LESSONS FOR LONG-TERM CARE POLICY

The Cross-Cluster Initiative on Long-Term Care

Noncommunicable Diseases and Mental Health Cluster
World Health Organization

and

The WHO Collaborating Centre for Research on Health of the Elderly
JDC-Brookdale Institute
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The World Health Organization gratefully acknowledges the valuable technical and scientific leadership of the JDC-Brookdale Institute, and the support of the Marshall Weinberg Fund for International Collaboration, in contributing to the “Bridging the Limousine – Train – Bicycle Divide” Meeting on Long-term Care.

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Introduction

Dramatic demographic and epidemiological changes over the last few decades are resulting in a serious transformation of the health care needs of the world’s population. Long-term care (LTC) needs resulting from population ageing, the HIV/AIDS pandemic, TB, traffic accidents, violence and other sources of injury are increasing in the developing world at a rate which far exceeds that experienced by industrialized countries.

Even more dramatically, many countries are experiencing these increases while simultaneously dealing with the significant burden of noncommunicable diseases. Moreover, the developing world is experiencing increases in LTC needs at levels of income that are far lower than that which existed in the industrialized world when these needs emerged.

For these reasons, the search for effective LTC policies is one of the most pressing challenges facing modern society. There is no single converging paradigm in the industrialized or developing world, and countries are experimenting with a number of different approaches.

Recognizing that such trends greatly increase the need for well coordinated and cost-effective LTC, the World Health Organization (WHO) launched an international initiative, with the JDC-Brookdale Institute leading this effort. This process is predicated on a number of major premises:

1. Previous efforts have not been successful in identifying meaningful policy guidelines that are appropriate to the unique situations of developing and middle-income countries.

2. A key resource in formulating LTC policies for developing countries is the existing experience of developing countries.

3. LTC policies in the developing world need to reflect the unique conditions in the developing world, which have to be understood with much more depth and complexity.
4. There is much to be learned from the experience of industrialized countries in order to define the range of options and to identify successful and unsuccessful policy practices.

5. There is a need to create a deeper and more informed dialogue between the experiences of industrialized and developing countries so that there can be a mutually beneficial learning process.

Over the last three years, a number of steps have been taken to implement this agenda. In 1998, a comparative review of the implementation of long-term care laws based on legislation and entitlement principles in five industrialized countries (Austria, Germany, Israel, Japan and the Netherlands) was carried out.

This was summarized in a widely distributed report: *Long-Term Care Laws in Five Developed Countries* (WHO/NMH/CCL/00.2). In implementing this study, a framework was developed for cross-national comparisons of long-term care policies that address the needs of policy-makers.

In December 1999, a meeting of a group of long-term care experts from the industrialized and developing world identified specific issues in LTC provision in developing countries. Their general recommendations were submitted in a report and accepted by the 108th WHO Executive Board (WHO Technical Report Series, No. 898).

Another lesson from this workshop was that it became clear that to go beyond previous discussions requires a more in-depth understanding of the existing situations in developing countries and the nature of the variance among countries. Thus, a plan was developed to request in-depth case-studies from experts in middle-income developing countries, and in April 2001 a second workshop was organized to discuss the framework for the preparation of these case-studies.

This framework was designed to emphasize additional elements that would be important in the developing country context, and also to examine the more general health and social policies and service structure along dimensions that have major implications for long-term care. Case-studies of the general health system and current LTC provision in nine developing countries were written by local health care experts (People’s Republic of China, Costa Rica, Indonesia, Lithuania, Mexico, Republic of Korea, South Africa, Thailand, and Ukraine).
Furthermore, to complete and broaden the picture of patterns of LTC policies in industrialized countries, case-studies of countries without a legislative framework, including Australia, Canada and Norway, were commissioned.

An additional perspective was provided on the experience of the industrialized countries by commissioning a set of papers on key cross-cutting issues such as:

- The interface of LTC with other components of health and social care systems.
- Human resource strategies.
- The role of the family and informal care.

A series of video conferences that opened a dialogue between WHO Headquarters and the six Regional Offices on desirable directions for long-term care was also conducted.

The next step was to convene the group of leading experts from industrialized and developing countries who had prepared the papers, together with WHO Regional Representatives and key WHO Headquarters’ staff. Two integrative papers on the overall patterns identified and lessons learned from the case-studies of industrialized and developing countries were prepared by the Brookdale team for the meeting, which took place in November 2001 in Annecy, France.

The purpose of the meeting was to assess what has been learned thus far from the experiences of both industrialized and developing countries that can contribute to the development of LTC policies for developing countries. The theme of the meeting, “Bridging the Limousine – Train – Bicycle Divide”, addressed the question:

“What can countries with very low economic resources (i.e. those at the bicycle – or even pushcart – level) learn from the experiences of countries with high economic resources (i.e. those at the limousine level) and vice versa, and what can countries with LTC systems already developed, but with declining resources (i.e. those at the train level) learn from both.”
This general report on the Meeting is designed to give a broad overview of the nature of the background materials that were prepared and the issues that were discussed. It also presents some general conclusions that were agreed on by the participants. It does not attempt to capture the full richness of the material or the discussions at the Meeting, which will be analysed in depth and summarized in a series of publications over the course of the next year.

Some of the specific questions that were addressed include:

1. **What is the rationale for addressing long-term care** in countries with modest resources and other pressing health care needs, and how can this best be presented to policy-makers? What are the factors contributing to the present and future *needs* for long-term care in developing countries?

2. **What are the critical issues** that need to be addressed in developing LTC, and what are some of the major alternatives to resolve those issues? How do we go beyond the resolution of specific issues to the consideration of alternative overall strategies?

3. **What is the experience of industrialized countries?** What are the problems and deficiencies in the LTC systems of industrialized countries? What are the factors that contribute to these deficiencies, can they be avoided, and how? What are the positive experiences in the industrialized countries that are relevant to developing countries? Should developing countries be pursuing a different pattern from the industrialized world? Are they at different points on the same developmental continuum or on a different one?

4. **What is the experience of developing countries?** What are the strategies or patterns of long-term care that are emerging in developing countries? Is there an underlying rationale for these patterns? To what extent are there emerging strategies that can serve as more general guides for further policy development?

5. **What are the key factors that distinguish industrialized and developing countries** and how does each factor affect the nature of long-term care strategies? Examples include the following: epidemiology, resources, culture and values, educational level, strength of informal care, stages of development of health and social care systems, obstacles to accessibility of LTC such as geographic spread, internal migration, transportation and infrastructure.
6. One of the unique dimensions of long-term care is the important role of the family and other informal supporters in providing that care. What is the extent of and likely trend in that support and how is it influenced by public policies? What are the needs of family carers, as well as those who are being cared for?

7. Which long-term care services should receive priority at any point in time, and how does this vary with the general socioeconomic status of the country and the country’s specific values and culture?

8. Another important consideration involves the links between the existing health and social service structures and the development of LTC. What is the nature of these links? To what extent should LTC be integrated with these systems? What are the opportunities they provide for developing LTC, and what are the obstacles they pose? How should one develop LTC against the background of that which already exists? To what extent do we develop a LTC strategy taking the health and social systems as a given, or do we consider simultaneously change in both? How do we integrate LTC in processes of health and social service reform?

These issues were discussed during the course of five days of full group sessions and small group meetings. Considerable progress was made in developing a framework for guiding LTC policy that is sensitive to the specific needs, possibilities and priorities of societies at different stages of social and economic development.
Long-term care (LTC) includes activities undertaken for persons that are not fully capable of self-care on a long-term basis, by informal caregivers (family and friends), by formal caregivers, including professionals and paraprofessionals (health, social, and others), and by traditional caregivers and volunteers.

It encompasses a broad array of services such as personal care (e.g. bathing and grooming), household chores (e.g. meal preparation and cleaning), life management (e.g. shopping, medication management, and transportation), assistive devices (e.g. canes and walkers), more advanced technologies (e.g. emergency alert systems and computerized medication reminders), and home modifications (e.g. ramps and hand rails). This mix of services, whether delivered in homes, in communities or in institutional settings, is designed to minimize, restore, or compensate for the loss of independent physical or mental functioning.

LTC does not include prevention, management of chronic disease, rehabilitation and acute care in general. However, it is necessary to ensure access of the long-term care population to these services. It also includes special assistance to meet basic housing and subsistence needs.

LTC includes efforts to ensure access of the long-term care population to acute and chronic care. It also includes efforts to prevent deterioration of the functional capacity of the disabled (such as preventing bedsores, preventing depression) by promoting appropriate lifestyles for the disabled and their caregivers, and adapting preventive care to maintain functional capacity and social interaction.

**Target population**

The population in need of long-term care includes all those who suffer from any kind of physical or mental disability. The focus, derived from the above definition of LTC, is on the care of persons with long-term health problems who need assistance with the activities of daily living. This target population includes persons of all ages who are experiencing some degree of functional dependence, as well as their care providers.
Link between dependency and need for assistance

This project focuses on services for persons of all ages who have long-term functional dependency. Dependency creates the need for a range of services, which are designed to compensate for their limited capacity to carry out activities of daily living. Dependency also results in difficulties in accessing health care and in complying with health care regimes. It impacts on the ability of the individual to maintain a healthy lifestyle, and to prevent deterioration in health and functional status. Dependency creates additional emotional needs and strains, which must be addressed. Social needs also arise from limitations in maintaining regular social contacts.

Unique health problems arise in part from the fact that either single or multiple chronic diseases may be the source of the disability. These in themselves require complex health services and special regimes of chronic care management. Moreover, when combined with functional limitations, the challenge becomes even greater. Most obvious among these are mobility limitations, which may require services to be brought to the home. Cognitive impairments prevent the individual from maintaining compliance with complex medical regimes.

Central to the care of dependency is the role of the family in providing that care, and the resultant needs of the family. The need to address dependency impinges not only upon various aspects of family function, but also upon relationships within the family. It creates a need to manage relationships between the disabled person and the family, as well as those between and among family members according to their respective roles in providing care. The need to address such dependency also has emotional consequences for family members and for their relationships with one another.

