to those elderly whose affluent grown children bear the expenses; but this covers only a very small percentage of the older population. There will increasingly be a high proportion of elderly people who have no one to depend upon and who have to be taken care of in homes

The tradition of younger generations being able to maintain their aged parents is gradually breaking down throughout the world.

run as charitable institutions by nongovernmental organizations (NGOs) and religious bodies.

Care of the elderly – strategy for the future

Financial and technical constraints prevent most developing countries from undertaking organized programmes to fully address the economic and health care issues of the elderly. The providing of home care, the obvious choice for a vast majority of families in the developing world, will face considerable obstacles in the coming years. Properly supervised old-age homes of appropriate standard constitute an expensive venture, to which the elderly cannot hope to contribute sufficiently.

Even in the developed countries making widespread use of such chronic institutions or keeping those with long-standing clinical disorders in hospitals, occupying scarce hospital beds for long periods, cannot be the solution.

Surveys carried out in the countries of the Eastern Mediterranean Region have confirmed that most people consider the home to be the place where the elderly should live and where they are likely to derive the greatest emotional satisfaction.

Life-expectancy at birth is becoming longer in most countries. How are they to maintain and care for their increasingly aging populations?

Grandfather and child. Healthy old people have a major contribution to make to the health and development of their community.

However, assistance will have to be provided to families. Various forms of support will be needed:

- financial, through old-age pensions;
- subsidized food, transport, medicines and other necessities;
- where families have no space, subsidized accommodation for the elderly (provided by the government) with families responsible for their care;
- free (or heavily subsidized) spectacles, hearing aids and equipment for mobility (provided by the government, NGOs and religious bodies);
- day-care centres for the aged (established by NGOs and religious bodies), with free meals when possible;
- well-prepared mass media messages to train "carers" in individual families;
- messages and advice to the elderly on hazards facing them and how to overcome them;
- special efforts by the social welfare sector and by NGOs to use healthy elderly people in various types of social, community and health development work.

Meeting health needs

Most diseases and disabilities in the elderly are of a chronic nature, needing home-based care. Primary or community health care workers, in the towns or countryside, should bear the major responsibility for providing health care to the elderly, and especially for "training" them in how to take care of themselves. The WHO Eastern Mediterranean Regional Office is in the process of publishing a manual to help in training primary health care workers in this work.

By and large, home care is the only solution for most developing countries, but this can only be made possible if the government, NGOs, religious bodies and the people themselves take action now as equal partners. ■

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The frail and elderly have special health requirements that must not be ignored.

An aging world population

Kevin G. Kinsella

In view of the rapid aging of their populations, developing countries are finding it necessary to restructure their health services.

Does longer life translate into healthier life, or are individuals spending a greater portion of their later years with disabilities, mental disorders, and disease?

very month, the present world total of 360 million persons aged 65 and over increases by 800 000 individuals. Three decades from now, the world's elderly are projected to number 850 million. This unprecedented growth of the older population has already changed the social and political landscape in industrialized nations, and will increasingly bear upon policies and programmes throughout the developing world. Although issues of health care policy and reform vary enormously among and within continents, most national decisions in the health arena are already – or soon will be – affected by the momentum of population aging.

The term "demographic transition" refers to a gradual process whereby societies move from high rates of fertility and mortality to low rates of fertility and mortality. For example, European and North American societies are growing older, as a result of persistent low fertility and increasing life expectancy. Sweden now has the world's "oldest" population, with more than 18% of its citizens aged 65 or over.

What some readers of *World Health* may not realize is that a majority of today's growth in the numbers of elderly is occurring in developing countries. The speed of aging is likewise more rapid there than in the industrialized world; while it took 115 years for the proportion of elderly to rise from 7% to 14% in France, the same change in China will occur in fewer than 30 years. The high fertility rates that prevailed in most developing countries from 1950 until at least the early 1970s ensure that the ranks of the elderly will continue to swell during the next four decades.

Related to the demographic transition is the epidemiological transition. This concept refers to a long-term change in major causes of death, from infectious and acute diseases on the one hand to chronic and degenerative diseases on the other. We know that the average individual's risk of becoming disabled rises with age. As entire populations age, the societal prevalence of disability is also likely to increase. And as we live to higher and higher ages, the debate is brewing: does longer life translate into healthier life, or are individuals spending a greater portion of their later years with disabilities, mental disorders, and disease?

Further research is needed to answer this question, but it appears inevitable that the sheer force of demographic change will compel most countries to grapple with increased demand for health care. Elderly populations themselves are becoming older on average as the growth rate of the "oldest old" (persons aged 80 and over) outpaces that of the elderly in general. Because the oldest old consume disproportionate amounts of health care and long-term services, provision of those services will become more costly. Many health systems today are being economically squeezed by the competing desires to keep pace with a growing elderly population and to expand basic coverage to all segments of society. Countries throughout the world are looking beyond their borders for clues about restructuring their health systems, avoiding primary reliance on institutional care, and promoting family care and home care for their aging populations. ■

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Towards a healthier, longer lifespan

Gene H. Stollerman

Live well, eat well and be positive. Those who have survived to old age should be well informed about the many ways to prevent disease, to maintain the quality of life, and to extend their survival.

ll of us would like to look forward to a full measure of life, with reasonable preservation of its quality. At its end, we hope for maximum prevention of morbidity and minimal terminal suffering. Progress towards these goals in recent years has been impressive, and such good fortune seems ever more achievable. Many preventive medicine and health maintenance initiatives, begun as early in life as possible, can assist us in this progress and all individuals – especially those entering the older years of their lives (and those caring for them) – should seize these initiatives. People should not depend on current health care systems alone, for the latter are too often geared towards crisis and acute care in hospitals where the high-tech fight for extension of life is very expensive and often too late. Those who have survived to old age should be well informed about ways to extend their survival.

Prevention of disease

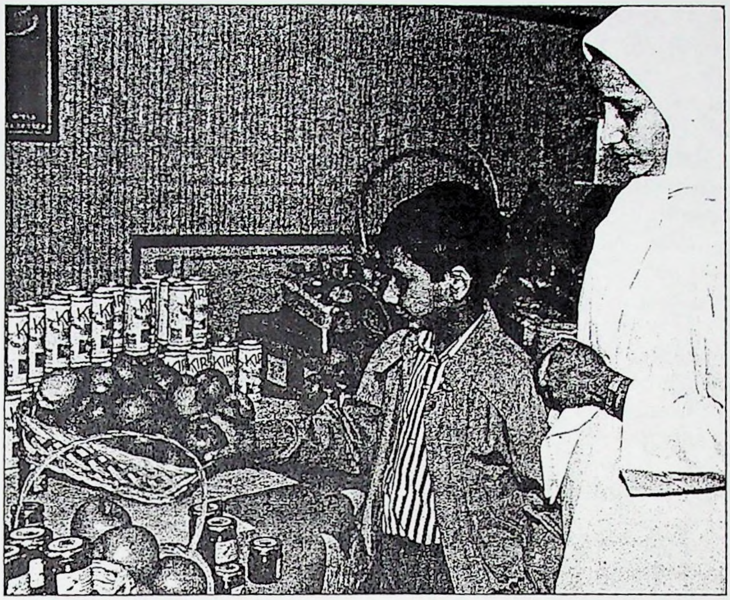
Immunization is by far the simplest and most cost-effective preventive measure. Many good vaccines are available, but regrettably are not given even when recommended by experts. At least four vaccines are already recommended for the elderly: influenza, pneumococcus, tetanus and diphtheria. Patients themselves should remind their primary health care provider that their vaccines may be due. Help your doctor to help you by asking what immunizations you may need.

Influenza vaccine requires an annual injection in the autumn. Don't expect the vaccine to prevent colds and other respiratory infections that are not influenza but merely imitate it. The vaccine is very safe, has only mild side-effects for the vast majority of persons and is quite effective, but not totally so. When protection is incomplete, the infection is nonetheless usually decreased in severity. The major disadvantage of influenza vaccine is its relatively brief protection period.

Pneumococcus vaccine needs to be given once only, except in special circumstances. Because pneumococcal pneumonia is primarily a winter disease in temperate climates and often comes in the wake of influenza, elderly persons who have not been immunized with pneumococcal vaccine should be reminded to take it when they report for influenza vaccination. Survival from pneumococcal pneumonia is particularly difficult for the elderly, who have less resistance to life-threatening infections than do young adults and are prone to post-infection blood-clotting complications such as stroke, myocardial infarction (heart attacks) and pulmonary embolism (lung clots).


Daily exercise helps to maintain good health and positive attitudes.

Tetanus-diphtheria vaccine is given routinely in childhood but immunity wears off within ten years; it therefore needs to be boosted every decade. By old age, most individuals will have lost or markedly decreased their immunity to tetanus and diphtheria if they have not received a booster injection in the past decade. Tetanus is always a risk from wounds that are contaminated with soil. Retaining immunity to diphtheria requires just a tiny amount of the vaccine, so it is usually incorporated into the tetanus vaccine that is used as a "booster" once every ten years. Have you received such a booster within the past ten years?



Healthy foods – your passport to a longer lifespan.

Other hazards

The use of the highly effective new vaccines for hepatitis B should be considered on the basis of an individual assessment of risk. Universal immunization of children with the hepatitis B vaccine may eventually make this a disease of the unimmunized elderly. Like smallpox and measles, hepatitis B has the potential to be eradicated by immunization, provided the vaccine becomes one of the routine childhood immunizations. Let's do it throughout the world! Regular skin testing for tuberculosis is another important preventive measure, especially in the elderly whose immune status to this disease should be regularly updated on their health record.

When seeing any health professional, it is worthwhile to ask about the status of your immunizations.

Eat wisely and take exercise

Another universal way of preventing disease is a healthy diet. Even in the most affluent countries, many of the elderly are undernourished (not enough food) or even malnourished (unbalanced diet). The impact of malnourishment on quality of life and longevity is enormous and can result in fatigue, insomnia, diminished resistance to infection and depression. Disease is often an appetite killer, and so is reactive depression, which haunts the elderly for whom causes of depression abound, such as bereavement or loss of physical functions. Depression and loneliness may cause weight gain as well as loss; some people eat for comfort or out of boredom, and obesity may become a problem. Adequate dental care and oral hygiene is another factor in maintaining adequate nutrition.

At least one meal a day should be in the company of others. Choose a balanced diet, preferably one with vegetable oils rather than animal fats and one high in complex carbohydrates such as pasta, potatoes, rice and corn but low in simple sugars such as sweets and other confections. Sufficient protein is found in beans, cereals, fish and chicken. The diet should be supplemented by generous amounts of green vegetables and fresh fruit which provide an adequate supply of vitamins. Foods with high fibre, low cholesterol and low salt are generally to be preferred. To lose weight avoid fad diets. A diet that cannot be sustained indefinitely is virtually worthless and may be harmful.

Don't forget about a high fluid intake! Water is one of the most important components of good nutrition and the best defence against constipation, a very common affliction of the elderly.

All older adults should be encouraged to exercise within the limits of their physical capacity and on the advice of their physician in order to avoid harm from overenthusiasm. Lack of enthusiasm to exercise is usually a bigger problem, however, and it is often aggravated by depression. Ironically, a major treatment for depression is exercise! A graduated exercise programme can reduce symptoms of heart disease, reduce bone loss associated with aging and increase muscle mass and strength as well. It can also improve mental functioning, elevate mood and contribute to an overall sense of well-being. Simple walking done regularly, especially with companions, may be all the exercise that is needed.

A positive attitude towards other people and society in general increases the quality of life.

Be positive!

Positive attitudes may not be easy to sustain in the face of chronic disease, the death of friends and a decline of physical and mental powers. One powerful force for survival in the face of adversity is commitment. Even devotion to a pet has been shown to increase survival! Join with a group of persons in an activity you enjoy so that you can give as well as get support.

Finally, consider the complications that could arise from unwanted and ineffectual care at the very end of your life. Confront squarely the issues of such management as you would like for yourself. Discuss this openly with your family, and nearest and dearest friends. Select your trusted agent (proxy) who has been instructed by you to carry out your wishes should you no longer be able to do so. Write out and have witnessed a statement of what limitations you may wish to place, if any, on your terminal care. The current social, legal and medical climate in the world is strongly in favour of a high degree of patient autonomy, and most physicians are ready to support your choice, unless what you desire is medically and/or morally unreasonable. ■

Sharing mealtimes with others encourages sensible nutrition and keeps morale high.

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Home care for the disabled elderly

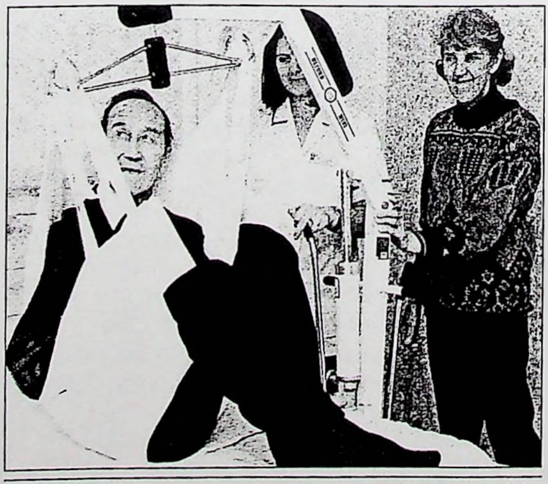
Judy Briggs

he occupational therapist has an important role to play in the provision of home care for disabled older persons. Preserving independence and improving function are central to this approach. The therapist consults with relatives and friends in the old person's life, building up a picture of perceived needs whether physical, emotional, social or economic. What does he or she want? How would they like to achieve it? And with whom? Together they then make a decision about the maximum independence achievable. "Enriched quality of life" is the agreed goal. Stereotypes of old age in modern society can influence our expectations of each other; society today is geared around youth, giving it much power and status. The therapist can help to redress this imbalance.

Housebound old people experience many physical problems – pain, limited mobility or an increased tendency to fall, with consequent injury and even death. Restricted movement of hips and shoulders means that seats and beds may need to be raised, and crockery and food made more accessible.

Demographic changes will result in more home-based very old people and fewer "young elderly". It is from these young elderly that the carers of tomorrow will emerge.

Old age also diminishes the senses. Hearing checks and aids should be encouraged to prevent increasing isolation; louder bells and increased volumes on the telephone, radio and television can help. Loss of visual acuity is in itself frightening, but therapists can recommend many low-vision aids, especially for use in the kitchen which is a dangerous area needing good lighting. Incontinence brings humiliation and loss of dignity which may be alleviated simply by the provision of a commode or referral to a specialist. For many activities of daily living an occupational therapist can recommend devices, however small, which may make the difference between self-reliance or dependence.



Therapists and family members can cooperate to enrich the quality of life for the homebound elderly.

The homes of old disabled persons need to be regularly checked to remove unnecessary hazards.

In winter many old people suffer from the cold, especially if their income is low. The solution may be to keep one warm room for living and sleeping. A limited budget also prevents the older person from using "convenience foods" which are now on the market; a dietitian can give useful advice about a nutritious diet. In general the old may suffer many losses – hearing, sight, memory and companions; the occupational therapist will try to address these concomitants of old age.

Hazards in the home

Old people tend to live in some of the worst housing, even though they are the people most at risk. In making an assessment, the therapist checks all physical aspects of the home such as

The carers of tomorrow will emerge from the group of the "young elderly".

Solving problems is the ideal approach adopted by occupational therapists.

access, steps, ramps, internal and external stairs, door widths, turning circles for wheelchairs, and the heights of chairs, beds and toilets. Hazards exist in all homes, but when an old disabled person is present it is imperative to reduce risks to a minimum. The therapist watches for trailing cables, overloaded electric sockets and loose rugs.

As we have already seen, the kitchen is the area of greatest hazard because of the hot oven, gas taps and scalding hot water. Add to this unsteady hands and feet and failing eyesight, and the problem is magnified. A sensitive assessment may result in a decision to close the kitchen and disconnect the gas cooker in extreme circumstances.

Role of physical therapists

Physical therapists too have an increasing role to play in the care of elderly persons. A report produced by the World Confederation for Physical Therapy (WCPT) in collaboration with WHO showed that only a small number of physical therapists had expertise in this area of practice. Their education and training did not seem to focus sufficiently on the needs of this age group. So in 1992, at a meeting arranged by WCPT at the International Institute on Aging in Malta, plans were drawn up to meet those needs. One result was a position statement which recognized the rapid escalation in the number of elderly persons throughout the world, and urged the active involvement of physical therapists in developing services for the elderly in policy and planning at international, national and local levels.

It is not uncommon for the carers themselves to be elderly and to have their own problems, in which case the occupational therapist should be sensitive to this in analysing the situation. The care-givers may be depressed by the seeming relentlessness of their task and loss of freedom or "personal space", and they may also have financial worries.

Carers often express feelings of guilt about the quality of the care they give. If the burden becomes too great and the old person needs residential care, then the carer may be left with feelings of helplessness or of being trapped. It is at this stage that they need to know where to turn for help.

A variety of resources are available in different countries. They may include homes run by the local authority, day hospitals offering multidisciplinary therapy, or disablement services centres. Rehabilitation in the community may be possible through home visits by physiotherapists, occupational therapists, speech therapists or district nurses as well as the general practitioner. Terminal and palliative care can be provided through specialist nursing homes and hospices.

Many societies are supported by voluntary bodies, such as local church groups, luncheon clubs, "Age Concern", self-help groups, "Meals on Wheels" and women's societies. There are also specific associations and societies caring for sufferers from Alzheimer's disease, motor neuron disease and other chronic diseases. There may be various types of sheltered housing, warden-assisted accommodation and residential care. Any of these options can become an attractive alternative to old persons failing to cope in their own home.

The problem-solving approach of the occupational therapist can help to check the deterioration of function in old age, and so be life-enhancing. Many countries will very soon face serious health and social problems as a result of the "greying" of society. In England and Wales between the years 1990 and 2000, for example, the number of people aged 85 years or over is projected to increase by 35%. At a time when the emphasis is on community-based rather than hospital-based care, these demographic changes will result in more home-based very old people and relatively fewer "young elderly". However, it is from these young elderly that the carers of tomorrow will emerge. The occupational therapist of the future can play an important part in supporting the carers as well as those who will need care. ■

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Rehabilitation in the community

Naomi Rumano

This young woman, despite her disability, has sewn a child's dress with her feet

ommunity-based rehabilitation (CBR) programmes are in principle multi-disability oriented and aim for joint multisectoral action at the level of the community, supported by an appropriate referral and supervisory system. Each programme implies the transfer of skills and knowledge of rehabilitation to people with disabilities, their families and their communities. It empowers disabled persons and facilitates their social integration. It is estimated that the CBR approach meets the essential needs of 70-80% of all disabled people in the community. The remaining 20-30% of the needs have to be met at referral levels, including institutions.

Community-based rehabilitation programmes aim:

- ■ to promote awareness, self-reliance and responsibility for rehabilitation in the community;
- ■ to build on local manpower resources in the community, including disabled persons, their families and other community members;
- ■ to encourage the use of simple methods and techniques which are acceptable, affordable and appropriate to the local setting;
- ■ to use the existing local organizations and infrastructure to deliver services, especially primary health care services, but also labour and social services including the education system.

Families who take care of children or adults with disabilities often face a lack of understanding about the disability as well as negative attitudes within the community. Because of heavy workloads, particularly during planting or harvesting, family members have little or no time to spare to assist someone with a disability. CBR addresses these problems and gives support to families so that they can be active in a rehabilitation process for a family member with a disability. The CBR programme may conduct public meetings to raise awareness about the causes of disability and the potential abilities of disabled people. It trains community workers who visit and advise disabled people and their families, and it encourages support from the community for those families. It also includes supervision from district level rehabilitation workers who visit homes where there are problems which cannot be handled by the community worker.

Achievements in Zimbabwe

A CBR programme in Gutu District of Masvingo Province, Zimbabwe, offers an example of what can be achieved. Fifteen self-help projects were started, and at the end of two years a total of 1087 disabled persons had been assessed:

- – 900 were on training programmes, and 316 of them were making good progress;
- – 68 had completed training and were discharged as functional;
- – 82 had achieved social integration at home, within families and in schools;
- – 6 were able to get employment locally;
- – 500 had benefited from referral services;
- – 167 were receiving appropriate aids. ■

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"High tech" home care

Mary Suther

A staff member of The Visiting Nurse Association of Texas examines a patient in her home.

