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HOME-BASED LONG-TERM CARE

Report of a
WHO Study Group

World Health Organization
Geneva

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WHO Study Group on Home-based Long-term Care

Ma'ale Hachamisha, Israel, 5–10 December 1999

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1. Introduction

The WHO Study Group on Home-based Long-term Care was opened on behalf of the Director-General by Dr M.J. Hirschfeld, Special Adviser on Home-based and Long-term Care to the Executive Director, Noncommunicable Diseases and Mental Health. The purpose of the Study Group was to provide Member States with guidance on the development, implementation, adjustment and monitoring of long-term care — more specifically, home-based long-term care.

The definitions of long-term care and home-based long-term care used by the Study Group are given below. Terminology differs from country to country, and terms such as continuing care, community long-term care, or home care may be encountered, but the underlying concept is the same.

1.1 Definitions[1]

Long-term care is an integral part of health and social systems. It includes activities undertaken for people requiring care by informal caregivers (family, friends, and neighbours), by formal caregivers, including professionals and auxiliaries (health, social, and other workers), and by traditional caregivers and volunteers.

The need for long-term care is influenced by changing physical, mental, and/or cognitive functional capacities that are in turn, over the course of an individual's life, influenced by the environment. Many people regain lost functional capacities, while others decline. The type of care needed and the duration of such care are thus often difficult to predict.

The goal of long-term care is to ensure that an individual who is not fully capable of long-term self-care can maintain the best possible quality of life, with the greatest possible degree of independence, autonomy, participation, personal fulfilment, and human dignity. Appropriate long-term care therefore includes respect for that individual's values, preferences, and needs; it may be home-based or institutional.

People who require home-based long-term care may also need other services, such as acute physical or mental health care and rehabilitation, together with financial, social, and legal support. Informal caregivers should therefore have access to supportive services, including information on and assistance in securing help, training, and respite.

1.2 Background

The next 20 years will see dramatic changes in the health needs of the world's populations. Noncommunicable diseases will become the leading cause of disability, although HIV/AIDS, tuberculosis, and malaria will continue to be major causes of morbidity (and death). With increases of up to 300% in the older population of many developing countries and the continuing — though less dramatic — increases in the numbers of elderly people in developed countries, there will be marked and universal growth in the need for long-term care.

Home-based care is already expanding rapidly in all countries. This expansion is due in part to increasing need but also, in developed countries, to a shift from hospital-based care to home and community care for economic reasons. In addition, public health services, and especially hospital services, in developing

countries are of poor quality, primarily because of diminishing resources, and most of the population cannot afford private health care. Cost considerations thus tend to shift the burden of both acute and long-term care to the family. In the very poor countries, health centres are overwhelmed, staff are not paid for months, drugs and equipment are often unavailable, patients' expectations of service quality are not met, etc. Most common ailments are therefore treated in the home and most people die at home.

In all countries, families have always been, and remain, the major providers of long-term care. This is true for the care both of elderly people and of people with chronic conditions such as HIV/AIDS, tuberculosis, and malaria. However, families cannot shoulder the increasingly heavy burden of care alone. Because of a wide range of social, economic, demographic, and epidemiological factors (e.g. migration, changing rural and urban social environments, poverty, ageing, or health problems affecting family members themselves), family resources are decreasing.

These developments require the adoption of a very different approach to health sector policy and health care services: a disease-specific approach alone is no longer appropriate. The one common result of the worldwide demographic and epidemiological changes mentioned above is growing functional dependence, with a concomitant increase in the need for assistance in managing everyday living. Well managed and adequately supported home care can improve both the quality of life of people of all ages requiring care and that of their caregivers. However, family caregivers need information, support, and skills if they are to succeed in providing the often complex care that is required.

The burden of caregiving is borne primarily by women, who generally have very little access to, or control of, the resources needed to assume this responsibility. Thus, while the need for home care is growing, there is a very real and increasing danger that families who have neither the means nor the knowledge required will be left to their own devices to shoulder caregiving responsibilities.

In all WHO regions there is great interest in, and rapidly growing need for, home care. However, there is also a danger that the label "home care" will be used to justify an abdication of public and government responsibility. This would have dire consequences for quality of care, for families, and in particular for the health and lives of women who, as already pointed out, are the main caregivers both for their own families and communities and within the formal health sector. An optimal balance between family and public responsibility must be sought.

WHO, in collaboration with Member States, therefore proposes to develop policies and programmes to address the growing need for home-based care (see Figure 1). This work will have different starting points in different countries. One country may choose to begin by strengthening district or local capacity; a second might begin by developing support for informal caregivers; and a third might begin by strengthening national capacity and policies. It is also possible that some countries may choose to start at several points simultaneously. In partnerships with Member States, other United Nations agencies, nongovernmental organizations (NGOs), academia, and other sectors, WHO is also committed to developing standards for effective home care based on research and experience in countries, regardless of patterns of development, according to the parameters shown in Figure 2.

1.3 Terms of reference

The Study Group decided to pursue its work along the following lines:

- A review of regional experiences and concerns related to long-term care and, more specifically, home-based long-term care, in the light of the:
  - — political, economic, and cultural context;
  - — demographic and epidemiological patterns;
  - — differences between urban, rural, and remote areas;
  - — changing family structures;
  - — roles of women.
- A review of different system components, including:
  - — the elements and scope of services, and target populations;
  - — the organization and management of long-term care systems;
  - — financing mechanisms for home-based and institutional long-term care systems;
  - — strategies related to human resource development and their impact on the acceptability and quality of home care (education and training, cadres of health workers, division of labour, organization of work, working conditions, and supervision).
- Development of strategies for achieving:
  - — cost-effectiveness and sustainability;
  - — equity of access and population coverage;
  - — adequate and high-quality services;
  - — adequate and high-quality formal human resources;
  - — support for family and informal networks.

This report first considers the target groups and the scope of home-based long-term care, and then examines policy development, organization and management, financing mechanisms, and material and human resources (both formal and informal). Each of these topics is viewed in the context of broader social and cultural systems; the demographic and epidemiological situation; urban and rural settings; and the role of women. The report also looks at the challenges of migration and living conditions; changes in the family and work-place; natural and other disasters and their aftermath; cost and sustainability; and accessibility, acceptability, adequacy, coverage, and quality of services and care. The Study Group's conclusions include lessons that countries can learn not only from their own experiences but also from those of others, regardless of their level of economic development. A number of recommendations are made.

2. Target groups, scope and elements of home-based long-term care

2.1 Target groups

The emphasis throughout this report, in conformity with the definition of long-term care, is on the care of people of all ages who have long-term health problems and need assistance with the activities of daily living (ADL) in order to enjoy a reasonable quality of life. Target groups include:

— people who are chronically ill, whether with communicable diseases such as

tuberculosis or with noncommunicable conditions such as cardiovascular diseases and cancer;
— individuals with disabilities, regardless of etiology, including developmental disabilities and disabilities caused by poliomyelitis;
— people with HIV/AIDS;
— people disabled by accidental injuries, e.g. victims of traffic accidents;
— people with sensory limitations;
— mentally ill individuals, including those suffering from depression and dementia;
— substance-dependent individuals;
— victims of natural and other disasters;
— perhaps most importantly, informal caregivers for any of the above, such as family, friends, and neighbours.

The circumstances and conditions that dictate how and where people live may limit or extend the target groups — and thus their eligibility for services — and may include:

— income levels;
— the degree or extent of family and informal support;
— the participation of male and female informal caregivers in the labour force and the distance between homes and workplaces;
— whether the home is permanent, transient, or even unstructured (as with homeless or street people, including unattached children and adolescents); and
— whether the home is in an urban or rural area, the impact of climate and geography, and the strength of the local community infrastructure.

