INTRODUCTION TO CASE-STUDIES

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Care for chronically ill and disabled persons and a steep rise in the numbers of elderly are a major and growing challenge in developing countries. The formulation of policies needs to reflect these countries’ unique conditions. As an essential element in this process, country case-studies provide an opportunity to learn from what already exists. They also help us to identify and better understand the differences that are relevant for the translation of experiences from industrialized countries to developing countries and vice versa, as well as the variations among developing countries. These include:

- epidemiology;
- available resources;
- culture and values;
- migration;
- strength of informal care; and
- stage of development of health and social systems.

This volume presents case-studies that examine the emerging needs and approaches to long-term care in ten developing countries: People’s Republic of China, Costa Rica, Indonesia, Lebanon, Lithuania, Mexico, Republic of Korea, Sri Lanka, Thailand, and Ukraine. These countries represent different levels of economic development and different stages of the demographic and epidemiological transition. The case-studies were written by national health care experts, with the professional guidance and support of the JDC-Brookdale Institute and WHO.

In this introduction, we describe the definition and scope of LTC and provide evidence of the growing need for LTC in the developing world. We also discuss the methodology used in choosing and organizing the case-studies, and provide highlights of the general characteristics of the existing LTC care systems found in the specific countries.
LONG-TERM CARE

Definition and scope of LTC

Long-term care refers to the provision of 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 and cognitive impairments which often impair a person’s self-care ability.

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. Relationships between the disabled person and the family, as well as those between and among family members need to be managed by all involved. In addition to managing care, functional dependency also has emotional consequences for family members and for their relationships with one another.

Dependency requires significant needs for information, guidance, and education for the disabled person and his or her family. It also creates a complex range of needs for services. This in turn creates a need to coordinate access to and management of these multiple services. This care management function is a need in itself.

Types of long-term care services

Long-term care may be either home-based or institutional. 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:

- Health-related care, which we refer to as home health.
- Care related to daily functioning, such as personal care (e.g., eating, bathing) and homemaking (e.g., cooking, cleaning).

Long-term care can be provided by formal caregivers, that is paid care, or informal care that is provided by persons who do not receive pay.

Formal care 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 para professionals (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 need for LTC policy in developing countries**

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. The need for LTC is determined by the interaction of the rate of increase in disability levels and the rate of change of the informal network and its capacity. For most countries, the development of public policies to address the consequences of these changes has become urgent.

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 elderly support ratio (the ratio of those aged 65 and over per 100 persons aged 20–64), and the parent support ratio (the ratio of those aged 80 and over per 100 persons aged 50–64). This increases the pressure on children who are a major source of support to the elderly.
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Provided in Table 1 on the following three pages are selected illustrative statistics for the developing countries included in this volume, which have been derived from international data bases.\(^1\) Although there occurs considerable variation in the proportion of elderly among the ten countries examined, each country expects a remarkable future increase in the population aged 65 and over. Most of the countries examined also expect a steep increase in the parent and elderly support ratios. In Lithuania, for example, 13.4% of the population is already 65 and over; there are approximately 22 persons over 65 to every 100 persons in the prime working age of 20–64; and the parent support ratio stands at 15.

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 increase to 24. In Indonesia, only 4.8% of the population is 65 and over, and there are approximately nine persons over 65 to every 100 persons aged 20–64. However, the proportion of those 65 and over will nearly double in the next 25 years, as in most of the countries included in the study.

There are additional factors that are affecting the prevalence of disability in developing countries. 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 broad scale have had similar consequences. In many developing countries, the sharp rise in traffic accidents and other injuries is also having a significant impact on functional disability rates. Among children and young adults there are significant limitations caused by injury, blindness and the debilitating effects of tropical diseases such as malaria and schistosomiasis.

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).*

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\(^4\) Due to tech. reasons, Table 1 is available in hard copy only.
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There is limited information on disability rates in developing countries. The existing data relate more to the prevalence of chronic and communicable diseases. However, some efforts have been made to use morbidity data to estimate disability rates. According to the World Health Report 2000, an approximately equal number of years of healthy life are 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 diseases.”

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 their life years (14% versus 9% in industrialized countries, on average) is lost to disability. These estimates are based upon calculations by Murray and Lopez (World Health Report 2000).

In a recent study Current and future long-term care needs, 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 (WHO, 2002).

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 involves the fact 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 combination creates a ‘double burden of disease’.

