



Towards an International Consensus on Policy for Long-Term Care of the Ageing



© Copyright World Health Organization and the Milbank Memorial Fund, 2000

This document is not a formal publication of the World Health Organization (WHO), and all rights are reserved by the Organization. The document may, however, be freely reviewed, abstracted, reproduced and translated, in part or in whole, but not for sale nor for use in conjunction with commercial purposes.

The views expressed in documents by named authors are solely the responsibility of those authors.



Table of Contents

- 3 *Foreword*
- 4 *Preamble*
- 5 *Rationale*
- 6 *Definition of Long-Term Care*
- 7 *Priority Issues for Long-Term Care and Guiding Principles for Policy*
 - 7 *Issue 1. Personal and Public Values*
 - 8 *Issue 2. Private- and Public-Sector Roles and Responsibilities*
 - 9 *Issue 3. Public Education*
 - 10 *Issue 4. Caregiver Roles, Responsibilities, and Rights*
 - 12 *Issue 5. Infrastructure: LTC Systems for Provision of Social and Health Care Services*
 - 13 *Issue 6. Income Security and Financing LTC Systems and Services*
 - 14 *Issue 7. Current and Future Technologies*
 - 15 *Issue 8. Research, Data Collection, and Strategic Analysis*
- 16 *Invitation to Comment on the Guiding Principles*
- inside back cover Acknowledgments*

Foreword

This report describes initial actions in devising an international consensus on policy for long-term care for frail elderly persons. The report is the work of policy makers and experts from 11 countries, convened by the Ageing and Health Programme of the World Health Organization (WHO) and the Milbank Memorial Fund. The Ageing and Health Programme's main aim is to promote principles that can ensure the attainment of the highest possible quality of life in older age for the largest possible number of people. The Fund is an endowed philanthropic foundation, established in New York in 1905, that works with decision makers in the public and private sectors on significant issues in health policy. Persons who participated in writing this report are identified in the Acknowledgments.

The report describes principles to inform policies for sustainable programs in long-term care that are consistent with the priorities of individual countries, whether industrialized or developing. The Director-General of WHO, Dr. Gro Harlem Brundtland, addressed the theme of this report when she launched the International Day of Older Persons in October 1999. "Older persons," she said, "who are in need of care are the ones who most need...leadership in developing right and affordable policies to ensure dignity and quality of life."

The members of the group that prepared this report emphasize that it is a first, incomplete step toward an international consensus on guiding principles for policy. On their behalf, we invite readers of this report to comment on it and particularly to offer principles and issues for inclusion in future editions. Comments can be addressed to either WHO or the Fund, either by mail, fax, or e-mail, as listed on the back cover of the report.

Daniel M. Fox
President
Milbank Memorial Fund

Alexandre Kalache
Chief, Ageing and Health Programme
World Health Organization

Preamble

Recognizing the Universal Declaration of Human Rights, the Vienna International Plan of Action on Ageing (IPAA), the United Nations (UN) Principles for Older Persons, and subsequent international research and policy efforts, the Ageing and Health Programme of the World Health Organization (WHO) and the Milbank Memorial Fund (MMF) agree that a consensus is emerging among international policy makers concerning the provision of long-term care for older persons in need. This coincides with the UN International Year of Older Persons 1999 and underscores the relevance of its theme, "towards a society for all ages." Within this framework, a conference in July 1998, jointly convened by WHO and MMF in Divonne les Bains, France, resulted in an agreement between the two organizations to prepare a consensus statement that would initiate the development of a coherent international policy on long-term care.

Seventeen years have passed since the World Assembly on Ageing adopted the IPAA, which was subsequently endorsed by the UN General Assembly. As the first international policy document on ageing to be adopted by consensus, the plan has guided the formulation and enactment of policies and programmes worldwide. It was designed to strengthen the capacities of governments and civil society to deal with the dependency needs of ageing populations while also promoting older people as vital resources for societies. The IPAA is an important part of a series of policy documents, including the UN Principles for Older Persons adopted in 1991, developed by the international community with the aim of promoting lifelong development and improving the quality of life of all older persons.

The International Long-Term-Care Initiative builds upon the foundations of the IPAA and the UN Principles for Older Persons. The concerns of older persons who need long-term care are the focus of this document, which encourages regional and international cooperation to secure older persons' independence, participation, care, self-fulfillment, and dignity.