The concern for equity will influence the setting of priorities among target groups. Decisions about priorities will depend on answers to the following questions:

- Should levels of functional capacity alone guide priority-setting?
- Should the etiology or type of impairment also be taken into consideration when allocating resources?

Thus, the severity and type of functional impairment may be used in addition to a person's circumstances to determine their eligibility and priority for service.

While "social dysfunction" and "extreme poverty" have not been included in the above list of circumstances, it is suggested that countries should consider their impact on long-term care needs. Street children, dysfunctional families, malnourished individuals, and abused women are examples of people affected by these considerations, and the needs of these people should not be neglected. If their needs are not met, people in these categories are likely to become functionally disabled and to require long-term care. In addition, since such people may themselves be informal or formal caregivers, failure to address their needs could compromise the capacity of countries to meet future needs for long-term care.

2.2 Types and sources of long-term care

Long-term care may be institutional or home-based, formal or informal. Institutional or residential long-term care is defined as the provision of such care to three or more unrelated people in the same place.

Home-based care may be provided exclusively in the home or combined with care

in the community (such as in day centres, or under arrangements made for respite care). The term includes foster care. Home-based care may also be considered to include care provided to people whose "home" falls outside conventional definitions (e.g. travelling families, people living on garbage dumps or in slums).

Formal care may be publicly financed and organized, but the services may be provided by governmental organizations, by NGOs (local, national, or international), or by the private sector. It is usually provided by professionals (doctors, nurses, social workers) and auxiliaries, such as personal care workers (who help with bathing, dressing, etc.). Traditional healers may be an important additional source of care.

Informal care includes that provided by members of nuclear and extended families, neighbours, friends, and individual volunteers, as well as assistance organized through voluntary organizations such as religious bodies.

2.3 Elements of home-based long-term care

There is no agreed list of minimum or core services in home-based long-term care, but the elements listed in Table 1 are the most common. Individual communities may wish to add others that are more relevant in a given place or situation or may choose not to provide all of the listed elements. It is essential to ensure that the decisions about what to include are made carefully and are well publicized, and that the information is easily accessible to those in the health care sector, to those who require care, to informal caregivers, and to members of the broader community. Communities may wish to consider alternative ways of meeting needs, taking into account the economy, personal and community preferences, client or caregiver mobility, and the availability of transport.

In addition to the list in Table 1, the following elements of health and social systems in general are also relevant to home-based long-term care:

— access to food, water and sanitation facilities, fuel, shelter, and a basic income;
— ensuring continuity of care between the home, community facilities, hospitals, and institutions;
— collection and recording of client data that can be used in information systems for planning, management, and policy-making;
— supervision and technical support;
— monitoring, evaluation, and feedback.

Table 1
Elements of home-based long-term care

Elements of home-based long-term care
Assessment, monitoring, and reassessment
Health promotion, health protection, disease prevention, postponement of disability
Facilitation of self-care, self-help, mutual aid, and advocacy
Health care, including medical and nursing care
Personal care, e.g. grooming, bathing, meals
Household assistance, e.g. cleaning, laundry, shopping
Physical adaptation of the home to meet the needs of disabled individuals
Referral and linkage to community resources
Community-based rehabilitation
Provision of supplies (basic and specialized), assistive devices and equipment (e.g. hearing aids, walking frames), and drugs
Alternative therapies and traditional healing
Specialized support (e.g. for incontinence, dementia and other mental problems, substance abuse)
Respite care (at home or in a group setting)
Palliative care, e.g. management of pain and other symptoms
Provision of information to patient, family, and social networks
Counselling and emotional support
Facilitation of social interaction and development of informal networks
Development of voluntary work and provision of volunteer opportunities to clients
Productive activities and recreation
Opportunities for physical activities
Education and training of clients and of informal and formal caregivers
Support for caregivers before, during, and after periods of caregiving
Preparation and mobilization of society and the community for caring roles

2.4 Care and dependence as elements of human development

People with functional dependence not only receive but also often provide care within their families and communities. They are frequently important role models of human dignity maintained in the face of pain and discomfort, showing how to cope with and overcome the hardships that may be part of anyone's life. For this reason, their dependence cannot be reduced to economic terms or viewed only as a burden.

The role of care in human development is fundamental (*1*). Children cannot develop without care, and most adults need emotional, if not physical, care. The positive effect of caring relationships on life expectancy is as great as the negative effects on it of, for instance, cigarette smoking, hypertension, and lack of physical exercise. It is therefore vitally important to support the family and the community, since the erosion of solidarity brings enormous costs in terms of crime, social upheaval, and an atmosphere of anxiety and resentment.

2.5 Questions to be considered

As with any complex issue, there are questions that countries, communities, NGOs, and other agencies will want to consider in developing policies and programmes and in generating the broadest possible support. The Study Group drew up a list of questions that can be used to assess readiness or capacity for home-based long-term care. The questions most relevant to the scope, elements, and target groups of long-term care, and specifically home-based long-term care, are listed below. However, the list should not be considered to be exhaustive; the questions are not

in any order of priority but are offered simply as a guide to assist in policy and programme development.

- How does society view people with a disability or a chronic illness?
- What are the values in society with regard to taking care of disabled people?
- How can any community stigma be removed?
- How can community attitudes and values be assessed?
- How can community attitudes be changed?
- How can services be prioritized and rationed, or target groups prioritized?
- What are the criteria for rationing and are the criteria based on need?
- How can resources for home-based long-term care be allocated in accordance with clearly defined priorities?
- Should there be different responses and strategies for different target groups?
- What can be done to stimulate community and collective responsibility?
- What can be done to encourage, and to share the responsibility for, development of initiatives for policy-making, provision of care, and financing, monitoring, and evaluation?
- Who monitors, supervises, and evaluates?
- How can roles and responsibilities be shared among clients, caregivers, families, communities, and government?
- How can the involvement of society, including the private sector, NGOs, and communities, be stimulated?
- Under what conditions will it be possible to work with traditional health care providers and practitioners of alternative medicine?
- What can be done to mobilize all those who have the potential to contribute to care and under what conditions will it possible to work with them effectively?

3. Home-based long-term care in health and social systems

Sustainable, affordable, and effective home-based care and other long-term care services must be an integral part of a country's health and social systems. Achieving this requires coordinated actions at various levels of government, and in the private, not-for-profit, voluntary, and — in some countries — traditional medicine sectors. It is also essential to ensure that home-based care is an integral part of overall primary health care[1] and health system reforms. Indeed, such reform provides an excellent opportunity to develop and implement, or strengthen, home-based long-term care.

The fundamental principles of successful home-based long-term care development include:

— respecting and encouraging grassroots initiatives;
— integrating home-based long-term care into the primary health care system wherever possible and appropriate;
— using local structures and means to ensure sustainability;
— ensuring that all sectors, including the voluntary and private sectors, work together;
— taking account of home-based and long-term care in all ongoing health system reform.

An additional factor in achieving successful home-based long-term care is an approach that focuses on the needs of people with functional dependence and of those who care for them, regardless of the etiology of the disability or the dependence, or of the age of the client. Unfortunately, most countries have so far not adopted this approach.

Health systems are often described as operating at three levels — national, district, and local — although this is not true for all countries. Even in countries in which operational levels are similarly designated, organization and management arrangements can differ greatly. Nevertheless, in many countries, responsibilities for policy reside at the national level and for service delivery at the local level; district (or other intermediate level) responsibilities vary widely among countries.

3.1 National-level responsibilities

At the national level, policies are needed to guide planning, legislation and regulation, the allocation of resources, financing, organization and management, including monitoring and evaluation of services, and the development of human and material resources.[1] The allocation of resources, however, must be based on clearly defined priorities.