This double burden of disease is associated with the fact that the developing world is ageing at much lower income levels than those which characterized the same demographic transitions in the industrialized world. The extent of the double burden of disease is reflected in the indicators of chronic disease (such as the percentage of elderly) and in the indicators of the extent of communicable diseases (such as the under-5 mortality rates). Its pattern over time is affected by the rate of change in these indicators. There is the added difficulty of facing this double burden of disease at very low levels of income. As a result, countries must adopt policies which are especially cost-effective and strategic when developing LTC services.
Concomitant with these demographic and epidemiological changes, statistical evidence from the ten 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 migration. 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%. Therefore, there appears to be a fundamental need to develop LTC services to share these growing responsibilities with families.

**Methodology**

As mentioned in the Preface, these case-studies are part of a WHO initiative to provide guidance to developing countries as they respond to growing needs for long-term care. This effort is based on the belief that significant progress can be achieved through a case-study approach that enables one to root the discussion of policy options in an in-depth understanding of existing realities in developing countries, and to learn from what already exists.

The case-studies provide an opportunity to learn on how countries are currently responding to needs for long-term care and to identify bases for further development that build on existing health and social infrastructures.

There were a number of considerations in choosing the countries for these case-studies. An effort was made to include a range of countries at different stages of demographic and epidemiological transition and at different levels of economic development, to illustrate the diverse picture of LTC needs and service development.

A further major consideration involved geographic diversity. Included are two countries from eastern Asia (People’s Republic of China, Republic of Korea), one country from south-central Asia (Sri Lanka), two countries from south-east Asia (Indonesia, Thailand), one country from the Middle East (Lebanon), two countries from Eastern Europe (Lithuania, Ukraine), and two countries from Latin America (Mexico, Costa Rica).

We included the two countries from Eastern Europe (Lithuania and Ukraine) that reflect broader patterns found in other Eastern European countries. Both countries have low levels of economic resources and have been challenged by major macro-societal transitions during the past decade.
Case-study outline

An outline for the organization of the case-studies was developed during a collaborative process involving the developing country case-study authors, the World Health Organization, and the JDC-Brookdale Institute. The outline provides a framework for understanding the general health and social systems and the current long-term care provision within these countries. It is useful to provide a brief description of this framework.

Section 1 includes a general description of the country’s social structure and information on important economic, demographic, and epidemiological trends. We make use of data available from international sources to present a standard and comparative perspective. This is important, because often these are the only data available to policy-makers in developing countries. In some cases, slight differences may exist between data in Section 1 and data obtained from domestic sources, which is presented in other sections.

In Section 2, each country’s general health and social system is described. Understanding a country’s general systems of health and social care provision and financing is important for a number of reasons. These systems reflect choices with regard to social policy principles that may influence the choices with respect to long-term care. Secondly, as LTC begins to develop, many countries may choose to develop LTC under the auspices of the general health and social systems. Therefore, background information on these systems, together with the author’s insights as to how and where LTC is developing, provides an opportunity to learn how LTC may be incorporated into existing health and social systems.

In general, the information in this section includes:

- the organization of the health and social system’s decision-making and implementation structures, including degree of coordination and decentralization;
- sources of public financial support;
- principles of coverage targeting and financing;
- the organization of the service delivery system;
- degrees of accessibility and reliability of primary health care; and
- availability of human resources in the health and social systems.
Section 3 presents information on current long-term services. Due to the various degrees of development of LTC services and systems in various countries, the information presented in this section varies from case-study to case-study. In general, the information in this section includes the following questions:

- What are the services designed for disabled persons, such as home care services (home health, personal care, homemaking, family education and training), other services in the community (such as day care services), and institutional services (nursing homes, geriatric hospitals, rehabilitation wards)?

- Have these services been developed on an integrated or non-integrated basis with the general health and social services?

- What are the respective roles of the government and nongovernmental sectors?

- What are the roles of volunteers and communal mobilization in the provision of LTC?

Section 4 addresses some general issues pertinent to LTC development. These include the present and future needs for long-term care, the author’s view of gaps between the need and provision of services, and an identification of resources (i.e. structures, human resources and organizations) at the national and local levels that may be utilized to promote LTC. It concludes with a discussion of emerging policy strategies and plans for future long-term care development, and perspectives on the preferred directions.

This common outline was intended to increase the likelihood that similar information would be collected from each case-study and facilitate comparisons. However, there was also an interest in allowing the case studies to reflect differences in the areas of expertise of the authors, the information available to them and the unique situations that exist in each country.
LONG-TERM CARE

Existing care systems in the developing world

Below, we briefly highlight the LTC policy directions that emerge from the case studies against the background of socioeconomic and epidemiological indicators as shown in Table 1.