In particular, this joint WHO/MMF initiative addresses two areas of concern: the importance of institutional arrangements for continued lifelong development, and the sustenance and care of older persons who require long-term care. An older

person requiring long-term care should be able to live with dignity while maintaining the highest level of functioning, regardless of the setting in which care is provided. In addition, the initiative recognizes that the considerable physical, psychological, economic, and social toll exacted from family caregivers should be addressed. Attention to the improvement of existing institutions must be paralleled by consideration of the situation of individual caregivers and care recipients.

The International Long-Term-Care Initiative framework document defines long-term care, lists the most critical issues, and outlines the guiding principles for policy development.

The meeting participants of the International Long-Term-Care Initiative believe, at a minimum, that policies must address the following issues:

- ▶ *personal and public values;*
- ▶ *private- and public-sector roles and responsibilities;*
- ▶ *public information and education;*
- ▶ *provision of formal and informal care, which includes training both formal and informal caregivers;*
- ▶ *an infrastructure of long-term-care (LTC) systems to provide social and health care services;*
- ▶ *income security and LTC financing;*
- ▶ *current and future technology;*
- ▶ *research, data collection, and strategic analysis;*
- ▶ *quality assurance, designed to satisfy both care recipients and caregivers.*

Rationale

Although current health care promotion and prevention practices have been devised with the goal of producing a healthier older population, long-term care for frail and/or disabled elderly people will always be needed. In the United States, for example, the probability of LTC institutionalization sometime during a person's lifetime is 17% for persons aged 65 to 74 years, but rises to 60% for those older than 85 years. In Norway, 25% of people 80 years of age and older are in nursing homes. In a comparison of ten developed countries, between 2% and 5% of elderly people (65 years of age and older) reside in nursing homes.¹ There are not enough available data to permit comparison with the situation in developing countries.

In addition to the social and demographic shifts that are compelling many countries to reform their LTC policies, rising health care costs and gender inequity issues, as well as changing family and work patterns, are compounding the need to readdress and rethink future LTC provision.



An international statement on care should provide a manageable strategic framework for developing policy and implementing sustainable programmes that are consistent with the policies of individual governments. Information on policies and programmes in developing countries is scarce; many of these countries rely on the experiences, both positive and negative, of developed countries when formulating their policies. Each country or community will have to extract what they need from the document and adapt the suggested policies and programmes in accordance with their own priorities and capacities.

It is not enough to measure institutional care alone, as the extended family is often the primary provider of care to persons with chronic diseases and disabilities.

Although it is difficult to calculate future LTC needs, the substantial recent increases in life expectancy in old age, which are projected to continue, may lead to increasing demand for supportive services and programmes for older persons and their family caregivers. The extent of the demand, however, will depend on the outcomes of current and future health promotion and public health practices and their impact on disability-free life expectancy.

Few governments have implemented a comprehensive LTC policy for older persons or their family caregivers. However, many countries have established channels of national, state, provincial, and/or private responsibility for the LTC needs of older adults and, in some instances, their informal caregivers. Some products of their concern are income security programmes, medical care and/or medical insurance, mixtures of public and private LTC policies, and housing policies. Specifically needed are plans for home care, respite care, institutional care, and sheltered housing arrangements.

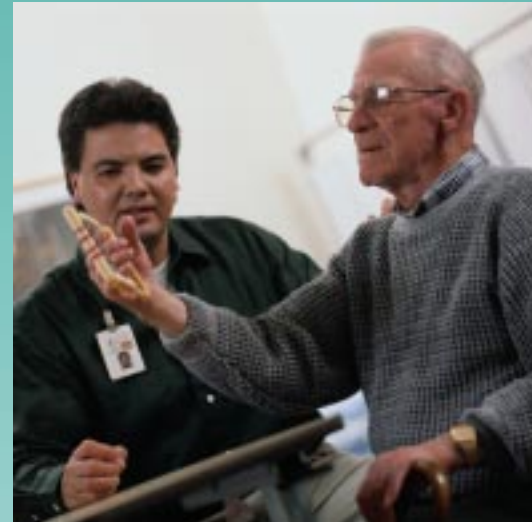
Participants at the Divonne les Bains conference agreed to focus on the needs and particular circumstances of older persons requiring care, their informal and formal caregivers, and LTC systems.