Complementary policies imply that each government sector develops policies within its particular area of responsibility to create the required environment for sustainable, affordable, and effective home-based long-term care. Income protection, population-based health and social funding, labour policies, and the exposure of schoolchildren to concepts of caring and community responsibility can all play a part.

Intersectoral cooperation is an often-used term, though achievement of cooperation is a challenge to all countries. For home-based long-term care, the government departments among which cooperation is needed — in addition, clearly, to the health sector — include, as a minimum, finance, labour, education, and social affairs.

Leadership in policy development must come from government. The responsibility for successfully managing intersectoral cooperation lies with departmental bureaucracies which, in every country, have their own cultures and concerns. The challenge for intersectoral cooperation in home-based long-term care is for the needs of all people with functional dependence and their caregivers to become a common concern, with all departments developing harmonized policies in the interest of effective outcomes. Organizational development strategies, including leadership and management development programmes, are beneficial in assisting departmental policy-makers to develop skills for establishing new partnerships and new ways of working.

Important partners at the national level include NGOs and the private sector; in some countries, e.g. China and India, they also include practitioners and organizations of traditional medicine. As with all policy development, that concerned with long-term care, and more specifically home-based long-term care, should both inform, and be informed by, service delivery realities and challenges, including community and client perceptions and needs.

In many countries, it is at the national level that guidelines will be developed for

implementation, monitoring, and evaluation, for training and information, education and communication strategies, for resource kits or packages, and for the development and maintenance of information systems.

3.2 District-level responsibilities

District-level management responsibilities will include resource allocation based on clearly defined priorities, and monitoring the quality of, and provision of support for, home-based long-term care services, including education, development of local guidelines, adaptation of national standards, and systems for rewards and incentives. Knowledge of home-based long-term care is, however, limited or non-existent at the district level in many countries. Considerable effort will therefore be needed to strengthen district-level capacity to develop and implement such care.

The district level should provide leadership and support for innovation and creativity at the local level. It can do this through developing sound management practices, community involvement, and quality standards against which performance and progress can be measured. All of these are prerequisites to developing community responsibility for home-based long-term care and supporting the caregivers on whom it depends.

At the district level in particular it is essential that partnerships are established with various government agencies, with the private sector and NGOs, with the community and the voluntary sector, and with all practitioners. Many health care managers need to completely change the way they work. For home-based long-term care to be effective, such a change will be necessary in many countries.

3.3 Community-level responsibilities

The decisions on mutual help and solidarity that largely determine whether home-based long-term care is both effective and human are taken at the local and community level. It is also at this level that daily interaction determines the quality of life of all those who receive and give care.

The first decision on whether to seek care and what type of care to seek are made within the family, which underlines the importance of including the family and the community in decisions about health services and the provision of care. In addition, it takes time for health systems to become aware of emerging long-term health needs. This is particularly true of mobile populations, such as transient or migrant workers, guest workers, and those displaced by civil unrest and by natural and other disasters. Communities themselves are sometimes the first to recognize these problems and to develop the means to deal with them.

At all levels, there is an urgent need to encourage and enable practitioners to report their successes and failures with home-based care. It is vital to expand knowledge of the field, especially in developing countries, and to provide more locally appropriate examples of good practice.

3.4 Integration of services

Home-based long-term care services cannot stand alone, but need to be an integral part of the health and social systems. It is therefore important to understand what is meant by integrated services at different levels of the health system (see Annex 1).

The term *integrated services*, like *intersectoral cooperation*, is often used by different people to mean different things.

Structural or system integration means that home-based long-term care is integrated into the organizational structure of the health care system. Planning and budgetary integration means that it is included in planning and budgeting at all levels, and functional integration means that caregivers have an appropriate range of skills to provide comprehensive — or integrated — home-based long-term care. The term integration is also used by some to describe the sharing of facilities, equipment, and/or transport.

The purpose of integration is twofold. First, integration makes it possible to provide, with as much continuity as possible, comprehensive services that are designed to meet clients' needs while respecting their preferences and values. Second, integrated services can be provided at lower cost than many separate services, as long as coordination is well managed and the types of services available are defined and provided according to need and budget allocations.

Successful integration requires consideration of the competencies, skills, and workloads of caregivers. Whether formal or informal, caregivers must have a minimum range of competencies and skills, and supportive and appropriate caregiver development programmes are thus essential. In addition, the education of clients will enable them to participate in their own care. It is important, however, to ensure that integration does not mean excessive workloads that overwhelm both caregivers and the health system.

While it is known that many countries are working towards comprehensive systems in which home-based long-term care is integrated into the broader health care system, few reports on such systems have so far been published from which others could learn. It is therefore hoped that as many case histories as possible can be collected, collated, and disseminated.

3.4.1 ***Integrating long-term care into the health services***

The importance of ensuring continuity of care and of maximizing the opportunities for providing an optimal balance of care makes a strong case for the integration of long-term care into the general health services (see Annex 2). The extent of such integration in industrialized countries, however, has been limited by two major problems. The first is the possibility that long-term care services will be neglected after integration and that acute health care needs will receive greater priority. The second problem is that of developing adequate financial mechanisms to compensate companies offering health insurance schemes for the risks of long-term care and thus avoid any disincentives to serve people with greater long-term care needs. This is particularly true in health systems where there are competitive health insurers that may prefer to avoid the more complex, difficult, and costly cases.

Where services are financed on a budgetary rather than an insurance basis, and in the absence of competition among alternative health care providers, these problems are less serious and integration of the systems becomes much more feasible. The very limited insurance systems that exist in many developing countries could still be designed to include basic long-term care needs, as health services are generally financed on a budgetary basis.

In discussing integration it is important to remember that there is also the possibility of integrating provider systems while maintaining some degree of separate financing. Within health systems, it is thus possible to arrange for the separate financing of long-term care services, although this will not necessarily ensure the optimal allocation of resources among different needs.

The case for integration is more compelling in countries in which there is a strong primary health care system. Here, integration means that home-based long-term care services are provided within a comprehensive primary health care approach. It also means that such care is part of the organizational structure of primary health care, has an identified budget for which it is accountable, and may share facilities, equipment, and transport with other parts of the structure.

The case for integration is also compelling when the health services infrastructure is weak and the ability to make staff available in the home is very limited. The need to take advantage of existing resources and to use those resources effectively then becomes an additional motivation for pursuing a more integrated approach. In low-income countries, for example, the network of community health volunteers and workers would seem to offer the greatest potential for the provision of long-term care in the home.

3.4.2 *Integration of home-based long-term care across different etiologies of functional dependence and across age groups*

The Study Group believed that efforts should be made to integrate long-term care programmes and policies across age groups and across groups with different needs for care. With appropriate supervision, advice, and continuing education, it should be possible to provide adequate training in the long-term care required for diseases and conditions with widely different etiologies and for different age groups. In developing countries, the limited resources and infrastructure and the difficulty of coordinating the activities of different categories of personnel emphasize the need for an integrated approach.

Some age-segregated services have been established in developing countries, influenced by the availability of donor funding. However, given the rudimentary health and social systems that exist in these countries, it would still seem preferable to promote age-integrated systems. In more developed countries, the different groups in need of long-term care are often served by segregated and entrenched bureaucracies that can make it more difficult to achieve integration. It should be noted, however, that recent legislation on long-term care has tended to introduce more age-integrated approaches (as, for example, in Austria, Germany, and the Netherlands).

3.5 Adaptation of home-based long-term care policies to countries at different levels of economic development

In order to achieve a better understanding of conditions and of the present state of health and social development in countries at vari-ous stages of economic development, the Study Group discussed in detail case histories from both developing and developed countries. It also examined a report on recent legislation on long-term care in the developed world (*3*).