As noted, 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 indicated by the percentage of elderly in the population.* The percentage of elderly, the percentage of women in the labour force, and the parent support ratio are used as indications of the availability of family support. 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 overlap between the percentage of elderly and the rate of child mortality is used to indicate the double burden of disease. The overall resources available to address these needs are estimated by the per capita GNI (gross national income - adjusted for purchasing power parity), and the level of per capita health expenditures (also adjusted). The percentage of health care expenditures from the GNI reflects the priority given to health-related needs.

Lithuania and Ukraine

very high percentage of elderly at low income level relative to developed countries, and moderate to low burden of communicable diseases

In general, both Lithuania and Ukraine combine a very rapid rate of ageing with low income levels. The proportion of elderly in these countries is between 13% and 14%. These populations are continuing to age and in the year 2025 the proportion of elderly will reach 20% and they are confronting a large current and rapidly rising burden of chronic disease and disability.

The level of communicable diseases is low in Lithuania but is still moderate in Ukraine. The income level is particularly low in Ukraine (6980 $PPP per capita in Lithuania and 3700 $PPP per capita in Ukraine). The ageing pattern is heavily influenced by very low fertility rates. In both countries, there has been a very high proportion of women in the labour force.

* While this is a valid indicator, it ignores the fact that many elderly are themselves caregivers to their spouses, disabled children and very old parents. The caregiving roles of old people are especially important in countries with a high HIV/AIDS burden and large numbers of orphans.
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Both countries have been challenged during the past decade by major macrosocietal transitions affecting all spheres of society – including their health and social systems, which have deteriorated considerably. Despite their low income level, both countries have a health system that covers the entire population. However, availability of the key services is very limited in these systems. In Lithuania, the level of expenditure on health is high relative to its economic situation compared with the other countries in the study having the same or higher level of resources.

In the past, institutional LTC services were emphasized in these countries. However, more recently they have developed home-based LTC services, including home health, personal care, and homemaking services. This broad package of LTC services, relative to the low income of these countries, may be understood in light of both the high rate of ageing and the desire to create a better balance between hospital-based and institutional-based service provision of care in the community.

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.

Republic of Korea

high income and rapid ageing, low burden of communicable diseases

The Republic of Korea has the highest income (17 300 $PPP per capita) and highest expenditure on health services (in terms of total expenditures) among the countries examined. There is a very low level of under-5 mortality (8 per 1000 births) and high life expectancy.

At present, there is a moderate proportion of elderly, at 7.1%. However, the population is ageing very rapidly and by the year 2025, 16.9% will be aged 65 and over. Consequently, the Republic of Korea is concerned with the rise of chronic disease and disability.
LONG-TERM CARE

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 home-making services. It has particularly emphasized family education and training.

Trends in the Republic of Korea may be understood in light of the relatively high proportion of elderly, the decline in family size, the rise in the proportion of women in the labour force, and the availability of resources due to its relatively high-income level. 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.

Costa Rica

Costa Rica has a moderate-income level (7980 $PPP per capita), but high health expenditure (per capita), and a strong health system. Under-5 mortality is low. The proportion of elderly is low, at 5%, but the proportion of those aged 65 and over will double during the next 25 years. As a result, Costa Rica is 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 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 its population 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 the low proportion of elderly in the population and the low proportion of women in the labour force.
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Mexico and Thailand

medium income, low to medium level of ageing,
high burden of communicable disease

In general, both countries have young but rapidly ageing populations. At present, the percentage of the population aged 65 and over is 4.7% in Mexico and 5.2% in Thailand. In 2025, these percentages will reach 9.3% and 11.4%, respectively.

Accordingly, these countries are facing rapid increases in chronic disease and disability. They both have high under-5 mortality rates and are therefore still confronting the challenges of communicable diseases. In both countries, the health system provides moderate coverage of the population and their needs.

The level of development of LTC services seems to be quite similar in these countries, despite the fact that Mexico has higher resources (at 8790 $PPP per capita, as compared to 6320 $PPP per capita in Thailand). Both countries are at the initial stages of developing LTC services and are beginning to develop home health. They do not provide personal care or homemaking services.

The rate of ageing in Mexico is lower, as is the proportion of women in the labour force. These factors might have until now moderated the pressure to develop LTC services. Each country has a strong interest in health promotion, which is consistent with their emphasis on home health.