¹ Ribbe, MW, et al. Nursing homes in 10 nations: a comparison between countries and settings. *Age and Ageing*, 1987, 26-S2:3-12.

Definition of Long-Term Care

Long-term care is the system of activities undertaken by informal caregivers (family, friends, and/or neighbours) and/or professionals (health, social, and others) to ensure that a person who is not fully capable of self-care can maintain the highest possible quality of life, according to his or her individual preferences, with the greatest possible degree of independence, autonomy, participation, personal fulfillment, and human dignity.

An older person's need for LTC is influenced by declining physical, mental, and/or cognitive functional capacities. Although the tendency is for progressive loss of capacity with increasing age, there is evidence, at least from some countries, that disability rates among older persons are decreasing and that declines or losses are not irreversible. Some older persons can recuperate from loss and reclaim lost functional capacities. Therefore, duration and type of care needs are often indeterminate and will require individually tailored responses.



Important elements of LTC include, but are not limited to, the following:

- ▶ *maintenance of involvement in community, social, and family life;*
- ▶ *environmental adaptations in housing and assistive devices to compensate for diminished function;*
- ▶ *assessment and evaluation of social and health care status, resulting in explicit care plans and follow-up by appropriate professionals and paraprofessionals;*
- ▶ *programmes to reduce disability or prevent further deterioration through risk-reduction measures and quality assurance;*
- ▶ *care in an institutional or residential setting when necessary;*
- ▶ *provision for recognizing and meeting spiritual, emotional, and psychological needs;*
- ▶ *palliative care and bereavement support as necessary and appropriate;*
- ▶ *support for family, friends, and other informal caregivers;*
- ▶ *supportive services and care provided by culturally sensitive professionals and paraprofessionals.*

Older people who require LTC should also have access to other services, such as acute medical and mental health care, along with financial, social, and legal support. Concomitantly, their informal caregivers should have access to supportive services, which may include information and assistance in securing help, caregiving training, and respite.

Priority Issues for Long-Term Care and Guiding Principles for Policy

This initiative incorporates broad issues and general principles for consideration that are believed to reflect universal and fundamental human values. A coordinated approach to policies that address LTC recognizes the interconnectedness of all aspects of the ageing process and of the context within which an older person lives. It is recognized, however, that integrating these areas into a broader framework of policies and programmes of action will pose a significant challenge. Comprehensive reforms may begin, necessarily, with smaller, carefully conceived, and incremental improvements in LTC. This section presents guiding principles for comprehensive LTC policies that address the needs of older persons who require these services.

Issue 1. Personal and Public Values

Because of the increasingly diverse nature of contemporary society, many communities around the world will be forced to respond to the differential LTC requirements of older persons and their families within their current and future resources. The interpretation and expression of chronic disease and disability may differ within cultures or regions, yet some basic tenets are universal. The corresponding need for care and assistance and the approaches to dividing the responsibility for providing this care among the individual, the family, and the larger society vary widely.



GUIDING PRINCIPLE 1. With due attention to the appropriate balance of private and public responsibilities, each community should be able to determine objectively the level and kind of assistance required by an older person in need of care or by family members providing this care. The subsequent eligibility and payment for this assistance must also be addressed. Accordingly, the following points are essential:

- ▶ recognition of fundamental basic standards;
- ▶ acknowledgment that diversity originating in culture, gender, ethnicity, unique regional setting, language, and other factors all play a role in shaping LTC needs and in defining appropriate supportive resources and interventions;
- ▶ assurance that care is of a high quality and is offered by culturally sensitive providers;
- ▶ clarification of the values and aspirations, roles, and responsibilities of individuals and families as defined by their particular social context, within the larger society, and in relation to their own government;
- ▶ reconciliation of the differences between these groups, and in the process, stressing the focus on the individual and the family.

Issue 2. Private- and Public-Sector Roles and Responsibilities

Although some countries regard their systems of providing LTC as satisfactory,² some do not have adequate systems, and all countries have policy concerns. The respective roles and responsibilities of everyone involved in LTC need clarification. Any reform or development of LTC provision or policy must be accomplished by adopting a systematic and orderly approach, in which the primary stakeholders take responsibility for identifying needs and incorporating reforms. Families, individuals, civil society, national, state, provincial, and/or local government, non-profit organizations, and for-profit organizations are the main stakeholders. This collaboration will be necessary to ensure continued development and sustained reforms. Legislation must be enacted to structure and direct these efforts.