From this review of current experience, a picture has emerged of the development

of home-based long-term care services within the context of a country's economic development and the underlying structure of the health and social services (see Table 2).

The poorest countries have few paid health workers, and rudimentary health care is often provided by local volunteers at the village level, as in Guinea-Bissau. These volunteers perform a number of tasks, such as providing advice to the family, distributing certain drugs and supplies, and referring patients to health care services. They may receive compensation in kind from the families themselves. Informal support networks still tend to provide most of the care to those in need of daily assistance, but more advice to families and additional supplies are required. Informal networks of this kind, given appropriate training and support, can be mobilized to provide long-term care as well. Where professional staff are available, they will generally have a more supervisory and consultative role.

At the next stage of economic development, volunteers are replaced by paid local community workers who are in regular contact with the families in the community. These workers undertake a number of health promotion, curative, and community development activities and receive rather more training than community volunteers. They can also be mobilized to provide long-term care, concentrating on guidance and distributing supplies to families. Direct long-term care will be provided largely by the informal sector, as in India, Kenya, and Peru for example.

In middle-income economies, the informal system is supplemented by direct care from auxiliary workers specializing in long-term care. In addition, some professional home care is provided by nurses or doctors (e.g. in the Republic of Korea), and there is a growing institutional sector.

Countries with high-income economies generally have highly developed systems in which specialized home-care workers provide long-term care. There are, however, considerable variations in the levels of staff who perform these functions; in some countries the services are largely professionalized while in others the emphasis is on auxiliaries. In addition, medically oriented home care is very highly developed. Nevertheless, families in all countries continue to be the major providers of long-term care.

It should be noted that:

- Voluntary work exists at every stage of economic development, varying in extent from country to country.
- There is a private sector for high-income groups in all countries, regardless of economic development.
- The quality of services and the extent of coverage vary in all stages of economic development.

The prevailing view is that home-based care systems should be kept as simple as possible to ensure their long-term sustainability. Over-medicalization and over-professionalization of home-based long-term care should be avoided, particularly where strong family and community networks are already providing care. These networks should be supported, not replaced, and specialist advice, support, and education should be available both to caregivers and to clients. When the care required is especially complex, the formal system should be able to

provide an appropriately qualified caregiver (or referral, if needed).

Governments need to be cautious about the undue influence still exerted by doctors, who often favour sophisticated technology and acute care in all aspects of health policy, regardless of appropriateness. At the same time, however, doctors have been among those who have initiated the most innovative programmes of home-based care. For example, in Villa El Salvador, Lima, Peru, they assisted members of a very poor displaced community to develop basic health and social services and to improve their quality of life (J.L. Aguilar Olano, personal communication).

In summary, the nature of home-care services necessarily differs at different stages of development and as the resources of the system expand; it varies as well with the degree to which the family and informal support systems can be relied on. By the same token, there may be areas or population subgroups in developing countries that require more comprehensive long-term care services because of breakdown of the informal system as a result, for example, of the overwhelming impact of the AIDS epidemic. Finally, it is important that government policy and regulations encourage partnerships, integration, and flexibility at the local level.

The Study Group strongly recommended that long-term care services should form part of basic primary health care in developing countries. It suggested that, if this principle is adopted from the outset, different and better ways of meeting long-term care needs may evolve in the future. Developing countries would not then have to repeat the mistakes made in industrialized countries, where services are often uncoordinated, over-medicalized, and very expensive.

3.6 Quality assurance

Quality assurance is another important aspect of the provision of appropriate long-term care services, but was not considered in depth by the Study Group. It deserves proper consideration by some other body.

A number of factors are involved in quality assurance, e.g. the training and supervision of formal and informal caregivers,[1] information system development, standard-setting, and guideline development. In addition, legislation can play a part in promoting quality. An important element in the quality of home-based care is the capacity of families as caregivers; this can be enhanced by social recognition, training, counselling, and appropriate support (respite services, assistance, material support, etc.). Clearly, the extent and nature of any efforts to improve quality will depend on the resources available.

Table 2
Patterns of development of home-based long-term care services at different stages of economic development

Lowest-income economies	Low-income economies	Middle-income economies	High-income economies
Almost all care is informal	Almost all care is informal	More limited informal care	More pressure on availability of informal care
Direct care is informal	Paid local community workers	Paid local community workers	Few community health workers
Largely voluntary community workers (payment in kind), some training	More training of these workers	Some personal care and home-making, and less clinical care	Specialized personal care and home-making workers with no clinical or community development roles
No personal care or home-making, but counselling, simple clinical responsibilities, and dispensing of supplies	No personal care or home-making, but counselling, simple clinical responsibilities, and dispensing of supplies	Professional staff involved in more direct home care	Varying professional training for these workers and concern for over-professionalization
Also community development role	Also community development role	Emergence of some social-system-based home care	Professional home care highly developed
Professional staff in a supervisory role	Professional staff in a supervisory role	Growing institutional care	Institutional care of major importance
			Segregated social- and health-based home-care systems

3.7 Selected strategies for home-based long-term care

A wide variety of strategies have been successfully used to implement home-based long-term care in various countries, and these are briefly described below.

The following considerations are important in raising social awareness and maximizing the use of existing resources:

- In establishing programmes to raise community awareness of the needs for long-term care, the way in which the community already deals with other problems should be taken into account.
- Awareness-raising activities should be organized according to target groups.
- Activities may be designed for specific target groups (e.g. professional groups, people living with HIV/AIDS, schools, religious organizations).
- The subject of home-based long-term care should be included in the training of health professionals at all levels.
- Community self-assessment can be facilitated by identifying needs, available

resources, and actions that have been, or could be, taken.

It will be particularly useful to identify, and build on, local financial, material, and human resources, and especially to identify opinion-leaders in the community who can see the benefits of their active involvement and thus become committed to the required action. A local "champion" of the cause, who can be a prime mover for change, is a crucial element in the successful implementation of a programme. In addition:

- Strategies should identify all activities that have been initiated by local groups and volunteers.
- It is essential to involve all relevant sectors and agencies, to identify organizational structures for action, and to encourage "ownership" of the initiative.
- Success is more likely if the new ideas can be incorporated into the agenda of an existing group, and is even more likely if efforts can build on ideas generated within the community.
- It is important to promote, publicly recognize, and reward creativity and innovation.
- It is important to safeguard local initiatives from the influence of external ideas and resources that tend to produce over-rapid or inappropriate change. Appropriate inputs, however, may include help with training, with building capacity to plan, manage, and maintain programmes, and with creation of a databank of available resources.
- Different communities will need to use different strategies.

The case for provision of home-based long-term care can be made on the basis of a variety of considerations:

- The burden of chronic diseases, including HIV/AIDS, is already overwhelming some health care systems.
- Everyone has a right to care, but most facilities are economically, geographically, psychologically, or socially inaccessible to large portions of many populations.
- Many of the traditional, informal care structures are already overwhelmed and liable to break down if they are not given support. These valuable resources need to be nurtured, protected, and strengthened.

It is often possible to use the same resources for home-based long-term care as are used in primary care. Primary health care workers, who are the first people in the health system whom the community deals with, are of vital importance in achieving this. However, they must be supported in taking on what is often an additional responsibility. If this can be done thoughtfully and creatively, home-based long-term care can reduce the burden on tertiary care facilities.

3.8 Questions to be considered

As with any complex issue, there are questions that countries, communities, NGOs, and other agencies and sectors will want to answer. Those that are most pertinent to the organization and management of home-based care are listed below; however, the list is not exhaustive and the questions have not been arranged in any order of priority. They are offered simply as a guide to the development of relevant policies and programmes.

- How can existing structures be used to speed up the implementation of home-based care?
- How can available resources and accumulated experience be identified and used

as a starting point for further development?