Home care has benefited from high technology. Of course, all "high tech" services are ultimately designed to support the human touch that home health agencies provide.

echnology has dramatically affected home care in three major ways. First, improvements in technology have resulted in the development of miniaturized and user-friendly procedures and helpful devices. Second, the availability of technologically advanced equipment has increased the need for professional home care services for an increasingly elderly and functionally impaired population. Third, advances in telecommunications and information management have promoted increased efficiency and timeliness in the delivery of home health services.

Let us consider what can be achieved now and what may soon be possible in "high tech" home care by looking at The Visiting Nurse Association of Texas (VNA) as an example. VNA is a non-profit home care agency serving the needs of a population of about 4.5 million persons. Its 1400 employees and 5000 volunteers minister daily to more than 8000 individuals with a wide variety of health and social problems. Technology has made it possible to provide a comprehensive home care programme with new clinical tools that may be used by a nurse, physical therapist, occupational therapist or speech pathologist or, at times, by a trained family member or patient.

Trained nurses are available 24 hours a day, seven days a week, to supervise patients with continuous intravenous drips. Blood products and blood, a variety of chemotherapeutic agents, total parenteral nutrition, and whatever drugs are necessary to achieve control of pain can be administered. Additionally, the intravenous administration of antibiotics, immune globulins, and agents used in the treatment of viral and fungal diseases can be routinely overseen.

These therapies can be administered safely at home with simple, portable infusion pumps that carefully regulate the flow of medications and chemicals. The procedures can, in most cases, be taught to the patient or family member, thereby decreasing cost and increasing the independence of the patient.

The care of the cardiac patient has been greatly expanded over the past decade and now routinely includes cardiac monitoring via a small hand-held device that records either a two or twelve-lead electrocardiogram. This information is then transmitted over a telephone

"High touch" – the indispensable complement of high technology care.

line to a central laboratory, where it is printed and retransmitted by fax to a physician who interprets it and makes the necessary decisions. The doctor can provide information to a nurse for immediate initiation of treatment if warranted. The telephone line can also be used to evaluate the functioning of a patient's pacemaker.

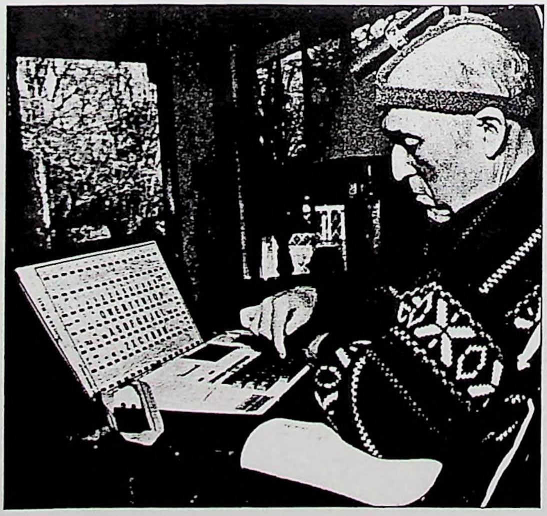
Increasingly, high-risk infants can be cared for effectively in the home environment. Apnoea monitoring devices are able to detect episodes of interrupted breathing and sound an alarm when the infant is in distress. Parents are taught emergency procedures to carry out until professional help arrives. The miniaturization of ventilators has been a boon in keeping infants and children out of institutions.

It goes without saying that computers have revolutionized the administrative functions of home care. They have enabled the scheduling of visits, the design of routes geographically for delivery, the measurement of productivity, and a more discrete costing out of goods and services. Fax machines too have improved the accuracy and timeliness of orders from physicians who oversee the care of these patients. VNA now uses over 500 fax machines; all nurses and therapists have one at home and can receive doctors' orders accurately and on time without having to come to the office. On this service the number of visits increased by 14% after all providers obtained fax machines.

Deep heat applied by ultrasound to decrease pain in arthritic joints.

Of course, all "high tech" services are ultimately designed to support the human touch that home health agencies provide. Home is where we want to be when we are sick, and home is where we can recover fastest if we have the proper care. ■

Ms Mary Suther is President and Chief Executive Officer of The Visiting Nurse Association of Texas, 1440 West Mockingbird Lane, Dallas, Texas 75247-4929, USA.



This tetraplegic patient – almost completely paralysed – communicates with his family and health staff by means of a computer.

An infant cardiac patient has to be fed by tube.

"That nurse-troublemaker"

Barbara Phillips

Disturbed by conditions she found on New York's Lower East Side at the turn of the century, Lillian Wald founded the Visiting Nurse Service of New York (VNS) in 1893. This innovation marked the birth of public health nursing in the United States. A social reformer and registered nurse, Wald also established New York's first public playground, the first school study hall, and the first special-education class for the handicapped. She lobbied successfully for school lunches and for nurses in the public schools. The powers-that-were called her "that nurse-troublemaker".

Today, under president and chief executive officer Carol Raphael, VNS is the largest non-profit provider of home health care in the United States, making more than two million home visits a year. In 1993, VNS provided more than US$ 10 million in free care to the uninsured and the indigent.

Nurses comforting an elderly patient in 1960. Serving the chronically ill elderly at home has always been and remains the major function of the Visiting Nurse Service of New York.

VNS has nearly 5000 employees. Nurses, home health aides, rehabilitation therapists, psychiatrists, physicians, social workers and case workers provide essential services to tens of thousands of the most vulnerable New Yorkers, from newborns to senior citizens (VNS serves 53 New Yorkers who are at least 100 years old), from HIV-infected children to terminally ill patients seeking the dignity and comfort of being cared for at home.

VNS is noted for its innovative programmes. Its First Steps Programme provides comprehensive services to substance-abusing women who are pregnant or have very young children. It delivers health care at several public schools (with the Children's Aid Society), and its paediatric asthma programme prevents the unnecessary, costly hospitalization of children. The agency is the single largest provider of home health care to people with AIDS in the United States. VNS provides mental health services for the homeless, and counselling to survivors of tragedies like the World Trade Center bombing. It provides free influenza vaccinations to the elderly (with the NYC Department of Health). Its "Nursing Home Without Walls" serves the chronically ill elderly at home. VNS is one of just four groups in the United States to receive Federal funds for studying how community nursing care can improve the health of the elderly.

VNS's new Research Center will help to answer other key questions: How can home care provide better outcomes for patients? How can it be made more efficient?

In *House on Henry Street*, Lillian Wald wrote, "The call to the nurse is not only for the bedside care of the sick, but to help in seeking out the deep-lying basic cause of illness and misery, that in the future there may be less sickness to nurse and to cure." VNS today continues Lillian Wald's legacy. ■

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Health care moves to the home

Knight Steel & Henk Tjassing

A high technology monitoring device enables the nurse to provide cardiovascular care in the home.

o underline the importance of home care to all nations of the world, WHO is sponsoring a conference entitled "As the World Ages, Health Care is Homeward Bound", scheduled for 22-23 October 1994, in Chicago, Illinois, USA. Held under the auspices of the World Organization for Care in the Home and Hospice, the Carnegie Council on Ethics and International Affairs, and the Alton Ochsner Medical Foundation, with a number of leading nongovernmental organizations as co-sponsors, the two-day conference will provide four concurrent "tracks" of interest: *International models, Accreditation and education, Economics and policy*, and *Research.*

International models will focus on a comparative analysis of present-day home care programmes, taking into account the diversity of present practices, expectations, needs and resources around the world. There can be no single international model for home care, and indeed the use of "high tech" home care is only beginning to be considered in most countries. By studying what has been successful and what has failed in the policy and practice of home care, we can design new and better systems to meet the world's forthcoming needs.

The track dedicated to *Accreditation and education* will concern itself with the training needs of doctors, nurses and other health workers who must function in the home setting. Special attention will be given to the educational needs of family members and other informal care-givers.

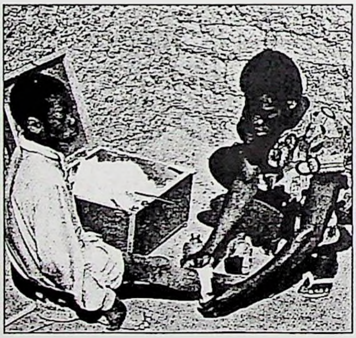
Economics and policy will highlight the political and economic climate in which care is being provided. Home care is not an isolated issue and must be seen in the context of limited resources and competing agendas. The emergence of new democracies and the costs of providing new technologies will come under discussion. The needs of the aged and the terminally ill will also be addressed, as well as the issues surrounding the provision of health insurance for all.

The fourth track, *Research*, will concern itself with three quite separate research agendas: health services research, the study of diseases frequently seen in the home (such as Alzheimer's disease), and preventive medicine. Comparisons between home care and institutional care, both acute and chronic, will be considered, with emphasis given to such items as nutrition, pain management and iatrogenic or hospital-caused disease (especially infections). Diseases seen predominantly in the home need to be a new focus of attention for researchers, since the functional deficits of chronic diseases create hardship for the enlarg-

Health workers counselling mothers in Pakistan. Models of h practices.

A visiting health worker examining a patient in China.

care need to take into account the wide diversity of current

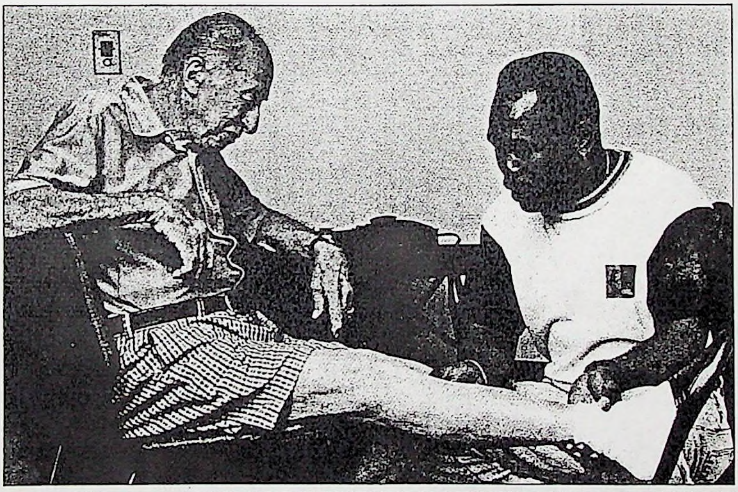


A health worker on her rounds provides home care for the villagers.

ing older population as well as for those who are younger yet afflicted with disabling illnesses.

This conference will bring together health care providers, researchers of many types, cultural anthropologists, educators, corporate representatives and policy-makers at both the national and international levels. While the agenda cannot satisfy all the questions pertaining to home health care, it will mark the beginning of a better understanding of this increasingly predominant setting of care. ■

Caring for the sick: this has always been a traditional role for the family.



As populations grow older, there will be increasing need for the care of functional disorders.

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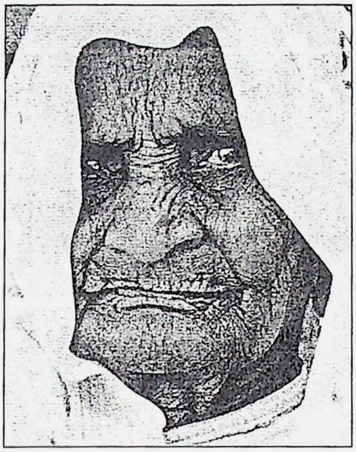
First International Home Care Week

The World Organization for Care in the Home and Hospice (WOCHH) in association with the National Association for Home Care (United States) would like to collaborate with all nations of the world in designating the week of 27 November to 3 December 1994 the First International Home Care Week. Interested parties should please contact Dr Knight Steel, Director-General of the WOCHH, 519 C Street NE, Washington, DC 20002-5809, USA. Tel. 202-546-4756. Fax 202-547-7126.

Does home care save money?

Michael Sorochan & B. Lynn Beattie

A home care programme can be very cost-effective and can save millions if not billions of dollars, both in capital costs and operating costs. But it must be accompanied by a reduction in the total number of institutional beds.



The rapid increase in the numbers of elderly people around the world calls for fundamental health care reforms.

Health care systems around the world are more studied and more ripe for change today than ever before in history. Many such studies recommend dramatic changes in the traditional "health care" system if the population requiring care is to receive, or to continue to receive, affordable and quality health care. Many factors underlie this need for health care reform.

Changing demographics and associated utilization rates. There is a significant increase in the proportion of the population which is elderly, especially in the developed world. For example, the number of persons in Canada aged 85 years of age and over is projected to double over the next 20 years and triple over the next 40 years.

Weakening informal support systems. It is estimated that over 85% of long-term care provided in society today is carried out by "informal" care providers such as spouses, children, relatives, friends and neighbours, at little or no cost to government. Lower birth rates have already begun to reduce the availability of children to support the older generation. Higher divorce rates and the increasing participation of women in the labour force will further decrease the availability of informal care.

A worldwide need to control the amount of money spent on health. Limited resources in most areas of the world have resulted in cutbacks on spending by governments for health care, social services and housing programmes. Hospitals and other sectors of health care are under pressure to "down size", while governments and health care agencies are frantically searching to find the least costly alternatives to the provision of high quality care. An expanded community care or home care system is frequently hailed as the possible "saviour" for the health care system's financial woes, especially as it also offers the promise of a better quality of life.

What is home care?

Home care can be defined as an array of health and social support services provided to clients in their own residence. Such coordinated services may prevent, delay or be a substitute for temporary or long-term institutional care.

A diabetic patient learns how to monitor her own blood glucose level without going to a clinic.

For almost all people, the home is the setting of choice for receiving health care.

Without question, the home is the desired setting for receiving care. Can we say with the same certainty that home care is more cost-effective than care provided in an acute or long-term institutional setting?

In one province of Canada, Ontario, an investment of only Canadian $300 million per year in the Home Care Programme is estimated to have produced savings of $1800 million in capital costs, and $500 million in annual operating costs. Reducing the numbers of elderly placed in institutions has been identified as the largest potential source of savings to the Canadian health care system. Similar studies in Denmark, the United States and other countries support the notion that many elderly and handicapped persons only require care in costly institutions because of the lack of adequate home care services. At the same time, over the last decade, home care programmes have managed to minister to the "high tech" needs of many persons – with services previously only provided in costly acute care hospitals.

The key to cost-effectiveness in the provision of home care is the appropriate "targeting" of persons who are suitable to be served. Services should reinforce rather than erode self-help and the informal support given by family members and friends. Furthermore, if home care is to be cost-effective, persons must become as independent as possible because of the availability of home services.

Thus, in one case, care in the home may be cost-effective because there is an available, caring spouse or other relative. In another case, home care may be much more costly than institutional care because of the pressing need for on-going, paid professional and non-professional care. One point always to remember is that, if the burden on the informal care-giver becomes too great, the home care arrangement may break down altogether, thereby resulting in a marked increase in cost to the health system.

The wife or husband is often the only care-giver for the ailing elderly companion.

Proving cost-effectiveness

It may be difficult to demonstrate the cost-effectiveness of home care programmes which focus on health maintenance and preventive services (e.g., wellness programmes, housecleaning, personal assistance, etc.), because persons served by these programmes are usually not at risk of being placed in acute or long-term institutions.

Home care may be more cost-effective in comparison to hospital care when an individual case is studied. However, the introduction of a service may result in a more costly health care system as a whole, unless other adjustments are made in the system. In order to realize a decrease in total costs to the health care system, the expansion of home care must be accompanied by a corresponding reduction in the supply of hospital or institutional beds.

Furthermore, while it may be more cost-effective for a government to provide care at home, it may not be cost-effective for the patient or family; the latter may face more "out-of-pocket" expenses when receiving care at home than would be the case if the sick person received care in a hospital. In many countries, a family must pay for drugs, equipment, dressings, food and home care services which would be provided in a hospital at no expense to the patient or family. Moreover, an informal care provider may have to forego employment in order to remain at home to look after an elderly person. A home care programme must therefore be structured with these facts in mind.

In summary, yes – home care can be very cost-effective and can save millions if not billions of dollars, both in capital costs and operating costs. However, specific targeting of clients is needed and institutional beds must be reduced in number or not added to. Additional benefits can be obtained because disabled persons can pursue work and educational opportunities which would not otherwise have been possible.

Although economic considerations are of great importance, it must never be forgotten that home care provides a holistic, client-focused philosophy of care, and allows maximum autonomy and independence for each individual in a familiar environment – the home. ■

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The challenge of AIDS home care

Sandra Anderson & Noerine Kaleeba

Some countries have set as a target that by the mid-1990s the majority of people living with AIDS will be managed at home. This challenge can only be met if a strategy exists to develop comprehensive care across the continuum from hospital to home.

Comprehensive care has to span the entire continuum from hospital to home, only using the hospital when there is a real need.

The numbers of people becoming ill as a result of HIV infection will dramatically increase over the next few decades regardless of the effectiveness of efforts at prevention being made today. Since AIDS is a chronic disease lasting months or years, some of the care required is likely to be supplied in hospital, but the home is increasingly considered the option of choice by sick individuals and by health care systems.

Home care relies on two strengths that exist around the world: the family and the community. People with chronic and terminal illnesses have been cared for by families in the home since time immemorial, regardless of the cost. But the AIDS epidemic presents new challenges.

Because home care lends itself to the "ups and downs" of a disease like AIDS, it is tempting to rely heavily on the families to provide care at home. Some countries have set as a target that by the mid-1990s the majority of people living with AIDS will be managed at home. This challenge can only be met if a strategy exists to develop comprehensive care (medical, nursing and counselling) across the continuum from hospital to home.

Once such a mix of services is available the ill person and the carers can jointly decide where the best quality and most cost-effective care is to be found. As with other chronic diseases, the best care depends on a continuity of services, with links and referrals to assist the sick individual to receive care at the right level, i.e. as close to the home as possible while still receiving comprehensive management, including proper diagnostic and therapeutic services for AIDS-related diseases, such as tuberculosis and diarrhoea.

Destigmatizing AIDS

When care is taken out of health care facilities and moved into the community, then community dynamics are added to the picture. People with AIDS and their families suffer from the stigma frequently found in communities and health care facilities. Fear stemming from a lack of knowledge contributes to the rejection of people with AIDS and sometimes their carers too. Without support, communities and families may abandon their traditional caring roles; this can result in despair among carers, and ultimately in the homelessness of

Family members deserve to be supported in their traditional caring role, since the family is a strong resource on which home care relies.

AIDS patients. *Living with AIDS in the community* is a booklet aimed at helping individuals, families and communities to understand AIDS and to live positively in spite of this disease (see box on next page).

The burden of AIDS on the health care system is experienced around the world. Some city hospitals in high prevalence areas have 50–60% of the hospital beds on medical wards occupied by people with AIDS and AIDS-related conditions. However, the impact of HIV/AIDS on households is also enormous: persons with AIDS are economically less productive being able to work fewer hours, so others in the household have to reallocate their time and priorities. And greater spending on caring for the person with AIDS may mean that less is available for the health care of other family members.

Caution is needed, especially to avoid allowing the full burden of home care to fall on females whatever their ages. The distribution of labour within the family should be carefully considered, and communities should develop supportive networks composed of neighbours, religious groups and clubs.

Providing AIDS home care can either bring a family closer together or drive it apart; certainly the family dynamics will be affected. In crowded families struggling with poverty it may be difficult to provide home care. People with AIDS can also experience forgetfulness, confusion and even dementia, which test the coping mechanisms of the family. In contrast, sick individuals who are living alone may be isolated and unskilled in meeting their own nutritional needs and unable to find willing carers and a social support system in nearby surroundings.

Concerns of carers

Care provided by family, friends or neighbours is not without problems. Very few carers will have had appropriate training. They will be worried about their lack of knowledge and

Even in the hospital, family members bear part of the care burden; but it is also an opportunity for them to learn about home care.

Why home care for AIDS?