GUIDING PRINCIPLE 2. Evidence of successes from the private and public sectors would provide a framework for developing and implementing LTC policies and programmes. Towards such an end, it is important to pursue a national consensus that encompasses the following goals:

- ▶ stimulation of collaboration and partnerships between the private and public sectors that involve each level of government, civil society, and the non-profit and for-profit sectors;
- ▶ clear definitions of the roles and responsibilities of the private and public sectors in order to achieve these ends:
 - create public programmes that provide the foundation for private-sector support and cooperation,
 - assure the development of measures to provide the necessary supply of supportive resources for older people in need of LTC and similar support for their family caregivers by the public and/or private sectors,
 - identify and assign specific responsibilities for assuring quality of care.

² Organisation for Economic Co-operation and Development. *Maintaining prosperity in an ageing society*. Paris, 1998.

Issue 3. Public Education

Effectively implementing policy changes requires building an understanding, informed public. Certainly, the values of the affected individual(s) and their communities should be ascertained. Community-wide understanding of the needs, realities, and choices pertaining to LTC is also essential if individuals and families are to plan for, receive, and provide supportive assistance. Strategies for educating the public should use credible resources to disseminate information in informal and formal settings.



GUIDING PRINCIPLE 3. Successful policy change requires an understanding, informed public and group of professionals. All efforts to inform and educate should be sensitive to issues of age, gender, and culture.



Issue 4. Caregiver Roles, Responsibilities, and Rights

Despite the declines in disability rates among older persons that have been recently observed in some developed countries, a growing aged population will, of itself, increase future needs. In addition, there is now more emphasis on enabling older persons to remain in their own homes. Long-term-care needs will continue to grow under the following projected circumstances:

- ▶ the family structure continues to evolve;
- ▶ geographic mobility becomes more pronounced;
- ▶ worker-to-retiree dependency ratios rise;
- ▶ the population of virtually all countries rapidly ages.

All these issues will be particularly important in the developing world, where LTC has traditionally been provided by the families alone and where competition for scarce resources is intense.



Formal Caregivers

An LTC system that provides continuous, comprehensive services must include the following measures:

- ▶ specialized training and education for formal caregivers;
- ▶ linked clinical, social, and public health services;
- ▶ standards of care for health care professionals and paraprofessionals:
 - establishing standards of care where absent;
 - monitoring adherence to standards of care and compatibility with an individual's desires;
- ▶ multisectoral arrangements for integrated, transportable provision of care.

Health and social care personnel working within LTC systems must be equipped to deliver a comprehensive range of home, community, and institutional services. Integration of service provision will be an important component of LTC policies.

Informal Caregivers

Throughout the world, family members still provide the largest proportion of LTC. In light of that reality, LTC systems should support, not replace, current informal caregivers. Provisions for specialized training and support for informal caregivers can enhance family solidarity and minimize the vulnerability of older people in



need of care. Existing community education institutions, respite care services, and support groups should be utilized in preparing and supporting these caregivers.

National policies should take into account workers with responsibilities for the care or support of family. Historically, the fact that these caregivers have not been reimbursed for providing services has kept the costs of LTC low. Inequalities in opportunity and treatment may threaten the economic and social security of informal caregivers, both men and women. Unfortunately, gender divisions continue in the labor market and in caregiving, as the bulk of informal care of older persons in need has traditionally been provided by women. Men and women, with or without family dependents, should have the full ability to prepare for, enter, participate in, or advance

economic activity. Informal caregiving services should be recompensed with benefits and/or entitlements, so that all caregivers can exercise their right to free choice of employment and fulfill their needs within their society's terms and conditions of employment and retirement.

GUIDING PRINCIPLE 4. Public policies must be designed to address the need for caregivers; to define their roles, responsibilities, and rights; and to respond to the challenges they face, either formally (in the case of professionals and paraprofessionals) or informally (when services are performed by family, volunteers, neighbours, or nongovernmental organizations). Future caregiving will require new and/or reformed models of formal and informal systems of care and systems for supporting caregivers. Support for informal caregivers could come in the form of social security coverage, training, respite care, visiting nurse services, and/or lump sum disbursements to cover costs, to name a few examples.