- How can action research be used to build an evidence base for policies on home-based long-term care?
- What mechanisms can be developed to allow the views of both clients and caregivers to be heard?
- How can the community be mobilized for home-based long-term care?
- What is the role of government in the quality assurance and regulation of care?
- How can the equity and quality of home-based long-term care be improved?
- What can be done to ensure the sustainability of access to home-based long-term care?
- How can an appropriate balance be achieved between home-based and institutional long-term care?
- What can be done to stimulate action at local, district, and national levels?
- What strategies will encourage bottom-up policy development?
- How can communities ensure that policy-makers and professionals will listen and learn?
- How can community organization and mutual care or support be facilitated?
- What can be done to ensure intersectoral collaboration in the policies and activities concerned with long-term care?
- How can long-term care be incorporated into existing primary health care activities?
- How can best practices be reproduced and small-scale (often pilot or demonstration) projects be expanded into full-scale activities?
- What can be done to ensure maximum benefit from the sharing of information on successful projects?
- How can successful and innovative projects be translated into sustainable services?
- What can be done to ensure consistency and coordination between the governmental, nongovernmental, and private sectors?
- How can families, and in particular women, be supported in their caregiving so that their contribution to society is recognized and rewarded?

Answers to the following questions may help to generate support from a broad range of potentially interested parties:

- What can be done to ensure that the government assumes responsibility for home-based care, in partnership with other service providers, without interference with local initiatives and capacities?
- How can governments be persuaded to listen to and learn from advocacy groups?
- What can be done to place long-term care visibly and forcefully on the political agenda and to ensure adequate political will for its implementation?

4. Financing of long-term care

4.1 Financing mechanisms

While this section deals mainly with financing mechanisms that may be used in a variety of settings, the poorest countries have virtually no means of increasing public financing at present and only limited access to such mechanisms through NGOs or international agencies. In these countries, home-based long-term care is either provided entirely by informal caregivers or is paid for in kind or by exchange

arrangements.

The following five approaches to the financing of home-based long-term care were identified by the Study Group:

- General taxation.
- Social or health insurance.
- Users' fees, possibly on a sliding scale, which may be voluntary (and paid in cash or in kind) or mandated by government.
- Private insurance (although the private sector offers little in the way of insurance for long-term care).
- Use of unpaid personnel.

These approaches may be general or specific: for instance, long-term care may be covered by general health insurance or an insurance programme may provide specifically for long-term care.

Countries, and even communities, may use combinations of these approaches, or may use different financing mechanisms for different kinds of long-term care services. They may also use mechanisms for financing health care that differ from those used in other sectors, e.g. welfare and education.

The mechanisms outlined above are linked to the nature of the right to services, which will generally fall into one of the following three categories:

- Service eligibility is subject to budgetary constraint (as with funding from general taxation).
- Eligibility is not subject to budgetary constraint (as with social insurance).
- Eligibility is not subject to budgetary constraint but access to services is regulated by waiting lists (as with many forms of health insurance).

4.2 Eligibility for long-term care services

The approaches listed in section 4.1 are further linked to eligibility criteria for long-term care, which may be divided into three types:

- Disability alone, when eligibility for services and the extent of entitlement are based solely on assessed need, usually expressed in terms of the activities of daily living (ADL).
- Disability plus income, when the extent of service entitlement is assessed on the basis of need and a means test.
- Disability plus income plus family support, when the extent of service entitlement is assessed on the basis of need, a means test, and the amount of support that the family can provide.

In addition, the criteria for defining eligibility for services, and the extent of service entitlement, may be applied either rigorously or with room for discretion in individual cases. Programmes funded through general finance or health insurance tend to include income and family support in their eligibility criteria but to leave considerable room for discretion. When programmes are funded through social insurance, however, eligibility is usually determined solely on the basis of disability, and the criteria are rigorously applied.

In most countries, financing is through general taxation, although there are a few major new legislative initiatives that provide for home-based care to be covered by

social insurance funds. Rather than being linked to health insurance, these funds tend to be designated for particular target groups and to focus on disability as the principal (though not necessarily the only) criterion for eligibility. They also have very strictly defined criteria for the extent of service entitlement at each level of assessed need (see section 4.3).

4.3 Legislation on home-based and institutional long-term care insurance

One of the problems in developing long-term care policies is the extent to which legislation is used as a basis for mandating care. So far, only a few countries — Austria, Germany, Israel, Japan, and the Netherlands — have enacted laws that entitle individuals to long-term care (*3*). These countries have formulated special, separate programmes for the provision of long-term care services by statutory insurance programmes, under which personal entitlement is not constrained by budgetary limitations. Most programmes include all age groups and provide comprehensive services, including community-based and institutional care. In developing their legislation on long-term care, however, these countries have adopted different approaches to such matters as choice of the target population, the process of eligibility assessment and the personnel responsible for the assessment, the types of benefit granted, how and by whom the services are provided, and financing mechanisms.

4.4 Cost containment and priority-setting in long-term care

One of the major concerns of policy-makers is to determine how costs can be contained — a problem that is closely linked to the setting of priorities. Even the wealthiest countries cannot provide entire populations with every intervention that may be of value. Priorities must be debated, agreed, and implemented. In most countries, the priorities that are set effectively exclude large numbers of people from access to organized care (*4*). The following measures are some of the most common methods used to limit costs:

- Users' charges, or user fees, may be imposed in the form of "co-payments", meaning that the patient (or family) pays a proportion of the costs. These charges are effective in limiting costs, but there is ample evidence that their imposition prevents those who cannot afford them from receiving needed services.
- User fees are imposed, but with exemptions for those who cannot afford them or with charges linked to income.
- Eligibility may be limited to more severely disabled people or to a set number of people.
- The eligibility of the individual may be capped, with the cap either based on the average cost of services or separately determined for each level or type of disability.
- The overall care service may be provided by different services or organizations, so that financing derives from multiple sources and is pooled. A distinction should be drawn between this approach and off-loading responsibilities to volunteer or informal services because these provide the "cheapest" care.
- Case management may be used to restrict inappropriate use of services.

Examples of this approach include screening by the service provider, and prescribing practices that insist on the use of generic (rather than proprietary) drugs.

- Programmes may be budget-limited, meaning that services end when the finances are exhausted.

4.5 Trade-offs

Generally speaking, there may be trade-offs in the following areas:

— more precisely defined rights or entitlements with more lim-ited eligibility, *or* less precisely defined rights and extended eligibility;

— more universal coverage of disabled people with less intensive care for each person, *or* more limited coverage of disabled people with more intensive care for each person, *or* universal coverage of the population and all their long-term care needs.

Alternatively, clients may be given cash or vouchers as an allowance towards care and be made responsible for defining their own trade-offs.

4.6 Questions to be considered

The Study Group generated the questions listed below relating to the financing of home-based long-term care. Again, the list is not exhaustive and the questions are in no particular order of priority.

- What mechanisms are available for increasing finance?
- What can be done to stimulate activities funded by nongovernmental bodies?
- What can be done to stimulate mutual help (e.g. small mutual insurance funds)?
- How can government funding be maximized?
- How can sustainability of financing be ensured?
- How can different sources of financing be coordinated?

5. Material resources

Shelter, safe water, sanitation, fuel, and heat are essential for a good quality of life, and without them people who are functionally dependent are particularly vulnerable. Certain specific commodities, equipment, and resources — such as drugs and transport — are also essential for everyone needing health care and are especially important for home-based long-term care.

Functionally dependent individuals often find mobility a problem; equipment that improves their mobility, such as walking sticks, walking frames, and wheelchairs, is therefore of great importance. Such people, and their caregivers, also need some form of transport if they have to travel longer distances, and care workers may need transport to enable them to make home visits.