- Good basic care with the most nurturing and flexibility can be given successfully in the home, as it enables the ill person to be as active and productive as the disease allows.
- People who are very sick or dying would often rather stay at home, especially when they know they cannot be cured in hospital.
- Sick people are comforted by being in their homes and communities, with family and friends around.
- Relatives should be able to carry out their other duties more easily while caring for the sick person who is at home.
- Home care is usually less expensive for families, and sometimes hospital care is not possible.
- Home care provides educational opportunities for personal messages about AIDS prevention, both in families and in communities.

Acknowledgement is given to the staff of the Health Care Support unit of the WHO Global Programme on AIDS.

Care at home involves more than a formal visit; it can also mean a sharing of emotions.

skills. They may be especially concerned about catching AIDS themselves, even though HIV is not spread through normal everyday contact or from taking care of a person with AIDS provided the carer covers any cuts or wounds on the patient and is careful not to touch fresh blood. They may be equally frightened about giving emotional support to a person who is terminally ill. WHO's Global Programme on AIDS has recently prepared an *AIDS home care handbook* (see box) to help health care workers teach and guide families in the emotional and physical care of people with AIDS, including detailed information about common AIDS-related problems. The handbook encourages health care workers to share their knowledge and to empower families to maintain quality of care at home.

Here are two examples of innovative AIDS home care programmes. The Uganda AIDS Support Organization, TASO, ensures that if its clients are well enough they join together for socialization, counsell- ing, medical care, and recreational and income-generating activities. However, if a client is too ill to come to a centre, a home visit – usually by a nurse – is made to provide direct nursing care in the home, to teach the family how to cope with common ailments, and to refer to a hospital if necessary.

In a situation where severe poverty and overcrowding make it very difficult to provide home care, a care unit has been started in Mashambanzou, Zimbabwe, where a patient and a family member share a small room together. The family member is trained to provide care for common ailments and to give comfort. If no family member is available, seropositive individuals who are well are trained to care for others who need home care but where there is no home available.

AIDS home care has to be developed and supported in the midst of poverty, inequality and discrimination. The ancient tradition of home care faces new challenges in the age of AIDS. Those challenges can be met with compassion and education provided families and communities are seen as partners along the continuum of care. ■

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AIDS: handbooks that will help

How can one cope with AIDS? How can one still get the most from life? What can one do in the home setting or after leaving hospital? How can one accept death? How can people suffering from AIDS be helped practically and emotionally?

There are a great many questions, and straightforward and easy-to-understand answers are difficult to find. This is why WHO has published its *AIDS home care handbook*, destined for health care workers, to help them teach people with HIV infection or AIDS, their families and communities. It can also be used by social workers, religious leaders, psychologists and companions, and administrators of health programmes.

The first part is a teaching guide for health care workers who have contact with AIDS patients and their families. It describes the evolution of the disease from HIV infection to AIDS, and suggests how to live positively with AIDS as well as how to care for the dying. The second part is a reference guide to the main symptoms of AIDS: fever, diarrhoea, skin problems, etc., and offers advice on what can be done to care for people at home and when to seek expert help. It also offers general advice covering such varied fields as hygiene, nutrition and maternal and child health.

The handbook is fully illustrated with drawings and uses a real life story to present the details of the disease and its impact on individuals, families and communities.

Another illustrated book – written and published jointly by the Ugandan AIDS Control Programme, TASO (Uganda's AIDS Support Organization), UNICEF and WHO – bears the title: *Living with AIDS in the community, a book to help people make the best of LIFE.*

Both books are available from Distribution and Sales, World Health Organization, 1211 Geneva 27, Switzerland, price Sw.fr. 18.– and Sw.fr. 6.– respectively. Single copies are free of charge to developing countries.

Young men in a hospital of Eastern Europe. AIDS patients have no need to be isolated and ought not to be stigmatized.

Adding life to years

S. D. Gokhale & Chandra Dave

ecently one of us visited the earthquake-shattered village of Killari in central India to review the progress of rehabilitation work carried out by our Community Aid and Sponsorship Programme. In one single-room house, the young breadwinner and his wife had slept inside, as is the local custom, while the grandmother and her grandchild had slept outside in the open. During the earthquake, the four walls had caved in, killing the young couple and leaving the other two persons destitute. Surprisingly, no one asked us to send the child to an orphanage or the elderly woman to an old-age home. Kisan, a disabled young man, said he would take care of both as he was very distantly related to them. Here is a typical example of the role of the extended family in India: to provide social security even in the circumstances of utter poverty – the real expression of kinship bonds.

To reach old age used to be the privilege of a few. Now it has become the ordinary experience in many countries of Asia. The vulnerable groups among the aging population in India are elderly widows, the childless elderly, the physically disabled, the elderly whose children have migrated abroad and the elderly in an alien environment. The objectives of the Old Age Policy as proposed by the Indian Federation on Ageing include providing employment options and family support, income security and health insurance, social and economic support to those elderly without families, access to health services and housing and area planning to suit the special needs of the elderly.

Using 60 as the age to designate "the elderly" this group in the population of India has been estimated at 55 million persons, comprising 6.5% of the total population of 844 million in the census year 1991. Most government pensions for destitute old people start at age 66 (earlier for women). The railways, the largest public enterprise, offer certain concessions in terms of fares to senior citizens beginning at age 65. The federal government also grants tax benefits to senior citizens aged 65 years and above.

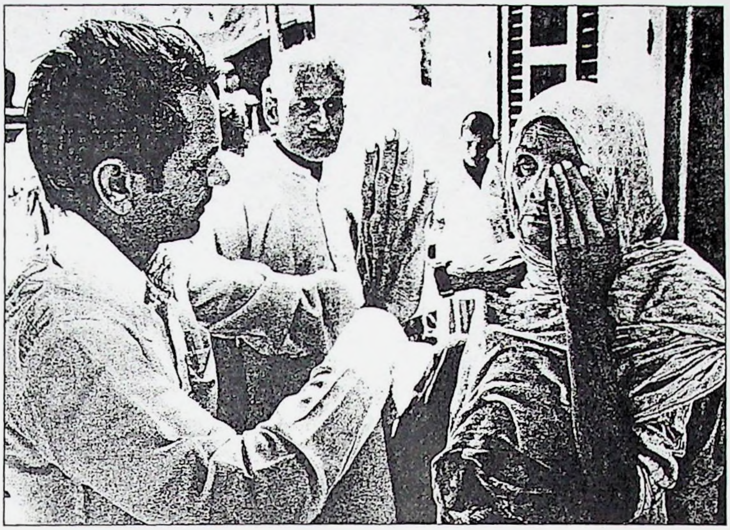
The pendulum of social thought has moved away from doling out cash and institutional services. Instead, society is looking forward to an aging process which is healthy, economically productive and politically participatory.

Living to a great age is beginning to be commonplace in many countries of Asia.

The kinship bonds of the extended family provide social security both for the old and for the very young.

The family as care-giver

For some years, Western social scientists have been worried about the future of the family as a social institution, and have publicly declared that the family system would wither away. But the family as an institution has not withered away in India. While the kinship arrangement is undergoing a tremendous change, the family as an institution has shown enough flexibility to cope with the changing times. It remains the main provider of care to the elderly.



Going to see the doctor may seem to be an expensive luxury for many elderly people.

Homes for the elderly total little more than 350, so these residential institutions clearly cannot cope with the problem. Therefore the vast majority of the old in India do not stay in institutions, which are mostly in urban locations. Most of the old are scattered among the 700 000 villages in a family setting. However, there are variations in the family arrangements. The much eulogized joint family system whereby the sons, their families and widowed sisters and aunts stayed under a patriarch has been found by sociologists not to have been as utopian as first portrayed. Furthermore, poverty, the growing population and urbanization are adversely affecting many traditional relationships.

There is no cut and dried definition of a family in India. Certain categories of relationships permit people to stay with a relative without arousing any social opprobrium. In oriental societies generally, the concept of dependence does not entail a sense of inadequacy or shame. Dependence is taken for granted. Certainly living in a family, however close or distant the kinship, protects the elderly from much social trauma, and the concept of care encompasses addressing whenever possible the physical and mental needs of old age, financial difficulties, the loss of meaningful relationships and generally declining functional capabilities.

To the extent that about 30% of the population live below the poverty line, financial considerations are a stark reality for the elderly. For the poor and old in the unorganized sector in India, there is no retirement. They continue to work, changing from hard labour to lighter tasks, but they share a sense of togetherness with the family that is often wanting in some who are better-off. The elderly may feel the loss of near and dear ones – a wife or a husband – but they are not lost, nor left to the mercies of society. On the other hand, during illness, they are often medically unattended as the logistics of arranging a visit to a doctor entail too much expense and effort.

For the poor elderly in India, there is no retirement and certainly no pension. Their working lives go on.

Stressful situations

It is among the middle-class and the middle-salaried that the care of an aged parent tends to cause especially stressful situations. The practice of the aged person staying with the son and his family means that the daughter-in-law – the home-maker and the carer – spends more time with the house-bound elderly. While the older person may easily adjust to the small, circumscribed world, the carer may experience great stress because of the workload and monotony of many tasks. The government's Department of Social Welfare offers monetary assistance to families who look after an indigent old person, and the idea of putting such a person in an institution is frowned upon. It is probable that, but for the cultural rejection of that idea, many more old persons would seek the shelter of old-age homes.

Neighbours in every village or town play a prominent role in the provision of home care, taking a lively interest in each other's lives and offering help on a reciprocal basis. In many neighbourhoods, the daily exchange of food items is a common occurrence. Old and young develop surrogate relationships which may offer an emotional catharsis in times of stress. Among middle-class people living in high-rise city buildings, this neighbourly reciprocity does not come to the fore. In such socially isolated apartments, the old may suffer a great deal.

Voluntary organizations most often operate in low-income housing complexes where the volunteers can easily visit the families of the old. After initial contacts, the elderly are coaxed to come to the centre for the activities run by the organization. These may include periodic health check-ups, the removal of cataracts, the making of handicrafts, the reading of newspapers, the arranging of picnics and participation in song sessions.

Aging is not merely a demographic issue, since how it is perceived is culture-dependent. In Western societies, there is little belief in the eternal cycle of life; aging is seen as a traumatic process, and retirement as a problem because it brings people nearer to death. To an Indian mind, death is not the end of a book but the end of a chapter. Consequently aging is not traumatic. There is no fear of being isolated or socially rejected when elderly.

In the context of sweeping changes in the economy and family structure, the question "what is and what should be the family's responsibility for older people?" needs to be examined. Policy-makers in India are now facing this challenge. Declining family size means there are and will continue to be fewer potential carers for the older person. Moreover, the increasing tendency for married women to become wage-earners restricts their availability to care for the aged.

While questions such as health, housing and employment are important, the most fundamental question is how the elderly look upon aging themselves. Perhaps many cultures have a lot to learn from the Indian philosophy. The pendulum of social thought has moved away from doling out cash and institutional services. Instead, society is looking forward to an aging process which is healthy, economically productive and politically participatory. This is the true meaning of adding life to the years that – thanks to medical advances – have been added to life. ■

Provided the elderly stay healthy and feel useful, they make a positive contribution to the life of society.

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Researching the health of the elderly

Stefania Maggi

WHO's strategies for the elderly are aimed at maintaining the quality of life for this population group.

Research projects by WHO's Health of the Elderly Programme will help minimize the decline in the quality of life that comes with age, so that everyone can have the most fulfilling life at home for as long as possible.

he need to gain an understanding of some of the most devastating chronic diseases of older persons was emphasized by a World Health Assembly resolution in 1987. It is, after all, these illnesses and similar afflictions which prevent all of us from functioning in our homes for as long as we might otherwise.

The research effort of the Health of the Elderly Programme, which is coordinated in the WHO Office for Research on Aging at the National Institute on Aging, National Institutes of Health, Bethesda, Maryland, USA, has undertaken a series of cross-national research projects directed towards an understanding of the age-associated dementias, osteoporosis, age-related changes in immune function and the determinants of healthy aging – all of which are relevant to home care. By carrying out cross-national research, the Programme hopes to identify risk factors for some of the conditions which are devastating to many of us as we age and at the same time to contribute to the basic needs assessment of the older population

The dementias

The objectives of the age-associated dementias project are to estimate age and sex-specific prevalence and incidence rates of dementias, and to investigate the distribution of several possible risk factors in Chile, Malta, Nigeria, Spain and the United States. The clinical manifestation of these illnesses appears to reflect cultural and environmental factors as well as genetic determinants. Over time, an impairment of cognitive function is virtually always associated with deficits in both the fundamental activities of daily living and the more complex daily activities such as shopping. These disabilities, which usually increase in severity, result in the need for both family members and health care agencies to provide progressively greater amounts of assistance to those afflicted.

Caring for a demented relative is among the most stressful of all activities, often interfering with the carer's work capabilities, with very negative consequences on family relationships and lifestyles. In turn, these problems may well affect the care provided to the sick individual. Respite care – allowing a welcome break – is therefore one of the greatest unmet needs expressed by carers. This project, designed to elucidate the causes of this disease or group of diseases, may also be instrumental in providing information on the unmet needs of millions of persons worldwide who have a dementing illness, as well as the needs of their families as they struggle to maintain these persons in the home setting

Brittle bones

Another project for research in the Programme addresses a serious and crippling illness, osteoporosis, which impairs function in older

Old women in Asian countries have fewer hip fractures than those in "Western" countries in spite of their lower bone density.

women especially. This effort, to be carried out in Brazil, China, Hong Kong, Hungary, Iceland and Nigeria, is designed to identify risk factors associated with hip fracture, a frequent consequence of this "brittle bone" disease and one which can result in devastating and irreversible loss of function. Dietary habits, reproductive history, physical activity, medication use, neuromuscular impairments, visual impairments and cigarette smoking are among the risk factors being studied to determine exactly what measures might limit or delay the likelihood of hip fracture.

This project may help to explain the differences in hip fracture incidence rates – for example, why older women in Asian countries, in spite of a relatively low bone density, appear to have fewer hip fractures than older women in some other countries. The research programme will focus on changes in bone mineral density over time and the risk factors involved. This will require individuals to be followed for a number of years so that deterioration in bone strength and difference in hip fracture rates can be measured. The incidence of hip fracture is projected to quadruple by the middle of the next century, at very high cost to individuals and nations in both economic and human terms.

Successful aging

A third research project is being carried out in Costa Rica, Israel, Italy, Jamaica, Thailand and Zimbabwe. It is designed to describe the health and functional status of that unique segment of the older population living at home which has aged successfully, often in spite of the accumulation of disease over a lifetime. This study will test hypotheses regarding the conditions that predict differences in rates of healthy aging both within countries and between countries. Each country should be able to profit from the experience of others by putting in place those preventive measures which will result in an even greater proportion of the population aging successfully.

Assessing the needs of the elderly all over the world will help to ensure that the strategies of care are put in place.

Better vaccines

In a related effort, the research programme is supporting the development of better vaccines for use in the home setting. In association with the Institute for Advanced Studies in Immunology and Aging, the programme is sponsoring collaboration among scientists involved in developing new technologies directed to the design of vaccines against influenza and pneumococcal infection. These diseases cause exceptionally high rates of morbidity and mortality in the older population. The need for tens of thousands of individuals to be sent to hospital would be eliminated if new and more effective vaccines were developed and widely used.

Healthy aging promotes the most fulfilling life at home for the longest possible time.

Home care assessment

Lastly, because the Health of the Elderly Programme is fundamental to the maintenance of older people in their homes, it is collaborating with scientists from Belgium, Italy, Japan, Sweden, the United Kingdom and the United States to design ways that can be used in several countries to assess the needs of this segment of the population. With a valid, reliable and easy-to-use needs assessment instrument, each country will be able to tailor effectively and appropriately its services for all persons as they age.

These research projects – dedicated to providing continuous, standardized, epidemiological surveillance of the rapidly increasing older population – will study both those who remain functional for the greatest length of time, and those who show a decline in function. We believe that these and similar efforts will help minimize the decline in the quality of life that comes with age, so that everyone can have the most fulfilling life at home for as long as possible. ■

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Sweden's Servicehouse concept

Britta Asplund & Ruth Bonita

Personal autonomy is important for the elderly and deserves to be encouraged by every means available.

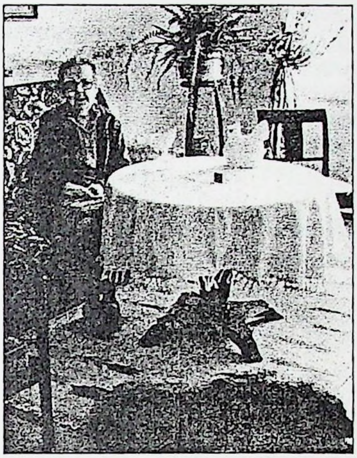
It is taken for granted in Sweden that older people have made an important contribution to society and now deserve a good life and the best that can be offered. The Servicehouse is regarded as a more pleasant alternative to hospital. It is also regarded as a right.

Up to 40% of people over the age of 80 in Sweden either have some sort of home care or are cared for in facilities provided by each local council. The municipal councils also have responsibility for group homes, which in turn are based on a social model where personal autonomy is regarded as an important ingredient. Usually 6-8 single apartments or single rooms are grouped around a living room and kitchen, and the residents have their own furniture and keys.

In 1992 there were around 6000 demented or confused elderly people living in group homes, although it is estimated that by the year 2000 places will be needed for 25 000.

Currently there are between 45 000 and 50 000 nursing-home beds and 40 000 sheltered homes. Most of the sheltered homes try to develop a familiar home-like atmosphere with routine activities and household tasks where the staff are seen as positive role models. Since hospital care is expensive and the communities have their own medical staff, sheltered homes are regarded not only as an inexpensive form of care, but also as a humane one. It is taken for granted in Sweden that older people have made an important contribution to society and now deserve a good life and the best that can be offered.

A model centre has recently been developed in Sweden for the care of older people. This "Servicehouse" comprises specially built self-contained apartments, provided by the local council and catering to people needing rest-home care, those needing considerable help and supervision, confused elderly people, and short-stay residents requiring respite from caring for elderly relatives in the community. The Servicehouse is an attractive building with 48 apartments, nine of which are for patients clinically diagnosed as having dementia. Before 1991 it was an "old people's home" where each person had just a single room and a toilet, with only two bathrooms in the whole building.



Home health services help elderly people who live alone to stay where they feel most comfortable – in their homes.

Help in the home

We visited one woman who was on the waiting list for one of the Servicehouse apartments. Although needing a walking aid she lives alone on the second floor of a building with no lift and where the washing machine is in the basement. She cannot manage the stairs by herself and has a home help every day, besides help from her relatives. When she had just come home from hospital after a hip fracture, she felt insecure and very afraid of another fall but managed quite well. Home service was provided three times a day and evening "patrols" dropped in and helped her prepare for bed. Food service was provided three times a week, with two days' supply of meals at a time. She has a safety alarm linked with the Servicehouse, and could use a community-subsidized taxi service.

Monthly rental for a Servicehouse apartment with a fully equipped kitchen and bathroom is around US$

350-400, or $700 including full service (cleaning and full personal care) and all meals. Residents have their own furniture and furnishings to their own taste. A restaurant is also available which provides three meals a day.

The Servicehouse plays an integral part in the community because it also provides respite care (alternative day care). There is no limit to the amount of relief that carers can provide; it depends entirely on the person's needs. Care in the Servicehouse is regarded as a less expensive alternative and a more pleasant one than hospitalization. It is also regarded as a right.

The "servicehouse" concept is satisfying both for the elderly who need care and for the students to whom it gives employment.

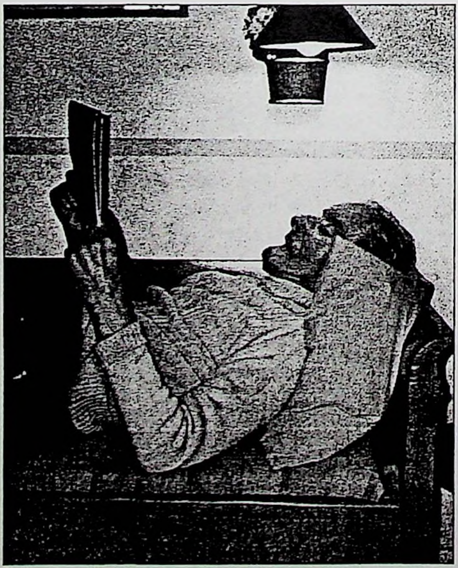
For the confused elderly

The special unit for the confused elderly consists of two separate sections, one containing four apartments and the other, five. It was opened only 18 months ago and all residents (and staff) have been carefully chosen. The staff furnished the place, planned all the activities, made schedules and received one week's in-service training and education from a doctor and advice from the psychogeriatric clinic.