All of these circumstances and their consequences require significant efforts to guide, educate, and inform the disabled person and his or her family. Dependency creates a complex range of needs for services, which in turn creates a need to coordinate access to and management of these multiple services. This care management function creates still another need in itself.

Types of long-term care services

Long-term care may be either institutional or home-based. It may be either formal or informal. Institutional or residential long-term care occurs when three or more unrelated persons are being cared for in the same place. Home-based care may occur either in the home, or in the community but outside the home.
It is useful to distinguish between two types of home-based LTC services:

1. Health-related care, which we refer to as home health.

2. Care related to daily functioning, such as personal care (e.g. eating, bathing) and homemaking (e.g. cooking, cleaning).

Formal care (i.e. paid care) may be publicly financed and organized. In this approach, services may be provided by governmental organizations; by local, national, or international nongovernmental organizations (NGOs); or by for-profit organizations. Formal care is usually provided by recognized professionals (e.g. nurses, doctors, and social workers) and/or by paraprofessionals (e.g. personal care workers). Traditional healers may be an important additional source of care.

Informal care includes care provided by nuclear and extended family members, neighbours, friends, and independent volunteers, as well as organized volunteer work through organizations such as religious groups.
The trends in developing countries clearly indicate the growing need for long-term care. These trends reflect two interrelated processes. One is the growth in factors that increase the prevalence of long-term disability in the population. The second is the change in the capacity of the informal support system to address these needs. Both of these processes enhance the need for public policies to address the consequences of these changes.

The ageing of the populations in these countries has an impact on both of these processes. As the population ages, the percentage with chronic diseases and related disabilities rises significantly. Moreover, population ageing is caused primarily by a decline in fertility, and it is thus associated with a decline in family size and a rise in the number of elderly in relation to the younger population (reflected in the parent and elderly support ratios\(^1\)). This increases the pressure on children who are a major source of support to the elderly.

Table 1 provides some illustrative statistics for the developing countries that have served as the case-studies in the WHO initiative. Although among the nine countries examined there is considerable variation in the proportion of elderly, each country expects a remarkable future increase in the population age 65 and over.

All the countries examined also expect a steep increase in the parent and elderly support ratios. For example, in Lithuania, 13.4% of the population is already 65 and over, and there are about 22 persons over 65 to every 100 persons in the prime working age (20–64). These indicators will rise at a rapid pace. The percentage of elderly in Lithuania will increase to 19.7% by 2025 and the parent support ratio is expected to grow by 50%.

In Indonesia only 4.8% of the population is 65 and over, and there are about nine persons over 65 to every 100 persons age 20–64. However, the proportion of those 65 and over will nearly double in the next 25 years and (as in most of the countries included in the study).

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\(^1\) Elderly support ratio: the ratio of those age 65 and over per 100 persons age 20–64. Parent support ratio: the ratio of those age 80 and over per 100 persons age 50–64.
There are additional factors that are affecting the prevalence of disability. The AIDS pandemic has had a devastating impact on the number of chronically ill and disabled adults and disabled or orphaned children. The numerous outbreaks of armed conflicts on a national scale have had similar consequences. In many developing countries, the sharp rise in traffic accidents and other injuries is having an important effect on functional disability rates.

There is very limited information available on disability rates in developing countries. The existing data relate more to the prevalence of chronic and communicable diseases. However, efforts have been made to use morbidity data to estimate disability rates.

According to WHO’s *World Health Report 2000*, an approximately equal number of years of healthy equivalent life is lost to disability in industrialized and developing countries (7 years). This is despite the fact that people in industrialized countries live longer and “have more opportunity to acquire non-fatal disabilities.”

“Disability makes a substantial difference in poor countries because some limitations — injury, blindness, paralysis and the debilitating effects of several tropical diseases such as malaria and schistosomiasis — strike children and young adults.” Because of the lower life expectancies in developing countries, it can be argued that disability makes a more significant impact on the lives of people in the developing world because a higher percentage of life (14% versus 9%) on average, is lost to disability (these statistics are based on Murray and Lopez’s calculations) (*World Health Report 2000*).

In a recent study *Current and future caregiver needs for people with disabling conditions*, commissioned by WHO’s Cross-Cluster Initiative for Long-term and Home-based Care (CCL), Rowan Harwood and Avan Sayer attempt to translate the increase in disability into projections that measure the need for caregiver assistance for daily needs. They find that these care needs will increase much more rapidly in developing countries (Harwood and Sayer, 2002).

In the report of the WHO meeting, *Innovative Care for Chronic Conditions*, the authors write that

> “the prevalence of chronic conditions, including noncommunicable diseases, mental disorders, and certain communicable diseases such as HIV/AIDS, is increasing dramatically. In developing countries, it is estimated that fully half of all required health care is now due to chronic conditions (including injuries and neuropsychiatric disorders)”

(*Innovative Care for Chronic Conditions Meeting Report, 2001*).
Further, it is estimated that by the year 2020, chronic conditions will be responsible for 78% of the global disease burden in developing countries (Innovative Care for Chronic Conditions, 2002). Similar calculations completed by D. R. Gwatkin and Michel Guillot for the world's twenty poorest countries show a similar rise (Gwatkin and Guillot, 2000).

It is important to emphasize an additional consideration that might make the issue of LTC policy especially complex in developing countries. One of the major concerns that has been expressed is that the rise in chronic disease and related disabilities is occurring in countries that are still grappling with a high burden of traditional communicable diseases. This is associated with the fact that the developing world is ageing at much lower income levels than that which characterized the same demographic transitions in the industrialized world.

The extent of the double burden of disease is reflected in the relative levels of the percentage of elderly and indicators of the extent of communicable diseases such as the under-5 mortality rates shown in Table 1, as well as the rate of change in both of these variables. With the added difficulty of facing this “double burden of disease” at very low levels of income, countries will have to be especially cost-effective and efficient when developing LTC services.

Concomitant with the demographic and epidemiological changes just mentioned, statistical evidence from the nine countries participating in the study indicates additional forces that impact on the ability of informal support systems to provide care. These factors include an increasing percentage of women in the labour force and increased internal migration.

This is evidenced in Table 1 by statistics showing the growth in female participation in the labour force from 1960 to 2000. For example, the percentage of women participating in the labour force increased in Mexico from 9.1% in 1960 to 27.1% in 2000, in Costa Rica from 9.7% to 25.2%, and in the Republic of Korea from 17.3% to 42.7%. It appears that there is a fundamental need to develop LTC services to share the responsibilities with families.
### Table 1: Selected Socioeconomic, Demographic and Epidemiological Indicators Relevant to the Determination of Long-Term Care Policy in Nine Developing Countries

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<thead>
<tr>
<th></th>
<th>China</th>
<th>Costa Rica</th>
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<th>South Africa</th>
<th>Thailand</th>
<th>Ukraine</th>
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<tr>
<td>% 65+ in 2000</td>
<td>6.9</td>
<td>5.1</td>
<td>4.8</td>
<td>13.4</td>
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<td>% 65+ in 2025</td>
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<td>8.4</td>
<td>19.7</td>
<td>9.3</td>
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<td>Elderly support ratio(^2) in 2000</td>
<td>11.4</td>
<td>9.7</td>
<td>8.9</td>
<td>22.4</td>
<td>9.1</td>
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\(^2\) Rank refers to the relative position on each indicator from highest (1) to lowest (9).

\(^3\) Elderly support ratio: the ratio of those age 65 and over per 100 persons age 20–64.
### Table 1: Continued

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<td>in 2000</td>
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<td>in 2025</td>
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<td><strong>HALE</strong>(^5) (2000)</td>
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\(^4\) Parent support ratio: the ratio of those age 80 and over per 100 persons age 50–64.

\(^5\) HALE: Healthy Life Expectancy
### Table 1: Concluded

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\(^6\) PPP = purchasing power parity: the rates of currency conversion that equalizes the purchasing power of different currencies by eliminating the differences in price levels between countries.

**Sources:**
There are a number of issues that need to be addressed when designing a long-term care system. Within the framework of this project, a classification of these key issues was developed, which also provided a basis for preparing the case-studies. In addition, a cross-cutting paper was prepared on a number of these key issues.

Additionally, a paper was prepared identifying broad overall strategies that combine the resolution of a number of specific issues by examining the nature of interaction in the resolution of the specific issues.

*Classification of key issues which need to be discussed*

1. **Priority of LTC in the country**
   a) Which LTC services to prioritize
   b) Relative priority of LTC among other needs

2. **Priority among goals within a system**
   a) Adequacy in meeting needs (level of support, access and quality)
   b) Equity across income and other groups
   c) Appropriate utilization and cost-effectiveness
   d) Total cost and control over cost dynamics

3. **Role of government**
   a) Stewardship
   b) Financing
   c) Resource generation
   d) Provision

4. **Role of the family**
   a) State vs family responsibility
   b) How to preserve the role of the family
   c) Mechanisms to support family (support, education, respite)
5. Priorities by age and etiology
   a) Whether to prioritize between age groups or etiologies
   b) Whether LTC systems should be age integrated

6. Service delivery strategies, balancing care in the home, in the community and in institutions

7. Role of cash grants vs direct service provision

8. Nature of entitlement, targeting and finance
   a) Entitlement vs budget constraint
   b) Degree of prioritizing by income, disability and family situation (targeting and rationing), minimal support to many vs greater support to a few
   c) Financing strategies

9. Purchasing/contracting strategies vis-à-vis providers

10. Decentralization of decision-making, financing, and responsibility for provision of LTC

11. Strategies for achieving integrated/coordinated care – links with:
   a) Preventive, acute, chronic health care
   b) Social care
   c) Integration/coordination among LTC services.

12. Role of volunteers
   a) The role of individual volunteers and volunteer community organizations
   b) How to preserve/strengthen the role of volunteers and community (recruiting, training, recognition and rewards)

13. Human resource strategies
   a) ‘Generic’ (utilizing existing health/social resources) vs specialized LTC staff
   b) Level of formal requirements and training
   c) Working conditions

14. Strategies of cost-containment

15. Role in provision of LTC by government, NGOs and for-profit organizations
In this section, the discussions at the meeting are illustrated by focusing on three issues:

1. The role of the family and informal care.
2. Human resource strategies.
3. Strategies for achieving integrated/coordinated care.