5.1 Supplies and equipment

For functionally dependent individuals, the most important equipment and supplies include those that aid mobility, specialized items such as syringes, sterile products, and incontinence supplies, assistive devices that help with ADLs (reaching devices, grab-bars, etc.), specially adapted telephones, hearing aids, and pharmaceuticals.

Whenever such items are required, it is important for clients and their formal and informal caregivers to have both basic and relevant technical information about products, and training or guidance in their use. Some of these will be more useful to clients and informal caregivers, others to formal caregivers.

The availability of supplies and equipment varies widely from country to country. Some countries have almost nothing available, not even the most basic supplies. In others, many supplies are either unavailable or extremely costly (and unfunded). Even in countries where supplies are adequate, it is often very difficult to fulfil all basic needs. Moreover, specific groups within the population, such as homeless people, migrant workers, and travelling families, often lack equal access to any aspect of care (see Annex 3).

Certain basic drugs and supplies and specialized devices and equipment are essential if home-based long-term care services are to be developed or sustained. Local production of supplies and equipment should be encouraged wherever feasible. It may also be possible for countries with similar needs for material resources to collaborate, and policy-makers should consider carefully whether high import duties and other taxes on the items concerned are in the best interests of society. New technology should be introduced cautiously if it has not been specifically assessed as suitable for the local physical and cultural environment.

5.2 Questions to be considered

The following is a list of questions that are particularly pertinent to the problems of material resources for home-based long-term care:

- What can be done to ensure a sustainable and affordable supply of drugs for people receiving home-based long-term care?
- How can low-cost supply sources for equipment be developed?
- What can be done to encourage local production of supplies, devices, and equipment?
- How can adequate distribution and maintenance of equipment be ensured?
- Do demand and other conditions warrant the local production of supplies, devices, and equipment?
- How can supplies be prioritized?
- How can health workers be encouraged to share material resources (e.g. transport)?
- How can communities be encouraged to share material resources?

6. Human resources[1]

Human resources are at the very core of home-based long-term care. Regardless of the location, the age of the client, or the etiology of the condition that has made care necessary, if there is no informal caregiver there can be no home-based long-term care. In many of the economically most disadvantaged areas and countries, the only human resources available to those who are functionally dependent may be informal caregivers, who often display enormous dedication under the most difficult conditions. Even in the richest countries, home-based long-term care would be unsustainable without families and/or other informal caregivers. Formal care resources complement and support informal care. When the client has no viable

informal support network, formal resources provide care to the extent possible, but long-term care outside a residential/institutional setting cannot be sustained indefinitely without informal caregivers.

6.1 Informal human resources

Family caregivers are the most important human resource in home-based long-term care. They usually provide the greater part of all care, yet the majority of them lack training in health care. Far too often their ability to provide for their own personal, social, and financial needs is seriously compromised by their caregiving roles.

6.2 Gender roles in the provision of care

Because most caregivers, both formal and informal, are women, this section deals specifically with the role of women in home-based long-term care. In all countries, women have the primary responsibility for the physical and emotional care of the family and care for those who cannot take care of themselves — the sick and functionally dependent, as well as children and elderly people.

Every human being, even a healthy adult, needs some degree of care. Within the family, the community, and the workplace, that care is provided primarily by women. In very poor countries women collect water and firewood and do most of the agricultural and domestic work in addition to caring for members of their families. Moreover, women's participation in the workforce of most countries is growing; their work is often badly paid and undertaken in poor conditions. In most industrialized countries there is a general trend to promote equality of the sexes in unpaid work, but there is little improvement in this respect in developing countries or in Eastern Europe and the newly independent states of the former Soviet Union.

Most care in formal health and social services is provided by nurses and other categories of community and care workers, many of whom also care for their own dependent family members. Women in most countries thus continue to carry the "double burden" of paid participation in the workforce and voluntary services to family, neighbours, and the community.

The first step towards equity and a fairer basis for home-based long-term care must be to acknowledge the enormous contribution that care makes to human development. Care must be recognized as a priority human need, and society must encourage the commitment of both men and women to caring work. While social norms are slow to change, policies should reflect the need to reward caring work, paid and unpaid, and encourage non-discriminatory attitudes within the family and at the workplace.[1]

6.3 Caregiving over the life course

The age of a functionally dependent person and the age of the caregiver are both important from the point of view of the duration of caregiving and its impact on the caregiver's life. The family of a child born with a mental handicap or an adolescent disabled by an accident will face the need to provide care throughout their lives. Children who care for parents dying of AIDS will have no opportunity to go to school for the most basic education or to receive the care that they themselves need for growth and development. An elderly woman who cares for terminally ill adult children faces the loss not only of those she loves but also of her future economic and social security.

A middle-aged woman caring for a parent with dementia or afflicted by stroke and the individual caring for a chronically sick spouse face different problems and challenges, not only in their caregiving roles but also in their own lives. Their own health problems, their social isolation, and their limited opportunities to earn a living (and make pension provisions), combined with the demands of providing long-term home-based care for others, will have a significant impact on their lives.

6.4 Formal human resources

Formal caregivers support and complement, but do not replace, informal caregiving in home-based long-term care. Implementation at all levels of the policies identified in this report will necessitate the acquisition of new skills as well as changes in working conditions.

In most countries it will be important to introduce skills in long-term care without creating "new" categories of workers; instead, the human resources already available should be reviewed, and additional training and development provided as necessary.

To ensure effective use of staff, it is essential to:

— improve working conditions (e.g. by providing adequate remuneration, recognition, housing when needed, and transport);
— establish career paths;
— provide effective management and technical back-up for staff to enable them to cope with increased workloads resulting from participation in long-term care;
— assist in work planning, monitoring, management, priority-setting, and determining when outreach is appropriate and when it is not;
— provide effective support, feedback, training, information, and education so that staff can assume responsibility for long-term care;
— ensure that specialists provide support to primary health care workers who can then support informal caregivers.

At present, auxiliary health workers of all types undertake a mixture of clinical, primary health care, community development, and home-care functions. This mixture is variable, both in quality and in the balance between the different elements. Efforts are needed to strengthen the commitment of auxiliary health workers and their supervisors to providing a sound mixture of health promotion, home-based care, and clinical services. In addition, the health workers need skills in community development. Finally, community services need to be strengthened at all levels and in partnership with those who live in the communities.

Core clinical, primary health care, and home-based care services are often provided by the health workers who have received the least training. It is important to ensure that these health workers are not asked to undertake tasks that are outside their range of competence, and that their knowledge and skills are strengthened. There is also a need for new categories of health workers, such as nurse practitioners and family health nurses, who are equipped with the knowledge and training to provide the full range of preventive, curative, and home-based primary health care services. In many communities, home-based long-term care programmes are already headed by public health nurses.

It is essential to develop appropriate standards of care and the knowledge necessary to achieve them. This requires the monitoring and evaluation of care

delivery and outcomes. Similarly, sharing information on successful programmes is a powerful means of improving the delivery of services and the quality of care. Management should ensure that all health workers understand that home-based long-term care is an integral element of their responsibilities. Job descriptions will need to be redrafted to reflect these expanded roles.

Particular attention should be paid to the support of volunteers, recruiting them when necessary, developing their skills, and — most importantly — rewarding their efforts. In addition, specialists who have the necessary skills to provide long-term care should act as advisers to other staff, practitioners of traditional medicine, volunteers, informal caregivers, and clients.

Even when policy-makers are equipped with the necessary information and philosophical outlook, policies will suffer unless capacity for their implementation, monitoring, and evaluation can be developed at all levels of the system. To accomplish this, all policy-makers and managers should receive adequate education and training.

6.5 Questions to be considered

The questions listed below relate to human resources and can be used to assess readiness or capacity to provide home-based long-term care. The questions are not exhaustive, nor are they presented in any order of priority; they are offered simply as a guide to assist in the development of relevant policies and programmes.