Issue 5. Infrastructure: LTC Systems for Provision of Social and Health Care Services

Before decisions can be made regarding the future direction of policy, the current infrastructure and systems will have to be evaluated. An LTC system should offer a repertoire of services to all older persons requiring care. A system that facilitates an individual's entry, exit, and re-entry according to his or her changing needs and circumstances would be ideal.

A comprehensive and continuous care provision plan would contain the following necessary elements:

- ▶ equity of access;
- ▶ scope of benefits and services;
- ▶ eligibility for coverage;
- ▶ entry points to care;
- ▶ links to and between health and social systems;
- ▶ adequacy of the infrastructure, including its ability to handle issues related to certain critical areas:
 - the workforce (including employee education, training and certification processes),
 - programmes and facilities,
 - information systems for assessments, clinical decisions, care coordination, and programme development,
 - the organizational capacity to respond to change and reorganize,
 - integration and sustainability of services,
 - standards and mechanisms for evaluating quality and satisfaction.



GUIDING PRINCIPLE 5. All older people in need of care should have access to LTC services regardless of age, gender, or income. A person's level of need and duration of care should be determined at the time of entry into the system and then regularly updated. New policy mandates must be carefully shaped in order to avoid fragmentation of care provision, to address service gaps, and to construct a seamless system of care.

Issue 6. Income Security and Financing of LTC Systems and Services

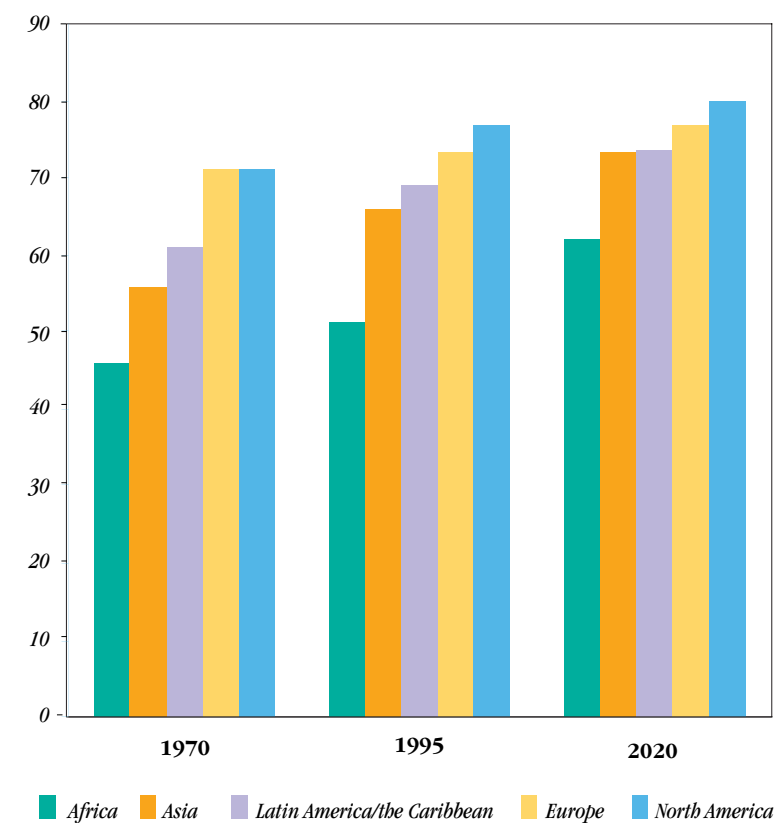
In general, cost-containment policies in health care are forcing the re-evaluation of LTC policy. Current investment in LTC provision is inadequate in many countries, with the result that many existing services and systems are being strained by the increased demand. The rising financial demands placed on society require innovative responses and cooperation between private and public sources to secure budgetary funding.

Public education, housing, and health care will require varied solutions to ensure adequacy:

- ▶ financial support methods that balance public, private, and individual obligations;
- ▶ revenue sources at each level of government;
- ▶ acceptable payment and cost-containment mechanisms;
- ▶ budgetary flexibility that links health and social care with other related budgets;
- ▶ fair and equitable solutions to the treatment of individual income and assets;
- ▶ funding sources based on social solidarity schemes.

GUIDING PRINCIPLE 6. Creating and supporting a system for providing care services will require a balanced approach that utilizes both public and private financial support. Similarly, policies should find fair and equitable means and payment mechanisms to secure or maintain economic security for older persons who need care.