At the end of this section, an effort is made to go beyond specific design issues to address the challenge of identifying and analysing broad overall strategies. These strategies are important because they greatly impact specific design issues and affect the nature of the LTC system as a whole.

The role of the family and informal care

Informal care can be defined as care given by relatives and friends to disabled individuals. Often this work is unpaid and done without formal training, but in recent years there has been some growth in the amount of education and training for informal carers in selected countries and some forms of payment for this work have come into being.

According to the background paper The Role of Informal Support in LTC, prepared by Joshua Wiener for the Meeting, despite the development of government, private (for-profit) and NGO services for disabled individuals, informal care is by far the dominant form of care throughout the world. Paid services — either at home or in institutions — play a relatively small role, except in a few countries.

Spouses, parents and children, and especially mothers, wives, daughters and daughters-in-law, have traditionally been the primary providers of informal care. Because of the potential fiscal and care implications of the decline in informal care, public policy-makers want to assure that this care is maintained.

However, there are many questions regarding the possibility and desirability of informal care maintaining such a large share of caregiving responsibilities. First, with the increased number of disabled and elderly people worldwide, it is unlikely that informal caring will be able to grow correspondingly with the greater needs.

Second, with an increasing number of women working outside the home, and with women largely being the primary caregivers, it will be difficult for them to continue to shoulder such a large burden of care.
Third, studies have shown that informal care can be physically and mentally damaging for caregivers, so it is questionable as to whether it is even desirable for informal care to continue as it has in the past, without offering different kinds of support.

Although most public policy and services in long-term care are aimed at the disabled person, some financing and services are aimed at informal caregivers, principally relatives. An underlying premise is that services or cash payments will result in informal caregivers experiencing less stress and will enable them to do a better job and provide care for a longer period of time.

Wiener provided a number of examples of support that various governments have provided to aid informal caregivers. One type is “education, training, counselling and support”. Examples of this type of support include providing “concrete skills, such as information on how to lift a disabled individual without creating back strain” and “emotional counselling through support groups”.

A second type of support is “respite care” that aims to provide caregivers with temporary relief. A third type of support is “regulation of labour initiatives”, and may include laws guaranteeing workers unpaid leave if they have to care for sick relatives. A fourth type of support is “pension credits” for informal carers, as many countries base the level of pension benefits on years of paid work (Wiener, 2001).

A fifth type of support, explored in detail in Marja Pijl's background paper, The Support of Carers and their Organizations in some North and West European Countries, is direct financial support. This includes “income support” (financial allowances for individuals who have limited or no income because of their caring duties); “compensation for loss of income” (payment to individuals that is directly tied to lost income because of commencement of caring); and “payment for work performed” (payments that are tied directly to the work performed and not necessarily to financial need or sudden loss of income) (Pijl, 2001).

These services are designed to increase the level of knowledge and emotional support of caregivers, provide relief from the unending burden of caring for a disabled person, or provide financial benefits to those who take on this responsibility.

Wiener raised a number of public policy issues and questions. These include the cost trade-off between providing services to informal caregivers and spending additional resources on formal care directed at the disabled; whether the provision of formal care reduces the amount of informal care; how work outside the home affects caregiving and vice versa; and whether support should be in the form of cash or services.
A particularly critical issue that he discusses is the balance of responsibility between society and the family. As Wiener stated, many long-term care policy issues revolve around that of whether the individual and family, or society as a whole should be responsible for providing and caring for persons with disabilities.

Some people believe that the primary responsibility for care of those with disabilities belongs with individuals and their families, and that governments should act only as a payer of last resort for those unable to provide for themselves. Proponents of this view generally favour means-tested programmes. This view predominates in the United States and the United Kingdom.

At the other end of the policy continuum are people who believe that long-term care is a societal responsibility and that, while individuals and families should do their part, formal care and public support for informal caregivers should play a large role in meeting the long-term care needs of disabled people. In this view, socially supported services should be available to all who need them regardless of financial status, in the same way that health insurance should be universally available.

Proponents of this view favour programmes that provide universal coverage and are not means tested. This perspective is characteristic of long-term care systems in the Scandinavian countries. Closely related to this issue is the question of whether or not the level of family support should be taken into account when allocating care and financial support to disabled individuals. Resolving this issue impacts the determination of who should be awarded aid (monetary or service support) from the state.

When looking at the role of informal care specifically in developing countries, there arises the question as to what is the ultimate goal as they develop, in terms of the role of the family and the division between the family and the state. Since this varies among industrialized countries, their experience does not point in any single direction. Certainly, there will always be variation among developing countries in this domain as well. The question is whether there will be some overall tendency that is different from that in the industrialized world.

A distinguishing factor that needs to be taken into account in addressing family policies is the fact that, in developing countries, a much larger percentage of those with long-term care needs will be living with their families, whereas in the industrialized world they typically live apart. Moreover, in many industrialized countries the needs of family carers for advice and training have been particularly neglected. In the developing world, the role of family care is at present, and will likely remain so for some time, much more significant. This requires all the more attention to effective support and counselling for families.
Human resource strategies

Developing and sustaining a long-term care labour force is particularly challenging because long-term care relies heavily on human labour. In the background paper prepared for the conference by Rosalie Kane, *Human Resources Strategies in LTC*, she analyses some of the major decisions related to LTC human resource policy.

She discusses the type of human resources that a country requires to provide long-term care, emphasizing lessons that can be drawn from the experience of industrialized countries. For the most part, these lessons are expressed as principles rather than formulas for how many personnel of various types are needed in particular care settings.

As argued by Kane, each country will have its own economic and demographic imperatives based on the age, gender, and ethnicity structure of the population; the educational and literacy levels of the working-age population; employment patterns; and the amount of regional variation in all of the above.

However, it is possible to state more specifically what kinds of skills and abilities are needed in any country’s labour force for long-term care. It is also possible to describe issues that must be considered in planning and shaping any country’s long-term care labour force, and the kinds of information that would be useful to guide national and local planning on human resources for long-term care.

Kane analysed what knowledge and skills (and, therefore, what occupations and expertise) are needed in the long-term care labour force by first considering what tasks need to be done. It is useful to define general tasks before identifying the professional occupations and job titles that may be necessary.

Tasks can be divided into those usually performed by persons with professional degrees and those usually performed by persons without advanced or specialized education. Some thirteen tasks were identified and divided into two broad categories:

1. **Professional or specialized tasks** (i.e. rehabilitation to improve or maintain functioning capabilities, management of or assistance with medication regimens, evaluation of needs and development of care plans).

2. **Care tasks for “front-line workers”,** meaning those without professional credentials (i.e. direct assistance with everyday life, such as assistance with mobility, bathing, dressing, etc.).
Those defined as professional or specialized tasks rely on a somewhat specialized knowledge-base and set of skills and raise some general issues such as the kind of profession needed for the different tasks and the possibility of substitution among professions. For example, to what extent can nurses substitute for physicians.

Another issue is the need for specialists versus generalists within a profession. For example, she writes that vigorous debates have been held about the need for geriatric physicians or geriatric nurses, and that the answers depend on the role envisaged for the specialist. Will, for example, a geriatric nurse care for most old people directly, provide direct care for just a segment of the population in need (perhaps those who suffer from complicated conditions), or will they largely provide consultation and education to general nurses?

With regard to the tasks of front-line workers, some skill and training to perform them are needed. However, it is important to remember that many are performed by family and friends without particular training, and many may be interchangeable among individuals who have wide variation in education.

These direct tasks are sometimes subdivided. The most common division is between personal care services (those that bring the worker into contact with the body of the person receiving care) and other help that involves contact with the patient’s possessions and environment (such as homemaking).

Thus, housekeeping, cooking, and cleaning may be done by one category of personnel and personal care by another. Such division of labour is sometimes deemed efficient, yet another school of thought holds that it is better to avoid fragmenting front-line care into multiple jobs. For home care, the fragmentation typically turns out to be inefficient because of costs of travel for multiple people, each to do a small task.

In general, answering these types of questions has much to do with efficiency and cost-effectiveness considerations that are specific to a given country or locality. No single formula can be developed that will be applied to all. However, while developing a system it is important to take into consideration some of the problems found in industrialized countries such as rigid job descriptions and rigorous credential requirements.

An appropriate mix of manpower and its cost is obviously a key element in the design of LTC systems, with crucial consequences for affordability and feasibility, particularly in developing countries. A number of issues can be raised, as follows.
1. What are the levels of training and education appropriate to developing countries in relation to various long-term care roles and how should they differ from industrialized countries?

2. What are the possibilities of integrating long-term care roles with other roles existing within the health or social services?

3. What is the role of volunteers/or semi-volunteers and how do they integrate with the paid staff?

4. Should developing countries consider:
   a) Lower levels of training and education
   b) More integration with acute care staff
   c) More reliance on volunteers and more investment in these volunteer systems (for further discussion see Brodsky, Habib, Hirschfeld et al., Doc. 1.4, 2001 and WHO Technical Report Series, No. 898).

Another human resource issue that is especially relevant in developing countries is the possibility of utilizing traditional healers to provide long-term care. In many societies, traditional healers already fulfil roles that may be considered long-term care — psychological counselling to ‘patients’ and caregivers, physiotherapy (massage), etc. Additionally, these healers are often respected and trusted members of the community. Therefore, providing further training for traditional healers in LTC and compensating them for their work may be a way to mobilize long-term care personnel.

Most industrialized and developing countries spend a large portion of their recurrent health budget on human resources for health (HRH). WHO has devised a framework for analysing the factors affecting the development and implementation of HRH policies and strategies, which addresses the wide variety of factors affecting the organization and quality of personnel. When discussing human resources in LTC, it is important keep the broader HR context in mind (Egger, Lipson and Adams, 2000).