Each staff member is assigned to one or two residents and takes a special interest in those persons by checking doctor's appointments and arrangements, providing a focal point for continuing care, and in general acting as an advocate and contact person for relatives. The contact staff member also prepares the box of medicines to be taken each night and keeps a log book for each resident. This becomes an important document and is available for staff and relatives to read. It is also a way of documenting changes over time. Electronic surveillance ensures that staff members know at any stage where an individual patient is.

The whole complex provides employment for students during the summer months. Up to ten students, mainly women, help in keeping the old people active and interested. By being paired with a full-time staff member, they are trained and eventually assigned their own special charges. The students are then able to take sufficient responsibility to allow staff members to go on annual leave. ■

Mrs Britta Asplund's address is c/o Department of Internal Medicine, University of Umeå, Umeå, S-901-85 Sweden, with acknowledgement to Mrs Dorothy Olofsson of the same department for her contribution to the article. Dr Ruth Bonita is Masonic Senior Fellow at the University Geriatric Unit, Department of Medicine, P.B. 93-503, Auckland, New Zealand.



Older people having made their contribution to society, in their later years they deserve a good life and the best care that can be offered.

Loving care: the recipe that makes everyone feel at home.

Community Action

Care of the elderly – a community health objective

Prosper Mihindou-Ngoma

Delegates to the World Health Assembly *and other health experts are invited to participate in Technical Discussions on a chosen theme of importance for international public health. This year the theme was "Community action for health", with the accent on the need for a dynamic partnership between health professionals and individuals in the community to ensure a focused improvement in each community's health status.*

ealth care services for people over 60 in Africa will need to be intensified in the next few years as they will number some 420 million by 1995 – 7% of the total population of the continent.

The traditional structures that once cared for the old are now in danger of disappearing for a number of reasons, including a rural exodus. Families have also suffered an enormous reduction in their financial capacity to provide for their elders as a result of the economic crisis engulfing the continent. It must also be said that most of the African countries have no specific social or medical policy for this vulnerable age group.

Traditional family ties are tending to break down. This throws a greater burden on the public services which are responsible for the welfare of the elderly.

This is the context in which, six years ago, the WHO Regional Office for Africa introduced a programme on the welfare of the elderly. Accordingly, it funded activities for the elderly in two countries in 1990 and 1991.

Designated as one of the targets for the community health programme, the welfare of the elderly is seen to depend on the utilization of their skills, economic independence, and the maintenance of physical fitness, mental health and social contacts. Stressing the community approach of primary health care, WHO regards the family as the indispensable circle within which older people must be made to feel valued and useful. Through dialogue with the young, for example, they may be able to pass on the cultural heritage of the past or teach the medicinal properties of certain plants.

To keep older people in good mental health, communities should entrust them with certain tasks, such as looking after children, or involve them in activities that interest them. As they are often poor, this could be a source of income for those who are physically fit. Older people should also be encouraged to join in committees to welcome visitors or village or district health committees, or to take part in interviews with the media.

Essential health care must be made available to the elderly and special attention must be given to the chronic diseases that sap their health (for example, diabetes, high blood pressure, degenerative joint disease). Their diet and personal hygiene need to be matters of concern for the community.

WHO'S African Member States are now being challenged to look for the means to develop domiciliary care, which is a much more important need for the elderly than hospital care. This will demand a change in attitudes among health workers and the public authorities. The former will have to explore a new aspect of their profession, while the latter must be brought to understand the need to increase their funding for this programme. ■

Prosper Mihindu-Ngoma is a journalist with the Congolese Information News Agency. His address is BP 2144, Brazzaville, Congo.

WHO in action

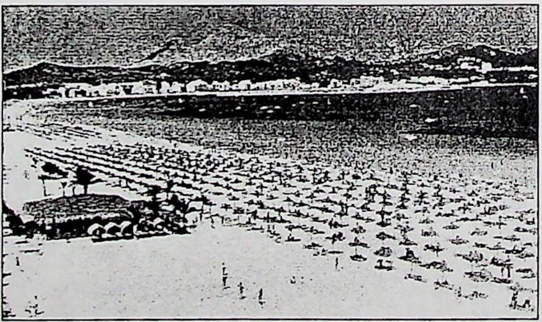
Risk-free beaches

n WHO's European Region, more than 100 million people each year use salt-water and fresh-water beaches for their recreation. Naturally, they want to be sure that they can enjoy their beach games or water-sports without the risk of falling ill from diseases caused by contamination or pollution. However, different countries have different ways of measuring water quality standards; most of them focus only on swimming and bathing as the main activities, and limit themselves to checking only the bacteria contents of the water. The "new" countries of Eastern Europe are also wondering what standards they should adopt.

The Mediterranean Action Plan – an initiative covering 17 coastal states and involving the UN Environment Programme (UNEP) as well as the WHO Regional Offices for Europe, Africa and the Eastern Mediterranean – laid down the microbiological basis for new, more comprehensive guidelines.

Now the WHO Regional Office for Europe is developing broader guidelines for the health-related monitoring of salt and fresh water as well as beaches. Dr Bent Fenger, water and waste scientist at the Rome-based WHO European Centre for Environment and Health, comments: "Recreational use does not begin at the water's edge. Beaches themselves are just as important, and guidelines are needed to evaluate their quality as well. Not only that, but service facilities and amenities such as toilets and food vending places have a health significance that needs to be considered."

The guidelines will also cover aspects that have hitherto received little attention. While people want bathing water that is free from any risk of infection, they also want water that does not stink, look cloudy, taste nasty or have oil, scum or litter floating in it. Then there are the physical characteristics of the bathing area. Is the bottom sandy or filled with sharp rocks? Does it contain broken glass or rusting cans? Is it flat, sloping or does it drop suddenly into deep water? The guidelines will provide clear explanations about what constitutes quality, and offer practical advice on how to achieve it.



Guidelines will provide precise explanations about what constitutes good quality for bathing water and surroundings.

"Our final customers are the people who use these recreational resources," says Dr Fenger. "We want to send a clear message to them about what WHO as a health organization recommends as good recreational quality." ■

Further details available from Dr Bent Fenger, WHO European Centre for Environment and Health, Via Vincenzo Bona 67, 00156 Rome, Italy.

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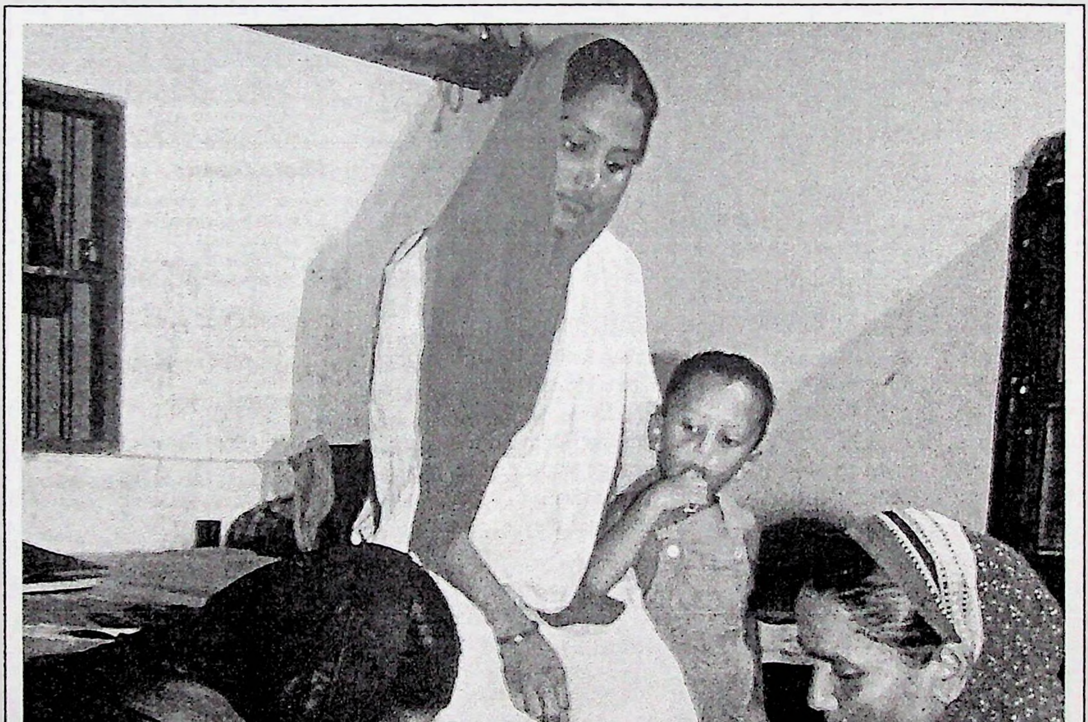
In the next issue

As we are approaching the 21st century many new developments are emerging in the socio-medical field. The next issue of *World Health* will describe some of the current trends which are shaping the medicine and the public health scene of tomorrow. ■

Printed in Great Britain by GreenShires Print Limited, Kettering, Northamptonshire, England.

HOME VISITS ARE A TRADITION THAT MUST BE STRONGLY ENCOURAGED



WORLD HEALTH ORGANIZATION

STUDY GROUP
HOME-BASED AND LONG-TERM CARE
Ma'ale Hahamisha, Israel § 5-10 December 1999

"THE INVISIBLE HEART—

CARE AND THE GLOBAL ECONOMY"

Chapter 3
Excerpt from *The Human Development Report 1999*
Published for the United Nations Development Program (UNDP)
New York Oxford
Oxford University Press
1999

CHAPTER 3

The invisible heart—care and the global economy

Studies of globalization and its impact on people focus on incomes, employment, education and other opportunities. Less visible, and often neglected, is the impact on care and caring labour—the task of providing for dependants, for children, the sick, the elderly and (do not forget) all the rest of us, exhausted from the demands of daily life. Human development is nourished not only by expanding incomes, schooling, health, empowerment and a clean environment but also by care. And the essence of care is in the human bonds that it creates and supplies. Care, sometimes referred to as social reproduction, is also essential for economic sustainability.

Globalization is putting a squeeze on care and caring labour. Changes in the way that men and women use their time put a squeeze on the time available for care. The fiscal pressures on the state put a resource squeeze on public spending on care services. And the wage gap between the tradable and non-tradable sectors puts an incentive squeeze on the supply of care services in the market. Gender is a major factor in all these impacts, because women the world over carry the main responsibility for these activities, and most of the burden.

In a globally competitive labour market, how can we preserve time to care for ourselves and our families, neighbours and friends? In a globally competitive economy, how do we find the resources to provide for those unable to provide for themselves? And how can societies distribute the costs and burdens of this work equitably—between men and women, and between the state and the family or community, including the private sector (box 3.1)?

To answer these questions requires an understanding of what care is, how it is provided, who bears the costs and the burdens and what the critical paths are to negotiating an equitable solution. These are little-explored issues, but an exciting new body of work is probing them.

Globalization is putting a squeeze on care and caring labour

Human development, capabilities and care

The role of care in the formation of human capabilities and in human development is fundamental. Without genuine care and nurturing, children cannot develop capabilities, and adults have a hard time maintaining or expanding theirs. But the supply of care is not merely an input into human development. It is also an output, an intangible yet essential capability—a factor of human well-being.

Most adults need care in the emotional sense, even if not in the economic sense of relying on one another. A clear manifestation of this is the positive effect of social support and social relationships on life expectancy—at least as significant as the negative effects of cigarette smoking, hypertension and lack of physical exercise. Married adults enjoy lower risks of mortality than those who are unmarried.

The difference that care makes for child health and survival is also well documented. A UNICEF analysis identifies caring as the third underlying factor in preventing child malnutrition, after household food security and access to water, health care and sanitation facilities. It is what translates available food and health resources into healthy growth and development. For example, risks of malnutrition and illness depend significantly on whether a child is breast-fed and how long, at what age it is given complementary foods and whether it receives immunizations on schedule. Many studies show that malnourished children grow faster when they receive verbal and cognitive stimulation—special attention can encourage a child in pain to eat.

Another link between human development and care relates to equity for the providers of caring labour. These activities are often identified with women's unpaid work in the domestic sector. This is an important source, but there are others. Not just the family but the community plays an important role. So do men, though their contribution is smaller than women's in most countries. The private sector provides domestic service, teaching, nursing and similar services. The public sector also provides many services in these areas (figure 3.1).

BOX 3.1

If we are going to compete, let it be in a game of our choosing

Once upon a time the goddesses decided to hold a competition, a kind of Olympics, among the nations of the world. This was not an ordinary race in which the distance was determined and the winner would be the runner who took the shortest time, but a contest to see which society, acting as a team, could move all its members forward.

When the gun went off, one nation assumed that the race would not last long. It urged all its citizens to start running as quickly as possible. It was every person for himself. Very soon the young children and the elderly were left behind, but none of the fast runners bothered to help them out because it would have slowed them down.

At first those who were in front were exhilarated by their success. But as the race continued some became tired or hurt and fell by the wayside. Gradually all the runners grew exhausted and sick, and there was no one to replace them. It became clear that this nation would not win the race.

Everyone's attention turned to a second nation, which adopted a slightly different strategy. It sent all its young men out ahead to compete, but required all the women to come along behind, carrying the children, the sick and the elderly and caring for the runners who needed help. The nation's leaders explained to the women that this was a natural and efficient arrangement from which everyone could benefit. They provided great incentives for the men to run fast, and gave them authority over the women.

At first this seemed to work, but the women found that they could run just as fast as the men if they were not burdened with caring for the weak. They began to argue that the work they were doing—caring for the runners—was just as important as the running and deserved equal reward. The men refused to make any changes. The nation began to waste a great deal of energy in bargaining and negotiation. Gradually it became clear that this nation, too, was losing the race.

So attention turned to a third nation, which had started out moving quite slowly, though making steady progress. In this nation everyone was required both to run and to take care of those who could not run. Both men and women were given incentives to compete, to run as fast as possible, but the rules required them all to share in carrying the burden of care.

Having agreed to rules that rewarded both kinds of contribution to the collective effort, people were free to choose their own speed, to find a balance between individual effort and collective responsibility. This freedom and equality contributed to their solidarity. Of course, it was this nation that won the race.

Perhaps this is a utopian fairy tale. But the global economic system tells us that we are all in a race. It tells us to hurry up. It tells us all to worry about our speed. But it does not tell us how long the race will last—or what the best long-term strategy is. And it does not tell us how victory will be defined. If we are going to compete, let it be a game of our own choosing. That is, in a nutshell, the challenge of the new global order: how to define a world economy that preserves the advantages of market competition, but establishes strict limits and rules that prevent competition from taking a destructive turn.

Source: Folbre 1999.

But in almost all societies the gender division of labour hands the responsibility for caring labour to women, much of it without remuneration—in the family or as voluntary activity in the community. *Human Development Report 1995* estimated that women spend two-thirds of their working hours on unpaid work (men spend just a fourth), and most of those hours are for caring work. The hours are long and the work physically hard—fetching water and fuel, for example—especially in rural areas of developing countries. In Nepal women work 21 more hours each week than men, and in India, 12 more hours. In Kenya 8- to 14-year-old girls spend 5 hours more on household chores than boys. These inequalities in burden are an important part of the obstacles women face in their life choices and opportunities.

Women also make up a disproportionate share of workers in domestic service and in professions such as child care, teaching, therapy and nursing. These occupations offer low pay relative to their requirements for education, skills and other qualifications—another source of gender biases in opportunities.

CARE—OR "TENDER LOVING CARE"

Care can mean a feeling of care, an emotional involvement or a state of mind. Personal identity and personal contact—especially face-to-face contact—are key elements of care services, involving a sense of connection between the givers and receivers. The care-giver may be motivated by affection, altruism or social norms of obligation. The care-receiver has a sense of being cared for. These elements are frequently there even when the care-giver is a paid employee. Individuals often choose caring jobs because they are a way to express caring motives and earn a living at the same time.

The commitment to care for others is usually thought to be altruistic—involving love and emotional reciprocity. But it is also a social obligation, socially constructed and enforced by social norms and rewards. A compelling example: when a mother gets up for the fifth time in the night to soothe her crying child, it is not necessarily because she gets pleasure from doing so. She may feel quite irritated. But she accepts a social obligation to care for her child, even at some cost to her health or happiness.

The word *care* often refers to looking after people who cannot take care of themselves: children, the sick, the needy, the elderly. But this misses the fact that even the healthiest and happiest of adults require a certain amount of care. Their need for that care may ebb and flow, but it sometimes comes in tidal waves.

GLOBALIZATION AND CARE

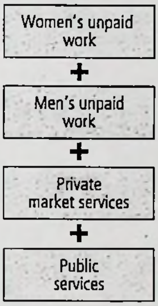
Economic analysis of care offers three insights into the impact of globalization on human development:

- Women's increased participation in the labour force and shifts in economic structures are transforming the ways care services are provided. Needs once provided almost exclusively by unpaid family labour are now being purchased from the market or provided by the state.
- Increases in the scope and speed of transactions are increasing the size of markets, which are becoming disconnected from local communities. As market relationships become less personal, reliance on families as a source of emotional support tends to increase—just as they are becoming less stable economically and demographically.
- Perhaps most important, the expansion of markets tends to penalize altruism and care. Both individuals and institutions have been free-riding on the caring labour that mainly women provide. Whether women will continue to provide such labour without fair remuneration is another matter.

Globalization is dominated by the expansion of markets and rewards profitability and efficiency. While economic growth reflects increasing private and public incomes, human development needs people to provide goods and services that fall outside the market—such as care and other unpaid services. A country can speed the growth of GDP by encouraging a shift in production from unpaid services such as care to market commodities. Care thus has clear analogies to environmental resources, with the characteristics of a resource outside the market. But a deficit of care services not only destroys human development—it also undermines economic growth.

This may be just what is happening in many OECD countries today, where there is a shortage of reliable, skilled labour in the midst of widespread unemployment. And despite universal schooling, there are widespread gaps in skills. Data from the International Adult Literacy Surveys in OECD countries show that nearly half the population in almost all these countries score below the level needed to be trained for a skilled occupation.

FIGURE 3.1
Four sources of caring labour



Source: Human Development Report Office.

The traditional restrictions on women's activities once guaranteed that women would specialize in providing care. Globalization's shifts in employment patterns have promoted and to some extent enforced the participation of women in wage employment. The supply of unpaid care services may be reduced, and daughters, cousins or nieces may have to take on more of the work. Nonetheless, women in most countries continue to carry the "double burden" of care services—ending up exhausted.

A challenge for human development is to find the incentives and rewards that ensure the supply of services—from the family, the community, the state and the market—all recognizing the need for gender equality and distributing the burdens and costs of care fairly (boxes 3.2 and 3.3).

Noble. But trends are moving in the opposite direction. In OECD countries the problem is that globalization has pulled back on state services and pushed more to private services. Many social commentators protest the ensuing deterioration in quality.

In the transition economies of Eastern Europe and the CIS these trends have been dramatic, contributing to the huge human costs of the transition. The dismantling and weakening of the welfare state have meant cuts and deterioration in services in health and education—across the board—contributing to the deteriorating human outcomes. Life expectancy was lower in 1995 than in 1989 in 7 of 18 countries—falling as much as five years since 1987. Enrolment in kindergarten declined dramatically—falling from 64% to 36% of 3- to 6-year-olds in Lithuania between

1989 and 1995, and from 69% to 54% in Russia. Responsibility for pre-primary education was transferred from the state to parents, with enormous consequences for mothers of children this age.

CARE AND MARKET REWARDS

The market gives almost no rewards for care. Much of it is unpaid—most of it provided by women, some by men. The market also penalizes individuals who spend time in these activities, which take time away from investing in skills for paid work or from doing paid work.