- What can be done to ensure that the capacity to develop, implement, monitor, and evaluate policies is available at all levels of the system?
- How can roles and responsibilities be shared among clients, caregivers, family, community, and government?
- What can be done to ensure cooperation with traditional health care providers and practitioners of alternative medicine?
- How can harmful practices be avoided?
- How can all those with the potential to contribute to care be mobilized?
- What can be done to ensure that caring skills (self-care and the care of others) are included in school curricula?
- How can the same health workers be used in several programmes without compromising any of their activities?
- What can be done to ensure that existing health care workers are given the necessary skills and support to extend their responsibilities to include home-based long-term care over the life course?
- What is the best means of including long-term care in the training curricula of all health professions?
- How can a continuing education system that covers home-based long-term care be developed and maintained for all health care workers?

7. Conclusions

7.1 Lessons from the experience of developed and developing countries

The Study Group provided an opportunity to compare the experiences of both industrialized and developing countries and to examine the differences in environment and in general health and social service structures that affect strategies for introducing long-term care services. The Study Group also looked at developing countries that have reached different stages of economic development.

Not surprisingly, the family remains a very important source of care in the home. In addition, there are often strong community initiatives to promote voluntary work and self-help on behalf of those in need of care. In a number of countries, religious institutions are major sources of support. The emphasis in developing countries needs to be on providing advice and training to family caregivers, making basic supplies available, and undertaking selective curative functions, rather than on personal and home-making assistance which is provided by the informal support system.

At the community level, maximum encouragement of mutual help and voluntary work is essential to sustaining and enhancing these efforts and to promoting their role in meeting long-term care needs. This is true of both developed and developing countries.

One of the most important findings of the Study Group is that the primary health care system in developing countries could form the basis for the provision of sustainable, cost-effective long-term care. Case reports from Africa, the Americas, and Asia underlined the importance of the role of community health workers, who have close links with the home and who, with appropriate training and support, can be mobilized to meet long-term care needs. A number of the programmes reviewed provided excellent examples of training, practice, and information system development, which could be used as models by others attempting to meet long-term care needs.

The pattern of development in industrialized countries is not necessarily appropriate or even desirable for developing countries. In developed countries, most systems of long-term care segregate age groups and have separate health and social services for acute and long-term care. Efforts to change these systems should be increased, but developing countries can avoid adopting them in the first place.

7.2 Priority steps for developing long-term care

Policies for long-term care should reflect economic and health system development. As income rises and the social structure changes, there may be a progression from simple support for informal caregivers through counselling and provision of supplies, to the introduction of unskilled, then skilled, home-care, and finally to the availability of institutional care. At the lowest income levels, volunteers may represent the only source of care beyond the family; paid workers, while important at all stages, can be brought in as economic resources increase.

Ideally, home-based care should be an integral component of all health and social systems. To start with, however, there should at least be health promotion, disability

postponement, and disease prevention programmes. A next step might be to support informal caregiving in a community-based and "locally owned" manner, and then to introduce community-based care, including home care. Facilities for chronic or extended treatment should follow, then rehabilitative care, general hospitals, and finally tertiary services. The last element of long-term care to be introduced should be institutional care. Allocation of public resources for services should follow the same sequence as the introduction of services. While it is too late for most countries to adopt this rational approach, all countries should be encouraged to fill gaps in their existing systems, or to implement services, beginning with the services that involve the least intervention before moving on to more complex activities.

This kind of approach would ensure continuity of long-term services throughout the health and social systems. For low-income countries, the integration of long-term care into the primary health care system seems to be the best — and indeed, economically, the only feasible — option. In developed countries, the desirability and feasibility of integrating long-term care into the health system remains an open question. However, the Study Group stressed that long-term care should meet the needs of clients regardless of age and regardless of the etiology of disability or functional dependence. Services must also address the needs of informal caregivers if this vital resource is to be sustained.

All long-term care must respect human rights and comply with the wishes of care recipients and their families, who should be involved in all care-related decisions, as well as in the policy-making process. Society as a whole must contribute to enhancing the supply, quality, equity, and sustainability of care, which is essential to the well-being of all people.

8. Recommendations

The Study Group recommended that Member States and society in general should:

1. Acknowledge care as a priority human need that everyone has an obligation to satisfy, and challenge the traditional roles of the sexes, building in both men and women a commitment to the work of caring.
2. Involve all sectors of society and government in supporting care and caregiving as essential elements of development, including long-term care for people with any type of functional dependence and support for their caregivers.
3. Make every effort to foster social solidarity among and within countries and communities, between men and women, and among age groups.

The Study Group also recommended that Member States and WHO should:

4. Assess the scope and nature of needs for home-based long-term care and the resources available to meet those needs.
5. Develop information systems to monitor changing needs and resources and provide a database for continuing policy development and planning.
6. Document best practices, as well as failures, and widely disseminate the lessons learned, within and among countries and regions, by encouraging and enabling health workers, especially in developing countries, to record and publish their experiences.
7. Develop policies that include home-based long-term care as an integral part of a

country's health and social systems and health reform efforts. These policies should guide the planning, legislation and regulation, financing, organization, management, and monitoring of services, as well as the development of human and material resources and clearly defined priorities for the allocation of such resources.

8. Encourage the involvement and collaboration of all sectors, both public and private, including the health and social sectors.
9. Encourage and respect creative community-based initiatives for long-term care, and examine the possibility of their full-scale implementation.
10. Base national policies and initiatives at all levels on existing structures and resources and give serious consideration to integrating home-based long-term care into primary health care.
11. Adopt an approach that focuses on health promotion and disability postponement over the life course and on the needs of functionally dependent people and of those who care for them, regardless of the etiology of the dependence and of the age of the client or caregiver.
12. Develop and coordinate policies and strategies in the different sectors of government to support incentives for caregiving, including those aimed at families, friends, neighbours, and organized volunteers, with a view to increasing the supply, quality, equity, and sustainability of home-based long-term care.
13. Provide support, training, and supervision to all formal and informal home care providers.
14. Initiate strategies in developing countries that take account of their strengths, cultural norms, and constraints, rather than copying those adopted in industrialized countries.
15. Develop home and community services to meet the needs of functionally dependent people and their families, before developing institutional services.

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Annex 1

Definition of integrated health services[1]

"Integration has been defined in *functional* terms as a series of operations concerned in essence with the bringing together of otherwise independent administrative structures, functions and mental attitudes in such a way as to combine these into a whole.

However, the expression "integrated health services" has also been defined in *organizational* terms as those services necessary for the health protection of a given area and provided under a single administrative unit, or under several agencies, with proper provision for their coordination.

Intersectoral cooperation leading to integration is easier at local and district levels than at higher levels (i.e. provincial or central). Integration is a way of optimizing the use of scarce resources and responding more effectively to people's needs. By improving efficiency and effectiveness and with the involvement of education and other social services, integration aims to increase consumer satisfaction with the health services.

Integration is not a strategy to fall back on when vertical programmes run out of funds, nor is it achieved by adding to the responsibilities of service providers without a corresponding increase in resources. It is not a panacea.

Integration does not mean that specialized disciplines, programmes, personnel and services will be abolished. It does not necessarily mean that all services will be provided by multipurpose workers. A rational referral system implies the need for specialists at secondary and tertiary levels; where resources permit, some specialization may be appropriate at the primary health care level.

The Study Group defined integration of health services as the process of bringing together common functions within and between organizations to solve common problems, developing a commitment to shared vision and goals and using common technologies and resources to achieve these goals. The aim is to promote primary health care services which are fully integrated under the management of a district health team, led by a district health manager, in order to make the most efficient use of scarce resources. . . .