**Strategies for achieving integrated/coordinated care**

As is discussed in the background paper *A Framework for Analysis of Overall LTC Strategies*, one of the defining characteristics of the challenge of integration of LTC services is that they include a broad range of services. These services include elements that are very similar to health services, and others that are sometimes viewed as more social in nature.
Therefore, when discussing LTC, we may refer to two types of integration. The first type of integration is between LTC and basic health and social services, and the second type is among the different components of LTC services themselves. A further consideration in discussing integration is that there are a number of different elements that can be integrated. These include:

1. Finance.
2. Administrative responsibility.
3. Organization of care (gate-keeping, assessment, and direct provision).

These need not go together. Pooling of finance need not coincide with the integration of the provision of care. Moreover, there is a distinction between inclusion in systems, as contrasted with concrete service frameworks. Thus, LTC could be provided under the auspices of the health system, but operate with a distinct budget, personnel and process of decision-making and access (Brodsky, Habib, Siegel et al., Doc. 1.2, 2001).

As noted by Dennis Kodner in the background paper *Long Term Care Integration in Four European Countries: A Review* that he prepared for the Meeting, regardless of the country, system or setting, difficulties are encountered with obtaining comprehensive assessments, putting together service packages, monitoring health status, supporting carers, coordinating services from multiple providers during periods of acuity, and performing all of these activities within existing funding constraints (Kodner, 2001).

The challenges cited above reflect shortcomings that are more or less found in the health and social service systems of virtually all industrialized countries. This is because services are the responsibility of many jurisdictions, institutions and professionals, and the various components work in parallel with separate funding streams and budgets, and frequently conflicting regulations.

The end-result is that the delivery of needed long-term care is often fragmented and uncoordinated, which can cause inefficiency in funding and delivery and can also create confusion and discomfort for the disabled and their families (Brodsky, Habib and Mizrahi, 2000). These problems indicate a need to create more integrated care systems.

The term “integrated care” has many meanings. In his paper, Kodner considers integrated care to be a discrete set of policies, methods and organizational models designed to create connectivity, alignment and collaboration at the funding, administrative and/or provider levels (Kodner, 2001).
Kodner describes three integrating strategies: “(1) linkage; (2) coordination; and (3) full integration”.

Linkage involves independent actors (both financially and service-wise) working together on a volunteer basis to provide a range of care. Coordination involves using more formal structures that “eliminate organizational and administrative barriers” to provide a more organized system of care. Full integration is the creation of a single unit that coordinates and finances a full package of long-term care services.

With these three basic strategies in mind, approaches to coordinating long-term care services in European countries were examined by Kodner:

- **Administrative consolidation**

  Long-term care integration can be facilitated by efforts to consolidate (and decentralize) key functions (e.g. client assessment, care planning, service coordination, quality management, and financial oversight) in a single agency at the level closest to the target population.

- **Co-location of services**

  By locating multiple agencies serving the frail elderly “under one roof” (in a so-called community centre or service centre), the potential is created to simplify access to needed services (e.g. by centralizing information, intake, and referral activities), and enhancing ongoing interagency communication, cooperation and teamwork. The synergies thus created can, at least informally, contribute to ensuring that long-term care clients and their families encounter fewer service barriers and gaps, and also receive the support they need, when and where appropriate. The strategy can also assist in improving local planning for long-term care, and encourage more efficient use of community resources. These are important system-wide integration goals, in and of themselves. As an example of co-location of services, in the Canadian province of Quebec non-institutional LTC services are co-located in what are known as “local community service centers” (CLSCs) (Bergman, Béland, Trahan, Caris, Perrault, 2001).
**Care network**

A care network is a group of legally separate health and social service institutions established to pursue important, shared delivery system goals that could not usually be attained by a single organization acting alone. Organizational collaboration in these strategic alliances is achieved, both vertically and horizontally, through a variety of mechanisms, some more formal and/or integrated than others: common ownership, affiliations and contracts, joint planning, and interagency programmes, services and provider teams.

**Case management**

The case management approach involves the planning, coordination, and monitoring of LTC services for individual clients through an extended period of service time. The case management role can be performed by individual case managers, teams of “social service professionals,” and other individuals or groups with financial or service provision responsibilities connected to the LTC needs of a client. An in-depth examination of the case management approach is provided in the Meeting background paper by David Challis, *Strategies for Achieving Integrated/coordinated Care Among LTC Services: The Role of Care Management*. According to Challis, there are major developments in long-term care occurring in many industrialized countries and some broadly similar trends can be discerned: a move away from institution-based care; the enhancement of home-based care; and the development of mechanisms of coordination. Care management has a central role as being the mechanism designed to achieve both the move away from institutional provision and the strengthening of home-based care (Challis, 2001).

**Service-enriched housing**

Consistent with the idea that housing plays a large role in facilitating or hindering the lifestyles of disabled people, there is a growing recognition that taking housing into consideration when organizing services can aid LTC policy-planners. Kodner describes two housing strategies that may be useful to LTC service provision.
Service-enriched housing (continued)

“One option is to ‘bundle’ health and social services with the housing, thus providing a support system in a particular setting. The other option is to ‘unbundle’ services from the housing. Portable services, delivered by outside agencies, can provide the elderly with broader choices of where to live, and which are more in keeping with lifestyle, socialization, recreation and care preferences” (Kodner, 2001). In Norway, special housing units “offer independent living, but also services and care to an extent which, in some cases, comes close to a modern, non-custodial institution. These kinds of sheltered accommodations are now substituting the traditional residential homes, and to some extent also nursing homes. They offer services on a 24-hour basis through the staff from community services” (Romoren, 2001).

The interest in integration arises out of a number of concerns for the quality and efficiency of care. These include the ability to provide for coordinated care packages, to combine services and to consider alternative services in the most appropriate and optimal way, and to ease the access to services by offering one easily identified source of provision. Integration also makes it possible to use personnel in more flexible and efficient ways, such as combining roles when appropriate. This can be particularly useful for personnel going into the home. (Brodsky, Habib, Siegel et al., Doc 1.2, 2001).

These considerations are fairly obvious when discussing integration among LTC services, but service integration with the health and social services gives rise to additional issues. Links with the health systems can create a continuity of care with general health care and with home health care. It makes it possible to take advantage of health providers that will be going into the home. It can make it possible to reduce acute hospital stays and thus free resources to finance LTC. It creates an incentive to provide adequate home health care, or to provide rehabilitation if health care providers can capture the benefits of reduced home and institutional long-term care.

At the same time, there are concerns about linking LTC with primary health care that generate interest in independent models of LTC. The impact of integration on incentives to provide adequate LTC is not certain or easily predictable. There is concern for a bias in health systems towards addressing acute care needs or more purely medically oriented needs, as opposed to those that are more chronic and function related.
Even if there are potential savings in providing more LTC, the system may not perceive them or be able to overcome the conflicting interests. A related concern is for the “overmedicalization” of LTC services if provided in a medically oriented system, and the consequences of higher costs as a result (examples include skilled nurses providing basic personal care and providing LTC residential care in general hospital settings).

Additionally, as raised in Robert Kane’s background paper, *The Interface of LTC and Other Components of the Health and Social Services Systems in North America*, in the United States the integration of acute and long-term care has depended on integrating medical and social care funding streams. There is a fundamental belief that such integrated funding is the basis for programme integration.

However, although this is necessary, it is not sufficient. Successful integration requires a major reorganization of the programmatic infrastructure, which can then be reinforced with funding approaches. Simply merging funding streams will not suffice. That is because health systems are built upon an acute disease model that is not appropriate to address long-term care needs.

Kane argues that the acute disease model is “shaped upon a 19th century notion of illness as a disruption of the normal state produced by a foreign presence or external trauma, e.g. infection or injury. In this context, *illness is a transient phenomenon that leads to death or recovery*. Under this model acute care is that which directly addresses the threat. As soon as the threat is gone, or the battle is clearly lost, care transitions to long-term care, *with a consequent loss in excitement and attention*” (Robert Kane, 2001).

Because studies have shown that a growing amount of health care expenditure (in industrialized and developing countries) is devoted to chronic illness, and because of the disadvantages of dealing with chronic disease and disability treatment under an acute disease focused system, there is a need to design policies with this in mind. The following will highlight some of the specific problems of dealing with chronic long-term care in this type of system, and it will suggest how improvements could be made.

One difference between the approach of the acute and chronic long-term care models lies in the perspective on time. Acute care often calls for interventions needed to deal with acute “events” that, it is hoped, will have prompt benefits. By contrast, chronic long-term care often works best when it entails coordinated care over an extended period of time, with the hope that the benefits will be gradual, sometimes only after a great deal of time.
Kane also suggests that chronic care “redefines the goals of care” in a way that is different from the acute model. Whereas an acute-centred system is often based on a disease “identification and elimination” approach (with the goal being the future non-existence of the problem), many functional disabilities that need to be treated under the rubric of long-term care do not have these kinds of possible solutions.

Unfortunately, an acute disease intervention mindset can sometimes cause a reduction in the development of strategies/technologies that may not work in curing a disease, but can improve significantly the quality of life of disabled individuals. An unfortunate example of this is when “efforts to ameliorate the environment to maximize functioning have been dismissed as ‘halfway technologies’ by adherents of the acute care model”.

Another important difference between acute care and chronic long-term care is the degree to which involvement by “the client” can assist care. Within the acute care model, the physician is more likely to assume a dominant role in monitoring and decision-making. For chronic long-term care, the client, because of the constant and long-term need for monitoring and treatment and treatment adjustment, may benefit from a “more active role in disease management”. This can involve the development of “shared decision-making” — a carefully structured technique that affords consumers impartial balanced information about various conditions and the risks and benefits of alternative treatments, where it is not clear which of several treatments is most appropriate. It is designed to supplement, not supplant doctor–patient communications” (Robert Kane, 2001).

There is another major consideration when addressing the integration issue. The integration of LTC with other health and social services creates a link between the principles of entitlement and finance in LTC and the general health and social systems. For example, if health is insurance based then LTC needs to be insurance based, when financing is pooled. Thus, the question of integration becomes a question of a choice of principles and not only of organizational advantages and provider incentives. This will also influence the choice between integration with the health or the social systems, as these are often based on different principles. Social systems are always non-entitlement, budget restricted. Health systems are often based on insurance principles (Brodsky, Habib, Siegel et al., Doc. 1.2, 2001).