Care produces goods with widespread benefits for those who do not pay for them

Care services are also provided in the market, usually underremunerated. What explains the financial penalty for doing caring work? Gender bias is one factor. A second is the intrinsic reward people get from helping others, allowing employers to fill jobs at lower pay. A third is that people feel queasy about putting a price on something as sacred as care.

And global economic competition has tended to reinforce these trends, as the wage gap increases between the tradable and non-tradable sectors. Wages for teaching, domestic service and other caring work have stagnated—or even fallen—in the industrial countries.

BOX 3.2

Globalization leads to the feminization of labour—but the outcome is mixed

Many empirical studies now allow analysis of how shifts in trade patterns affect employment. A study covering 165 countries from 1985 to 1990 concludes that greater trade openness increases women's share of paid employment. Further analysis of plant-level data from Colombia and from Turkey—both with rapid export growth—shows that firms producing for export employ more female workers, often in skilled functions.

But increasing participation has not always meant less discrimination. Women constitute a large share of workers in informal subcontracting, often in the garment industry—at low wages and under poor conditions. Highly competitive international markets in garments also mean that the work is volatile—with contracts moving with small changes in costs or trade regulations.

Globalization has also been associated with home work, tele-work and part-time work. In the United Kingdom the share of workers with unconventional work arrangements rose from 17% in 1965 to 40% in 1991. In 1985 the shares of such work arrangements were up to 15% in Japan, 33% in the Republic of Korea and 50% in Mexico, Peru and Sri Lanka. And in Greece and Portugal women constitute 90% of the home workers. This is a mixed blessing. Informal work arrangements can accommodate women's care obligations in the family. But such jobs are often precarious and poorly paid.

Source: Özler 1999.

Care produces goods with social externalities—widespread benefits for those who do not pay for them. It creates human and social capital—the next generation, workers with human and social skills who can be relied on, who are good citizens. But mothers cannot demand a fee from employers who hire their children. This care will be underproduced and overexploited unless non-market institutions ensure that everyone shares the burden of providing it. The traditional patriarchal family, and gender biases in society that limit opportunities for women outside the role of wife and mother, have been the traditional way to solve this problem. But this is obviously inequitable, and no solution at all.

REDISTRIBUTING THE COSTS AND RESPONSIBILITIES OF CARE—TO FAMILY, STATE AND CORPORATION

Where do the effects of globalization fit in the larger conflicts over the distribution of the costs of care? Consider a mother who devotes much time and energy to enhancing her children's capabilities and a country that devotes much of its national budget to family welfare. In the short run both are at a competitive disadvantage: they devote fewer resources to directly productive activities. But in the long run their position depends on their ability to claim some share of the economic benefits produced by the next generation.

The family today is a small welfare state. Women invest time and energy in children—essentially a "family public good". They pay most of the costs—while other family members claim a greater share of the benefits. What they do is far less transferable outside the family than investments in a career. The resulting loss of bargaining power can mean less consumption or leisure time for women, even if they remain married and enjoy some of their husband's market income.

Public spending on children is modest compared with that by parents. Take public spending in the United States, about 38 percent of all spending. Over the past 30 years the elderly in the United States have received far more than the young for a simple reason—the elderly have more votes than parents with children. Studies in Western and Eastern European countries show similar biases against children. Parents who invest in the next generation of workers are not explicitly rewarded for their efforts. Their efforts are socially important but economically unproductive.

For much of the past 200 years nations have exercised a lot of control over the production of care services such as education, health and provision for dependants. The analogy of the family to the state is clear. Both institutions demand commitment to the welfare of the collective rather than the individual. But on the negative side, both institutions can generate oppressive hierarchies that interfere with the development of human capabilities.

Take a multinational corporation, tired of the frustrations of negotiating taxation and regulation with host governments, that buys a small island, writes a constitution and announces a new country—Corporation Nation. A citizen automatically receives a highly paid job. Sounds good, but some restrictions apply. Individuals must have advanced educational credentials, be physically and emotionally healthy, have no children and be under the age of 60. They do not have to emigrate but can work from their country over the Internet. And they immediately lose their new citizenship if they require retraining, become seriously ill, acquire children or reach the age of 60.

Corporation Nation can free-ride on the human capabilities of its citizen workers without paying for their production or their maintenance when ill or old. It can offer high wages to attract the best workers from around the world without threatening its profitability. Footloose capital of the globalized economy weakens the connections between corporations and communities, and the obligations to citizens. Why then would multinational firms remain in countries that tax them to support the production of human capabilities when they can go elsewhere and free-ride? They will remain for a while, out of habit and loyalty. But the ones that jump first to take advantage of new opportunities will win the race if the finish line is defined by maximizing the short-term value of market output.

THE CHALLENGE OF CARE IN THE GLOBAL ECONOMY

How can societies design new arrangements for care in the global economy—to make sure that it is not squeezed out?

Many fear that there is no alternative to the traditional model of the patriarchal household in which women shoulder much of the responsibility through unpaid work. The resurgence of religious fundamentalism around the world testifies to the anxieties about changing traditional patriarchal relationships that have ensured a supply of caring labour. Many social conservatives fear that globalization fuels market-based individualism at the expense of

BOX 3.3

More paid work doesn't reduce unpaid work

Women are responsible for most unpaid care work—a social norm slow to change. A review of time-use surveys in *Human Development Report 1995* showed a general trend to greater gender equality in unpaid work in the OECD countries, but no equalization in developing countries and a deterioration in the transition economies of Eastern Europe and the CIS.

Bangladesh had one of the largest increases in the share of women participating in the labour force—from 5% in 1965 to 42% in 1995. This has been important for export growth, with women as the main workers in the garment industry. But women still spend many hours in unpaid work. A survey of men and women working in formal urban manufacturing activities shows that women put in on average 31 hours a week in unpaid work—cooking, looking after children, collecting fuel, food and water (box table 3.3). Men put in 14 hours in activities such as house repair. Workers in the informal sector show similar patterns.

Women in Eastern Europe and the CIS spend more hours in paid employment than those in most other countries. But the gender disparity in sharing the burden of unpaid work remains stark, and it is worsening under the economic dislocations of the transition. In Bulgaria men's total work burden was 15% less than women's in 1977 but 17% less in 1988. Women increased their share of both paid and unpaid work—in 1977 men did 52% as much household work as women, but in 1988 only 48% as much. In Moldova women work 73.5 hours each week.

In OECD countries men's contribution to unpaid work has been increasing. But a woman who works full time still does a lot of unpaid work. Once she has a child, she can expect to devote 3.3 more hours a day to unpaid household work. Married women who are employed and have children under 15 carry the heaviest work burden—almost 11 hours a day.

BOX TABLE 3.3

Time spent in paid and unpaid work in Bangladesh, 1995

(hours per week)

	Formal sector workers		Informal sector workers	
	Men	Women	Men	Women
Unpaid work	14	31	14	24
Paid employment	53	56	23	21
Total	67	87	37	45

Source: Zohir 1998; UNDP 1995.

social commitments to family and community. A consistent theme of religious fundamentalism worldwide: re-establish rules that restrict women's rights for fear that women will abandon caring responsibilities.

At the other end of the spectrum is market provision of care—but often the people who need care cannot afford to pay for it. And finally there is state provision. But the search for efficiency in today's global economy imposes a "market discipline" that is at variance with quality. Cost-minimizing standards drive down quality in schools, hospitals and child-care centres. So public services alone are not a total answer, though state support must be a big part of it.

In all this, the challenge is to strike a balance between individual rights and social obligations of care. Competitive market societies emphasize values that encourage individualism—and say little about obligations and commitment to the family and community. The extreme responses of the patriarchal backlash and the marketization of care require far less effort and negotiation than the democratic response, which requires serious thinking about how to enforce responsibilities for care in the community.

So the first step must be to challenge social norms—to build commitment of both men and women to their responsibilities for caring labour. Societies—through public and corporate policy—then need to acknowledge care as a priority human need that they have a social obligation to foster.

A clear policy path is to support incentives and rewards for caring work, both paid and unpaid, to increase its supply and quality. This does not mean sending women back to the traditional role of housewife and mother, closing off other opportunities. It means sharing unpaid care services between men and women, reducing men's paid work time and increasing their time on family care. And it means increasing the supply of state-supported care services. Nordic countries have a long tradition of such approaches, which give public recognition and payment for care, rewarding family commitment but without reinforcing traditional gender roles (box 3.4).

BOX 3.4

Support for men's child-care responsibilities in Western Europe

Although several countries in Western Europe have encouraged gender-neutral family-oriented work policies, in 1995 only 5% of the male workforce in the European Union (EU) worked part time, and only 5% of fathers took paternity leave. Men often cite their work environment as a constraint when explaining their reluctance to make full use of parental and paternal leave rights or to work part-time to care for a child. Private sector employers in particular are seen as unsupportive of such arrangements. Traditionally it has been women who have had to move into part-time labour or take a career break after the birth of a child. EU Commissioner for Employment and Social Affairs Padraig Flynn has stated that "even where there are policy instruments aimed at breaking down the gender imbalance in caring . . . the assumption that caring is the responsibility of women persists."

Time use

Austria. Men spend an average of 70% of their time in paid labour, 30% in unpaid; women spend an average of 30% of their time in paid labour, 70% in unpaid. Women make up 98% of part-time employees.

Denmark. About 65% of men in the labour force work 30–39 hours a week, 30% work more and 5% less; 69% of women work 30–39 hours, 11% work more and 20% work less. In 1987 men spent 10 hours a week in unpaid work, women 21 hours; in 1997 men spent 13 hours in unpaid work, and women 18.

Germany. A third of women work less than 35 hours a week; only 2–3% of men do so.

Italy. Married women with children spend 7.5 hours each day in care work, men 1.5 hours.

Netherlands. Women spend twice as much time in unpaid work at home as men (women 32 hours, men 16). But women who work more than 30 hours a week spend only 18 hours in unpaid housework, compared with 19 hours for their husbands.

Spain. Women spend seven times as many hours doing domestic work as men.

Paternal and parental leave

Denmark. Fathers are allowed a 2-week paternal leave for the birth or adoption of a child. They can also use the last 10 weeks of maternity leave (10% of fathers do this). And there is a 4-week extension for fathers only.

Finland. Fathers may take 6–18 days of paternal leave, and 158 days of parental leave can be shared after maternity leave ends (parental leave is used by only 3% of fathers). One parent can take unpaid leave until the child is three. And parents are allowed 2–4 days a year to care for a sick child.

Italy. During the child's first year a 6-month parental leave can be taken after maternity leave ends (at 30% pay).

Norway. Employees may take parental leave for 42 weeks (at 100% pay) or 52 weeks (at 80% pay). Fathers must use at least 4 weeks of the parental leave; otherwise that period is lost. Parents may also combine their leave with part-time work. Employees are allowed 10–15 days each year to care for a sick child, single parents 20–30 days.

Sweden. Employees are allowed 10 days' paternal leave for the birth or adoption of a child, 450 days' parental leave (at 80% pay). One parent, usually the father, has an absolute right to one month (at 85% pay). Parents have the right to a 25% reduction in their work hours until a child is eight; child care is a legal right.

Source: Flynn 1998; EU Network 1998.

Citizens could be given tax credits for contributing care services that develop long-term relationships between individuals. And this model could be extended further. For example, many young adults benefit from public support for higher education. They could repay the costs through mandatory national service that takes some responsibility for children and other dependants in their community. The care services they could provide would be at least as valuable as military service, and they could develop important skills as well as reinforce the value of care.

Policies to foster more caring labour appear unproductive or costly only to those who define them as narrowly contributing to GDP or short-term profit. The erosion of family and community solidarity imposes enormous costs reflected in inefficient and unsuccessful education efforts, high crime rates and a social atmosphere of anxiety and resentment. The nurturing of human capabilities has always been difficult and expensive. In the past it was assured by a gender division of labour based on the subordination of women. Today, however, the cost of providing caring labour should be confronted explicitly and distributed fairly—between men and women, and among the state, the family or community and the employer.

WORLD HEALTH ORGANIZATION

STUDY GROUP
HOME-BASED AND LONG-TERM CARE
Ma'ale Hahamisha, Israel § 5-10 December 1999

"STRENGTHENING FAMILY-BASED CARE FOR FRAIL ELDERS"

LESSONS FROM U.S. AND U.K RESEARCH

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An earlier version of this paper was published as a chapter in a book: Archbold PG, Stewart BJ (1996) "The nature of the family caregiving role and nursing interventions for caregiving families", in E.A.Swanson and T. Tripp-Reimer (Eds.). *Advances in Gerontological Nursing*. (pp. 133-156). New York: Springer.

This paper was developed to address, in part, a recommendation identified in the Paper to the WHO Cabinet (WHO, 1999) entitled "Home-Based and Long-Term Care". Specifically, this paper contributes to the evidence base related to home care by reviewing research from the US and UK on family care for frail elders. Two categories of research are reviewed: 1) evaluations of interventions to improve family care in the home that could be adapted to other settings, and 2) descriptive reports about the nature of family care for frail elders that can lay the groundwork for the development of intervention strategies as yet untested. This paper assumes that home care for elders is inherently a public health issue and that strategies to assist and prepare persons to provide home care can be employed at a district level through existing structures such as public health nurses.

In the last two decades, two trends have interacted to increase the salience and visibility of home care for elders. One is the rapid increase in the absolute number and relative percentage of elders globally. The second is reliance on home care as a method for reducing hospital utilization. Both trends have increased the demands placed on family units.

Background

The family is the major provider of long-term and medically related services to elders in most countries. Home care by family members is increasingly prevalent in industrialized countries. For example, in 1996, nearly one in four US households contained at least one person who had provided unpaid assistance to a relative or friend aged 50 of older (National Allliance for Caregiving and the American Association for Retired Persons, 1997).

Provision of home care by family members can be very labor-intensive and long in duration. In the US, about half of the family caregivers for elders have been providing unpaid assistance for one to four years, and another quarter have been providing assistance for five years or more. Eighty percent of family caregivers provide unpaid assistance seven days a week and spend an average of four extra hours per day--more than a half time job--on family care tasks (Stone et al., 1987). Estimates indicate that the average care costs incurred by families of dementia patients were $4,564 for a three-month period, with 71% of the costs for unpaid labor (Stommel, Collins, and Given, 1994).

Family care to elders is undergoing unprecedented expansion. In 1950, in the US, the "parent-support" ratio (the number of persons 85 years old and over, divided by the number of persons 50 to 64 years old, times 100) was three. By 1993, the parent-support ratio had tripled to ten. By 2050, it is projected to triple again, to 29. Having living parents who are 85 and over will become commonplace in just over 50 years. Clearly, this dramatic increase in the parent-support ratio means that the effectiveness of relying on families as the mainstay of home care for frail elders must be examined in setting social policy (Boaz and Hu, 1997). In the meantime, we need to find ways to support the family in its home care efforts.

Typically, families take on home care responsibilities with little or no preparation from health care professionals. Home care by family members who are unprepared for and unsupported in their care has been linked to higher acute care utilization and costs for the elder (Anderson, 1990; Berry and Evans, 1985/86). Despite the health care system's increasing reliance on the family as the provider of home care, researchers have not addressed the capacity of the family to respond to these expectations, or looked at variations in the quality of family care. Family care for frail elders is sometimes "hidden" from view until a problem of significant magnitude triggers contact with the health care or social service systems (Phillips, Morrison, Steffl, Chae, Cromwell, and Russell, 1995).

Provision of home care to frail elders has been found satisfying, meaningful and rewarding by family caregivers (Farran, 1997; Fredman, Daly, and Lazur, 1995; Kramer, 1997; Miller and Lawton, 1997). However, it has also been linked to caregiver stress and role strain (Given and Given, 1991; Pearlin et al., 1990) and to negative health outcomes (Dura, Haywood-Niler and Keicolt-Glaser, 1990), including depression (Schulz et al., 1995) and prolonged grief following the death of the elder (Bass and Bowman, 1990). Families vary in their responses to providing home care. Some families do not have difficulty, while others do. Further, the same family can have difficulty at one time but not at another time (Archbold and Stewart, 1987). Among families experiencing difficulty in family care, the areas of difficulty vary considerably. Some families find providing personal care very hard, while others find that easy but have difficulty because of the impact of caregiving on other roles. Families in similar care situations also reported different levels of rewards of caregiving (Archbold and Stewart, 1988).

Interventions for Elders and Their Family Caregivers

In this background paper we have chosen to describe in detail those intervention studies that we think are particularly relevant for districts and countries wishing to support and improve the quality of home care. We have limited the review to research that includes outcomes for family caregivers. We have grouped the interventions into seven types: psycho-educational, respite, health services, comprehensive interdisciplinary home care, transitional care, telephone, and support groups.

work six hours per week (one hour per day) with the patient in the programme. Experimental families (n = 25) and comparison dyads (n = 28 placebo and n = 25 wait list controls) participated in the study for a period of nine months. Care recipients in the wait list control declined on the cognitive and behavioural outcomes, and the experimental group maintained baseline by the nine-month post-treatment testing. Care recipients in the experimental group actually exhibited cognitive improvements at the three-month post-treatment testing.

Effectiveness of Psycho-Educational Interventions

Despite the limitations of psycho-educational interventions, they appear to be effective in reducing strain and depression in some family caregivers. Knight et al. (1993) conducted a meta-analysis of interventions for caregivers, including ten controlled studies of psycho-educational interventions that attempted to change emotional distress in caregivers; emotional distress included subjective caregiver burden and emotional dysphoria (e.g., depression, anxiety, hostility). They reported average effect sizes for group interventions as .15 for burden (5 studies, 95% confidence interval [CI] = -.43 to .73) and .31 for emotional dysphoria (7 studies, 95% CI = -.38 to 1.00). The average effect sizes for individual interventions were .41 for burden (5 studies, 95% CI = -.04 to .86) and .58 for emotional dysphoria (3 studies, 95% CI = -.17 to 1.33). Thus, on the average, the group interventions had small effect sizes and the individual interventions had moderate effect sizes, with a greater effect on emotional dysphoria than on subjective caregiver burden in both group and individual interventions. The wide confidence intervals also reflect the degree to which intervention effectiveness varied across studies, ranging from large. Positive-effect sizes to small, negative-effect sizes. When effect sizes reported by Knight and colleagues are summarized by the randomization status of the studies, the results on effectiveness are less definitive; the median effect size in studies not fully randomized was .73 (range = .03 to 1.03), whereas the median effect size in studies where caregivers were randomly assigned to conditions was only .16 (range = -.22 to .66). Despite mixed results, we believe that psycho-educational interventions should be included as part of home care interventions and used when the caregiver has identified a lack of skill in care activities, high strain or negative affect as a problem.

Respite Studies

Respite care is a method of providing relief to the caregiver from the burden and strain of home care activities. It includes such interventions as day care, adult day health, and in-home respite. In some cases, respite involves the temporary admission of the elder to a hospital or long-term care facility overnight or for a longer period. With the exception of two studies (Lawton, Brody, and Saperstein, 1989; Montgomery and Borgatta, 1989), studies of respite care have not used true experimental designs. In Montgomery and

Borgatta's study, 94 caregivers received respite only; 89 caregivers received respite plus education, a family consultant, and a support group; 85 caregivers formed the control group. While the findings of Montgomery and Borgatta are encouraging regarding the beneficial effects of respite in reducing subjective burden (effect sizes = .74 and .75), the results by Lawton and colleagues (Lawton et al., 1989) are not as promising with regard to burden (effect size = .08), perhaps because the comparison group received high levels of respite from other community sources. However, families with respite care (n = 317) in Lawton's study maintained the patient with Alzheimer's disease in the community an average of 22 days longer than families in the control group (n = 315). Because previous research suggests that respite can be beneficial to families, it is one strategy that should be included in any home care programme.