As in many other Latin American countries, Mexico strongly emphasizes highly-credentialed professions in home health care. This emphasis impacts the ability of Mexico to disseminate this service. By contrast, Thailand emphasizes personnel with much lower levels of formal credentials.
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Lebanon

*low to medium income, low level of ageing, challenged by high level of injuries and disability caused by the civil war*

Lebanon's per capita GNI of 4500 $PPP is in the middle of countries in the study. However, total health expenditure in Lebanon represents 11.8% of GDP, the highest among the countries.

The current percentage of elderly in Lebanon (6%) also puts it in the middle of the range of countries in the study. The percentage of elderly is expected to increase to 9% by the year 2025, somewhat slower than the other countries.

Still, chronic and degenerative diseases are becoming more prevalent and represent a growing share of the country's overall disease burden. Moreover, the problems of injuries and disability have been augmented by the civil disturbances. While the prevalence of communicable diseases has steadily declined over the last 20 years, it is still high (male mortality under age 5 stands at 34 per 1000 births).

The civil war, from 1975 through 1990, considerably weakened the institutional and financial capacity of the Government and public sector, and its role in the provision of health care services steadily declined during this period. However, health and social service development has now been resumed.

LTC services have been slower to develop, and are still provided primarily by informal caregivers. However, home health programmes are beginning to develop in the formal sector as an extension of primary care. Primary care development has been a priority for the Lebanese Government. This policy can be understood in light of the priority of the health system to develop care in the community (as opposed to hospital-oriented care) and to contain health expenditures.
**China** *(with Shanghai as a more specific example)*

- high percentage of elderly, low income,
- very large disparities between urban and rural areas

Excluding the Eastern European countries, China has a higher proportion of elderly in relation to its income level than do the other countries included in these case-studies (3920 $PPP per capita). 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, at 15% (which is 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 diseases and has much less health coverage and infrastructure.

Home health programmes that provide a range of services, with an emphasis on family education, have begun to develop in urban areas such as Shanghai and Beijing. Despite the decline in family networks, personal care or homemaking services have not developed. In these areas there is some institutional LTC provision that may 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.

**Sri Lanka**

- low income and ageing rapidly, low to medium burden of communicable disease relative to income level

Similar to China, Sri Lanka already has a relatively high percentage of elderly relative to its income level and its population is ageing very quickly. It has a gross national income of 3640 $PPP per capita. The proportion of elderly will double during the next 25 years, rising from 6% to 12% in 2025. The chronic disease burden is increasing, with a consequent increase in long-term care needs, while Sri Lanka still faces a moderate level of communicable disease burden.
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Sri Lanka is at the very initial stages of developing LTC services. Mainly nongovernmental organizations, together with a network of volunteers, have addressed the rapid process of ageing and the increasing need for LTC. Formal LTC services and especially home health programmes have just begun to develop (mostly by for-profit organizations, for those who can afford to pay).

The Government has played more of a role in the provision of institutional LTC, although at a low scale. Very recently, the Government has begun to sponsor clinics for the elderly, which place more emphasis on home health.

**Indonesia**

Indonesia represents countries characterized by a low proportion of elderly; very low economic resources (gross national income of 2830 $PPP per capita); and an extremely high burden of communicable diseases, as reflected in a high under-5 mortality rate (50 for males and 40 for females). At the same time, it is ageing rapidly – the proportion of those aged 65 and over will nearly double in the next 25 years, rising from 4.8% to 8.4% in 2025. It will therefore be confronted with a rapid increase in the burden of chronic disease and disability.

The Indonesian situation poses the basic issue, involving the question 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. Long-term care 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 as well as of the limits of expectations from voluntary activity.

As reflected in many other developing countries, traditional healers in Indonesia play an important role in the health system in general and already fulfil certain roles in LTC. The training of traditional healers in LTC has been identified as a way to enhance provision of long-term care.
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We hope that the richness of the material presented in these case-studies will enable the reader to better understand both the factors contributing to the growing need for LTC and the unique conditions that affect the policies to address these needs in developing countries. There is much to be learned from these case-studies, including:

- existing systems of care;
- gaps between the needs and provision of services;
- potential resources that can be utilized to promote the provision of LTC; and
- emerging policy directions to care for the disabled in these countries.

These case-studies also illustrate creative efforts to address LTC needs despite obstacles. They expand the vision of the possible. Hopefully, this volume will be useful in establishing and improving long-term care policies throughout the developing world.