In practice, almost no industrialized country has fully integrated all aspects of LTC into the health system except for the Netherlands in which there is administrative and organizational integration, although with a separate earmarked budget. At the same time, this issue continues to be discussed and debated and there have been experiments such as the SHMO programme in the United States (Kodner, 2001 and Robert Kane, 2001).
Finally, several characteristics of developing countries need to be considered when addressing the integration of LTC with other health and social services.

1. Because of the absence of a social service structure providing personal social services in many developing countries, there may be fewer conflicts between the integration of services in health versus social frameworks.

2. The predominance of health systems based on budget restricted principles in developing countries, rather than entitlements and insurance principles, can facilitate the integration of LTC. However, there is a trend in developing countries towards encouraging contributory programmes. There is also a tendency for multiple publicly financed health systems. Sometimes, this is divided between the poor and other more organized groups of employees. Often, it is based on the proliferation of collective risk pooling funds. This proliferation complicates the integration of LTC into the health system.

3. The nature of existing general health and social manpower also helps to determine the possibilities for integrating roles and not only administrative frameworks and budgets. It can provide further incentive to a decision to integrate. For example, many health systems in developing countries already have various semi-professional staff that visit in the home and may also be able to address LTC needs.

4. The issue of integration with health in developing countries may also depend on the nature of existing long-term care services. For example, if services are focused on home health, it will be natural to develop these services as part of the health system. Moreover, if home health is based on paraprofessionals or on less trained staff, then it will be possible to consider the integration of some personal care into their role definitions. In systems which also emphasize the provision of personal and homemaking services, and in which the level of training and the professional level of home health care is higher, the issues of separating personal care and of integrating personal care and homemaking arise. This is often accompanied by the development of a social service system and thus the development of an alternative to the health system as a long-term care provider. It is at this point that the critical choices with respect to integration must be made (Brodsky, Habib, Hirschfeld et al., Doc. 1.4, 2001).
Overall strategies

In the background paper for the Meeting, *A Framework for Analysis of Overall LTC Strategies*, Brodsky et al. make an effort to go beyond the delineation of specific design issues to present broad paradigms of alternative systems that combine in various ways the resolution of these specific issues. They also illustrate and clarify how the resolution of various design and financing issues are interdependent. Moreover, they raise the question of where to begin in addressing the various LTC issues.

The specification of alternative strategies requires that one identify issues or dimensions that are primary, and those that are more derivative. This is related to the question: “If I want to design a LTC system, where do I begin?” The answer to this question may be presented from various angles. In *A Framework for Analysis of Overall LTC Strategies*, the authors focus on two basic decisions:

- Whom do you want to support – the poor only or also the non-poor?
- Should access to services be based on an entitlement, or subject to budget constraints?

The resolution of whether one wants to design a programme to support the poor, or to support the non-poor as well, is an issue that arises in all areas of social need. What is unique to LTC is the additional possibility that the family might meet these needs for many individuals, which is not an option in the same way for many other services such as medical care. Thus, the decision to provide LTC assistance is based in part on assessments as to whether the family can, will, and should be expected to provide care as discussed in the previous section. This issue is not specifically discussed in the paper, but its resolution underlies the alternatives discussed.

The decision with respect to poor/non-poor gives rise to three options:

- A desire to support the poor, and programmes only for the poor.
- A desire to support the poor as a primary goal, but financing through frameworks that include the non-poor.
- A desire to support the non-poor as well, as a primary goal.
Support for the poor is obviously based on a concern for their inability to purchase these services and can lead to an exclusive focus on this group. Even if support for the poor is one’s primary goal, this can lead to a strategy that supports the non-poor, if it is believed that including them in a more universal programme is the best way to mobilize support for the poor, and to avoid the problems associated with programmes for the poor, such as low quality.

Interest in assisting the non-poor as well can be a primary goal. Support for the broader population can have several rationales including:

- There is an interest in the population insuring itself against LTC risks.
- The catastrophic potential nature of LTC costs implies that broad segments of the population may find it difficult to pay for them and will become impoverished, and when their resources are depleted, they will become a burden on public programmes.
- Concern with the broader social costs of care provision and an interest in easing the burden on families and particularly on female caregivers who provide much of the care.
- Concern for the decline in the availability of family support because of separate living arrangements, fewer numbers of children, women’s participation in the labour force, changes in values in relation to caring, or family disruption due to HIV/AIDS.
- The general belief that social needs should be financed through collective tax-based financing mechanisms, rather than on a private pay basis.
- Interest in reducing the utilization of more costly acute care (particularly hospitalization) services by substituting LTC.

The consideration of all these rationales will be tempered by the consideration of cost and the relative priority that is assigned to LTC versus other health and social needs.

A second key question is whether access to LTC services should be based on an entitlement, or subject to budget constraints. When examining the importance of providing a LTC programme on an entitlement or non-entitlement basis, it is necessary to understand the definition of an entitlement programme.
An entitlement programme means that, irrespective of available budgets, everyone who fulfils the eligibility criteria must be granted benefits from the programme. These types of programmes are especially difficult to carry out in developing countries because of limited budgeting and economic instability. There are several bases for choosing between entitlement and non-entitlement programmes:

- The broader philosophy with respect to social service provision. In short, does one believe that these services should be defined as rights and protected from the general budgetary process, or does one believe that they should be subject to controls based on budget allocations that can be more flexibly adjusted to fit the general budgetary situation?

- Considerations of the ability to mobilize finance.

- The nature of the allocation of benefits among population groups and the targeting of services.

- The ability to control costs.

The interaction between the resolutions of different design issues can now be illustrated. The resolution of these two basic issues of “whom one wants to support” and “the nature of entitlements” influences directly the resolution of a number of additional design issues. Below, some of the implications of choosing between an entitlement and a non-entitlement programme are discussed.

1. Entitlement programmes are generally financed through insurance-type payments, whereas non-entitlement programmes are usually financed through general taxation. This is so because pre-payment is viewed as granting a right to a service. Additionally, one can more easily find support for general population programmes if they are based on direct contributions. Indeed the relationship works both ways. Concern for the ability to finance can lead to the preference for contributory programmes, which leads to the need to adopt an entitlement approach.7

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7The authors do note that there are exceptions to this general rule. For example, the health care systems in the United Kingdom and Ireland are financed through general taxation, but benefits are awarded to the general population on an entitlement basis.
2. Choosing between entitlement and non-entitlement programmes involves the fact that contributory, entitlement programmes will usually have limited income tests for their services so that no one is excluded. If a contributory, entitlement based approach is adopted, this implies that there should not be any, or at most, a very liberal income test so as not to exclude individuals who contributed to the programme’s financing. Non-entitlement programmes focused on the poor can have relatively strict to very strict income testing.

3. The availability of family support (key in many LTC programmes) is usually not taken into account under an insurance framework, so as not to eliminate someone who has “paid for their services”.

4. For the same reason, eligibility criteria will tend to be rigorously defined in terms of precise measures and cut-off points and generally a few discrete levels of support will be defined, rather than a full continuum.

5. In entitlement programmes there is a tendency to contain cost through relatively high minimum disability levels so as avoid overloading the system with people who are eligible.

6. Also for cost-containment purposes, there will usually be a limited amount of benefits given under an entitlement system. Benefit levels are set lower because family support is not a criterion, and benefits will be provided to many people who are receiving significant family support. Setting low benefit levels also reflects concern with the degree of controllability of costs. In an entitlement system, the level of costs is not easily predictable or defined because it is determined by the number of eligible applicants.

7. Entitlement programmes are more likely to have cash and non-cash benefits, in accordance with most insurance-based systems, as a way to avoid problems with service availability.

8. Under a contributory system, generally there will not be expectations for the contribution of family members other than the spouse to finance care, while these do exist in many non-insurance based programmes.
Brodsky et al. present examples of how different countries have chosen to resolve the poor/non-poor and entitlement/non-entitlement decisions according to the model presented in their paper. In the United Kingdom and Australia, LTC services are focused on the poor and provided on a non-entitlement, budget-restricted basis.

In recent years, a number of countries have adopted a broader insurance-based approach and a full entitlement LTC laws. The focus on the broader population through a social insurance approach has been adopted in Japan. The Medicaid programme in the United States is an interesting example of a system that focuses on the poor, and is financed by general tax revenues, but provides an entitlement.

The systems in Germany and Israel are examples of the possibility of combining different principles in the same country, generally through separate complementary programmes. They both provide services to the general population through a social insurance-based entitlement programme. In addition, they both have supplementary systems that provide support which is targeted to the poor and based on a strict budget constraint.

Austria represents an interesting example of a country providing broad support on an entitlement basis, but with funding based on general tax finance.

The Netherlands is also an interesting variant. LTC funding is integrated with health insurance and financed through contributions. However, the Netherlands’ system has adopted a set of eligibility criteria that characterizes non-insurance, tax-based programmes, such as family support, and allows for flexible continuous levels of support.

The Scandinavian countries provide support to the general population. However, this support is based on tax financing and a weak form of entitlement.

The differences between the countries in their overall approach to LTC also reflect differences in their more general approach to financing and targeting social programmes. These examples illustrate that the generalizations that we have suggested broadly hold up in regard to the interactions concerning decisions on various key design issues. At the same time, countries sometimes do also adopt exceptions.

Brodsky et al. go on to explain how decisions related to whether LTC programmes will be aimed at the poor and/or the non-poor and whether they will be offered on an entitlement or non-entitlement basis interact with one another. Additionally, they explain how these decisions impact on other service delivery questions such as how long-term care services will interface with the health and social systems (Brodsky, Habib, Siegel et al., Doc. 1.2, 2001).
One of the fundamental principles of the long-term care initiative is that the development of policy guidelines needs to be based on an in-depth understanding of the conditions and emerging experience in developing countries. To this end, experts from the developing world prepared detailed reports on nine middle-income countries. These countries are the People’s Republic of China, Costa Rica, Indonesia, Lithuania, Mexico, the Republic of Korea, South Africa, Thailand and Ukraine. The discussion of these reports and their broader implications was a major focus of the Annecy meeting.