Comprehensive Home Health Care

The classic experiments in providing comprehensive interdisciplinary home health care for very frail elders are by Zimmer and colleagues (1985) and Hughes and colleagues (1990) and, for families of persons with AD, by Mohide and colleagues (1990). In these studies, in-home services were usually 6-12 months in duration and included nursing, social work, and medical assessments; skilled nursing care; care planning; 24-hour telephone support; individualized teaching; support groups; and respite care to relieve caregivers from the strain of family care activities. The results were promising—patients who received services had significantly fewer hospitalizations, nursing home admissions, and outpatient visits than controls (Zimmer) and caregivers reported greater satisfaction with care (Zimmer and Hughes). However, the Zimmer, Hughes and Mohide samples were too small (Zimmer: n = 70 experimental, n = 76 control; Hughes: n = 119 experimental, n = 114 control; Mohide: n = 30 experimental, n = 30 control) to obtain significant differences on cost (Zimmer and Hughes) and caregiver emotional response (Mohide). Such comprehensive home health programmes have been found to be beneficial for frail elders with moderate to severe heart failure (Ekman et al., 1998) and cancer (McCorkle, 1988).

Transitional Care

One critical time in home care is the period following an acute illness and hospitalization. Transitional care by nurse specialists was successful in producing beneficial outcomes in elders who were discharged from the hospital (Naylor et al., 1994). The total sample included 276 older patients (n = 142 with medical diagnoses, and n = 134 with surgical diagnoses) and 125 caregivers. The transitional care administered to those people randomized to the intervention group (n = 140 patients and 74 caregivers) involved a comprehensive assessment by the nurse of the functional status of the older person as well as the primary caregiver's post-discharge needs. Most care was provided in the hospital and involved at least two visits by the nurse specialist during the hospitalization. In addition, the intervention included the availability of a nurse specialist by phone during and after the hospitalization. Further, the nurse initiated at least two telephone contacts to the patient within the first two weeks after discharge. For patients having medical diagnoses, the intervention group exhibited significantly fewer re-hospitalizations, shorter duration of re-hospitalizations, and smaller charges for re-hospitalizations than the control group. Differences were not found between the intervention and control patients with surgical diagnoses. This study indicates the value in placing nurses with advanced practice skills in a position to provide transitional care after an elder is hospitalized.

Telephone Advice and Monitoring

Two types of telephone interventions—telephone advice lines and telephone monitoring— have been used with success in a variety of health care arenas. Telephone advice lines through which families can receive timely responses to their health and home care questions from a health provider familiar with their situation have been used in hospice care since its inception and with frail elders and their families (Schler, Granadillo, and Vargas, 1985).

Telephone monitoring in which a health professional makes systematic assessments and, when needed, recommends interventions, has been used successfully in a broad range of health care situations (e.g., Gortner et al., 1988; Savage and Grap, 1999). In some of the interventions described earlier (e.g., Naylor, 1994; Zimmer et al., 1985), the availability of telephone advice lines and/or telephone monitoring was included in the system of care. At this point, we believe that evidence supports the institution of telephone monitoring and support systems for frail elders and their caregivers, and would encourage health care delivery systems to include phone advice in their service plans.

Support Groups

We chose to include a section on support groups because they are by far the most accessible intervention for caregivers in the US, especially caregivers for persons with Alzheimer's disease. These groups vary considerably in purpose and nature, and rigorous evaluation of their effects is difficult because people self-select into them when they are ready thus creating difficulties for randomizing to experimental and control conditions. The distinction between psycho-educational interventions and support-group interventions is blurred, because most psycho-educational groups provide support and most support groups provide some education; however, we distinguish psycho-educational groups from support groups by their more systematic educational focus. Most evaluations of support groups have been based on anecdotal comments from participants. Gonyea (1991), however, examined systematically the relationship between participation in a support group and the caregiver's sense of well-being. She concluded that although there were statistically significant (p < .05) Pearson correlations between support group participation and the three dependent variables of objective burden, subjective burden, and morale, the significant rs were small, with absolute values ranging from .10 to .19. Further, in multiple regression analyses, the strongest predictors of caregiver well-being were caregiver and elder characteristics. Because of the availability of support groups, providers may want to recommend them to family caregivers who express a need to interact with people who share a common family care experience. This recommendation should be made with the recognition, however, that the beneficial effects of support groups for elder caregivers have yet to be demonstrated empirically.

Distinguishing Features of Family Home Care Interventions

We would like to highlight some of the main strengths and limitations of different types of interventions, in terms of their relevance for home care. Two strengths of the psycho-educational interventions are that they are the most fully evaluated of the family care interventions and they are often targeted to specific family care problems. The comprehensive interdisciplinary interventions have long-term contact with the family as one important advantage; such sustained contact allows for monitoring of transitions and for the development of a therapeutic relationship with families. These comprehensive home health care interventions also have the advantage of an interdisciplinary approach to care and care planning that is tailored to the impaired older individuals and their families, but exactly how those interventions differed from usual care, except for there being more care, is not well described. In contrast, the interventions evaluated by the Quayhagen and Mohide research teams were described in much more detail. While promising, these three studies used small sample sizes and need to be evaluated in larger intervention trials before affirming their effectiveness.

In comparing the various types of family care interventions it is clear that the underlying goals of the interventions vary widely. For example, the goals of psycho-educational interventions are mainly to provide information, teach problem-solving skills, and help caregivers deal with their negative responses to family care (e.g., burden, depression). The goal of respite is to provide relief from everyday family care. The goals of support groups are to provide opportunities to obtain support from, and give support to, other caregivers who share the common experience of family care. The goals of most comprehensive interventions, transitional care, and telephone interventions are to improve the well-being of the impaired elders by augmenting care, often around times of health transitions, and include the goal of improving the way in which caregivers perform their family care role.

Most family caregivers want to do a good job in family care. Thus, they may be especially open to receiving assistance regarding the care they give. Home care interventions that focus attention on the way in which care is delivered by the family caregivers may be particularly helpful to elders and acceptable to families.

The Family Care Role

In this section we summarize results of descriptive, correlational and longitudinal research on the nature of the family care role that hold promise for home care interventions. Home health care providers intervene to help caregivers reduce burden, strain or depression and also to help family caregivers improve their ability to carry out the family care role. The nature of the family care role includes: (a) the type and amount of family care activities that are done, (b) the way in which the care is provided, and the quality of the care, and (c) transitions in the care provided.

In our opinion, the nature of the family care role is one of the most salient variables for home care interventions. The health care provider most often in contact with families in the community are nurses—themselves skilled caregivers-- who possess knowledge that is useful for family caregivers. Nurses in many settings have contact with elders and their family caregivers during times of health transitions; times when caregivers may feel unprepared for a new aspect of the family care role.

Type and Amount of Family Care Activities

In the last decade, findings from research have helped us understand the underlying purposes and meanings of the family care role to caregivers (e.g., Albert, 1991, Bowers, 1987). Bowers (1987) identified five categories of family care activities reported by 31 offspring caregivers of impaired elders including: anticipatory family care (behaviours or decisions based on possible needs of the parent), preventive family care (activities engaged in to prevent illness, injury, complications or deterioration in the parent), supervisory family care (activities such as arranging for, checking on, setting up), instrumental care (hands-on family care), and protective family care (protect the parent from threats to his or her self esteem). These findings could serve as the basis for new home care interventions; for example, health systems could offer courses for potential caregivers providing information about the range of activities that might be involved in future family care and sources of support and help for these activities.

Albert (1991) reported on how family caregivers think about the tasks they perform. In his study, he treated family care tasks as a cognitive domain, asking caregivers to specify "what sorts of things they do regularly for their parent", then eliciting judgments from them of similarities in tasks using a card sort. Using multidimensional scaling, Albert found that caregivers "think about the tasks they perform using three cross-cutting sets of distinctions: the type of impairment giving rise to the task (physical vs. cognitive-emotional limitation); where the task is performed (within the household vs. outside, involving others); and whether the task enhances parental autonomy or responds to a parent's incompetence" (p. 72). Caregivers did not categorize tasks according to the extent they were burdensome. Albert concluded that caregivers have an organized lay or folk understanding of their home care activities that sometimes differs and sometimes coincides with the view of the clinician or researcher. It is important, therefore, to try to understand the family care role from the caregiver's view.

While evidence suggests that there are many commonalities in family home care activities across illness categories (Kirschling, Stewart, and Archbold, 1994), it is also important to understand how family care differs across these categories. In all disease categories, caregivers provide help with personal care, transportation, housekeeping and emotional support. On the other hand, researchers have identified important and clinically relevant differences in the nature of the family care role such as pain management in cancer (Given and Given, 1994), managing behaviour problems in dementia (Pearlin et al., 1990), and assistance because of slowness in moving in Parkinson's disease (Stewart et al., 1993).

The Way in Which Care Is Provided and The Quality Of Care

Currently, we have a great deal of information about what activities caregivers do, but not a lot of information about the way caregivers do these activities (Biegel et al., 1991). Intervention planning has been hampered because of the lack of systematic information describing what caregivers try, what works, and what does not work. Cartwright and colleagues (1994) described ways in which caregivers report using enrichment processes to enhance family care; the two main types of enrichment processes identified were customary routines (e.g., bedtime rituals) and innovative routine breakers (e.g., enjoying a special dessert). Gilliss and Belza (1992) described ways in which caregivers provide comfort to people who have had open-heart surgery. Comfort measures included: helping the patients get up and out of chairs, beds, couches, and providing and positioning pillows while the patient is sitting up or lying down. Harvath (1994) described strategies used by caregivers to manage dementia-related behaviour problems, including such strategies as going along, putting off, and guiding.

In contrast to looking at task-specific family care, health care providers may also benefit from understanding how caregivers organize the totality of the role they need to perform. Nkongho and Archbold (1996) found that African

American caregivers engaged in a process of "working out systems" of care. These systems facilitated family home care by creating routines of care that attended to the needs of the older person and other family members and to the work roles of the caregiver. Caregivers reported that it took time to work out a system, and that systems had to be modified based on changes in the health status of the elder or other family members.

At this point, there is no standard measure of the quality of family care in the home. Work in the area to date has produced tools to detect poor quality care (e.g., neglect and abuse) (Phillips et al., 1990a, 1990b), but not to measure the positive aspects of quality. Clinical determination of poor quality care is confounded by legal issues (e.g., assignment of blame). Because a main goal of health systems may be to improve the quality of care provided by families, we think it is very important to develop measures of the quality of family care that are sensitive to the effects of interventions. Further, although there is some research linking amount of care provided to burden and strain (Oberst et al., 1989), little research exists about the association between the family care role variables of how care is provided and the quality of care and such responses to family care as burden, strain, rewards and depression.

Transitions in the Care Provided

In a longitudinal study of family care to 103 post-hospitalized elders, one quarter of caregivers interviewed at six weeks after the discharge reported that as time went on, family care had become somewhat or much more difficult for them, indicating difficulty in ongoing family care transitions (Archbold and Stewart, 1988). Between six weeks and nine months after hospital discharge, 3% of the caregivers died and 16% of the elders died. In the year after entry to the study, more than 60% of the elders were re-hospitalized--28% were hospitalized once, 22% were hospitalized two or three times, and 11% were hospitalized four times or more. These findings illustrate the magnitude and frequency of transitions that occur in family care. Bull (1992) found that in the transition from hospital to home care, caregivers worried about: (a) learning new skills needed to manage the medical condition, (b) modifying the environment, and (c) changing roles or functions within the family unit.

Caregivers of older persons recently discharged from the hospital reported that they used multiple sources of information in learning to provide care, including talking with professionals such as doctors, nurses and social workers (69%), using a trial and error approach (59%), talking with friends or relatives (53%), reading books and articles (37%), and a previous job taking care of a sick or disabled person (15%) (Stewart et al., 1993). Of these information sources, caregivers reported learning the most about how to take care of the elder's physical needs and how to find out about and set up services for the elder from health professionals. In sharp contrast, however, health professionals were one of the two poorest sources of information about taking care of the elder's emotional needs and handling the stress of family care. These findings suggest that health professionals may not be addressing caregivers' needs to learn how to handle the elder's emotional problems or the stress of family care--two important components of the family care role.

Specific disease categories and trajectories have been linked to transitions within home care. Given and Given (1994), for example, describe the process of shifting caregiver role responsibilities as the person undergoing cancer treatment is more or less able to perform their normal and illness-related roles. The model presented by these authors suggests that the following transitions to, and within, family care may occur: (a) transition to the acute, diagnosis period, (b) transitions to and across adjuvant therapies (chemotherapy, radiation, hormone), and (c) transition to palliative care. Even within one of the treatment categories (radiation), there may be multiple shifts required in the family caregiver role because of the patient's experience of physical (e.g., fatigue) and psychological effects of the treatment (Oberst et al., 1989).

In acute conditions, the family care role changes with the progression of the disease, the effects of treatment, and the rate of recovery. For example, Gilliss and Belza (1992) delineate changes in the priority goal of care and predominant caregiver work types for each week following cardiac surgery. Initially, the caregiver's goal is managing the illness, and the predominant work types are comfort and monitoring. In the second week, the goal shifts to managing everyday life, and predominant work types are functional and monitoring. Similar shifts in priority goals and work types continue through the fifth post-operative week. Preliminary evidence from the Parkinson's Spouses Study indicates that as this chronic disease progresses, caregivers do more of almost every type of family care activity, even those that one might assume are part of a regular spousal role, such as sitting and spending time with one's spouse (Stewart et al., 1993).

Such findings suggest that when caregivers experience transitions, they are sometimes faced with issues for which they are unprepared. We think that transition points may be times when caregivers are especially open to nursing interventions. Interventions such as Naylor's (1990) may be particularly useful at such times.

Creating Partnerships With Family Caregivers

Changes in health care financing in many industrialized countries, including the US and UK, create incentives for providing care in the least expensive setting--outside hospitals and long-term care institutions. These changes shift the responsibility of care from the health system to the family or other informal provider. In light of these changes, it will be important for health care providers to consider families as partners in the provision of health care to frail elders, and to develop innovative ways in which to collaborate with families in this endeavor.

Descriptive research has provided a basis for understanding of how family members create partnerships to manage chronic illness (Corbin and Strauss, 1988) and how family caregivers view their relationships with nursing home staff (Duncan and Morgan, 1994). Recently, nurses and other professionals have experimented with innovative strategies for developing partnerships with family caregivers (Harvath et al., 1994) focused on blending local (family) and cosmopolitan (health care provider) knowledge in developing and tailoring intervention strategies for family-identified care issues.

Conclusions

In this paper we have argued that health systems have an important role in providing services to family caregivers and that community and public health nurses are in an excellent position to provide these educational and support services.

Finally, based on descriptive and correlational studies of family care, and a pilot study of nursing interventions to support family caregivers in the home (Archbold et al., 1995), we recommend the following strategies to strengthen family care supports.

1. **Establish systems for systematically assessing family care.** Systematic assessment of the family care situation is needed to identify family strengths and family care issues known to be associated with caregiver role strain. Issues identified through assessment may include unpreparedness and lack of skill for specific care activities, unpredictability in the care routine, low enrichment, low mutuality, caregiver role strain, and caregiver and elder health problems.

2. **Train health care personnel to focus interventions on the family rather than an individual patient/client.** The management of chronic illness requires the cooperative efforts of involved family members. Such an approach enhances the health status and satisfaction of both the elder and family caregiver.

3. **Train health care personnel to work together with families to blend family and provider knowledge.** Resolution of family care issues is facilitated by families and health care providers working together to blend their knowledge to identify issues and generate strategies to solve them. Family involvement in generating strategies to solve issues is more likely to lead to success than imposition of strategies by health care providers.

4. **Recognize that complex family care issues may require multiple intervention strategies tailored to the family.** Working in partnership, family members and the health provider can implement and evaluate multiple strategies that are tailored to the specific family situation until the family care

issue is resolved. Interventions are tailored based on elder, family and cultural characteristics, and family preferences

5. **Set up systems to detect problematic transitions in family care.** The final principle is detecting problematic transitions in family care over time. Transitions occur for many reasons, including illness or death of the elder or caregiver, a change in the family care environment or the level of support available to the family. Methods to detect and respond to transitions in family care include access for the family to a provider familiar with their situation and periodic monitoring of families for change.

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ANNEX 1

Guidelines for Development of Framework for Implementation of Community-based and In-Home Programmes for Care of Older Persons

1. Introduction

Old age per se is not necessarily accompanied by serious illness, disability and dependence. Advanced age does however mean an increased vulnerability to a range of potentially disabling conditions. A significant minority of older persons will experience chronic disabling illness at some time. The public and private health services available generally to the community may be inappropriate and insufficient to provide the necessary services to such an older person and their family. Care of older persons in the community who exhibit frailty, chronic illness or disability beyond the capability of immediate family and other informal support arrangements to satisfactorily cope with calls for a system of formal in-home assessment, management, rehabilitation and long term care aimed at maximizing the older persons independence and avoiding unnecessary institutionalization.

These guidelines propose a series of considerations that should govern the development of an effective national framework for the implementation of such programmes.

A comprehensive approach to implementation of community-based, in-home care programmes must consider both national policy and local organizational and service issues.

2. National policy on long term care

2.1 It is important for any community-based services provided by government, non-profit organizations or the private sector to be planned and implemented in the context of a comprehensive national system of long-term care for older persons.

2.2 It is most common for such systems to be devised for the advice of the government by a formally established and appropriately structured top level national advisory council.

2.3 The structure of such an advisory council should reflect the multisectoral and multidisciplinary nature of the task and the necessary involvement of all levels of government in partnership with nongovernmental organizations, the community and families.

2.4 One of the first tasks of such an advisory body is to confirm the justification for formulation of national policy and establishment of a national system of long term care by reference to the demography, epidemiology, health and social care needs of older persons in an ageing population and the potential impact of ageing on the quality of life, health and well-being of older persons themselves, their families, society and the implications for national development.

2.5 Another task of the advisory body is to set forth, for government adoption, the basic principles that should underpin the provision of a long term care system for older persons. Such principles must be drawn up in the context of each country's political, social and cultural context but as a minimum should encompass the rights of older persons to access services that: are suitable to their assessed needs, provide for personal choice, are comprehensive and coordinated, and provide high quality, effective and efficient services.

2.6 A further critical consideration at the outset is to establish the appropriate nature and sources of funding to ensure sustainable long-term care. Here again, an appropriate funding arrangement possibly incorporating elements of public funding, social insurance and user payment in various combinations must be devised taking into account broader national considerations.

3. *Loci of responsibility for long-term care of older persons*

3.1 A comprehensive long-term care system providing community-based in-home care is inevitably a complex arrangement involving health and social welfare bodies, government authorities and agencies, non-profit and private organizations, community groups, families and older persons and their organizations. Such a system also must interact with other major related national programmes including health and hospital care services, and social welfare programmes including income security provisions where these are in place.

Consequently it is essential for the mandates and specific role and responsibilities of participating sectors, agencies, services and units to be defined to avoid dispute, overlap and confusion in practice.

3.2 To implement a national system a responsible lead agency should be designated and provided with the necessary resources. The need for multisectoral involvement and wide community consultation should be acknowledged.

3.3 The active involvement of non-profit and private agencies in addition to the government should be sought to ensure a comprehensive and coordinated approach to providing care

4. Identification of needs and establishment of norms for level of provision

4.1 Historically the establishment of levels of provision of care for older persons has generally been arbitrary and based on ad hoc consideration of the services provided in the past as a result of demand and supply forces rather than any rational approach. The determination of needs is a complex process and many countries have now instituted more formal and structured processes for determining needs of the community and establishing norms for provision of long-term care. The definition of needs and the identification of the characteristics, numbers and location of target populations for long term-care can be identified through:

- analysis of existing census information, data collections, past surveys and studies of older persons and their carers
- community consultations with all 'stakeholders' involved in long-term care of older persons including older people themselves and their families
- the conduct of purposely designed new national and local studies and surveys.

4.2 Through these and other methods national norms can be formulated that provide a basis for planning and also for controlling the future provision of long-term care services and the balance between different forms of provisions. For example using these approaches the Japanese authorities estimated that about 1.5% of their population aged 65 to 69 years were in need of long term care rising to 11.5% for those aged 80 to 84 and 24% for those aged 85 years and over. Such figures when derived can be analysed in conjunction with demographic projections to identify future requirements for care.

4.3 Studies throughout the world have identified the family, especially female children of older persons, as the main source of long term care. Both older persons and their family members in may studies have expressed a preference for in-home care provided principally by family members rather than institutional care. The burden on family care givers needs to be recognized and this too can be systematically identified and measured so the need to provide support to sustain the ability of families to continue this role can be taken into account.