Average Life Expectancy at Birth for Both Sexes in the World Regions



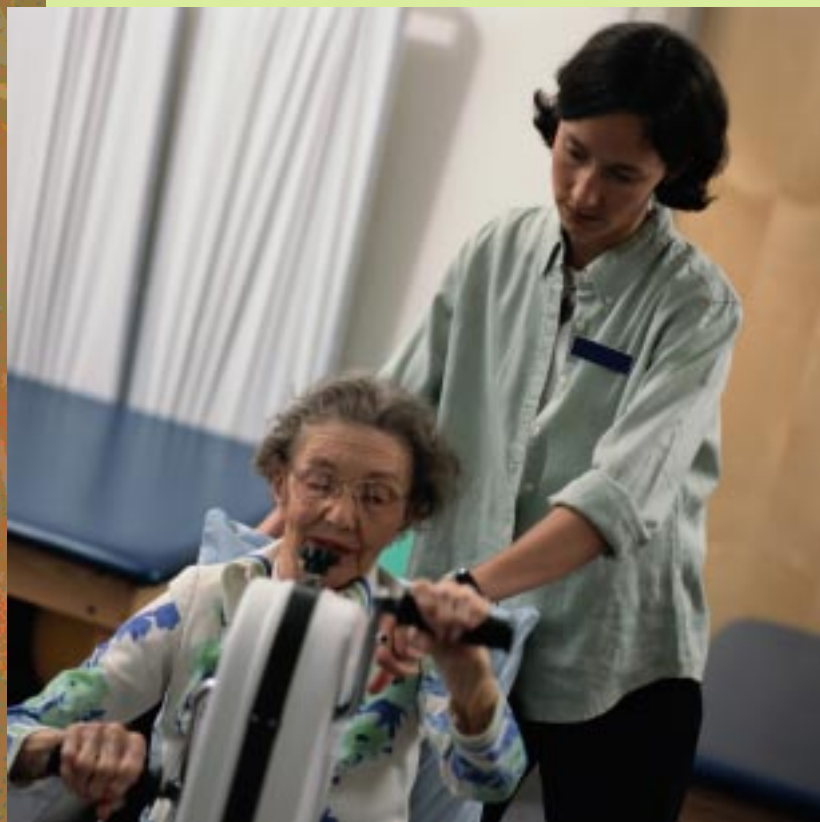
Source: UN, *The Population Prospect, 1998 up-date*

Issue 7. Current and Future Technology

Both existing and new technologies will contribute significantly to future care provision. When these technologies are also cost effective, every means should be used to incorporate them into the existing system of care as rapidly as possible.

Policy makers should consider adopting the following measures:

- ▶ facilitating the use of existing technology;
- ▶ assessing new and developing technology;
- ▶ encouraging and rewarding the development, dissemination, and use of assistive devices and new technology.



GUIDING PRINCIPLE 7. Optimizing the use of current technology and incorporating new, appropriate technologies will be crucial for the health of future LTC systems.

Issue 8. Research, Data Collection, and Strategic Analysis

Studies of LTC provision and systems will form a crucial foundation for evaluating outcomes and promoting further policy development.

A clear mandate for investigation will assist researchers to achieve certain goals:

- ▶ setting research priorities;
- ▶ assessing the usefulness of existing research;
- ▶ attracting resources for research;
- ▶ initiating research projects;
- ▶ applying research findings to policy development;
- ▶ balancing clinical, epidemiological, and social science research methods and findings.



GUIDING PRINCIPLE 8. Research should be planned to assess and monitor reforms in LTC provision and systems. This research should focus on effective implementation and outcomes. The rapid growth of the elderly population worldwide adds to the importance of encouraging research on interventions that prevent or delay the onset of disabilities.

Invitation to Comment on the Guiding Principles

The working group for the International Long-Term-Care Initiative presents this document as an initial framework for the development of global policies regarding the provision of LTC. The group is committed to sharing the central messages of this initiative with governments, institutions, communities, and individuals. The initial intended audience comprises decision-makers for health and social policy from the public and private sectors. An interactive World Wide Web site will be dedicated to this initiative, which will assist in translating actions into practice and in expanding the audience to include professionals, direct service providers, advocates, and consumers. We expect that this resource will provide a forum for ongoing, rapidly expanding, and timely communication. The goal of this Web site is to facilitate global interaction, communication, and collaboration while simultaneously advancing the priorities for action in LTC.