In the following section, we briefly highlight the emerging LTC policy directions against the background of the general health and social services and key socioeconomic and epidemiological indicators. In this analysis, use is made of general indicators readily available from comparable international sources. This is important because often these are the only data available to policy-makers in developing countries.

The extent of need for long-term care is determined by the extent of disability and the availability of informal support. The extent of disability is estimated using the percentage of elderly in the population. The percentage of elderly, the percentage of women in the labour force and the parent support ratio\(^9\) are used as indications of the availability of family support. The fertility rate is used as an indicator of population ageing because a decline in fertility is a primary cause of ageing of a population.

Competing resource demands are estimated by the rate of under-5 child mortality, which reflects the need to address traditional communicable diseases (acute and non-disabling diseases). The greater the overlap between a high percentage of elderly and a high rate of child mortality, the greater the extent of the double burden of disease. The overall resources available to address these needs are estimated by the per capita GDP (adjusted for purchasing power parity), and the level of per capita health expenditures (also adjusted). The level of health care expenditures also reflects the priority given to health-related needs.

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\(^8\) The information in this section is derived mainly from the case-study reports and the integrative analysis *General Patterns of Health, Social and Long-Term Care in the Developing Countries Participating in the Study* (Brodsky, Habib, Siegel, Bentur and London).

\(^9\) Parent support ratio: the ratio of those age 80 and over per 100 persons age 50–64.
General characteristics of specific countries and their links to LTC development

A. Lithuania and Ukraine

“very high percentage of elderly relative to low income level and moderate burden of communicable diseases”

In general, both countries combine a very high rate of ageing with low income levels. Income is particularly low in Ukraine and is the lowest of the nine countries studied. The ageing pattern is heavily influenced by very low fertility rates.

The proportion of elderly in these countries is between 13% and 14%. These populations are continuing to age, and they are confronting a large current and rapidly rising burden of chronic disease and disability. In both countries there are, and have been, very high proportions of women in the labour force.

Both countries have very low levels of economic resources — especially low in Ukraine — and have been challenged by major macrosocietal transitions during the past decade affecting all spheres of society including their health and social systems, which have deteriorated. Despite their low income level, both countries have a health system that covers the entire population, however with limited availability of some of the key services. In Lithuania, the level of expenditure on health is high relative to their economic situation (as compared to the other countries with the same or a higher level of resources).

In addition to institutional LTC services that were emphasized in the past, these countries have more recently developed home-based LTC services including home health, personal care and homemaking services. This development may be understood as responding to the needs of the ageing of these societies.

The patterns described in Lithuania and Ukraine reflect broader patterns found in other Eastern European countries. Most of these countries were heavily biased towards institutional care, and only now are they moving towards services that are more community centred. (Summary based on information provided in Aleksandras Krisciunas’ case-study on Lithuania and Vladislav Bezrukov’s case-study on Ukraine.)
**Lithuania**

GDP per capita (PPP) 4800
% of elderly:
2000 13.4  
2025 19.7

Parent support ratio:
2000 151  
2025 239

Fertility rate (children born per woman) 1.3

Life expectancy 72.1

Under-5 male mortality (per 1000) 15

% of women in labour force 47.2

---

**Ukraine**

GDP per capita (PPP) 2200
% of elderly:
2000 13.8  
2025 19.0

Parent support ratio:
2000 129  
2025 187

Fertility rate (children born per woman) 1.3

Life expectancy 68.0

Under-5 male mortality (per 1000) 18

% of women in labour force 46.3
B. Republic of Korea

“high income and ageing rapidly, low burden of communicable diseases”

The Republic of Korea has the highest income and highest expenditure on health services (per capita) among the countries examined. There is a very low level of under-5 mortality and high life expectancy. At present there is a moderate proportion of elderly (7.1%), but the population is ageing very rapidly, and by the year 2025 16.9% of its population will be age 65 and over. The Republic of Korea is consequently concerned with the rise of chronic disease and disability.

The Republic of Korea has a strong health system and a significant social service sector, both of which participate in the provision of LTC services. These services include a broad package of home health, personal care and homemaking services. It has particularly emphasized family education and training.

These trends in the Republic of Korea might be understood in light of its relatively high proportion of elderly, the decline in family size, along with a higher proportion of women in the labour force and the availability of resources due to its relatively high income level (the highest of the nine countries). Institutional LTC is very limited in the Republic of Korea, but there is an interest in developing more institutions in order to reduce acute hospital usage by individuals in need of LTC. (Summary based on information provided in the Republic of Korea case study by Chung Yul Lee and Euisook Kim.)

<table>
<thead>
<tr>
<th>Republic of Korea</th>
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</thead>
<tbody>
<tr>
<td>GDP per capita (PPP)</td>
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<tr>
<td>% of elderly:</td>
</tr>
<tr>
<td>2000</td>
</tr>
<tr>
<td>2025</td>
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<tr>
<td>Parent support ratio:</td>
</tr>
<tr>
<td>2000</td>
</tr>
<tr>
<td>2025</td>
</tr>
<tr>
<td>Fertility rate (children born per woman)</td>
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<tr>
<td>Life expectancy</td>
</tr>
<tr>
<td>Under-5 male mortality (per 1000)</td>
</tr>
<tr>
<td>% of women in labour force</td>
</tr>
</tbody>
</table>
LESSONS FOR LONG-TERM CARE POLICY

C. Costa Rica

“medium income, low proportion of elderly, high life expectancy and low burden of communicable disease relative to income level”

Costa Rica has a moderate income level, but high health expenditure (per capita), and a strong health system. Under-5 mortality is low. The proportion of elderly is low, but the proportion of those age 65 and over will double during the next 25 years. For this reason, Costa Rica is mostly concerned with the rise of chronic disease and disability, rather than with the burden of communicable diseases.

It should be emphasized that Costa Rica’s choice, at a relatively low income level, to spend a considerable amount of money on health care is quite unique, and it appears to have contributed to the very low communicable disease burden. In this way, it is avoiding the emergence of a double disease burden as it ages.

Costa Rica has focused on developing home health provision emphasizing family education and training. A broader package of LTC services including personal care and homemaking have not been introduced. Institutional LTC is almost non-existent. These patterns can be understood in light of their low proportion of elderly and low proportion of women in the labour force. (Summary based on information provided in the case-study on Costa Rica by Felicia Knaul and Gustavo Nigenda.)

<table>
<thead>
<tr>
<th>Costa Rica</th>
</tr>
</thead>
<tbody>
<tr>
<td>GDP per capita (PPP)</td>
</tr>
<tr>
<td>% of elderly:</td>
</tr>
<tr>
<td>2001</td>
</tr>
<tr>
<td>2025</td>
</tr>
<tr>
<td>Parent support ratio:</td>
</tr>
<tr>
<td>2000</td>
</tr>
<tr>
<td>2025</td>
</tr>
<tr>
<td>Fertility rate (children born per woman)</td>
</tr>
<tr>
<td>Life expectancy</td>
</tr>
<tr>
<td>Under-5 male mortality (per 1000)</td>
</tr>
<tr>
<td>% of women in labour force</td>
</tr>
</tbody>
</table>
D. Mexico and Thailand

“medium income, low to medium level of ageing, medium burden of communicable disease”

In general, both countries are young but rapidly ageing and are thus facing an increase in chronic disease and disability. They both have moderate under-5 mortality rates and thus still are confronting the challenges of communicable diseases. In both countries, the health system provides moderate coverage of the population and their needs.

Both countries are at the initial stages of developing LTC services and are beginning to develop home health. The level of development of LTC services seems quite similar in both countries, despite the fact that Mexico has relatively higher resources. The rate of ageing in Mexico is lower, as well as the proportion of women in the labour force, which might have moderated the pressure until now to develop LTC services. Both focus on initial efforts to develop home health services and do not provide personal care or homemaking services. Both countries have a strong interest in health promotion, which fits in with the emphasis on home health.

Additionally, it should be noted that in Mexico, as is reflected in many other Latin American countries, there is a strong emphasis on highly-credentialed professions in home health care. This emphasis impacts ability to disseminate the service. (Summary based on information provided in the case-study of Felicia Knaul and Gustavo Nigenda on Mexico and the case-study of Somsak Chunharas and Kanittha Boonthamcharoen on Thailand.)
## Mexico

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>GDP per capita (PPP)</td>
<td>8500</td>
</tr>
<tr>
<td>% of elderly:</td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>4.7</td>
</tr>
<tr>
<td>2025</td>
<td>9.3</td>
</tr>
<tr>
<td>Parent support ratio:</td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>98</td>
</tr>
<tr>
<td>2025</td>
<td>111</td>
</tr>
<tr>
<td>Fertility rate (children born per woman)</td>
<td>2.7</td>
</tr>
<tr>
<td>Life expectancy</td>
<td>73.6</td>
</tr>
<tr>
<td>Under-5 male mortality (per 1000)</td>
<td>31</td>
</tr>
<tr>
<td>% of women in labour force</td>
<td>27.1</td>
</tr>
</tbody>
</table>

## Thailand

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>GDP per capita (PPP)</td>
<td>6400</td>
</tr>
<tr>
<td>% of elderly:</td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>5.2</td>
</tr>
<tr>
<td>2025</td>
<td>11.4</td>
</tr>
<tr>
<td>Parent support ratio:</td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>57</td>
</tr>
<tr>
<td>2025</td>
<td>88</td>
</tr>
<tr>
<td>Fertility rate (children born per woman)</td>
<td>1.9</td>
</tr>
<tr>
<td>Life expectancy</td>
<td>69.2</td>
</tr>
<tr>
<td>Under-5 male mortality (per 1000)</td>
<td>35</td>
</tr>
<tr>
<td>% of women in labour force</td>
<td>56.0</td>
</tr>
</tbody>
</table>
E. China

“high percentage of elderly, low income, huge disparities between urban and rural population”

Excluding the Eastern European countries, China has a higher percentage of elderly in relation to its income level as compared with the other six countries. There are huge differences between urban and rural areas with regard to demographic characteristics and health system development. In Shanghai, for example, the proportion of elderly people is unusually high (15%) (even higher than in many industrialized countries) and the health system is relatively more developed. Rural China on the other hand is facing the double burden of communicable and chronic disease and has much less health coverage and infrastructure.