4.4 It seems likely that the level of need for long-term care by gender, age and social circumstances will mostly be very similar from country to country. However different social, cultural and environmental circumstances will prevail. Also, variation in existing arrangements and provisions as well as differing attitudes and expectations means that each country must establish its own appropriate norms and be prepared to review these periodically as circumstances and experiences change over time.

5. *Review of existing systems, services and programmes*

5.1 Prior to any major development of community-based long-term care for older persons a comprehensive review of existing programmes and services should be undertaken in order to establish the baseline situation.

5.2 The following questions among others should be addressed in such a review:

- What are the existing sectors, groups, units, organizations and agencies involved in the provision of community-based services for older persons?
- What are the specific programmes and services currently provided?
- What are the criteria for assessing older persons for provisions of services?
- What are the financial arrangements for funding and payment for services provided?
- What are the arrangements for coordination of services provided to individuals and what are the existing relationships and linkages between various service providers?

5.3 Based on the finding of such a review an assessment of the existing deficiencies and gaps in service provision should then be made as a basis for planning and future development.

6. *Definition of community-based services to be provided*

6.1 The range and scope of community-based services provided to older persons and their carers should substantially be defined by the needs analysis carried out nationally as set out above. There are however a number of basic services that may be provided in any community-based programme for older persons. These include the following:

In-home services including:

- assessment
- home help services (basic housekeeping, cleaning and home duties assistance)
- delivered meals
- home nursing
- assistance with bathing
- personal care
- in-home respite care
- household shopping
- home alterations
- laundry services (especially for incontinent persons)
- certain specialist services such as incontinence support, dementia support and mobility assistance
- medical assessment and care

Day care services

- assessment
- meals
- bathing and grooming
- recreations
- physical activities
- nursing care
- special dementia care

6.2 The above in-home and day care services may be linked to community rehabilitation programmes that provide active rehabilitative services including medical, nursing, allied health and assistive devices services aimed at restoration and maintenance of function for disabled older persons.

Linkages should also be established with hospital-based services and with institutional long term care facilities particularly to ensure a continuity of care as people may move from one mode of care service to another.

In addition the types of services identified above may be linked to broader preventative and health promotive activities that may include identification of 'at risk' individuals, screening, health education and health promotion programmes that may also be directed at well older persons.

Apart from direct care provisions community programmes may extend into wider activities aimed at maintaining the activity and productivity of older community dwelling adults in such programmes as older volunteer services, self help, foster grandparenting schemes and local income generating schemes for older persons.

6.3 It should be stressed that the above are indicative only and the precise activities that are included in particular home-care programmes will be governed by many factors that should be taken into account in national and local planning and development.

7. *Organizational structures*

7.1 As noted above the level and range of organizations involved in the provision of long-term care for older persons and especially for community-based care may be quite complex. In addition government instrumentalities may vary according to the size, political and structural organizations of government in each country. The precise role should be defined for each level viz. national, provincial and local levels of government where they exist. In general, national government will be involved primarily in policy, national guidelines and standards and in funding while provincial and local government may be involved more directly in provision of services.

7.2 A very common form of structure in provision of community-based care for older persons is where non-profit organizations are subsidized by government to provide services. The type of NGO involved may vary and the level and range of services provided by individual organizations will also vary considerably. In these circumstances government have an important role in ensuring comprehensive coverage and in monitoring and enforcing basic standards and quality of care.

7.3 Many countries at present do not have clearly articulated national policies and funding arrangements and subsidy provisions are not managed systematically. While the requirements for community-based care for older persons is small and provision is relatively patchy this situation may tend to prevail. As demand inevitably increases, there becomes an urgent need to systematically approach the issues from a national and local perspective and the sooner action is taken by government to put in place the appropriate policies, enact necessary legislation and plan systematically the better placed any national and community will be to cope with the ageing of its population and the needs of the community for these services in the future.

7.4 In circumstances where provision of community-based services remain limited and the national policy and organizational frameworks outlined above have yet to be developed there is a valid case for demonstration programmes at local level to act both as a preparatory exercise to meet future demand and to help catalyse the progress towards more comprehensive services in the future. The experience of rapidly ageing societies in the Western Pacific Region such as Japan, Hong Kong (China) and Singapore has been that it is better to put the necessary structures for comprehensive and coordinated national provision of long term care for older persons in place in advance of the urgent need for such services as the increase in proportion and numbers of the older population eventually demand.

8. *Assessment*

8.1 Especially in a long-term care system provided by a substantial subsidy from national government and/or long-term care insurance a systematic approach must be taken to the identification (and certification) of individual need. A fair and objective system of professional assessment within prescribed standards for certification is necessary to ensure the most appropriate application of limited resources and to maximize the efficiency and effectiveness of the services provided. Even if the control of government funded or subsidized services is not a consideration assessment is essential to establish need and to ensure the provision of quality of care.

8.2 Assessment in formal sense has been defined as: "A multidimensional, usually inter-disciplinary, diagnostic process used to quantify an elderly individual's medical, psychosocial and functional capabilities and problems with the intention of arriving at a comprehensive plan for therapy and long term follow-up".

8.3 An essential component of assessment to determine need is involvement of the older persons themselves and their carer(s). Ultimately, the assessment procedure and subsequent provision of care involve the wishes of the older person to whom care is to be provided and they should be enabled to make those decisions with the assistance of the people who are making the formal assessment of their need.

8.4 The level and sophistication of assessment will depend to a considerable extent on the nature of the organizations and the services for which the individual assessment is being undertaken. It should be recognized however that assessment is a very central process in provision of quality services to older persons and as such is a powerful element in influencing their quality of care and indeed their quality of life and well-being. Wherever possible assessment arrangements should be coordinated and comprehensive and multiple assessments by many agencies should be assiduously avoided through coordinated care arrangements.

8.5 Comprehensive assessment of an older person seen as in need of community support should incorporate all the following elements. Though the degree of depth to which each factor is pursued will depend on the nature of the assessment and individual circumstances:

- Demographics
- Social support
- ADL/IADL
- Nutritional Status
- Mental Health Status - mood & cognition
- Sleep
- Health related behaviours
- Medical history
- Medication
- System Review
- Physical examination & performance-based functional assessment
- Financial circumstances
- Psychosocial relationships/elder abuse
- Caregiver(s)
- Physical environment including home itself
- Community resources

Other specialist assessment such as diagnostic and laboratory testing may be undertaken as dictated by the specific health and medical circumstances of the individual and the judgement of their medical care adviser.

8.6 Assessment procedures and documentation must be established to include these elements and others that may be necessary for particular programmes. This comprehensive approach to assessment serves a number of key functions including:

- Allocation of scarce resources on basis of demonstrated need
- Matching of needs to correct care options

Providing data base for:
planning individual programmes of care,
needs-based planning,
identification of gaps in service,
evaluation, and
meeting reporting requirements of authorities.

9. Coordination of care

9.1 With development of community-based care services for older persons it has become apparent from the experience of many countries that as programmes are developed and expanded frequently under differing auspices older people and their carers may be faced with a bewildering array of different programmes and multiple organizations. In addition many programmes in these circumstances will have individual mechanisms for care assessment.

9.2 A major problem with the provision of multiple programmes in the community is the potential for overlap, duplication, even unproductive competition, and sometimes conflicting provision of specific services to individuals.

9.3 A comprehensive system of provision of community-based services needs to be supported by a systematic approach to assessment in the first instance followed by an organized method of developing a care plan tailored to individual needs and developed in consultation with the older person and their informal carer

9.4 Once an appropriate care plan has been agreed it is necessary to ensure that care arrangements are managed efficiently and are periodically reviewed. Assessment should be seen in this arrangement as an ongoing process that helps monitor the older persons' changing circumstances and needs and make provision for adjustment of any care plan according to any change in circumstances.

10. Quality assurance

10.1 All community-based services for older persons should be supported by a system of continuous quality management.

10.2 Outcome standards should be established for all services provided and a system of monitoring and improving quality of care should be instituted.

11. *Human resources development*

11.1 All personnel working in community-based programmes should receive appropriate basic training and be given the opportunity of continuing education to maintain knowledge and skills.

11.2 Training opportunities should also be extended to volunteer personnel.

11.3 Training should also be made available to prepare and help informal carers to more effectively carry out their functions in providing ongoing care and assistance in the home.

12. *Evaluation and planning*

12.1 The introduction of new services especially as a part of demonstration programmes should incorporate built-in plans for evaluation at the outset.

12.2 Evaluation is essential to test the efficacy and the efficiency of community-based interventions and care and to assist in the determination of the wider application of the services and programmes developed on a trial basis.

12.3 Evaluations may have both a summative purpose (designed to test and report on the extent to which a service or programme has achieved the objectives set for it) and formative purpose (designed to provide guidance on the further development and directions of a service or programme).

13. *Research and development*

13.1 Community-based care for older persons is in many circumstances in an early stage of development. It is important to provide the necessary conceptual and factual underpinning of programmes and services being provided. Systematic collection of data and its scientific analysis is essential to support the formulation of community needs and to measure the impact and outcomes of services provided.

13.2 The ongoing development of community-care services for older persons should be guided by information obtained through evaluation as mentioned above and through a systematic approach to epidemiological and health systems (operational) research in the field.

13.3 Cross-national and international collaborative efforts in research should be encouraged so that the experience of other countries that may be at different levels of development in terms of their community-based services for older persons can share experience, technical expertise and findings to mutual benefit.

LTH/HSC/SG/99.4-1, Rev. 1

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WORLD HEALTH ORGANIZATION
ORGANISATION MONDIALE DE LA SANTE

Study Group Home Based And Long Term Care

Ma'ale Hachamisha, Israel, 5-10 December 1999 30 August 1999

PROVISIONAL PROGRAMME

1. Sunday 5 December 1999

-	5:00-6:00	Registration
-	6:00-8:00	Informal Get-together and exchange of views

2. Monday 6 December 1999

-	9:00-9:30	Opening
-	9:30-10:30	Overview Review of Study Group Objectives and mode of work
-	10:30-11:00	Refreshment
-	11:00-12:30	Discussion on elements and scope of home care including necessary basic resource availability in the home.
-	12:30- 1:30	Lunch
-	1:30-3:00	Overview of home care initiatives in the WHO Regions AFRO AMRO EMRO
-	3:00-3:30	Refreshment
-	3:30-5:00	Overview of home care initiatives in the WHO Regions EURO SEARO WPRO

3. Tuesday 7 December 1999

-	9:00-9:30	Review of previous day's work
-	9:30-10:30	Sectoral and inter-sectoral policies on home care
-	10:30-11:00	Refreshment
-	11:00-12:30	Discussion on implications for countries at different levels of development and different epidemiological/demographic profiles
-	12:30- 1:30	Lunch

- 1:30-3:00 Financing of home care
- 3:00-3:30 Refreshment
- 3:30-5:00 Discussion on implications for countries at different levels of development and different epidemiological/demographic profiles

4. Wednesday 8 December 1999

    - 9:00-9:30 Review of previous day's work
    - 9:30-10:30 Organization/management of health services, basic material resources and human resources (formal and informal)
    - 10:30-11:00 Refreshment
    - 11:00-12:30 Discussion on implications for countries at different levels of development and different epidemiological/demographic profiles

    - 12:30- 1:30 Lunch

    - 1:30-3:00 Organization/management of health services, basic material resources and human resources (formal and informal)
    - 3:00-3:30 Refreshment
    - 3:30-5:00 Discussion on implications for countries at different levels of development and different epidemiological/demographic profiles

5. Thursday 9 December 1999

    - 9:00-9:30 Review of previous day's work
    - 9:30-10:30 Home Care and the Life Cycle: Review implications for policies and financing of home care
    - 10:30-11:00 Refreshment
    - 11:00-12:30 Discussion on implications for countries at different levels of development and different epidemiological/demographic profiles

    - 12:30- 1:30 Lunch

    - 1:30-3:00 Home Care and the Life Cycle: Review Implications for organization/management of health services, basic material resources and human resources (formal and informal)
    - 3:00-3:30 Refreshment
    - 3:30-5:00 Discussion on implications for countries at different levels of development and different epidemiological/demographic profiles

6. Friday 10 December 1999

-	9:00-9:30	Review of previous day's work
-	9:30-10:30	Discussions and recommendations in relation to countries at different levels of development and different epidemiological /demographic profiles
-	10:30-11:00	Refreshment
-	11:00-12:30	Discussions and recommendations, continued
-	12:30- 1:30	Lunch
-	1:30-3:00	Discussions and recommendations, continued
-	3:00-3:30	Refreshment
-	3:30-4:30	Approval of Recommendations and Outline of Study Group Report
-	4:30-5:00	Closing

WORLD HEALTH ORGANIZATION **ORGANISATION MONDIALE DE LA SANTE**

Téléphone central/Exchange: 791. 21.11
Direct: 791

With the compliments

of the

Director-General

Avec les compliments

du

Directeur général

and
Dr Miriam Hirschfeld
Special Adviser to the Executive Director
Social Change and Mental Health

Dr Mohan K. Issac
Professor & Head, Department of Psychiatry
National Institute of Mental Health &
Neurosciences
Post Bag No. 2900, Bangalore 560 029
Inde

Dear Dr Issac,

3 November 1999

Please find initial background documentation for the Study Group on Home Based and Long-Term Care to be held 5-10 December 1999 in Ma'ale Hahamisha, Israel.

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WORLD HEALTH ORGANIZATION
ORGANISATION MONDIALE DE LA SANTE

Study Group Home Based And Long Term Care

Ma'ale Hahamisha, Israel, 5-10 December 1999 5 November 1999

PROVISIONAL AGENDA

1. Opening of Meeting, Executive Director's Speech
2. Adoption of Agenda
3. Review of Study Group Objectives and Mode of Work
   - 3.1 Discussion on elements and scope of home care
   - 3.2 Overview of home care initiatives in WHO Regions
4. Sectoral and inter-sectoral policies on home care
   - 4.1 Discussion on implications for countries at different levels of development and different epidemiological/demographic profiles
5. Organization /management of health services
   - 5.1 Discussion on basic material resources and human resources (formal and informal)
   - 5.2 Discussion on implications for countries at different levels of development and different epidemiological/demographic profiles
6. Home Care and the Life cycle: Review of implications for policies and financing of home care.
   - 6.1 Discussion on implications for countries at different levels of development and different epidemiological/demographic profiles
7. Recommendations
   - 7.1 Discussion and recommendations in relation to countries at different levels of development and different epidemiological/demographic profiles
   - 7.2 Approval of Recommendations and Outline of Study Group Report.
8. Closing Speech

LTH/HSC/SG/99/List of Working Documents

WORLD HEALTH ORGANIZATION
ORGANISATION MONDIALE DE LA SANTE

Study Group Home Based And Long Term Care

Ma'ale Hahamisha, Israel, 5-10 December 1999 5 November 1999

LIST OF STUDY GROUP WORKING DOCUMENTS

LTH/HSC/SG//99-WD	List of Working Documents
LTH/HSC/SG//99/1-1	Provisional Terms of Reference
LTH/HSC/SG//99/2-1	Provisional Agenda
LTH/HSC/SG//99/3-1/3-3	Provisional Programme
LTH/HSC/SG//99/4-1/4-3	Provisional List of Participants

WORLD HEALTH ORGANIZATION
ORGANISATION MONDIALE DE LA SANTE

Study Group on Home-Based and Long-Term Care

Ma'ale Hahamisha, Israel, 5-10 December 1999 7 December 1999

LIST OF STUDY GROUP WORKING DOCUMENTS

LTH/HSC/SG//99, Rev.1	List of Working Documents
LTH/HSC/SG//99.1-1	Terms of Reference
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LTH/HSC/SG//99.3-1	Provisional Programme
LTH/HSC/SG//99.4-1, Rev.1	Provisional List of Participants
LTH/HSC/SG/99/1	Archbold PG and Stewart BJ. Strengthening family-based care for frail elders: lessons from U.S. and U.K. research.
LTH/HSC/SG/99/2	The invisible heart – care and the global economy. In: *The Human development report 1999,* chapter 3. New York, Oxford University Press, Published for the United Nations Development Program, 1999.
LTH/HSC/SG/99/3	Health care is homeward bound. *World health.* July-August 1994, No. 4.
LTH/HSC/SG/99/4	Issues in home care services. Issues in informal care. In: Social Policy Studies, No. 19, *Caring for frail elderly people, policies in evolution,* chapters 4 and 5. Paris, Organisation for Economic Co-operation and Development, 1996.
LTH/HSC/SG/99/5	Home-based long-term care. Paper to Cabinet, Social Change and Mental Health. World Health Organization, 25 May 1999.
-X LTH/HSC/SG/99/6 MISSING	Confronting AIDS: public priorities in a global epidemic. Washington DC, The International Bank for Reconstruction

	and Development and The World Bank, 1997 (A World Bank policy research report).
LTH/HSC/SG/99/7	Sungkhobol D. Home care initiatives in the WHO South-East Asia Region.
LTH/HSC/SG/99/8	Fritsch K. Western Pacific Region overview of work in progress and major concerns on home-based and long-term care (expanded version [copy without cover]).
LTH/HSC/SG/99/9	Home care issues – AMRO-PAHO.
LTH/HSC/SG/99/10	Mwanzia JN. Review of regional experiences and major concerns on home-based and long-term care in the African Region.
X WHO/HSC/LTH/99.1 MISSING	Havens B. *Home-based and long-term care; home are issues at the approach of the 21st century from a World Health Organization perspective: an annotated bibliography.* Geneva, World Health Organization, 1999 (unpublished document).
WHO/HSC/LTH/99.2	Havens B. *Home-based and long-term care: home care issues and evidence.* Geneva, World Health Organization, 1999 (unpublished document).
ISSA/CONF/BRAT/99	Scheil-Adlung X. Health: new requirements for long-term care. Conference paper, International Social Security Association: "Demographic trends and globalization: Challenges for social security". Bratislava, Slovak Republic, 14-15 October 1999.
–	Annex 1: Guidelines for development of framework for implementation of community-based and in-home programmes for care of older persons. In: *Guidelines for national policies and programme development for health of older persons in the Western Pacific Region.* Manila, World Health Organization Western Pacific Region, 1998.
–	Aging in developing countries: source materials and highlights from the literature. Jerusalem, JDC-Brookdale Institute, December 1999.

Ageing and Health Programme
World Health Organization

Milbank Memorial Fund

WHO/HSC/AHE/00.1
Distr.: General
Orig.: English

Towards an International Consensus on Policy for Long-Term Care of the Ageing

Ageing and Health Programme
World Health Organization

Milbank Memorial Fund

WHO/HSC/AHE/00.1
Distr.: General
Orig.: English

Towards an International Consensus on Policy for Long-Term Care of the Ageing

Table of Contents

Foreword

This report describes initial actions in devising an international consensus on policy for long-term care for frail elderly persons. The report is the work of policy makers and experts from 11 countries, convened by the Ageing and Health Programme of the World Health Organization (WHO) and the Milbank Memorial Fund. The Ageing and Health Programme's main aim is to promote principles that can ensure the attainment of the highest possible quality of life in older age for the largest possible number of people. The Fund is an endowed philanthropic foundation, established in New York in 1905, that works with decision makers in the public and private sectors on significant issues in health policy. Persons who participated in writing this report are identified in the Acknowledgments.

The report describes principles to inform policies for sustainable programs in long-term care that are consistent with the priorities of individual countries, whether industrialized or developing. The Director-General of WHO, Dr. Gro Harlem Brundtland, addressed the theme of this report when she launched the International Day of Older Persons in October 1999. "Older persons," she said, "who are in need of care are the ones who most need…leadership in developing right and affordable policies to ensure dignity and quality of life."

The members of the group that prepared this report emphasize that it is a first, incomplete step toward an international consensus on guiding principles for policy. On their behalf, we invite readers of this report to comment on it and particularly to offer principles and issues for inclusion in future editions. Comments can be addressed to either WHO or the Fund, either by mail, fax, or e-mail, as listed on the back cover of the report.