Although the circumstances of older persons were the impetus for this initiative, we do not mean to minimize the situation of younger persons with health problems or physical or intellectual disabilities, nor do we intend to overlook the need for policies to address the problems faced by these populations. Certainly, they require

attention and, in the future, this document could be used to incorporate all ages within comprehensive LTC policies. Many aspects of LTC are not age specific, such as similarities in care needs, services, and facilities. A comprehensive policy that is part of a general health care strategy would reap many benefits: for example, it would help to minimize competition for limited funding and would cut down service overlap while strengthening the prospects for intergenerational LTC facilities. Yet, at this time, the urgent needs of older persons merit the specific focus on this population.

At a broader level, countries and regions will experience similar needs, but each locality will establish its own priorities for work and policy development,

depending on its own particular expressed needs. Countries may choose to begin at different or multiple points of entry, for example, by strengthening district-level capacity, supporting informal caregivers, or increasing national capacity through policy development. National governments and nongovernmental organizations are urged to use this International Long-Term-Care Initiative to cultivate and sponsor networks for LTC provision within and between countries. The working group of this initiative entrusts the World Health Organization and the Milbank Memorial Fund to promote alliances, enable developed and developing countries to implement the recommendations for action, and introduce sustainable reforms.



Acknowledgments

The following persons participated in meetings to plan this report and/or reviewed it in draft. They are listed in the positions they held at the time of their participation.

Kathleen S. Andersen, Senior Program Officer, Milbank Memorial Fund, New York; Ken Black, Programme Associate, Ageing and Health Programme, World Health Organization, Geneva; Jo Ivey Boufford, Dean, Robert F. Wagner Graduate School of Public Service, New York University, New York; June Crown, Chairman Designate, Age Concern England, London; Charles J. Fahey, Program Officer, Milbank Memorial Fund, New York; Kathleen M. Foley, Chief, Pain Service, Department of Neurology, Memorial Sloan-Kettering Cancer Center, New York; Gloria M. Gutman, Professor and Director, Gerontology Research Centre, Diploma and Masters Program, Simon Fraser University at Harbour Centre, Vancouver; Jack Habib, Director, JDC-Brookdale Institute of Gerontology and Human Development, Jerusalem; Peter Hicks, Co-ordinator, Policy Implications of Ageing, OECD Directorate for Education, Employment, Labour and Social Affairs, Paris; Irene Hoskins, Programme Officer, Ageing and Health Programme, World Health Organization, Geneva; Ursula M. Karsch, Pontificia Universidade Catolica de Sao Paulo, Sao Paulo; Kimmo Leppo, Ministry of Social Affairs and Health, Helsinki; José M. Martín-Moreno, Director, Escuela Nacional de Sanidad, Instituto de Salud

Carlos III, Madrid; Otto Christian Roe, Project Manager, Norwegian Board of Health, Oslo; Jeanette C. Takamura, Assistant Secretary for Aging, U.S. Department of Health and Human Services, Washington, D.C.; Noriyasu Watanabe, Professor of Social Security Laws and Pensions, Faculty of Sociology, Edogawa University, Nagareyama City; Liz Wolstenholme, Head of Continuing Health Care, National Health Service Executive, London.

Special credit is given to Paul Kowal, Programme Officer, Ageing and Health Programme, World Health Organization (WHO/AHE) for drafting this document and for maintaining regular correspondence with all other contributors.

Ingrid Keller, Sheel M. Pandya (WHO/AHE) and Jeff Edelstein (Milbank Memorial Fund) were instrumental in assisting in the final stages of this production.

Photo Credits

Front cover and page 1: Digital Stock; page 2: Gilbert Awekofwa/HelpAge International; page 4: PhotoDisc; page 5: WHO/PAHO; page 6: PhotoDisc; page 7: WHO/PAHO; page 8: P. J. Griffiths/Magnum Photos,

Inc.; page 9: Barney Bruno/Magnum Photos, Inc., WHO/PAHO; page 10: PhotoDisc; page 11: WHO/PAHO, page 12: Digital Stock; pages 14 and 15: PhotoDisc; page 16: WHO/PAHO; inside back cover: Digital Stock; back cover: PhotoDisc.

Design: Marilyn Langfeld