LTC services, namely home health programmes which provide a range of services that includes an emphasis on family education but not personal care or homemaking, have begun to develop in urban areas such as Shanghai and Beijing. In these urban areas there is also some institutional LTC provision that could be a response to rapid ageing of the population, a high rate of women’s labour force participation, and reliance on the family as the only providers of home-based personal care and homemaking. (Summary based on information provided in the case study of Fu Hua and Xue Di on China.)

<table>
<thead>
<tr>
<th>China</th>
</tr>
</thead>
<tbody>
<tr>
<td>GDP per capita (PPP)</td>
</tr>
<tr>
<td>% of elderly:</td>
</tr>
<tr>
<td>2000 (in Shanghai)</td>
</tr>
<tr>
<td>2025</td>
</tr>
<tr>
<td>Parent support ratio:</td>
</tr>
<tr>
<td>2000</td>
</tr>
<tr>
<td>2025</td>
</tr>
<tr>
<td>Fertility rate (children born per woman)</td>
</tr>
<tr>
<td>Life expectancy</td>
</tr>
<tr>
<td>Under-5 male mortality (per 1000)</td>
</tr>
<tr>
<td>% of women in labour force</td>
</tr>
</tbody>
</table>
F. Indonesia

“low income, high burden of communicable disease, low proportion of elderly”

Indonesia represents a country with a low proportion of elderly and very low economic resources, which is highly concerned with the burden of communicable diseases as reflected in a high under-5 mortality rate. At the same time, it is ageing rapidly, as the proportion of those 65 and over will nearly double in the next 25 years. It thus confronts a rapid increase in the burden of chronic disease and disability.

The Indonesian situation raises the primary issue of where to begin to support the development of LTC services in the face of a low level of health infrastructure and a high communicable disease burden. LTC services in Indonesia, to the extent that they are available, are largely based on volunteers. This raises the question of how to strengthen volunteer roles and of the limits of expectations from voluntary activity (summary based on information provided in the case-study by Agus Suwandono, Suhardi Qomariah, and Ingerani).

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### Indonesia

<table>
<thead>
<tr>
<th>Metric</th>
<th>2000</th>
<th>2025</th>
</tr>
</thead>
<tbody>
<tr>
<td>GDP per capita (PPP)</td>
<td>2800</td>
<td></td>
</tr>
<tr>
<td>% of elderly:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>4.8</td>
<td></td>
</tr>
<tr>
<td>2025</td>
<td>8.4</td>
<td></td>
</tr>
<tr>
<td>Parent support ratio:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>53</td>
<td></td>
</tr>
<tr>
<td>2025</td>
<td>71</td>
<td></td>
</tr>
<tr>
<td>Fertility rate (children born per woman)</td>
<td>2.6</td>
<td></td>
</tr>
<tr>
<td>Life expectancy</td>
<td>65.4</td>
<td></td>
</tr>
<tr>
<td>Under-5 male mortality (per 1000)</td>
<td>61</td>
<td></td>
</tr>
<tr>
<td>% of women in labour force</td>
<td>39.4</td>
<td></td>
</tr>
</tbody>
</table>
G) South Africa

“relatively high income level, high burden of communicable disease (especially related to the HIV/AIDS crisis), low life expectancy, attempting to introduce some forms of community long-term care”

South Africa is a country that has been devastated by the HIV/AIDS pandemic. Although the country has a fairly high level of economic resources as compared to the other countries in this study, and although it spends a relatively high percentage of GDP per capita on health care, the effects of HIV/AIDS and other communicable diseases has driven down South Africa’s life expectancy to the lowest level of any of the countries participating in the study. The under-5 mortality rate in South Africa is also the highest among the countries studied.

Largely in response to the disabling effects of HIV/AIDS on the general population and the destruction of the traditional family unit, the Government of South Africa has begun to develop some forms of community care for individuals suffering from the disease. The community care programme, as proposed, will take a comprehensive approach to the needs of all ages in the family and builds heavily on the participation of volunteers from the community. Alternative models, some integrated into primary health care and some independent, are being experimented with. (Summary based on information provided in the case-study by Zukiswa Pinini on South Africa.)

<table>
<thead>
<tr>
<th>South Africa</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>GDP per capita (PPP)</td>
<td>6900</td>
</tr>
<tr>
<td>% of elderly:</td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>3.6</td>
</tr>
<tr>
<td>2025</td>
<td>7.2</td>
</tr>
<tr>
<td>Parent support ratio:</td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>51</td>
</tr>
<tr>
<td>2025</td>
<td>113</td>
</tr>
<tr>
<td>Fertility rate (children born per woman)</td>
<td>2.5</td>
</tr>
<tr>
<td>Life expectancy</td>
<td>50.9</td>
</tr>
<tr>
<td>Under-5 male mortality (per 1000)</td>
<td>90</td>
</tr>
<tr>
<td>% of women in labour force</td>
<td>29.8</td>
</tr>
</tbody>
</table>
Summary of developing country case-studies

There is a wide range of LTC development in the countries participating in the study. In Indonesia, there are not yet any formal initiatives of LTC provision. In South Africa, some forms of community care are beginning to develop in response to the HIV/AIDS crisis. Shanghai’s and Beijing’s unusual rates of ageing contributed to the development of home health provision. There are a range of countries which are still relatively young but that have also prioritized the development of home health care, such as Costa Rica, or that are beginning to do so, such as Mexico and Thailand.

In Lithuania and the Ukraine, the ageing of the population has created a great incentive to prioritize LTC provision and develop a range of services despite their low incomes. Finally, in the Republic of Korea there is a relatively lower rate of ageing as compared with Lithuania and Ukraine, but with much higher resources and relatively more development of a range of LTC services.

Broad trends emerging from the case-studies

1. There are important efforts being made to provide home-based LTC in a number of countries. Some are providing a broad package of services that include home health, personal care and homemaking (Lithuania, Republic of Korea, Ukraine); and some are more narrow and focused on home health only (urban China, Costa Rica, Mexico). LTC is not provided or only to a very limited extent in Indonesia, South Africa and Thailand.

2. Where it exists, home health is linked to the health system (financially and organizationally). There are some very good examples of integration of home health into primary care (Costa Rica, Republic of Korea, and to some extent China, Lithuania, Mexico, and Ukraine).

3. Family guidance and counselling is highly emphasized in a number of countries. There seems to be a strong emphasis on this education and counselling through home health systems, which have become neglected in the home health systems of industrialized countries (Costa Rica, Republic of Korea).

4. Where it exists, personal care and homemaking services are targeted towards the very poor and those without families. None of these countries provides publicly funded personal care services to the non-poor population. Home health, on the other hand, is not necessarily targeted towards the poor, and health conditions and disability are more of a criterion.
5. Institutional LTC is provided by a number of countries. It is provided more extensively in Lithuania and Ukraine, and to some extent in China and the Republic of Korea. In the other countries, publicly financed institutional LTC is hardly provided. In countries that do provide institutional care, an issue that requires greater clarification is the degree of coordination between home-based and institutional LTC.

6. Countries with a broader package of services have not integrated all LTC services into one system. These countries generally split such services between the health and social systems. Therefore, fragmentation between health and social services and among LTC services is a general problem, similar to that which exists in most industrialized countries. In the Republic of Korea for example, despite the fact that there is one ministry responsible for health and social services, there is fragmentation of service provision and some overlapping. On the other hand, in some countries like Ukraine, even though there are two ministries, and a division responsible for the care of the elderly in each of them, there is a coordinating mechanism at the level of local service provision (district physician).

7. The degree of age integration seems to vary. In general, home health is age integrated. Other home care services are often but not always age integrated. Age segregation is more typical of institutional LTC.

8. Most health systems are making special efforts to develop community health care. This health policy seems compatible with the development of home-based LTC, especially in Lithuania and Ukraine, where there is an objective to shift the relatively high emphasis on institutional LTC to community care. In some countries with hardly any institutional services, such as the Republic of Korea, there is also an emphasis on developing institutional LTC to avoid utilization of more expensive acute hospital services by patients whose primary need is LTC.

9. In some countries, such as in Mexico and the Ukraine, NGOs are playing an important role in the development of LTC.
10. The level of volunteerism seems to vary, as does the degree to which volunteers receive training. The role of volunteers in the LTC arena was emphasized in China, Indonesia and Ukraine. Both Indonesia and Ukraine provide training to volunteers. In Ukraine, training is provided in formal training institutions. South Africa is considering developing community care that will heavily utilize volunteers.

11. There is a great deal of variation in human resource patterns. There is a clear pattern showing that as economic resources increase, countries have staff with higher levels of formal professional credentials. But one finds a broad range of educational levels among the staff in primary health care and in the various types of LTC. In many countries there is a feeling that there is a need for more training of various staff levels in LTC. These general patterns give rise to questions that need further exploration, such as whether there is a trend to over-professionalization of LTC roles, and to what extent general health personnel can play more of a role in LTC. While highly trained nurses lead many of the home-care programme initiatives, as for instance in the Republic of Korea, Thailand and South Africa, we do not find, in general, that they provide more basic personal care services, as is the case in some industrialized countries.

12. There seems to be a hierarchy in the development of home-based LTC. The first priority is for home health with an emphasis on training and educating the families, while personal care and especially homemaking develop later. That is, most countries do not provide publicly funded personal care or homemaking services, and these have remained a family responsibility, or a service provided by volunteers. However, despite the appearance of these stages, it is important to emphasize that this pattern need not be prescriptive, and it may not describe the order of development of home-based LTC in all countries because of local cultural factors and national priorities.
In this section, we present some of the key points emphasized by individual participants in the discussions.

- **Cultural sensitivity is important when designing long-term care in developing countries.**

  Wilfred Nkhoma (AFRO) argued that the initial incentive to provide informal care might not be connected to financial reward, but rather to cultural or religious traditions. Service to the family and to the community is an important motivator in some cultures.