From the success stories related by the participants, it appears that the success or failure of integration will depend on the attitude of service providers, who will need to pool resources, show unity of purpose and give up some of their territorial rights. It was also emphasized that integration will require close coordination between individuals, departments and sectors."

Annex 2

Integrating home-based long-term care into the health and social system

Policy	Planning	Legislation and regulations	Financing and sustainability	Organization and management	Monitoring and evaluation
A. Services					
Develop only what can be sustained. Intersectoral national policies (e.g. income protection; continuity of social and health services; education and promotion of health in a life course approach) that enable home-based long-term care to be an integral part of the health and social system and part of sector reforms. National policies informed by local service needs, preferences, and community expectations.	National planning Management processes that incorporate analysis of burden of disease, prevalence of functional disability, extent of informal caring, and capacity of primary health care system to integrate home-based long-term care. District and local planning that informs national planning and makes possible the integration of home-based long-term care into the primary health care system based on the local situation. Community consultation as an input to planning at all levels.	National legislation Guidelines on and regulations that support policies and facilitate flexibility of services at the local level to meet client needs.	Funding mechanisms that support comprehensive services, continuity of care, and affordability, and minimize over-servicing while ensuring access.	environment that encourages and supports innovation, creativity, and community participation. Services organized to support client and family needs: continuity of care required, including specialist back-up and referral services.	standards of care and quality assurance. Monitoring of standards of care. Information systems that ensure efficient data-gathering at the local level, timely feedback, and use of the information at local level.

Policy	Planning	Legislation and regulations	Financing and sustainability	Organization and management	Monitoring and evaluation
B. Human resources					
National health and social workforce policies that: (a) minimize the categories of workers; (b) avoid over-medicalization or over-professionalization; (c) ensure appropriate numbers and skills; (d) make possible a comprehensive approach to home-based long-term care. Social and labour policies that provide rewards and incentives for formal and informal caregivers. Education and support for formal and informal caregivers. Non-discriminatory policies.	Planning that ensures appropriate skill mix and appropriate basic and continuing education for all health workers, formal and informal.	Legislation and regulations that enable health workers and protect the public without stifling the flexibility required to meet client needs. Non-discriminatory labour laws to ensure standards of formal caregivers.	Satisfactory working conditions (e.g. fair remuneration, housing, career advancement opportunities).	Ensure effective leadership and improve management skills at all levels. Encourage a clear understanding of division of labour, and collaboration, with sharing of resources to ensure accountability, motivation, and coordination of formal and informal carers.	Ongoing monitoring of numbers, quality, deployment. Monitoring of present and expected attrition and future workforce availability (e.g. age profile, HIV/AIDS).

C. Material resources					
National policies and guidelines to ensure the availability of essential equipment and supplies (e.g. gloves, soap, syringes, drugs). National policies that encourage local manufacture (e.g. crutches, walking frames). National policies that minimize customs duty on imported material resources required for home-based long-term care. Local policies of sharing transport and equipment in the primary health care system.	Provision of appropriate guidelines, learning materials, equipment, and supplies.	Legislation and regulations that facilitate affordable and accessible supplies and equipment and contain costs.	Funding mechanisms that ensure availability	Systems that ensure supply continuity, appropriateness, and affordability.	Monitoring and evaluation of availability, appropriateness, cost, and affordability.

Annex 3

Availability of material resources for home-based long-term care in countries at different stages of economic development

Material resources	Industrial market economies	Transitional economies	Developing economies	Least-developed economies
Shelter	Satisfactory quality available to the majority. Increasing numbers of homeless and transient populations.	Satisfactory to poor quality available to the majority. Accelerated increase in numbers of homeless and transient populations without shelter. Growing numbers of refugees and internally displaced people.	Satisfactory to poor quality available to the majority. Growing urban slums. Growing numbers of refugees and internally displaced people.	Poor quality available to the majority. Growing urban slums. Growing numbers of refugees and internally displaced people.
Safe water	Available to the large majority.	Available to the majority in most countries.	Coverage: urban 85% rural 60%	Coverage: urban 64% rural 37%
Sanitation	Available to the large majority.	Available to the majority.	Coverage: urban 60–70% rural 25–35%	Coverage: urban 60–75% rural 15–25%
Supplies (e.g. disinfectants, gloves)	Available to the majority.	Not affordable for poor and homeless people.	Not affordable for poor and homeless people.	Not available to the majority.
Fuel and heat	Cost denies access to growing numbers of poor people, including poor elderly people.	In many countries, not available to the majority. Cost denies access to growing numbers of poor people.	Cost and diminishing resources deny access to growing numbers of poor people.	Available to the majority only through personal gathering of fuel, e.g. firewood. Cost denies access to growing numbers of poor people.

Basic equipment	Often not available to the poor or people with low incomes.	Not affordable for poor and homeless people.	Local production may increase access.	Local production may increase access.
Special equipment	Often not available to the poor or people with low incomes.	Restricted availability.	Restricted availability.	Largely unavailable.
Assistive devices (e.g. glasses, hearing aids)	Often not available to the poor or people with low incomes.	Often not available to the poor or people with low incomes.	Often not available to the poor or people with low incomes.	Often not available to the poor or people with low incomes.
Prostheses	Often not available to the poor or people with low incomes.	Restricted availability.	Local production may increase access.	Local production may increase access.
Drugs	Often not available to the poor or people with low incomes.	Often not available to the poor or people with low incomes.	Often not available to the poor or people with low incomes.	Often unavailable.
Transport	Cost denies access to growing numbers of poor people, including poor elderly people.	Often not available to the poor or people with low incomes.	Often not available to the poor or people with low incomes.	Often unavailable.

[1] Ad apted from *International long-term care initiative: towards a consensus on policy development*. Geneva, World Health Organization, 1999 (unpublished document HO/HSC/AHE/99.1: available on request from Noncommunicable Diseases and Mental Health, World Health Organization, 1211 Geneva 27, Switzerland.

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[1] "Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods, and made universally accessible to individuals and families, at a cost they can afford. It should address their main health problems, providing promotive, preventive, curative and rehabilitative services accordingly. Since these services reflect and evolve from the local economic conditions and social values, they vary in different countries and communities. . . . The three prerequisites for successful primary health care are a multisectoral approach, community involvement and appropriate technology" (*2*).

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[1] For a discussion of issues relating to the development of health policies, see Janovsky K, ed. *Health policy and systems development. An agenda for research*. Geneva, World Health Organization, 1996 (unpublished document, WHO/SHS/NHP 96.1; available from Organization of Health Services Delivery, World Health Organization, 1211 Geneva 27, Switzerland).

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[1] For a discussion of the globalization of care work, see Chapter 3 of *The human development report 1999* (1).

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[1] Reproduced from: *Integration of health care delivery. Report of a WHO Study Group*. Geneva, World Health Organization, 1996:4 (WHO Technical Report Series, No. 861).

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The adequate planning of home-based long-term care (HBLTC) is essential in the current European setting where long-term care (LTC) demand is increasing rapidly, and where home-based care represents a...Â World Health Organization: Home-based long-term care: report of a WHO study group. World Health Organization, Geneva (2000)Google Scholar. Copyright information. home-based long-term care -- 2.4 Care and dependence as elements of human development -- 2.5 Questions to be considered -- 3. Home-based long-term care in health and social systems -- 3.1 National-level responsibilities -- 3.2 District-level responsibilities -- 3.3 Community-level responsibilities -- 3.4.Â |a Records the conclusions and recommendations of a study group commissioned to explore the use of home-based care as a strategy for coping with the growing number of individuals in need of long-term care. Addressed to policy-makers the report responds to striking demographic and epidemiological changes that have created an urgent need to expand the availability of cost-effective chronic care.