Daniel M. Fox	Alexandre Kalache
President	Chief, Ageing and Health Programme
Milbank Memorial Fund	World Health Organization

Preamble

Recognizing the Universal Declaration of Human Rights, the Vienna International Plan of Action on Ageing (IPAA), the United Nations (UN) Principles for Older Persons, and subsequent international research and policy efforts, the Ageing and Health Programme of the World Health Organization (WHO) and the Milbank Memorial Fund (MMF) agree that a consensus is emerging among international policy makers concerning the provision of long-term care for older persons in need. This coincides with the UN International Year of Older Persons 1999 and underscores the relevance of its theme, "towards a society for all ages." Within this framework, a conference in July 1998, jointly convened by WHO and MMF in Divonne les Bains, France, resulted in an agreement between the two organizations to prepare a consensus statement that would initiate the development of a coherent international policy on long-term care.

Seventeen years have passed since the World Assembly on Ageing adopted the IPAA, which was subsequently endorsed by the UN General Assembly. As the first international policy document on ageing to be adopted by consensus, the plan has guided the formulation and enactment of policies and programmes worldwide. It was designed to strengthen the capacities of governments and civil society to deal with the dependency needs of ageing populations while also promoting older people as vital resources for societies. The IPAA is an important part of a series of policy documents, including the UN Principles for Older Persons adopted in 1991, developed by the international community with the aim of promoting lifelong development and improving the quality of life of all older persons.

The International Long-Term-Care Initiative builds upon the foundations of the IPAA and the UN Principles for Older Persons. The concerns of older persons who need long-term care are the focus of this document, which encourages regional and international cooperation to secure older persons' independence, participation, care, self-fulfillment, and dignity.

In particular, this joint WHO/MMF initiative addresses two areas of concern: the importance of institutional arrangements for continued lifelong development, and the sustenance and care of older persons who require long-term care. An older person requiring long-term care should be able to live with dignity while maintaining the highest level of functioning, regardless of the setting in which care is provided. In addition, the initiative recognizes that the considerable physical, psychological, economic, and social toll exacted from family caregivers should be addressed. Attention to the improvement of existing institutions must be paralleled by consideration of the situation of individual caregivers and care recipients.

The International Long-Term-Care Initiative framework document defines long-term care, lists the most critical issues, and outlines the guiding principles for policy development.

The meeting participants of the International Long-Term-Care Initiative believe, at a minimum, that policies must address the following issues:

- *personal and public values;*
- *private- and public-sector roles and responsibilities;*
- *public information and education;*
- *provision of formal and informal care, which includes training both formal and informal caregivers;*
- *an infrastructure of long-term-care (LTC) systems to provide social and health care services;*
- *income security and LTC financing;*
- *current and future technology;*
- *research, data collection, and strategic analysis;*
- *quality assurance, designed to satisfy both care recipients and caregivers.*

Rationale

Although current health care promotion and prevention practices have been devised with the goal of producing a healthier older population, long-term care for frail and/or disabled elderly people will always be needed. In the United States, for example, the probability of LTC institutionalization sometime during a person's lifetime is 17% for persons aged 65 to 74 years, but rises to 60% for those older than 85 years. In Norway, 25% of people 80 years of age and older are in nursing homes. In a comparison of ten developed countries, between 2% and 5% of elderly people (65 years of age and older) reside in nursing homes.[1] There are not enough available data to permit comparison with the situation in developing countries.

In addition to the social and demographic shifts that are compelling many countries to reform their LTC policies, rising health care costs and gender inequity issues, as well as changing family and work patterns, are compounding the need to readdress and rethink future LTC provision.

An international statement on care should provide a manageable strategic framework for developing policy and implementing sustainable programmes that are consistent with the policies of individual governments. Information on policies and programmes in developing countries is scarce; many of these countries rely on the experiences, both positive and negative, of developed countries when formulating their policies. Each country or community will have to extract what they need from the document and adapt the suggested policies and programmes in accordance with their own priorities and capacities.

It is not enough to measure institutional care alone, as the extended family is often the primary provider of care to persons with chronic diseases and disabilities. Although it is difficult to calculate future LTC needs, the substantial recent increases in life expectancy in old age, which are projected to continue, may lead to increasing demand for supportive services and programmes for older persons and their family caregivers. The extent of the demand, however, will depend on the outcomes of current and future health promotion and public health practices and their impact on disability-free life expectancy.

Few governments have implemented a comprehensive LTC policy for older persons or their family caregivers. However, many countries have established channels of national, state, provincial, and/or private responsibility for the LTC needs of older adults and, in some instances, their informal caregivers. Some products of their concern are income security programmes, medical care and/or medical insurance, mixtures of public and private LTC policies, and housing policies. Specifically needed are plans for home care, respite care, institutional care, and sheltered housing arrangements.

Participants at the Divonne les Bains conference agreed to focus on the needs and particular circumstances of older persons requiring care, their informal and formal caregivers, and LTC systems.

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[1] Ribbe, MW, et al. Nursing homes in 10 nations: a comparison between countries and settings. *Age and Ageing*, 1987, 26-S2:3-12.

Definition of Long-Term Care

Long-term care is the system of activities undertaken by informal caregivers (family, friends, and/or neighbours) and/or professionals (health, social, and others) to ensure that a person who is not fully capable of self-care can maintain the highest possible quality of life, according to his or her individual preferences, with the greatest possible degree of independence, autonomy, participation, personal fulfillment, and human dignity.

An older person's need for LTC is influenced by declining physical, mental, and/or cognitive functional capacities. Although the tendency is for progressive loss of capacity with increasing age, there is evidence, at least from some countries, that disability rates among older persons are decreasing and that declines or losses are not irreversible. Some older persons can recuperate from loss and reclaim lost functional capacities. Therefore, duration and type of care needs are often indeterminate and will require individually tailored responses.

Older people who require LTC should also have access to other services, such as acute medical and mental health care, along with financial, social, and legal support. Concomitantly, their informal caregivers should have access to supportive services, which may include information and assistance in securing help, caregiving training, and respite.

Important elements of LTC include, but are not limited to, the following:

- *maintenance of involvement in community, social, and family life;*
- *environmental adaptations in housing and assistive devices to compensate for diminished function;*
- *assessment and evaluation of social and health care status, resulting in explicit care plans and follow-up by appropriate professionals and paraprofessionals;*
- *programmes to reduce disability or prevent further deterioration through risk-reduction measures and quality assurance;*
- *care in an institutional or residential setting when necessary;*
- *provision for recognizing and meeting spiritual, emotional, and psychological needs;*
- *palliative care and bereavement support as necessary and appropriate;*
- *support for family, friends, and other informal caregivers;*
- *supportive services and care provided by culturally sensitive professionals and paraprofessionals.*

Priority Issues for Long-Term Care and Guiding Principles for Policy

This initiative incorporates broad issues and general principles for consideration that are believed to reflect universal and fundamental human values. A coordinated approach to policies that address LTC recognizes the interconnectedness of all aspects of the ageing process and of the context within which an older person lives. It is recognized, however, that integrating these areas into a broader framework of policies and programmes of action will pose a significant challenge. Comprehensive reforms may begin, necessarily, with smaller, carefully conceived, and incremental improvements in LTC. This section presents guiding principles for comprehensive LTC policies that address the needs of older persons who require these services.

Issue 1. Personal and Public Values

Because of the increasingly diverse nature of contemporary society, many communities around the world will be forced to respond to the differential LTC requirements of older persons and their families within their current and future resources. The interpretation and expression of chronic disease and disability may differ within cultures or regions, yet some basic tenets are universal. The corresponding need for care and assistance and the approaches to dividing the responsibility for providing this care among the individual, the family, and the larger society vary widely.

GUIDING PRINCIPLE 1. With due attention to the appropriate balance of private and public responsibilities, each community should be able to determine objectively the level and kind of assistance required by an older person in need of care or by family members providing this care. The subsequent eligibility and payment for this assistance must also be addressed. Accordingly, the following points are essential:

- recognition of fundamental basic standards;
- acknowledgment that diversity originating in culture, gender, ethnicity, unique regional setting, language, and other factors all play a role in shaping LTC needs and in defining appropriate supportive resources and interventions;
- assurance that care is of a high quality and is offered by culturally sensitive providers;
- clarification of the values and aspirations, roles, and responsibilities of individuals and families as defined by their particular social context, within the larger society, and in relation to their own government;
- reconciliation of the differences between these groups, and in the process, stressing the focus on the individual and the family.

Issue 2. Private- and Public-Sector Roles and Responsibilities

Although some countries regard their systems of providing LTC as satisfactory,[2] some do not have adequate systems, and all countries have policy concerns. The respective roles and responsibilities of everyone involved in LTC need clarification. Any reform or development of LTC provision or policy must be accomplished by adopting a systematic and orderly approach, in which the primary stakeholders take responsibility for identifying needs and incorporating reforms. Families, individuals, civil society, national, state, provincial, and/or local government, non-profit organizations, and for-profit organizations are the main stakeholders. This collaboration will be necessary to ensure continued development and sustained reforms. Legislation must be enacted to structure and direct these efforts.

GUIDING PRINCIPLE 2. Evidence of successes from the private and public sectors would provide a framework for developing and implementing LTC policies and programmes. Towards such an end, it is important to pursue a national consensus that encompasses the following goals:

- stimulation of collaboration and partnerships between the private and public sectors that involve each level of government, civil society, and the non-profit and for-profit sectors;
- clear definitions of the roles and responsibilities of the private and public sectors in order to achieve these ends:
  - create public programmes that provide the foundation for private-sector support and cooperation,
  - assure the development of measures to provide the necessary supply of supportive resources for older people in need of LTC and similar support for their family caregivers by the public and/or private sectors,
  - identify and assign specific responsibilities for assuring quality of care.

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[2] Organisation for Economic Co-operation and Development. *Maintaining prosperity in an ageing society.* Paris, 1998.

Issue 3. Public Education

Effectively implementing policy changes requires building an understanding, informed public. Certainly, the values of the affected individual(s) and their communities should be ascertained. Community-wide understanding of the needs, realities, and choices pertaining to LTC is also essential if individuals and families are to plan for, receive, and provide supportive assistance. Strategies for educating the public should use credible resources to disseminate information in informal and formal settings.

GUIDING PRINCIPLE 3. Successful policy change requires an understanding, informed public and group of professionals. All efforts to inform and educate should be sensitive to issues of age, gender, and culture.

Issue 4. Caregiver Roles, Responsibilities, and Rights

Despite the declines in disability rates among older persons that have been recently observed in some developed countries, a growing aged population will, of itself, increase future needs. In addition, there is now more emphasis on enabling older persons to remain in their own homes. Long-term-care needs will continue to grow under the following projected circumstances:

- the family structure continues to evolve;
- geographic mobility becomes more pronounced;
- worker-to-retiree dependency ratios rise;
- the population of virtually all countries rapidly ages.

All these issues will be particularly important in the developing world, where LTC has traditionally been provided by the families alone and where competition for scarce resources is intense.

Formal Caregivers

An LTC system that provides continuous, comprehensive services must include the following measures:

- specialized training and education for formal caregivers;
- linked clinical, social, and public health services;
- standards of care for health care professionals and paraprofessionals:
  - establishing standards of care where absent;
  - monitoring adherence to standards of care and compatibility with an individual's desires;
- multisectoral arrangements for integrated, transportable provision of care.

Health and social care personnel working within LTC systems must be equipped to deliver a comprehensive range of home, community, and institutional services. Integration of service provision will be an important component of LTC policies.

Informal Caregivers

Throughout the world, family members still provide the largest proportion of LTC. In light of that reality, LTC systems should support, not replace, current informal caregivers. Provisions for specialized training and support for informal caregivers can enhance family solidarity and minimize the vulnerability of older people in need of care. Existing community education institutions, respite care services, and support groups should be utilized in preparing and supporting these caregivers.

National policies should take into account workers with responsibilities for the care or support of family. Historically, the fact that these caregivers have not been reimbursed for providing services has kept the costs of LTC low. Inequalities in opportunity and treatment may threaten the economic and social security of informal caregivers, both men and women. Unfortunately, gender divisions continue in the labor market and in caregiving, as the bulk of informal care of older persons in need has traditionally been provided by women. Men and women, with or without family dependents, should have the full ability to prepare for, enter, participate in, or advance economic activity. Informal caregiving services should be recompensed with benefits and/or entitlements, so that all caregivers can exercise their right to free choice of employment and fulfill their needs within their society's terms and conditions of employment and retirement.

GUIDING PRINCIPLE 4. Public policies must be designed to address the need for caregivers; to define their roles, responsibilities, and rights; and to respond to the challenges they face, either formally (in the case of professionals and paraprofessionals) or informally (when services are performed by family, volunteers, neighbours, or nongovernmental organizations). Future caregiving will require new and/or reformed models of formal and informal systems of care and systems for supporting caregivers. Support for informal caregivers could come in the form of social security coverage, training, respite care, visiting nurse services, and/or lump sum disbursements to cover costs, to name a few examples.

Issue 5. Infrastructure: LTC Systems for Provision of Social and Health Care Services

Before decisions can be made regarding the future direction of policy, the current infrastructure and systems will have to be evaluated. A LTC system should offer a repertoire of services to all older persons requiring care. A system that facilitates an individual's entry, exit, and re-entry according to his or her changing needs and circumstances would be ideal.

A comprehensive and continuous care provision plan would contain the following necessary elements:

- equity of access;
- scope of benefits and services;
- eligibility for coverage;
- entry points to care;
- links to and between health and social systems;
- adequacy of the infrastructure, including its ability to handle issues related to certain critical areas:
  - the workforce (including employee education, training and certification processes),
  - programmes and facilities,
  - information systems for assessments, clinical decisions, care coordination, and programme development,
  - the organizational capacity to respond to change and reorganize,
  - integration and sustainability of services,
  - standards and mechanisms for evaluating quality and satisfaction.

GUIDING PRINCIPLE 5. All older people in need of care should have access to LTC services regardless of age, gender, or income. A person's level of need and duration of care should be determined at the time of entry into the system and then regularly updated. New policy mandates must be carefully shaped in order to avoid fragmentation of care provision, to address service gaps, and to construct a seamless system of care.

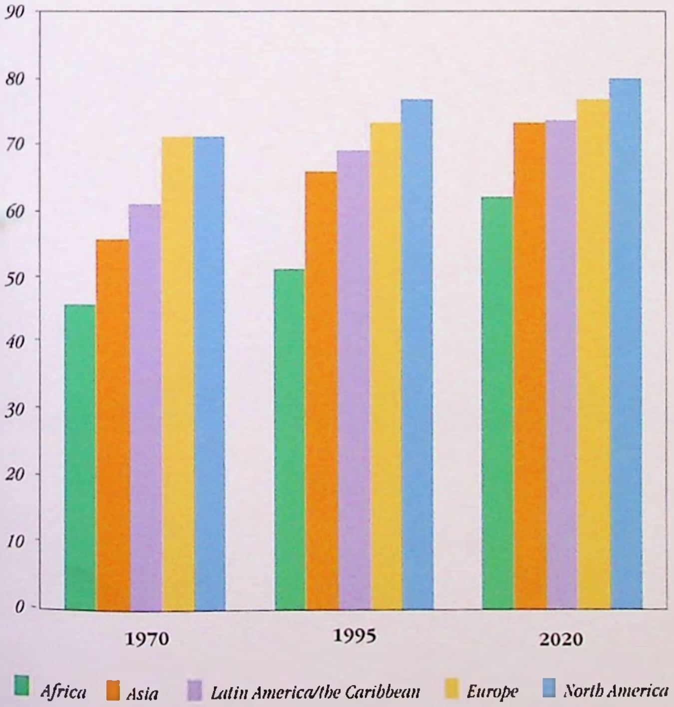
Issue 6. Income Security and Financing of LTC Systems and Services

In general, cost-containment policies in health care are forcing the re-evaluation of LTC policy. Current investment in LTC provision is inadequate in many countries, with the result that many existing services and systems are being strained by the increased demand. The rising financial demands placed on society require innovative responses and cooperation between private and public sources to secure budgetary funding.

Public education, housing, and health care will require varied solutions to ensure adequacy:

- financial support methods that balance public, private, and individual obligations;
- revenue sources at each level of government;
- acceptable payment and cost-containment mechanisms;
- budgetary flexibility that links health and social care with other related budgets;
- fair and equitable solutions to the treatment of individual income and assets;
- funding sources based on social solidarity schemes.

Average Life Expectancy at Birth for Both Sexes in the World Regions



Source: UN, The Population Prospectus, 1998 up-date

GUIDING PRINCIPLE 6. Creating and supporting a system for providing care services will require a balanced approach that utilizes both public and private financial support. Similarly, policies should find fair and equitable means and payment mechanisms to secure or maintain economic security for older persons who need care.

Issue 7. Current and Future Technology

Both existing and new technologies will contribute significantly to future care provision. When these technologies are also cost effective, every means should be used to incorporate them into the existing system of care as rapidly as possible.

Policy makers should consider adopting the following measures:

- facilitating the use of existing technology;
- assessing new and developing technology;
- encouraging and rewarding the development, dissemination, and use of assistive devices and new technology.

GUIDING PRINCIPLE 7. Optimizing the use of current technology and incorporating new, appropriate technologies will be crucial for the health of future LTC systems.

Issue 8. Research, Data Collection, and Strategic Analysis

Studies of LTC provision and systems will form a crucial foundation for evaluating outcomes and promoting further policy development.

A clear mandate for investigation will assist researchers to achieve certain goals:

- setting research priorities;
- assessing the usefulness of existing research;
- attracting resources for research;
- initiating research projects;
- applying research findings to policy development;
- balancing clinical, epidemiological, and social science research methods and findings.

GUIDING PRINCIPLE 8. Research should be planned to assess and monitor reforms in LTC provision and systems. This research should focus on effective implementation and outcomes. The rapid growth of the elderly population worldwide adds to the importance of encouraging research on interventions that prevent or delay the onset of disabilities.

Invitation to Comment on the Guiding Principles

The working group for the International Long-Term-Care Inititative presents this document as an initial framework for the development of global policies regarding the provision of LTC. The group is committed to sharing the central messages of this initiative with governments, institutions, communities, and individuals. The initial intended audience comprises decision-makers for health and social policy from the public and private sectors. An interactive World Wide Web site will be dedicated to this initiative, which will assist in translating actions into practice and in expanding the audience to include professionals, direct service providers, advocates, and consumers. We expect that this resource will provide a forum for ongoing, rapidly expanding, and timely communication. The goal of this Web site is to facilitate global interaction, communication, and collaboration while simultaneously advancing the priorities for action in LTC.

Although the circumstances of older persons were the impetus for this initiative, we do not mean to minimize the situation of younger persons with health problems or physical or intellectual disabilities, nor do we intend to overlook the need for policies to address the problems faced by these populations. Certainly, they require attention and, in the future, this document could be used to incorporate all ages within comprehensive LTC policies. Many aspects of LTC are not age specific, such as similarities in care needs, services, and facilities. A comprehensive policy that is part of a general health care strategy would reap many benefits: for example, it would help to minimize competition for limited funding and would cut down service overlap while strengthening the prospects for intergenerational LTC facilities. Yet, at this time, the urgent needs of older persons merit the specific focus on this population.

At a broader level, countries and regions will experience similar needs, but each locality will establish its own priorities for work and policy development, depending on its own particular expressed needs. Countries may choose to begin at different or multiple points of entry, for example, by strengthening district-level capacity, supporting informal caregivers, or increasing national capacity through policy development. National governments and nongovernmental organizations are urged to use this International Long-Term-Care Initiative to cultivate and sponsor networks for LTC provision within and between countries. The working group of this initiative entrusts the World Health Organization and the Milbank Memorial Fund to promote alliances, enable developed and developing countries to implement the recommendations for action, and introduce sustainable reforms.

Acknowledgments

The following persons participated in meetings to plan this report and/or reviewed it in draft. They are listed in the positions they held at the time of their participation.

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Special credit is given to Paul Kowal, Programme Officer, Ageing and Health Programme, World Health Organization (WHO/AHE) for drafting this document and for maintaining regular correspondence with all other contributors.

Ingrid Keller, Sheel M. Pandya (WHO/AHE) and Jeff Edelstein (Milbank Memorial Fund) were instrumental in assisting in the final stages of this production.

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