  Gustavo Nigenda (Mexican Health Foundation) noted, as did many others at the meeting, the importance of traditional healers in providing care.

  Tawfik Khoja (GCC, Saudi Arabia) cited a 1993 study in Saudi Arabia, and a 1997 follow-up, of care giving patterns. The findings stressed the importance of self-image and reluctance to expose oneself as being in need of assistance, and the importance of trust between clients and providers (e.g. the concern of admitting strangers into one’s home), as factors to consider when organizing home care.

- **Volunteers are an important human resource that should be utilized.**

  Agus Suwandono (Ministry of Health and Social Welfare, Indonesia) emphasized the importance of mobilizing volunteers and other natural community resources in caring for the disabled.
- **Training and educating families as a strategy to improve care of the disabled.**

  Xue Di (Shanghai Medical College for Health Staff, People’s Republic of China) stressed the importance of family education as a strategy for both improving quality of care for the disabled and alleviating some of the stress felt by family caregivers.

- **Incorporating long-term care into the existing primary care infrastructure might be efficient and cost-effective.**

  Somsak Chunharas (Ministry of Public Health, Thailand) stressed the importance of considering how long-term care can be integrated into primary care and integrated with the treatment of chronic diseases, and considering different ways to provide and finance these services. He emphasized the importance of considering long-term care in the processes of health care reform.

- **The instability of political and economic systems in developing countries (generally) makes implementing good policy in all areas very difficult.**

  A number of meeting participants noted that long-term planning, which is necessary for implementing high quality social programmes, is difficult in countries where there are frequent changes in regime.

- **Long-term care is considered a low priority in many developing countries. This points to the importance of raising awareness about the indicators of the present and future needs for LTC.**

  Abdul Samad Abdullah (SEARO) noted that LTC is considered a low priority in the South-East Asia Region because of the coexistence of a major infectious disease problem. Additionally, he said that it is still socially unacceptable for elderly parents not to be taken care of by family members.
When approaching governments with proposals about LTC service development, it is important to remember that cost–effectiveness is a top priority for most policy-makers.

Ahmed Abdel Latif (EMRO) commented that long-term care must be presented as a cost-effective policy direction. In particular, he noted that informal care should be viewed as a cost-effective, built-in resource that needs to be preserved.

In order to mobilize resources for new services in developing countries, it has often proved beneficial to work with NGOs, the private sector and international donors.

This point was emphasized by Gustavo Nigenda (Mexican Health Foundation) based on his experience in Mexico.

In many developing countries, especially in selected areas of Africa and Asia, the HIV/AIDS crisis is creating a high demand for long-term care among the affected population, while at the same time undermining the family structure.

Zukiswa Pinini (HIV/AIDS, Department of Health, South Africa) noted that the effects of HIV/AIDS were having an especially devastating effect in South Africa. In particular, she cited the need to provide care for orphans of mothers who have died of HIV/AIDS. Evelyn Isaacs (AFRO) and Magda Awases (AFRO) highlighted the effects of the epidemic on all aspects of life in Sub-Saharan Africa.
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General consensus reached by Meeting participants

While the purpose of the meeting was not to finalize a set of guidelines or conclusions, there were points of general agreement that will guide the continuation of the process and have immediate implications.

- All countries need and are able to develop a LTC strategy that corresponds to the resources of low-, middle-, and high-income countries.

- The development of LTC services should evolve over time, and adapt to changing national conditions.

- Specifically, it is important to consider the pattern and pace of increases in LTC needs as they are affected by epidemiological phenomena, and the availability of family support.

- A ‘double burden’ is created when LTC needs develop before the impact of infectious diseases has been reduced.

- It is necessary to clarify and deepen our knowledge of the epidemiological burden, so as to be able to present LTC needs in the most accurate and convincing way.

- Cultural differences and values should also play a major role in determining the appropriate LTC strategy.

- LTC should be integrated into the overall health and social policy framework of each country; as such, it should also be included in the processes of planning and reform, taking into account not only existing needs but also the ways in which they are likely to change. A vision of LTC for these countries must be developed.
It is important to recognize that addressing LTC needs, while it involves costs, represents an important asset to any society. It provides a solution to many other pressures on the health and social systems that can lead to unnecessary service utilization. Addressing LTC needs also prevents additional and unnecessary mental and physical morbidity and handicaps.

In order to address the LTC challenge, a major effort must be undertaken to educate policy-makers and planners to enable them to take these needs into account.

Various stakeholders need to be involved in this process, including the directors of ongoing WHO programmes such as management of noncommunicable diseases, health systems, HIV/AIDS, TB, injury and violence, and health of the elderly, to develop a ‘critical mass’ of committed stakeholders. They should be allowed to ‘own’ LTC in their own domain (programme).

The implementation of a LTC strategy will require a major educational effort, directed at health care providers at all levels.

Community organizations and local communal structures should be mobilized to play an important role in developing LTC.

Special situations that should be addressed include countries that are experiencing rapid increases in LTC needs while at very low levels of income, and countries affected by the HIV/AIDS pandemic which creates a unique pattern of needs with particular implications for the family structure. Another special situation is that of the countries of Eastern Europe that already have extensive LTC needs and are undergoing major restructuring of their health and social systems.

The development of LTC should take into account existing infrastructures and resources and the opportunities they provide.
Support should be provided to families, especially taking into consideration that the majority of caregivers are women, and with attention to providing opportunities to women to participate in the labour force.

A variety of strategies should be developed to support the family unit so as to sustain their important role in meeting LTC needs.

The case-studies of the developing countries revealed that significant beginnings (as for example through home health, mobilizing communal organizations, and specialized training) to address these issues have been made, and that important initiatives from which we can learn are emerging. We need to continue to learn more about the experience of various developing countries and identify the ingredients that are the seeds for further success.

At the same time, there is also evidence that low- and middle-income countries are repeating some of the same mistakes that industrialized countries are now attempting to correct, highlighting the importance of developing better guidance now.
The report of the “Bridging the Limousine–Train–Bicycle Divide” Meeting in Annecy, France, has given a broad overview of the Meeting’s background materials and the issues that were discussed at the Meeting. It also presented some general conclusions that were agreed on by Meeting participants. It does not attempt to capture the full richness of the material or the discussions at the meeting, which will be analysed in-depth and summarized in a series of publications over the course of the next year.

At the meeting, a great deal of progress was made in understanding the current forms of LTC provision in developing countries and some of the unique challenges and opportunities they face in attempting to address the growing need for LTC. The experience of the industrialized world has been summarized and analysed in new ways that provide a much better basis to learn from it.

All of the background material will be published in a series of publications focusing on the experience of the developing and industrialized world, so that they will be widely available. In addition to the publication of the existing materials, the next major step will be to apply all that has been learned to prepare a practical framework for guiding the development of national LTC policies in developing countries.

The framework will address the major issues and alternatives in LTC service organization, and it will spell out the advantages and disadvantages in organizing LTC provision according to these choices. The framework is not intended to provide specific prescriptions, but rather a basis for translating national conditions, values, culture, and existing health and social policies into a long-term care policy.

Another important outcome of the process up to now has been the formation of a group of experts from the developing and industrialized world who are engaged in an ongoing collaborative effort. This group will provide an important resource for WHO in pursuing this agenda.
1. **Overall workshop documents**

1.1 *Developing LTC: What can we learn from case-studies and what are the major policy decisions?* – Jenny Brodsky, Jack Habib, Miriam Hirschfeld, Ben Siegel.


1.3 *General Patterns of Health, Social and Long-Term Care in the Developing Countries Participating in the Study* – Jenny Brodsky, Jack Habib, Ben Siegel, Netta Bentur, Naomi London.

1.4 *Designing LTC from a developing country perspective – unique aspects: Notes for discussion* – Jenny Brodsky, Jack Habib, Miriam Hirschfeld, Ben Siegel.

2. **Case-studies of developing countries: original papers and separate summaries**

2.1 People’s Republic of China – Fu Hua and Xue Di

2.2 Costa Rica – Felicia Knaul and Gustavo Nigenda

2.3 Indonesia – Agus Suwandono, Qomariah, Suhardi and Ingerani

2.4 Republic of Korea – Chung Yul Lee and Euisook Kim

2.5 Lithuania – Aleksandras Krisciunas

2.6 Mexico – Felicia Knaul and Gustavo Nigenda

2.7 South Africa – Zukiswa Pinini

2.8 Thailand – Somsak Chunharas and Kanittha Boonthamcharoen

2.9 Ukraine – Vladislav V. Bezrukov

3. **Case-studies of developed countries**

3.1 Australia – Anna Howe

3.2 Canada – Howard Bergman, François Béland, Lysette Trahan, Patricia Caris, Anne Perrault

3.3 Norway – Tor Inge Romoren
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4. Background papers on selected key issues in LTC

4.1 The Interface of LTC and Other Components of the Health and Social Services Systems in North America – Robert Kane

4.2 Long-Term Care Integration in Four European Countries: A Review – Dennis Kodner

4.3 Strategies for Achieving Integrated/coordinated Care among LTC Services – David Challis

4.4 Human Resources Strategies in LTC – Rosalie Kane

4.5 The Role of Informal Support in LTC – Joshua Wiener

4.6 Effective Coverage of Long-Term Care – Itziar Larizgoitia

4.7 The Support of Carers and Their Organisations in some North and West European Countries – Marja Pijl


7. Bibliography on LTC:

7a) General Issues

7b) Comparative Perspectives

7c) Selected Developed Countries

7d) Selected Developing Countries
Additional bibliography


United States Bureau of the Census – International Database www.census.gov/ipc/www/idbnew.html


ANNEX B

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Dramatic demographic and epidemiological changes over the last few decades are resulting in a serious transformation of the health care needs of the world’s population. Long-term care (LTC) needs resulting from population ageing, the HIV/AIDS pandemic, TB, road traffic injuries, violence, and other sources of injury are increasing in the developing world at a rate which far exceeds that experienced by industrialized countries. This volume seeks to address these needs for long-term care, and to suggest appropriate ways of meeting them.